
Staff Findings and Recommendations

Transitional Services for Youth and
Young Adults with Autism Spectrum
Disorder

December 17, 2014

Legislative Program Review
and Investigations Committee

Connecticut General Assembly

**CONNECTICUT GENERAL ASSEMBLY
LEGISLATIVE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE**

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LEGISLATIVE PROGRAM REVIEW
& INVESTIGATIONS COMMITTEE

Transitional Services for
Youth and Young Adults with
Autism Spectrum Disorder

DECEMBER 2014

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Transitional Services for Youth and Young Adults with Autism Spectrum Disorder (ASD)

Background

In May 2014, the committee authorized a study to identify the needs of, and services available for, individuals with ASD, focusing on the transition from secondary school completion to young adulthood (up to age 25).

The adequacy and accessibility of transitional resources available from state agencies and other organizations was reviewed. The study examined transitional planning during secondary education, programs and services following secondary education, levels of independence attained, and barriers to independence.

Individuals with ASD are likely to have varying needs throughout their lifetimes in a myriad of domains such as education, vocational training and support, medical and behavioral health, activities of daily living, socialization, and community living, including financial and housing supports. Services may be accessed through a combination of public and private agencies and formal and informal supports, which are paid for by a variety of federal, state, private and family resources.

Committee staff had ongoing meetings on a number of cross-cutting topics with various state agency staff from the Departments of Education (CSDE), Developmental Services (DDS), Rehabilitation Services (DORS), and Mental Health and Addiction Services (DMHAS).

Interviews and a public hearing were held with representatives of several advocacy groups, parents of children with ASD, employers, service providers, and other interested stakeholders.

Staff conducted a literature review and two surveys of transition coordinators and parents to collect original data. Tours and visits were taken to a variety of programs and autism-related fairs and meetings.

Main Staff Findings

- There is a need to strengthen transitional services during high school.
- High schools, parents, students, and colleges can take steps to increase the likelihood of successful college experience.
- Employment is a major barrier for individuals with ASD transitioning to independence.
- New and creative ways of developing housing solutions must be examined to address the oncoming wave of individuals with ASD.
- With proper supports, individuals with ASD may live on their own, be employed, and participate in community activities.
- A strong solid infrastructure must be in place if the state is to meet the demand for ASD services, which already exceeds capacity.

PRI Staff Recommendations

Education. Begin the transition process sooner; implement the Student Success Plan; train transition coordinators; use an IEP checklist; and distribute useful publications to parents on transition.

Post-Secondary Education. Reduce reliance on supports while in high school; have students participate in a bridge program or 'boot camp' prior to college; and replicate several promising programs across state higher education system.

Employment/Vocational. Provide transitional services-only; prepare families for logistical burdens of employment; encourage participation in summer employment; establish central DDS position for employment; and develop a shared definition of competitive employment.

Independent Living. Establish ASD housing coordinator position; assist families to develop housing plans; establish a one-stop housing information resource for individuals with ASD; produce a report on the present and future ASD residential needs with best practices guidelines and plan of action.

Supports. Consider expanding ASD coverage to non-Medicaid insurance plans; survey families on ASD waiver waitlist; establish advisory subcommittees on transportation and life skills; create interim ASD family grant program; consider legislation for tax-free accounts; additional ASD resource specialist; provide 'ASD only' families access to education and transition advisors.

System Infrastructure. Establish shared agency data system; explore opportunities for coordination of state level work on ASD; identify flexible, diversified, and sustainable funding; promote more outreach to key stakeholders; continue building ASD training infrastructure; and prepare an annual progress report on ASD accomplishments and activities.

Acronyms

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
BRS	Bureau of Rehabilitation Services
BSE	Bureau of Special Education
CDC	Centers for Disease Control and Prevention
DCF	Department of Children and Families
DDS	Department of Developmental Services
DORS	Department of Rehabilitation Services
DMHAS	Department of Mental Health and Addiction Services
DSM	Diagnostic and Statistical Manual of Mental Disorders
FAPE	Free Appropriate Public Education
HCBS	Home and Community Based Services
ID	Intellectual disability
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IPE	Individualized Plan for Employment
LMHA	Local Mental Health Agency
LRE	Least Restrictive Environment
OPA	Office of Protection and Advocacy for Persons with Disabilities
OPM	Office of Policy and Management
OT	Occupational Therapy
PT	Physical Therapy
PPT	Planning and Placement Team
PDDNOS	Pervasive Developmental Disorder Not Otherwise Specified
SSA	Social Security Administration
SSI	Social Security Income
SSDI	Social Security Disability Income
SDE	State Department of Education
YAS	Young Adult Services

Executive Summary

Transition Services for Youth and Young Adults with Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is the fastest growing group of developmental disabilities. Given the growing prevalence of ASD, there is increasing focus, understandably, on the screening, diagnosis, and interventions for young children. However, there is less attention placed on the challenges faced by youth and young adults with ASD who are making the transition from the education entitlement system to an adult system based on available funding.

These students entering adulthood will need specialized secondary transitional services, postsecondary education programs, day programs, employment supports and vocational training, family supports, and residential services. The current education and adult service systems are unlikely to be prepared for the anticipated numbers and need to take steps to prepare.

With this rise in prevalence, the need for effective services continues to far exceed the available resources, leaving an emerging generation of people with ASD and their families in service and financial uncertainty. Appropriate resources must be available and policy must be examined to ensure that individuals on the spectrum have access to services and supports to meet their needs.

The committee staff recommendations contained at the end of the Executive Summary addresses the following issues and concerns found in this study.

Transitional Services During High School

There is a need to strengthen transitional services provided during high school. As expressed by both transition coordinators and parents, it would be beneficial to students with ASD (and other disabilities) to begin the transition process sooner, many recommending IEP transition goals established as early as sixth grade. Another way to promote school personnel to start thinking about transition sooner is to implement the Student Success Plan, a recently required individualized plan for every student in grade 6 through grade 12 that is intended to address all the student's needs and interests to help him or her stay engaged in school and achieve postsecondary education and career goals.

The transition process itself could be strengthened by training transition coordinators to develop more realistic and specific IEP post-school goals, use a secondary transition planning IEP checklist, and make sure they distribute publications helpful to parents on the transition process. There also seemed to be a need to improve the relationship between the transition coordinators and state agencies such as the Department of Developmental Services (DDS) Division of Autism Spectrum Services and the Department of Mental Health and Addiction Services (DMHAS). Transition coordinators reported difficulties making referrals, and having the agencies attend planning and placement team (PPT) meetings and making outreach efforts to students and families. More access and consistent information from state agencies was also viewed as a deterrent to transitioning students with ASD.

Not all parents appeared aware that transitional services-only for 18-21 year olds was an option, a service that was found to be helpful in transitioning to adulthood. Parents also expressed difficulty in contacting state agencies and receiving services after their children exited high school.

Post-Secondary Education

High schools, parents, students, and colleges can take steps to increase the likelihood of a successful college experience. There are certain skills such as self-advocacy, time management/organization, and study skills, that are associated with greater success in college for students with ASD. If these skills can be learned in high school, then students would be better prepared for college. Part of attaining these skills is to reduce supports while in high school to more closely mirror what will occur when the student enrolls in college.

Another way to improve the transition to college for students with ASD is to have the student participate in a bridge program or “boot camp” prior to entering college. The report also identifies several promising programs at Connecticut state colleges and universities that could be replicated across the Connecticut public higher education system.

Post-High School Employment/Vocational Services

Employment is a major barrier for individuals with ASD transitioning to independence. A key to employment for some individuals with ASD is gaining access to vocational programs, which currently appears to be challenging for many families. There may be more that transition coordinators can do to assist students and parents in this area, including providing transitional services-only to promote vocational training and opportunities.

Since many of the jobs will at least initially be part-time, transition coordinators need to partner with and prepare families to take on the responsibilities and added burdens created by their son or daughter’s employment schedule and related transportation needs. While in high school, students and parents can be encouraged by transition coordinators to participate in summer youth employment programs, an experience seen as critical to future employment.

The Department of Rehabilitation Services is the primary state agency available to assist individuals with disabilities to become competitively employed. However, there was confusion expressed during study interviews and survey responses regarding who was potentially eligible for services from BRS. There is also some misunderstanding by parents regarding the impact of employment--including part-time employment--on benefits, such as social security.

Although the Department of Developmental Services is placing increased emphasis on employment for its clients, there is currently no centralized position dedicated to the promotion of employment. Also, different state agencies define “competitive employment” in different ways, and, depending on the definition, the number of employed individuals can vary significantly. As a state, there needs to be a shared definition if progress on increasing competitive employment is to be assessed for individuals with ASD or other disabilities.

Post-High School Independent Living

There are different housing options for individuals with ASD depending on a number of factors including the individual's level of independence, family and/or individual's preference, financial considerations, and availability.

Similar to the concerns for individuals with intellectual disabilities, persons with ASD often remain in their family homes far into their adult years with aging caregivers. Long waiting lists and limited funding prevents residential programs from serving all eligible clients. Without state and federal funds for residential services, families must pay for housing and residential supports on their own, out-of-pocket.

As a result, new and creative ways of developing housing solutions must be examined to address the oncoming wave of residential demand for the growing number of individuals with ASD and their aging caregivers. Navigating for resources on traditional and alternative residential models can be daunting for families. As a first step, a workgroup of knowledgeable professionals and advocates should be convened to examine present and future statewide affordable supportive housing needs and options for the state population with ASD. The workgroup's objective would be to establish short and long-term goals for housing strategies for the state to consider.

Supports for Independent Living

Supports are a significant part of independent living and self-determination. With proper supports, individuals may live on their own, be employed, and participate in community activities. As the prevalence of ASD rises, demand for support and services are expected to grow. This growth will present significant challenges. State programs are already face lengthening waitlists.

When youth with ASD leave the school-based entitlement system, if they do not have an intellectual disability or a mental health diagnosis, they may fall off the proverbial special education cliff when they turn 21. This may result in extreme delay or disruptions of ongoing training and services youth receive while in school and continue to need while awaiting eligibility-based services. Without resources or necessary skills, these individuals may languish on wait lists, with little to no work and few social programs.

Proper assessments are important to ensure an appropriate level and type of services. Part of the challenge and expense of services may be that services are not always well-matched to the particular needs of the population of individuals with ASD. The lack of a qualified or trained workforce together with a 'one size fits all' approach may leave segments of the population with ASD poorly served. Without proper support systems, persons with ASD may likely appear in more costly support systems such as mental health facilities, emergency rooms, crisis placements, or correctional facilities.

System Infrastructure

The growing population of youth and young adults with ASD who are leaving school with substantial service needs will exacerbate the demands on an already-stressed adult service system. Those demands will continue in the coming years due to the increasing number of young people identified with ASD in early childhood who are progressing through school and into the adult services system.

Coordination is a crucial component for all transition efforts. This requires communication and collaboration on a number of levels: between various state agencies/divisions; between state agencies and local and federal agencies; and between state agencies and non-governmental groups. A strong solid infrastructure must be in place if the state is to meet the demand for ASD services, which already exceeds capacity.

There is variation in the level of coordination for transition efforts. Several efforts to strengthen coordination are underway. However, no single entity is charged with serving and tracking all individuals with ASD. It is crucial for different programs and agencies to have a centralized mechanism to communicate and coordinate so they can be aware of services being provided by other state agencies. This better enables them to provide the maximum level of service possible to the individuals in need. With reliable information, baseline data can be established on needs around the state, benchmarks developed and trends monitored. A monitoring system could inform policy, funding, resource allocation, research decisions, and the public at large.

Training and credentialing will promote more uniform standards of care statewide. The use of interagency agreements for clarification of roles and responsibilities, communication, information sharing, and reporting of progress and outcomes must be considered. For successful collaboration, the involved groups must have a shared vision, leadership, a variety of partnerships, joint planning, strong communication structure, consistent training, and sustainability. Additional partnerships with public and private entities will help create a comprehensive multisystem statewide asset map of available services and supports.

When implemented, there are a number of new state initiatives and recent developments such as the Medicaid State Plan Amendment that will go far to improve and expand the needed services for the population with ASD. Meeting the needs of individuals with ASD is a complex and expensive undertaking that will require new funding when state resources are scarce. Nevertheless, there are a number of challenges, barriers, and gaps identified throughout this report that need additional attention.

PRI Committee Staff Recommendations

Based on this study of transitional services for youth and young adults with ASD, committee staff makes 34 recommendations:

RELATED TO TRANSITIONAL SERVICES DURING HIGH SCHOOL

- 1. The Connecticut State Department of Education (CSDE) should promote a best practice of establishing individualized education program (IEP) goals related to transition to adult life sooner, prior to high school.**
- 2. CSDE should provide training to transition coordinators on the development of more realistic and specific IEP post-school goals.**
- 3. CSDE should require school districts to use the Secondary Transition Planning IEP Checklist.**
- 4. CSDE should formally monitor implementation of the Student Success Plan.**
- 5. CSDE shall monitor the requirement for parents of high school students with ASD (and other disabilities) to be provided with a copy/website link to “Building a Bridge” or other transition-related materials by their local school districts, and add this requirement to the Secondary Transition Planning IEP Checklist.**
 - CSDE should assess reasons why parents are questioning the usefulness of “Building a Bridge” or other transition-related materials they may have received from their school districts, and revise the materials accordingly.**
- 6. CSDE shall develop and distribute a written Parents Bill of Rights to all parents of students with ASD (and other disabilities). This single-page document shall inform parents of the following:**
 - They have the option to request consideration of provision of transitional services-only (18-21 programs) for their son or daughter.**
 - They are entitled to receive a copy of “Building a Bridge” or other transition-related materials.**
 - Their son or daughter is required to have a Student Success Plan beginning in sixth grade and parents must be given a copy of this plan (which addresses transition to adult life).**

- Their son or daughter will benefit from realistic and specific IEP post-school goals.
7. The Autism Spectrum Disorder Advisory Council (ASDAC) should identify possible strategies to improve interactions between the DDS Division of Autism Spectrum Services, DMHAS, and DORS/BRS with both transition coordinators and parents.
 8. CSDE should consider the feasibility of recommending a law similar to the Massachusetts “Turning22Law”, requiring the identification of which state agency is best able to support the student after he or she exits high school.

RELATED TO POSTSECONDARY EDUCATION

9. CSDE should offer training to transition coordinators on the development of IEP transition goals related to self-advocacy (including accessing college disabilities office), time management/organization, and study skills for college-bound high school students with ASD.
10. For college-bound students with ASD, CSDE should consider incorporating decreasing reliance on supports prior to high school graduation into IEP or Student Success Plan.
11. CSDE should publicize the advantages of a college immersion experience.
12. The Board of Regents should consider replicating the Step Forward programs at other Connecticut community colleges.
13. The Board of Regents should consider replicating the Disability Resource Center model at Southern Connecticut State University to other Connecticut State Universities.
14. The University of Connecticut should consider replicating the Beyond Access Program at other University of Connecticut campuses.

RELATED TO POST-HIGH SCHOOL EMPLOYMENT/VOCATIONAL SERVICES

15. The Autism Spectrum Disorder Advisory Council (ASDAC) should explore ways to increase accessibility/availability of vocational programs for individuals with ASD.
16. DORS should develop an information campaign clarifying who may be eligible for BRS services.
17. Local school districts should provide transitional services for students interested in vocational training and competitive employment.
18. DORS should promote the advantages of at least part-time employment.

19. In collaboration with other state agencies, DORS should take the lead on developing an informational campaign regarding the impact of employment on benefits.
20. CSDE should work with transition coordinators on the need to address advantages and logistics of youth employment with parents/caregivers.
21. CSDE and BRS should encourage families and students with ASD to experience summer employment while in high school.
22. DDS should consider establishing a full-time position dedicated to the promotion of employment.
23. DORS should develop a shared definition of “competitive employment” across state agencies.

RELATED TO POST-HIGH SCHOOL INDEPENDENT LIVING

24. DDS should consider establishing a housing coordinator position for the autism division. Within available resources, the housing coordinator should assist the resource specialists working with wait list families to develop an individual housing plan.
25. The autism division should establish a one-stop housing resource for individuals with ASD.
26. The Autism Spectrum Disorder Advisory Council (ASDAC) should establish a subcommittee on housing to produce a report on the present and future ASD residential needs, best practice guidelines, and plan of action proposals.

RELATED TO SUPPORTS FOR INDEPENDENT LIVING

27. The Department of Social Services, in coordination with the DDS autism division, should examine the feasibility of providing children served in the HUSKY B program with the same coverage being considered under the Medicaid State Plan amendment.
28. A survey of the individuals and families on the autism waiver wait list should be conducted to compile basic information regarding their immediate and upcoming needs and their levels of existing resources and support.
29. The Autism Spectrum Disorder Advisory Council should consider establishing additional subcommittees on transportation and life skills.
30. DDS should consider creating an interim family grant program for the ‘ASD only’ population similar to the one already established for individuals with intellectual disabilities to help offset disability- related expenses.

- 31. The Connecticut legislature should consider passing its own Achieving a Better Life Experience (ABLE) act modeled after the federal legislation.**
- 32. DDS shall, within available appropriations, consider hiring additional ASD resource specialists.**
- 33. The DDS autism division should have access to education and transition advisors for the ‘ASD only’ population. Upon request and within availability, these advisors could provide guidance or referral to other state and/or community-based supports to individuals and families on the wait list.**

RELATED TO SYSTEM INFRASTRUCTURE

34. The DDS autism division, as the state’s lead agency for autism, should:

- Establish and maintain an integrated confidential data system that facilitates shared agency information.**
- Serve as a one-stop resource regarding statewide resources, assessments, lifespan services, waivers, healthcare, housing, transportation, employment, education, and community supports for individuals with ASD.**
- Keep exploring opportunities to further develop and strengthen the system infrastructure through coordination of state-level work on ASD.**
- Identify funding sources that are flexible, diversified (public and private, state and federal), and sustainable that can be used in a variety of ways to meet the ASD population’s unique, and evolving needs.**
- Promote outreach activities that bring together significant stakeholders and interested parties.**
- Continue to develop an ASD training infrastructure.**
- Prepare an annual progress report listing accomplishments and activities of the division and council.**

Introduction

Transition Services for Autism Spectrum Disorder

Autism spectrum disorder (ASD) is the fastest growing group of developmental disabilities. The most recent prevalence estimates from the federal Centers for Disease Control and Prevention (CDC) are that 1 in 68 children in the United States have ASD. This prevalence is an emerging crisis for families and state agency services. There is an evolving generation of children becoming adults who will need specialized secondary transitional services, postsecondary education programs, day programs, employment supports and vocational training, family supports, and residential services.

Presently, the demand continues to far exceed the available resources, leaving large numbers of individuals with ASD and their families in service and financial uncertainty. In order to serve this population, there must be an expansion and improvement of traditional services as well as the development of new and creative alternative options.

Study Focus

In May 2014, the Legislative Program Review and Investigations Committee (PRI) authorized a study to identify the needs of, and services available for, individuals with ASD, focusing on the transition from secondary school completion to young adulthood (up to age 25).

As part of the study scope, the adequacy and accessibility of transitional resources available from state agencies and other organizations were reviewed. In particular, the study examined transitional planning during secondary education, programs and services following secondary education, levels of independence attained, and barriers to independence.

Given the broad range of the autism spectrum, individuals with ASD are likely to have varying needs throughout their lifetimes in a myriad of domains such as education, vocational training and support, medical and behavioral health, activities of daily living, socialization, and community living, including financial and housing supports. Services may be accessed through a combination of public and private agencies and formal and informal supports, which are paid for by a variety of federal, state, private, and family resources.

Methodology

Over the course of the study, PRI committee staff used the methods described below to gather information related to transitional services for youth and young adults with ASD.

Literature review. The literature included research on other state models and approaches. Also examined were research studies on autism prevalence and needs of the population related to education, employment, housing, and independent living. Reports produced by the Office of Legislative Research and statutorily required reports were also reviewed.

Interviews with state agency personnel, advocacy groups, and other interested parties. PRI committee staff had ongoing meetings on a number of cross-cutting topics with the following Connecticut state departments: Education (CSDE), Developmental Services (DDS), Rehabilitation Services (DORS), and Mental Health and Addiction Services (DMHAS). PRI committee staff also met with other governmental bodies including the Department of Public Health, Governor's Liaison to the Disability Community, Office of Protection and Advocacy for Persons with Disabilities, and state legislators.

Interviews were also conducted with representatives of several state and national advocacy groups, parents of children with ASD, employers, service providers, and other interested stakeholders and experts.

Public hearing. A public hearing was also held on September 24, 2014, to obtain input and comments on the study topic. Approximately two dozen individuals testified representing state agencies, organizations, parents, and other key stakeholder groups.

Tours and visits to public and private transition programs, academies, universities, and facilities with services available to the ASD population. The committee staff visited transitional academies for 18-21 year old high school students and private residential programs serving youth and young adults with ASD. The committee staff also toured the employment training facility operated by Walgreens, which employs a substantial number of individuals with disabilities in Windsor, Connecticut.

Presence at autism-related fairs and meetings. The committee staff participated in the annual autism resource fair sponsored by one of the largest advocacy organizations in the state. In addition, PRI staff reviewed material from the ASD conference at the University of Saint Joseph, and attended Autism Awareness Day at the Capitol.

Committee staff was also in attendance at autism advisory council meetings and various other taskforce, forums, and hearings on the needs of individuals with developmental disabilities such as the M.O.R.E. sub-committee on special education.

Original data collection from transition coordinators and parents. While some surveys had previously been conducted by CSDE, none had been specific to transitional services for youth and young adults with ASD. PRI staff determined that the best way to receive input from as many transition coordinators as possible was to develop and administer a survey relevant to the current study topic.

Similarly, although a number of surveys of parents of children with disabilities had been conducted by CSDE and advocacy organizations in the past, no findings had been reported that were specific to transitional services for youth and young adults with ASD. PRI staff determined that the best way to receive input from as many parents as possible was to develop and administer a survey relevant to the current study topic. The PRI survey of parents was especially important as it was an attempt to reach not only parents of children currently in high school, but also parents with sons and daughters no longer in high school, up to age 25 years old. A Spanish

translation, paper, and online surveys were made available in an effort to reach as many parents as possible.

Analysis of data provided by state agencies. A primary goal for PRI committee staff was to examine the services and programs available for the transition of youth and young adults with ASD and to analyze potential gaps between transitional needs and resources. To accomplish this, PRI staff requested and received data collected by the four major state agencies (CSDE, DORS, DDS, and DMHAS) involved with the study’s target population.

Report Organization

This report is organized into ten chapters and multiple appendices. Each chapter may be read as a standalone document. Chapters V through X contain the committee staff recommendations. Due to the size and scope of the report, the following table serves as a roadmap for where to turn depending on the reader’s interest.

If you are interested in:	Then focus on:
Overview of autism and transition planning	Chapter I and II
Results of the PRI staff survey of 174 transition coordinators and professionals	Chapter III
Results of the PRI staff survey of 236 parents of children with ASD aged 15-25	Chapter IV
Description of transitional services received by students with ASD during the high school years	Chapter V
Description of transitional services and preparation for college-bound high school student with ASD	Chapter VI
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Concerns and issues related to housing and residential supports for individuals with ASD	Chapter VIII
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Chapter I: Overview of Autism Spectrum Disorder

Overview

This chapter provides a general overview of autism spectrum disorder (ASD). Specifically, it offers brief descriptions on how ASD is defined and diagnosed, ASD prevalence and current trends in Connecticut, and the major state entities involved in the transitioning of youth and young adults with ASD into the adult state services system.

What is Autism Spectrum Disorder?

Autism is part of a group of complex developmental disabilities of neurobiological origin that were previously separate disorders sharing many core characteristics that now are under the broader umbrella term known as Autism Spectrum Disorder (ASD). Although there are distinctions, the terms autism and ASD are often used interchangeably.

As a developmental disorder, ASD usually presents during early childhood and is expected to persist indefinitely. Developmental disabilities can affect a person's brain, body, or both. Individuals with ASD are often characterized by difficulty in social interactions or relating to others. They may have developmental difficulties in verbal and non-verbal communication. They may also exhibit repetitive behavior or movements. As a spectrum disorder, the symptoms associated with ASD may present along a continuum of intensity and in many combinations. Therefore, individuals with ASD vary widely in ability and presentation.

Presentation of ASD. While not always visible, the deficits from ASD may contribute to difficulties with learning, self-care, mobility, and being able to live or work independently. Individuals may exhibit an intellectual disability or be extremely gifted in their intellectual or academic accomplishments. They may require minimal to no supports or require substantial assistance in daily functioning. ASD is a lifelong condition; however, there is research evidence that some therapeutic approaches, especially with early intervention, may help lessen some of the symptoms or manifestations. Symptoms may improve with treatment but will almost always require continuous services and ancillary supports throughout an individual's lifetime.

As noted above, ASD is usually characterized by deficits in social interactions, communication, and repetitive behaviors. Additionally, characteristics such as resistance to changes in routine or environment, sensitivity to sensory stimulation, and stereotypical movements may be seen in varying degrees. Strengths may include rote memorization, visual thinking, long-term memory, and focused attention to detail in preferred tasks that are often complex in nature. Table I-1 lists some of the common ASD characteristics that may vary in severity.

Table I-1. Some Common Characteristics of ASD
<ul style="list-style-type: none"> • Difficulty understanding language and social cues • Excessive or minimal speech • Concrete thinker, often has difficulty with abstract concepts • Difficulty relating to others • Social awkwardness • Intense interests or concentration • Repetitive behaviors such as pacing, rocking or hand flapping • Sensitivity to light, sound, smell or other sensory issues • Anxiety or abnormal fears • Complex and sometimes challenging behaviors • Difficulty managing transitions or changes in routine • Strong visual skills • Excellent memory for facts and statistics • Adherence to rules and honesty to a fault • Musical, mathematical, technological, artistic ability or interest
Source: Autism Speaks

How is ASD Diagnosed?

ASD is diagnosed on the basis of behavioral and developmental features. There is a clinical diagnosis and an educational definition for ASD. The clinical diagnosis is the medical scientific diagnosis. The educational classification is used to determine whether autism or ASD impacts a student’s educational ability.

Educational classification. Autism, as defined by the federal Individuals with Disabilities Education Act (IDEA), refers to a developmental disability significantly affecting verbal and non-verbal communication and social interaction that adversely affects a child’s educational performance. Meeting the educational definition of ASD typically makes a child eligible for special education services. Students with ASD often have academic struggles such as:

- Difficulty following directions
- Inability to communicate
- Disinterest
- Disruptive behavioral problems

Given the deficits, ASD may adversely impact a child's performance in the educational process. However, a child with ASD may respond well with appropriate supports and accommodations tailored to meet his or her individual needs. (This is explained further in the next chapter.) An educational determination is made by a multidisciplinary evaluation team of various school professionals. The evaluation results are reviewed by a team of qualified professionals and the parents to determine whether a student qualifies for special education and related services under IDEA.

Clinical diagnosis. The principal clinical source for diagnosing ASD is the Diagnostic and Statistical Manual (DSM) prepared by the American Psychiatric Association. In May 2013, DSM-5 was released and replaced DSM-4. One of the significant changes, as mentioned earlier, is that a number of autistic conditions that were previously separate are now under one label known as ASD.¹

ASD typically appears during the first three years of life and early screening is critical. Parents are usually the first to notice if their child is not reaching developmental milestones or seeing unusual behavior in their child. However, a formal diagnosis is usually provided by a pediatrician, psychologist, child psychiatrist, or neurologist.

The American Academy of Pediatrics recommends a number of different screening tools and checklists that can be used by professionals to determine whether a child should be further evaluated. Many different instruments can be used in ASD diagnosis depending upon the chronological age and developmental phase of the person being assessed.

Diagnosis is based on observation of behaviors and abilities. There is no specific medical test (e.g., blood test, CT scan, or X-ray) that can diagnose ASD but medical tests may be conducted to rule out medical causes for symptoms or other disorders.

ASD can also be diagnosed in adulthood, often in relation to learning, social, or emotional difficulties. However, it is usually more difficult if there is no childhood history available or if the individual may have been misdiagnosed previously with another condition. Autism may also be present along with other conditions, other medical issues, or mental health concerns.

Co-occurring conditions. People with ASD often have late developing nervous systems and may have sensory disorders leading to issues with hearing, touch, taste, or sight. There may be additional medical problems such as epilepsy, food allergies, or gastro-intestinal issues.

Individuals with ASD are more likely to also have an intellectual disability (ID) than the general population. According to the federal Centers for Disease Control and Prevention (CDC), the proportion of children with ASD who also have a cognitive impairment (i.e., IQ less than 70)

¹ An ASD diagnosis now includes autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's syndrome.

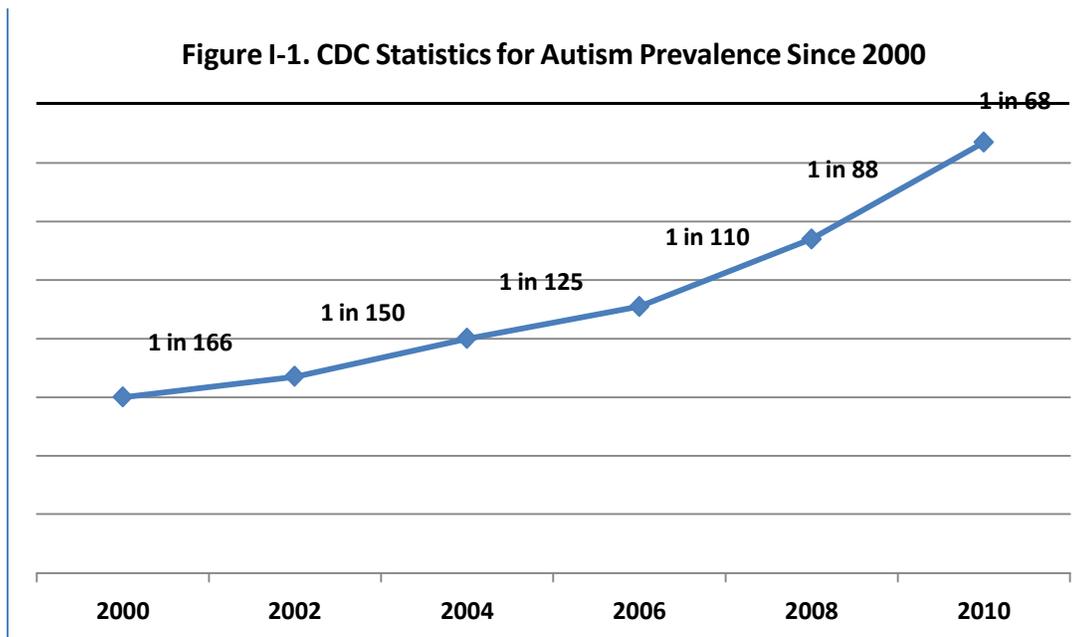
ranges between 33 to 58 percent.² Some individuals, particularly those with high-functioning ASD or Asperger’s syndrome have above-average IQs.

Mental health issues can also be present such as obsessive compulsive disorder, anxiety, or depression. Some research suggests children and adults with ASD have a higher rate of psychiatric disorders than that of the general population.³ As a result, some of the co-existing issues may make it more difficult to isolate and diagnose ASD from these other conditions. Therefore, a multidisciplinary evaluation is the best way to determine a diagnosis of ASD.

Causes and cure. Although research continues on several theories, ASD has no single cause or any known cure. However, there is emerging evidence suggesting intensive early intervention may help lessen behavior and symptoms so that individuals may no longer meet ASD criteria.⁴

How Prevalent is ASD?

The prevalence of ASD has been steadily increasing since the 1990s. The CDC has been monitoring this trend for a number of years.⁵ According to CDC statistics, there has been a significant increase since 2000, shown in Figure I-1. In 2000, the autism rate among 8 year olds was 1 in 166; the most recent CDC report issued in May 2014 estimates 1 in 68.



²Centers for Disease Control and Prevention, Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network (2002), page 10

³The Lancet, Volume 381, Issue 9875, Pages 1371 - 1379, 20 April 2013

⁴Ruth Padawer, “The Kids Who Beat Autism”, New York Times, July 31, 2014

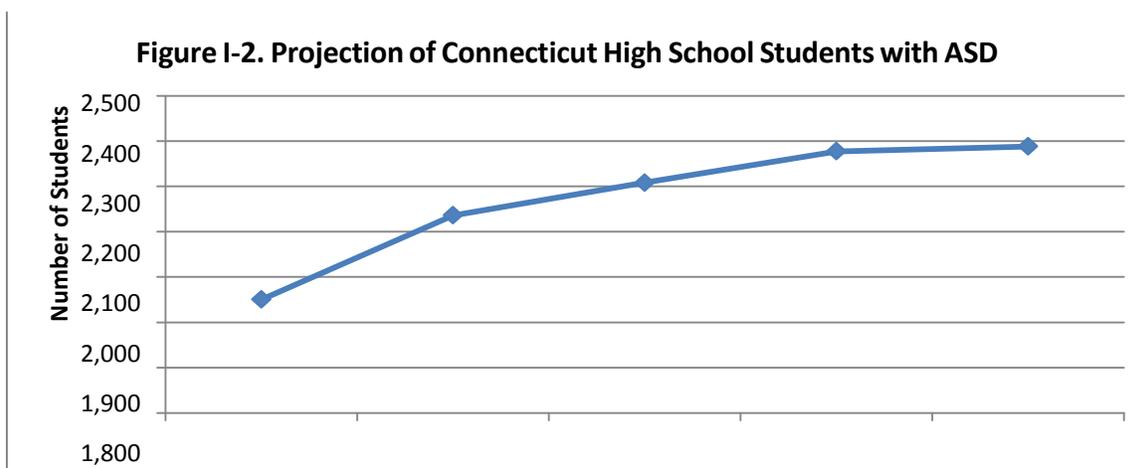
⁵ The current approach is based on data collected on 8-year-olds in multiple communities across the country. Researchers review medical and education records for the children to identify any existing diagnosis of autism or symptoms that suggest a child is on the spectrum.

Autism is almost five times more common in boys. It occurs in all racial, ethnic, and socio-economic groups. To date, there is no definitive cause of autism although several theories exist. It is thought that the increase in prevalence may be due to a number of factors including more awareness, more screening and testing, and more actual cases.

ASD Trends in Connecticut

While the actual number of all individuals with ASD in Connecticut is not known or tracked, PRI committee staff took the approach used by a recent Autism Taskforce Report to determine a state estimate. Using the most recent CDC prevalence rate and Connecticut census data – it is estimated that 52,636 individuals across all ages have ASD in the state. Close to 12,000 of them are under the age of 18.

High school students with ASD. During the school year 2013-14, there were 70,785 students in Connecticut with disabilities. According to the Connecticut State Department of Education (CSDE), approximately 7,729 (11 percent) had ASD. Of these students, 2,241 were in grades 9 through 12, with 794 in 12th grade. Figure I-2 shows the anticipated growth in the number of high school students with ASD in the coming years.



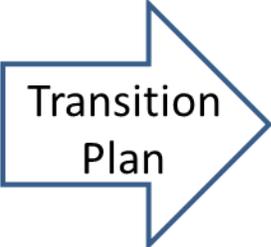
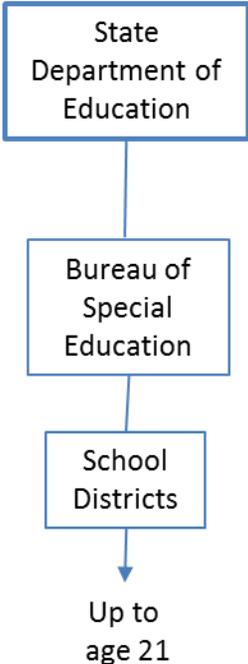
As illustrated in Figure I-2, there will be a significant increase of high school students with ASD in the next few years. These projected figures are conservative estimates based on the existing student population data where an ASD diagnosis is currently known or documented. It is conservative in that it does not account for youth who have yet to be diagnosed.

Major State Agencies Involved

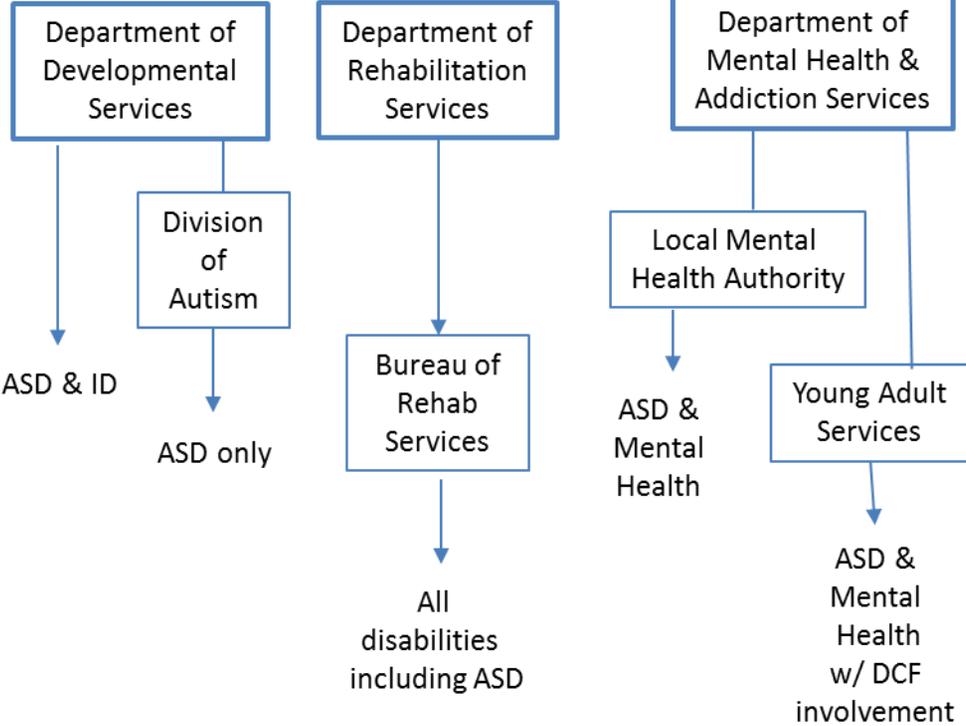
Figure I-3 illustrates the major state agencies involved with the population with ASD. There are three points demonstrated with this graphic. First, there is a distinction between entitlement and eligibility-based services. Pursuant to state and federal law, students with disabilities including ASD are entitled to free and appropriate education up to age 21. (This will be further explained in Chapter II.)

Figure I-3. Major State Agency Involvement for ASD Population

ENTITLEMENT



ELIGIBILITY BASED ADULT SERVICES



Once students graduate, entitlement services end and students may be referred to adult services. Those services are eligibility-based and provided within available appropriation. The second point of the graphic is to highlight the transition plan between school entitlement and adult services. Often parents and professionals refer to transitioning as “falling off a cliff.” This is the cliff - not being prepared for what happens after school ends. Finally, the graphic illustrates there are various state agencies involved that differ in who is served depending on either age and whether there is a co-existing diagnosis.

Below is a brief description of each of the major state agencies involved in transitioning youth and young adults with ASD.

Connecticut State Department of Education (CSDE). The Bureau of Special Education within CSDE works with school districts to implement various federal and state laws to ensure students receive the educational services they are entitled to up to age 21. Services must be provided in the least restrictive environment. More on the role and responsibilities of CSDE and local school districts is described in the next chapter.

Department of Developmental Services (DDS). The department primarily serves individuals with intellectual disabilities, defined in state law as having an IQ under 70. The department also serves individuals with ASD in two different ways. Individuals who have both an intellectual disability (IQ under 70) and co-existing ASD are considered part of the general intellectual disability population at DDS. Individuals with ‘ASD only’ with no intellectual disability are serviced by Division of Autism Spectrum Services within DDS.

Division of Autism Spectrum Services. Often referred to as the DDS autism division, the division was created in 2011 to serve individuals with ‘ASD only’ – without any co-existing diagnosis of ID. The division’s primary responsibility is to manage its Medicaid Autism Spectrum Waiver services program specifically for individuals with ‘ASD only’. The waiver has limited enrollment with capped funding for services.

ASD Advisory Council (ASDAC). The council consists of 23 professionals, state agency staff, legislators, parents, and self-advocates. It was established in 2013 to expand and improve the statewide delivery of ASD services for individuals across the lifespan. The goal is to develop a system that is accessible, affordable, accountable, and offers quality services. The council examines the use of promising and best evidence-based practices; educates professionals and the community; facilitates interagency collaboration; and utilizes data-driven decision-making to evaluate effectiveness.

Department of Mental Health and Addiction Services (DMHAS). The primary responsibility of DMHAS is to assist individuals with mental health and substance abuse issues. The department will serve individuals with ASD if they are aged 18 and older and also have a co-existing mental or behavioral health condition.

The department manages and/or funds local mental health authorities (LMHAs) both private non-profit and state-operated offering a wide range of therapeutic programs and crisis intervention services throughout the state. There are also many contracted agencies through each

of the LMHAs. In addition, DMHAS operates inpatient treatment facilities for persons with severe addiction and/or psychiatric problems.

Young Adult Services (YAS). The department has a program especially for young adults aged 18 to 25 who have had a Department of Children and Families (DCF) connection or involvement. The program offers a supportive educational/employment component for individuals who are being transferred from DCF and require assistance transitioning to adult life.

YAS offers psychiatric services, case management, clinical services, nursing, trauma and crisis services, assessment and consultation services, rehabilitation services, linkage to vocational and educational services, and residential or housing support. Services are provided through a network of state operated and contracted private non-profit agencies.

Department of Rehabilitation Services (DORS). Another agency involved with the population with ASD is the Department of Rehabilitation Services (DORS) which uses federal and state funds to help individuals with cognitive, sensory, physical, or emotional disabilities find employment and achieve increased independence. Within DORS, the Bureau of Rehabilitation Services (BRS) provides time-limited services to individuals who are competitively employable. DORS services are not entitlements; therefore, not all students receiving special education services can receive services.

Other state agencies. It is important to note that individuals with ASD and their families may also seek adult services or support from an array of other state agencies. Among these agencies include the Departments of Social Services (DSS), Housing (DOH), Public Health (DPH), and Labor (DOL). However, they are aimed at the whole population of disabled and/or low-income individuals and do not or cannot separately track or monitor services for individuals with ASD from all disabilities groups. Particular programs or services, where relevant, are mentioned throughout the report.

ASD Studies and Taskforces

There have been a number of workgroups, taskforces, and commission studies conducted on autism issues in Connecticut.

Education of Children with Autism. In 1996, the Connecticut State Department of Education convened a task force on the educational needs of children with autism. Based upon its findings, the task force prepared a "Report of the Connecticut Task Force on the Issues for the Education of Children with Autism," which was revised in 1998. In 2005, the report was updated and re-titled to "Guidelines for the Identification and Education of Children and Youth with Autism." Known as the guidelines report, the 2005 revision serves as a best practices guide to educating children with autism.

Autism Pilot Program and Evaluation study. In 2006, the legislature authorized an autism pilot program to provide coordinated support and services, including case management, to people with ASD who did not also have mental retardation (i.e., IQs above 70). The pilot served up to 50 people until 2008 after which a statutorily mandated evaluation was conducted. DDS

engaged the University of Connecticut Health Center to evaluate the program and prepare a report with recommendations concerning a system addressing the needs of persons with ASD.

Autism Services in Connecticut Feasibility study. In 2011, the legislature requested a study of issues related to the needs of persons with ASD, including the feasibility of a center for autism and developmental disabilities. A mix of state agencies, educators, professionals and advocacy groups reviewed state agency data, discussed data limitations, and identified gaps in the service system. The report resulted in a number of short and long-term goals to address certain gaps. After the report was completed in 2012, members of the workgroup began a strategy for implementation of the study's recommendations in coordination with the efforts of the ASDAC council. These are explained in their relevant subject matter throughout this report.

Connecticut Children's Behavioral Health Plan. After the 2012 mass shooting tragedy in Newtown, legislation was enacted calling for comprehensive reforms to overhaul the state's emergency and long-term behavioral health care system. The mandated evaluation covered behavioral health services for all youth and young adults and builds upon other recent initiatives or efforts still underway. Part of this evaluation was pursuant to P.A. 13-178 requiring DCF to prepare a long-term plan to reform the children's behavioral health system. In October 2014, a final report was issued including four steps specific to upgrading treatment for youth with ASD.

The plan proposes immediate increases in emergency care capacity with specific accommodations for individuals with ASD. There were also recommendations for long-term changes. One change was the development of a Medicaid State Plan amendment clarifying provision of medically necessary treatment for children with ASD up to age 21. (This is discussed further in Chapter IX.) Another proposal creates up to three teams of specially trained practitioners to address the needs of youth with ASD receiving care in psychiatric residential treatment facilities and other settings. The plan also proposes an in-home care program to divert adolescents with ASD aged 13-21 with severely challenging behaviors from inpatient settings. A fourth recommendation is the designation of three specialized inpatient beds for individuals with ASD and co-occurring psychiatric disorder experiencing intense behavior challenges.

Medicaid and Medicaid Waiver Services

Not all families can afford to privately support an adult with significant behavioral and/or medical needs. Because individuals with ASD have a disability and usually have limited earned income, they typically qualify for the government benefits available to the general population with low incomes. The largest benefit program is Medicaid and Medicaid waivers services.

Medicaid. Medicaid is a government-funded health insurance for individuals with low incomes and limited assets. To qualify for Medicaid, individuals must meet income and assets requirements and fit into specific categories of aged, blind, or disabled. This federal program provides funding for medically necessary services and is paid directly to the service provider. Connecticut has a 50 percent funding match for these services. Services covered may range from long-term services such institutional care to traditionally non-medical services like respite or case management. Each state establishes its own Medicaid state plan and sets own guidelines with federal approval.

Waiver services. A different way to cover other non-Medicaid state plan services is through a waiver program. The federal government allows states to “waive” some Medicaid rules in order to serve individuals, who would otherwise need institutional care, to remain or be served in the community or own home. Waivers are usually approved for a five-year period. Typically, waivers are capped at set dollar amounts and limit the number of people enrolled.

The federal government reimburses Connecticut 50 percent of the cost of services and supports for people enrolled in the waiver. This allows states to fund a program that otherwise would be unaffordable. The reimbursement is received through an individual’s Medicaid number; therefore, a person must be enrolled in Medicaid to participate. Connecticut has several Medicaid waiver programs. Currently, there are two waivers specific for the ASD population. These are explained in more detail in Chapter IX.

Chapter II: Overview of Transition Planning

Federal and State Laws Requiring Transition Planning

According to the Connecticut State Department of Education (CSDE), the purpose of transition planning is to assist students in becoming the most independent, responsible, self-determined individuals they can be.⁶ Secondary transition age is formally considered to be ages 16-21. As will be described in greater detail in this chapter, transition planning mandates a focus on both postsecondary education or training, and employment/career (independent living is a third optional goal of transition planning).

This chapter describes federal and state requirements for the provision of transitional services for youth and young adults with special needs, including those with Autism Spectrum Disorder. Both federal and state laws define “special education” as a specially designed instruction, developed in accordance with federal and state regulations, to meet the needs of each exceptional child, including related services recommended by the child’s planning and placement team. In Connecticut, special education—including transitional services—must be provided for children who require it from age three until they either graduate from high school or turn 21 years of age.

Federal Laws

There are three federal laws that pertain to transitional services for youth and young adults with ASD: the Individuals with Disabilities Education Act (IDEA); the Rehabilitation Act; and the Americans with Disabilities Act (ADA). The relevance to each law to this population are now described.

IDEA. The primary federal law impacting transitional services for youth and young adults with Autism Spectrum Disorder is the Individuals with Disabilities Education Act, or IDEA of 2004. Originally enacted in 1975, the intent of the law was to ensure that children with disabilities have the opportunity to receive a free appropriate public education, just like other children. The IDEA is also referred to as the federal special education law (P.L. 108-446), and is administered by the U.S. Department of Education Office of Special Education Programs. One of the stated objectives of IDEA is to prepare children with disabilities to “lead productive and independent adult lives, to the maximum extent possible” (U.S.C. 1400(c)(5)(A)(ii)).

IDEA has four parts:

- Part A: General Provisions (includes definitions of children with disabilities, free appropriate public education, and transition services);
- Part B: Assistance for the Education of All Children with Disabilities (special education funds for students in grades K-12);

⁶ Topic Brief on Post-School Outcome Goal Statements Frequently Asked Questions, July 2009, State Department of Education online library.

- Part C: Infants and Toddlers with Disabilities (requires early intervention services for children age birth to three⁷); and
- Part D: National Activities to Improve the Education of Children with Disabilities (includes State Program Improvement Grants for Children with Disabilities, and coordinated research, personnel preparation, technical assistance, support, and dissemination of information).

The majority of federal funds for special education are provided to Connecticut through IDEA Part B. In FY 13, Connecticut distributed \$119.88 million in IDEA Part B funds to local school districts.

Relevant definitions contained within IDEA

Autism. A developmental disability significantly affecting verbal and nonverbal communication and social interaction, autism is generally evident before age three, that adversely affects a child’s educational performance. Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

Free Appropriate Public Education. The IDEA requires public schools to provide a Free Appropriate Public Education (FAPE) to students with specific disabilities including autism.⁸ FAPE means the provision of special education and related services at public expense that meet the standards of the state education agency. FAPE includes an appropriate preschool, elementary school, and secondary school education, as outlined in the child’s individual education program (IEP) plan.

Transition services. “Transition services” are defined in IDEA as a coordinated set of activities designed within a results-oriented process for a student with a disability that:

- are focused on improving the academic and functional achievement of the student to facilitate the transition from secondary school to post-school activities such as vocational education, integrated employment (including supported employment), adult services, and independent living;
- are based on the needs of the individual student, and take into consideration strengths, preferences, and interests; and
- include instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and as appropriate, daily living skills and functional vocational evaluation.

⁷ In Connecticut, all children referred to the Birth to Three program who are 16 months old or older, are screened for ASD.

⁸ The other disabilities are: intellectual disability, hearing impairment, speech or language impairment, visual impairment, emotional disturbance, orthopedic impairment, other health impairment (such as attention deficit disorder), special learning disability, deaf-blindness, traumatic brain injury, developmental delay (ages 3-5 only), and multiple disabilities.

Requirements for provision of transitional services. In requiring students to receive transitional services, IDEA states, “As the graduation rates for children with disabilities continue to climb, providing effective transition services to promote successful post-school employment or education is an important measure of accountability for children with disabilities.”

Efforts to provide transitional services are documented in the student’s Individualized Education Program (IEP). As for all special education students, the IEP process must include transition planning no later than age 16, or earlier if determined appropriate by the Planning and Placement Team (PPT).

In 2003, Connecticut adopted the IDEA standard for providing transitional services. The IEP Manual and Forms of the CSDE Bureau of Special Education, Fifth Revision December 2013, states that IEP transition plans must have at least one post-school outcome goal statement (PSOGS)⁹ related to postsecondary education or training, and at least one post-school outcome goal related to employment. If independent living is appropriate, then another goal should be related to that outcome, or preparation for that outcome. As required by IDEA and as stated in the CSDE IEP manual, the PSOGs are to be written as measurable statements that are to be achieved after leaving secondary school.

IDEA requirement of a State Performance Plan. Also required by IDEA, each state must have a State Performance Plan (SPP) that is used to assess efforts to meet requirements of the Act. The SPP requires each state to report annually to the U.S. Department of Education Office of Special Education Programs (OSEP) on 20 indicators (Appendix F lists all 20 indicators on the State Performance Plan). Indicator 5, for example, assesses the percent of time students are spending in the regular classroom as opposed to alternative settings away from the mainstream. Indicator 8 measures the extent to which parents report that the school facilitates parental involvement. Two of the indicators (indicators 13 and 14) are specific to transition for postsecondary students.

Indicator #13: Percent of youth aged 16 and above with IEPs that include appropriate measurable postsecondary goals that are: based on age-appropriate transition assessments and transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals; and annual IEP goals related to the student’s transition service needs updated annually. There also must be evidence that the student was invited to the Planning and Placement Team (PPT) meeting where transition services are to be discussed and evidence that, if appropriate, a representative of any participating agency was invited to the PPT meeting with the prior consent of the parent or student who has reached the age of majority.

Within Indicator 13, there are three distinct requirements:

1. Coordinated (set of activities), measurable, annual IEP goals and transition services;
2. Student invited to transition PPT meeting; and
3. Appropriate outside/participating agencies invited to transition PPT meeting.

⁹ Post-School Outcome Goal Statement is Connecticut’s term for the “appropriate measurable postsecondary goals” required by IDEA for transition-age students.

Within the requirement to have coordinated, measurable, annual IEP goals and transition services, there are five criteria that must be met:

- post-school outcome goal statement (PSOGS) for postsecondary education/training;
- PSOGS for employment (and, if appropriate, independent living skills);
- annual goal and objectives for PSOGS in postsecondary education/training;
- annual goal and objectives for PSOGS in employment (and, if appropriate, independent living skills); and
- all PSOGS are based on age-appropriate transition assessment.

To assess compliance with this indicator, CSDE created the Indicator #13 Transition Services Checklist for use by the local school districts. The purpose of the checklist is to assess whether the IEP goals and transition services are following the requirements and criteria just described. The Transition Checklist is based on an instrument created by the National Secondary Transition Technical Assistance Center¹⁰ and was adapted to the Connecticut IEP in collaboration with the Interagency Transition Task Force.¹¹

Figure II-1 summarizes some outcomes for Indicator 13. The statistics show that nearly all youth 16 and older had IEPs with transition goals. However, one out of five times, adult agencies were not invited to the transition PPT meeting.¹²

Figure II-1. Indicator 13 Outcomes

Indicator 13: Percent of youth aged 16 and above with IEPs that include transition goals

For 2011-2012 found:

- Nearly all (99.7%) had IEPs with transition goals
- Most (95.5%) students were invited to transition PPT meeting
- Evidence that 81.7% had invited adult agencies to transition PPT meeting

¹⁰ The National Secondary Transition Technical Assistance Center is a technical assistance and dissemination center funded by the U.S. Department of Education Office of Special Education Programs. The Center is directed and staffed by special education program personnel at the University of North Carolina and Western Michigan University.

¹¹ The 42-member Connecticut Interagency Transition Task Force was formed in 1989 and serves as an advisory group to the CSDE Bureau of Special Education.

¹² The one in five figure excludes situations where IEP states inviting adult agency was not appropriate, or the student/parent did not give written consent for agency to be invited to PPT.

Indicator #14: Percent of youth who are no longer in secondary school, had IEPs in effect at the time they left school, and were:

- A. Enrolled in higher education within one year of leaving high school
- B. Enrolled in higher education or competitively employed within one year of leaving high school
- C. Enrolled in higher education or in some other postsecondary education or training program; or competitively employed or in some other employment within one year of leaving high school

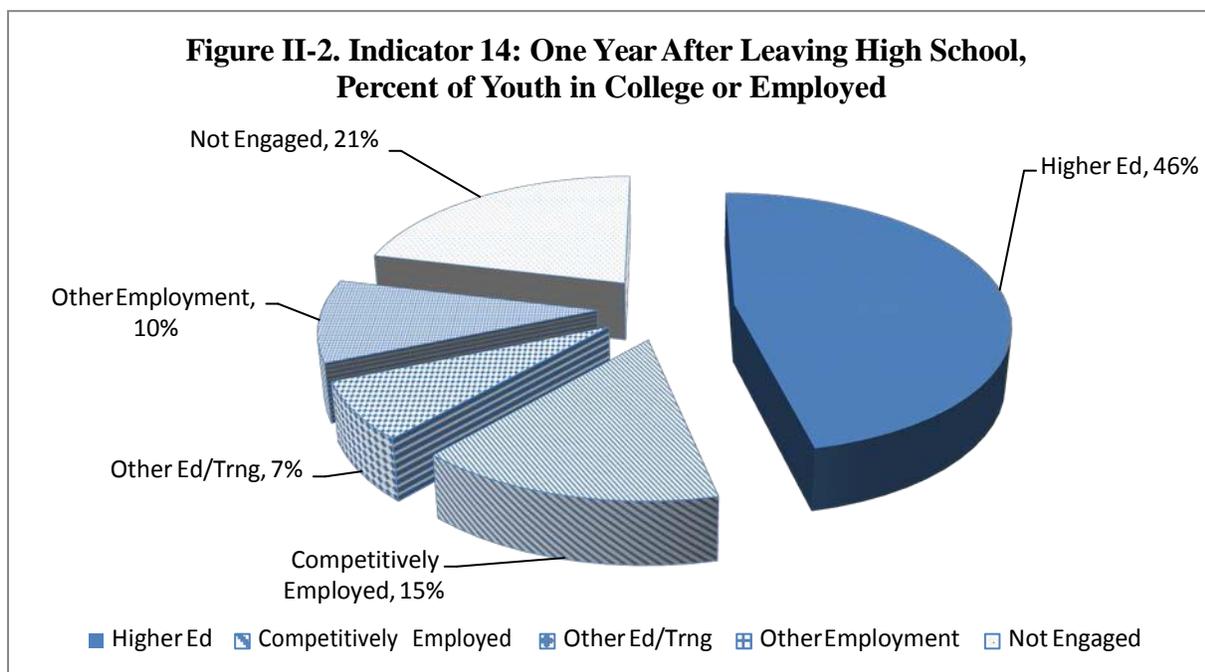
Progress on Indicator 14 is measured by responses to a mailed survey to graduates or exiters of Connecticut high schools who received special education. Surveys are mailed one year after the student left the public school system. The survey contains 12 items that ask about:

- enrollment in any postsecondary education;
- employment;
- receipt of services from agencies;
- level of satisfaction with life since leaving high school; and
- suggestions for high school students currently in transition.

Of the 4,918 students who left special education services in Connecticut in 2011, 611 surveys were completed and returned (12.4 percent). An additional 780 surveys were returned as undeliverable due to incorrect or outdated address information. Considering deliverable surveys only, the response rate is slightly higher (14.7 percent).

CSDE will provide a school district with a written summary specific to the district if at least 20 exiters completed and returned their surveys.

Figure II-2 summarizes some outcomes for Indicator 14. Given the low response rate, the results should be interpreted with caution. Of those who responded to the survey, four in five were engaged in some activity, often attending college.



Rehabilitation Act of 1973, as amended (Rehabilitation Act). The Rehabilitation Act of 1973 is the federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also contains Section 504, a civil rights law that protects individuals with disabilities from discrimination in a variety of settings including schools that receive federal financial assistance. The Rehabilitation Act is administered by the Rehabilitation Services Administration of the U.S. Department of Education Office of Special Education and Rehabilitative Services.

The Rehabilitation Act has seven titles:

- Title I: Vocational Rehabilitation Services;
- Title II: Research and Training;
- Title III: Professional Development and Special Projects and Demonstrations;
- Title IV: National Council on Disability;
- Title V: Rights and Advocacy;
- Title VI: Employment Opportunities for Individuals with Disabilities; and
- Title VII: Independent Living Services and Centers for Independent Living.

Relevant definitions contained within Rehabilitation Act

Disability. The Rehabilitation Act applies to individuals with any physical or mental impairment that substantially limits one or more major life activities,¹³ such as learning, working, and performing manual tasks.

Rehabilitation services. The Rehabilitation Act defines vocational rehabilitation services as “...any services described in an individualized plan for employment necessary to assist an individual with a disability in preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual...”¹⁴

Transition services. Under the Rehabilitation Act, transition services are defined as “...a coordinated set of activities for a student, designed within an outcome-oriented process, that promotes movement from school to post school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student’s needs, taking into account the student’s preferences and interest, and shall include instruction, community experiences, the development of employment and other post school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.”¹⁵

Relevant sections contained within Rehabilitation Act. Two of the Act titles include sections especially relevant to transitional services for youth and young adults with ASD (and other disabilities): Title I, Section 103 (Vocational Rehabilitation Services) and Title V, Section 504 (Nondiscrimination Under Federal Grants and Programs).

Title I, Section 103 Vocational Rehabilitation Services. Federal funding for Connecticut’s Department of Rehabilitation Services (DORS) vocational rehabilitation services is provided by the Rehabilitation Act of 1973. Section 103 of the Rehabilitation Act specifies that vocational rehabilitation services be provided to, among others, transitioning students with disabilities, for the purpose of facilitating the achievement of employment outcomes identified in an individualized plan for employment (IPE).

The Department of Rehabilitation Services has vocational rehabilitation counselors assigned to school districts to provide vocational assistance to students, often in their junior or next to last year of high school.

Title V, Section 504 Nondiscrimination Under Federal Grants and Programs. Some students with ASD are receiving services in school under Section 504 of the Rehabilitation Act of 1973 as opposed to the federal special education laws (i.e., IDEA). Section 504¹⁶ prohibits

¹³ Rehabilitation Act, Section 9(B).

¹⁴ Rehabilitation Act, Section 103(a).

¹⁵ Rehabilitation Act, Section 7((37).

¹⁶ Section 504 states: No otherwise qualified individual with a disability... shall solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal assistance... (29 U.S.C. Section 794(a))

discrimination against persons with disabilities. It is intended to protect the civil rights of persons with disabilities through equal access to programs, services, and activities that receive federal funding. Section 504 is enforced by the Office of Civil Rights of the U.S. Department of Education.¹⁷

Public schools receive federal funding, and, therefore, are included under Section 504. While IDEA lists very specific disabilities, Section 504 includes individuals with any physical or mental impairment that substantially limits major life activities, such as learning, working, and performing manual tasks. Also included are individuals with a record of such impairment, or regarded as having such an impairment.

Some examples of impairments which may substantially limit major life activities, even with the help of medication or aids/devices are: AIDS, asthma, alcoholism, blindness or visual impairment, cancer, deafness or hearing impairment, diabetes, drug addiction, heart disease, and mental illness.

Students who do not meet the disability definitions required for special education under IDEA, but whose disabilities are covered by Section 504, must be given reasonable accommodations for the disability to allow them to benefit from their education. This requirement is interpreted to mean that services must be provided to disabled children so that they have an opportunity to participate in education to the same extent as their non-disabled peers.

Any student with a disability under IDEA is automatically considered to have a disability under Section 504. Also, the IEP developed for students under IDEA, automatically meets the requirements for a Section 504 plan for the student.

However, for students who are only eligible for services under Section 504, there is no requirement that an IEP/PPT Team be established. Instead, school district personnel may convene a Section 504 team.

Also, unlike IDEA, there are no federal funds for Section 504, and IDEA funds may not be used to serve students only found eligible under Section 504.

Rehabilitation services in Connecticut. The Connecticut Department of Rehabilitation Services Bureau of Rehabilitation Services (BRS) provides assistance to individuals with significant disabilities who want to find or keep employment. There is no financial means test for BRS services. A person with a physical and/or mental impairment that is a substantial barrier to employment, and who could benefit from vocational rehabilitation services to ultimately become competitively employed, is eligible for services.

Once an applicant has been deemed eligible to receive such services, an Individualized Plan for Employment (IPE) is developed through a partnership between the BRS vocational rehabilitation counselor and the individual.

¹⁷ An individual who feels his or her rights have been violated may file a complaint with the office, which will investigate, and if warranted, may issue a remedial order that the violation be corrected.

Regarding transitional efforts for high school students with disabilities that are expected to impact employability, BRS has approximately 70 liaisons working with all 143 Connecticut school districts that provide secondary services. Most liaisons work with 80-100 students at a time. The liaisons are responsible for working with the school, student, and family on the transition process. While BRS may work with students as young as 14 years old, priority is given to students in the junior year or next to last year of high school.¹⁸ The role of BRS counselors is to help schools advise their students on what vocational assessment instruments to use. They also work with individual students to determine eligibility for BRS services and, if eligible, develop individualized plans for employment (IPEs) that specify what services and supports BRS will provide directly upon graduation from high school. Although BRS does not pay for services until the student has graduated,¹⁹ agency liaisons may be available to assist with transition planning, including attending PPTs if BRS is already working with the student.

When it is time for the student to find employment, BRS can assist them with job placement, additional training, job coaching, transportation assistance, and assessing a worksite for accessibility—these services are sometimes referred to as Vocational Rehabilitation.

The Bureau has a Transition Committee that develops training, best practices, and better ways to engage schools. One member of the committee is the transition consultant from the State Department of Education. This individual's position is jointly funded by the state education and rehabilitation services departments, and provides consultation and technical assistance, coordinates transition planning between the two agencies, as well as outreach and identification strategies.

The Bureau also has an Autism Committee that reviews cases for persons of any age with ASD. Unlike the Transition Committee, the BRS Autism Committee is strictly about individual cases and does not develop or recommend general policies related to individuals with ASD.

ADA. A third federal law that could be relevant to transitioning youth and young adults with ASD is the American with Disabilities Act (ADA). The ADA is a federal civil rights law intended to prohibit discrimination on the basis of disability in employment, public services, and accommodations. Similar to Section 504, ADA defines disabilities as individuals with physical or mental impairment that substantially limits one or more life activities. The ADA further broadens the definition to also include a past history of an impairment, including alcoholism, drug addiction, and cancer.

The American with Disabilities Act has five titles:

- Title I: Employment;
- Title II: Public Services;
- Title III: Public Services and Accommodations Operated by Private Entities;

¹⁸ Technically, vocational rehabilitation counselors may work on transitions with students who are 14-24 years old, but they rarely deal with 14-year-old students.

¹⁹ The summer youth jobs program is funded with state dollars as opposed to federal BRS money.

- Title IV: Telecommunications services for hearing-impaired and speech-impaired individuals; and
- Title V: Miscellaneous Provisions.

Titles I-III may be especially relevant to transitional services for youth and young adults with ASD. Title I protects people with disabilities from discrimination by employers, including transitioning students who might be employed by either a public or private employer with 15 or more workers.

Title II protects people with disabilities from discrimination in the programs and activities offered by state and local governments, including public schools, regardless of whether they receive any federal funding. Specifically, the ADA extends to nonsectarian private schools that do not receive federal financial assistance.²⁰

Title III gives people with disabilities access to public accommodations, including commercial facilities and places of private education. It covers examinations and courses related to licensing and obtaining credentials for educational, professional, or trade purposes. ADA requires reasonable accommodations (i.e., a modification or adjustment to a job or work environment that will enable the applicant to do the job) for eligible students in job training or community-based placements as part of their special education programs. As long as the individual with disabilities can perform all the essential functions of a job and meet the educational and experience requirements, an employer must consider providing a “reasonable accommodation.” Examples of “reasonable accommodations” are: modifying equipment, assigning aides, providing written communication in alternative formats, modifying tests, adjusting work schedules, redesigning services to accessible locations, altering existing facilities, and building new facilities. ADA applies to restaurants, hotels, movie theaters, doctors’ offices, factories and warehouses, and many other private employers—potential locations where students in transitional programs may be working.

State Laws

State Special Education Law (C.G.S. Sec. 10-76). State requirements for “Students with Disabilities Requiring Special Education” are captured under C.G.S. Sec. 10-76(a)-(q) and regulations (R.C.S.A. Sec. 10-76a-1 to 10-76h-16). Under Connecticut regulations, a student with a disability is eligible for services from the school district through the end of the school year (June 30) in which the student turns 21 years old.

The Connecticut statute and regulations mirror the IDEA with the following few slight differences:

Eligibility determination decision makers. Under federal IDEA, eligibility for services is decided by the IEP Team, which consists of: “a qualified team of professionals and the parent(s).” Under Connecticut state law, however, decisions regarding eligibility are made by the Planning and Placement Team (PPT). In addition to the student and parent(s), the team must also

²⁰ Private schools controlled by religious organizations are excluded from ADA requirements.

include representatives of the teaching, administrative and pupil personnel staff (R.G.S.A. Sec. 10-76a-1(p)).

Service and placement decision makers. Another difference between the IDEA IEP Team and the Connecticut PPT Team, is in who decides the services and placement of the student. Under IDEA, these decisions are made by “a group of persons, including the parent(s), and other persons who are knowledgeable of the child, the evaluation data and placement options” (34 CFR Section 300.306 and .320). On the other hand, the same team that determined eligibility also determines the services and placements (i.e., Connecticut PPT Team). The Connecticut PPT includes representatives of the teaching, administrative and pupil personnel staffs (R.G.S.A. Sec. 10-76a-1(p)).

Timeline to determine eligibility/presence of a disability. The IDEA requires that eligibility determination (i.e., the child has a disability identified in IDEA) occur within 60 calendar days, from the day after the district receives the signed parental consent to evaluate the child form to the eligibility determination at the PPT meeting. Connecticut state law requires eligibility determination and onset of program to occur within 45 school days, from the day the district receives the referral for an evaluation to the date of program implementation (assuming the student was found eligible).

Notification of team meeting. Connecticut state law requires parents/guardians to be given at least five school days written notice in advance of the PPT (R.G.S.A. Sec. 10-76d(8)). The notification requirement was expanded in 1995 to the students themselves if emancipated or at least 18 years old, and also to surrogate parents.²¹ In contrast, IDEA does not specify a minimum amount of time for notification of the PPT meeting. IDEA requires that parents be notified of the meeting early enough to ensure that they will have an opportunity to attend, and that the PPT meeting be scheduled at a mutually agreed upon time and place (34 C.F.R. Sec. 300.322).

Time to develop the plan. With few exceptions, IDEA requires IEPs to be implemented within 30 calendar days of eligibility (34 C.F.R. Sec. 300.323 (c)), while Connecticut requires that evaluations be completed and a program implemented within 45 school days of referral or notice (except for private placements or out-of-district placements, when the program must be implemented within 60 school days) (CT Reg. Section 10-65d-13).

Legislation relevant to the study population. Appendix G summarizes recent legislative changes related to ASD and/or transitional services for secondary school students. One of the more significant changes occurred in 2006, when DDS began a pilot program for individuals with ASD who were not eligible for DDS services because they did not have an intellectual disability. In 2007, the DDS Division of Autism Spectrum Services was established in statute. Legislation pertaining to treatment of ASD, including the establishment of the DDS ASD Advisory Council, and insurance coverage, is also addressed in public acts related to Applied Behavior Analysis.

²¹ The Surrogate Parent Program appoints persons to advocate for children who are under the guardianship of DCF and who need or may need special education services in accordance with state and federal laws.

Also, Special Act 08-5 required the development of recommendations for a new state plan for instructors of students with autism and other developmental disabilities, including characteristics of students with autism, curriculum, assistive technology, and educational practices.

Several bills have attempted to provide tax credits for hiring people with ASD, but none have passed—e.g.:

- SB 360 (2009)
- SB 477 (2010)

Lastly, the Connecticut Parent Advocacy Center (CPAC) fulfills federal and state requirements to expand parental knowledge on effective advocacy for children with special education needs.²² Established approximately 30 years ago, CPAC is primarily funded by the federal government, through a competitive grant process. The grants tend to be for three to five year periods. Additionally, CPAC receives a small amount of state funding through the State Department of Education.

CPAC offers training and workshops as well as telephone consultation to parents of students with disabilities. Their services are provided free of charge.

Finally, in 2012, P.A. 12-173 (AAC Individualized Education Programs and Other Issues Relating to Special Education) required school districts to provide parents or students with disabilities with any CSDE information and resources relating to IEPs as soon as a student is identified as requiring special education. For students of transition age, the publication, Building a Bridge²³ is recommended by CSDE.

²² As Connecticut's federally-funded Parent Training and Information Center (PTI), CPAC's core funding comes through the U.S. Department of Education.

²³ Building a Bridge from School to Adult Life: A Handbook for Students and Family Members to Help with Preparation for Life After High School, Revised 2009, prepared by the CT Transition Task Force. Available online at: <http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/BuildingABridge.pdf>.

Chapter III: Results of PRI Transition Coordinator Survey

Results of PRI Transition Coordinator Survey

Overview

While some surveys had previously been conducted by the Connecticut State Department of Education (CSDE), none had been specific to transitional services for youth and young adults with ASD. PRI staff determined that the best way to receive input from as many transition coordinators as possible was to develop and administer a survey relevant to the current study topic. In consultation with personnel from the CSDE Bureau of Special Education Resources, PRI staff developed a 23-item survey that was sent to all CSDE contacts for secondary transition. The original pool of 352 possible survey respondents included 293 public school personnel and 59 individuals affiliated primarily with a regional educational service centers (RESCs) or private schools.

The online survey focused on the transition from secondary school completion to young adulthood (up to age 25). In particular, the study examined transitional planning during secondary education, programs and services following secondary education, levels of independence attained, and barriers to independence.

On October 1, 2014, the CSDE Bureau of Special Education forwarded a letter from PRI staff to CSDE contacts for secondary transition announcing the online survey. Two followup reminder emails encouraging recipients to complete the online survey were sent on October 12 and October 27.

Current Analysis

Since the email recipients could forward the survey to other individuals within their school districts, it is unknown how many individuals actually had the opportunity to complete the survey; however, a conservative estimate would be 352 CSDE contacts for secondary transition received notification of the survey. Out of 352 survey recipients, a total of 174 individuals responded to the survey (49 percent participation rate). Table III-1 provides a profile of the setting and roles of the 174 respondents for which this information was known.

The survey questions fell into four areas:

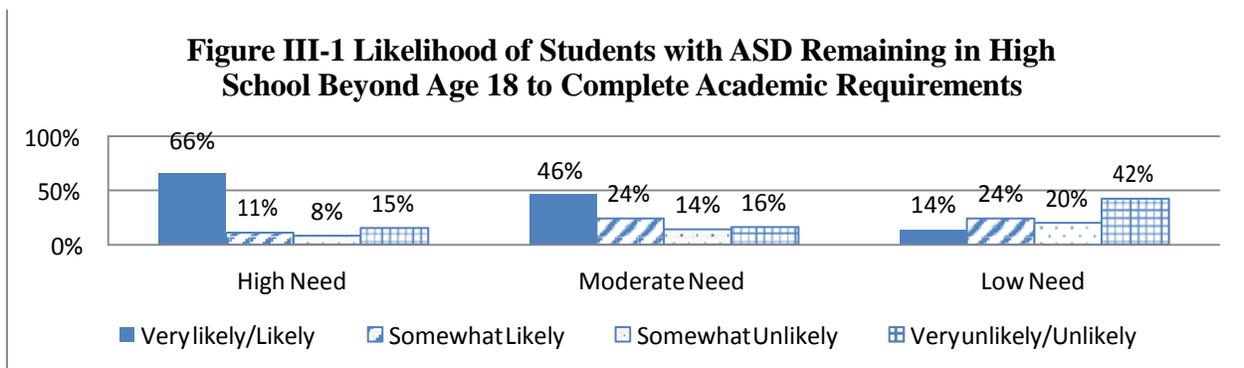
1. services provided/experiences of students with ASD while in high school;
2. use of certain planning tools related to transition by school district: the Secondary Transition Planning IEP Checklist; and the Student Success Plan;
3. post-high school outcomes for students with ASD; and
4. suggestions about ways to help students with ASD transition from high school including: comments regarding what could be done differently to help students with ASD transition

from high school; and comments regarding additional resources or assistance needed by school personnel to better serve students with ASD to prepare for adult life after high school.

Table III-1. Profile of Survey Respondents	
Setting:	Percent of Respondents Who Answered Question:
Public school district	84%
Regional Educational Service Center (RESC)	7%
Private school	2%
Other	7%
Total (135 of 174 responded to question)	100%
Role:	Percent of Respondents Who Answered Question:
Transition Coordinator	38%
Special Education Teacher	22%
Director	20%
Mental Health professional	5%
Case Manager, Care Coordinator, Job Coach	4%
Other	11%
Total (133 of 174 responded to question)	100%
Source: PRI Transition Coordinator Survey.	

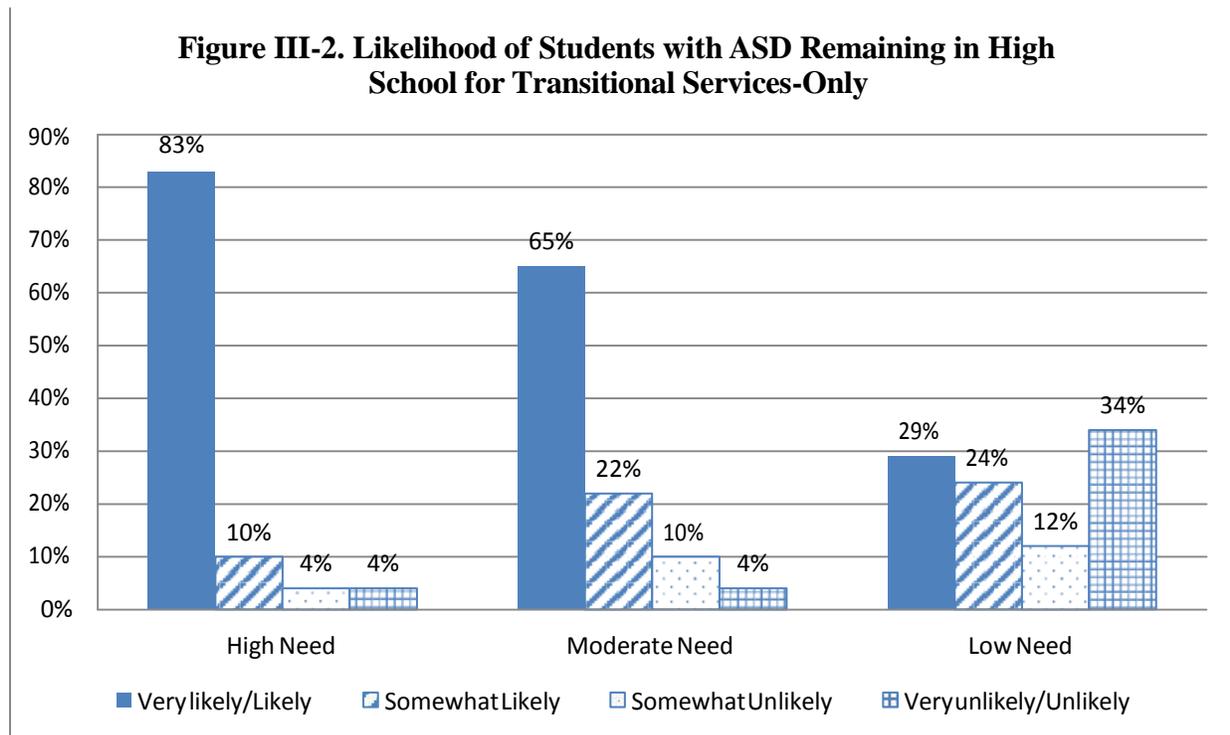
Services provided/experiences of students with ASD while in high school.

Time needed for high school students with ASD to complete academic requirements. Figure III-1 shows the predicted likelihood of students with ASD remaining in high school beyond age 18 to complete academic requirements. Two-thirds of those identified as high need students with ASD²⁴ were considered likely or very likely to remain in high school beyond age 18 to work on academic requirements. In contrast, just 14 percent of students with ASD considered low need were expected to remain in high school for purposes of fulfilling academic requirements.

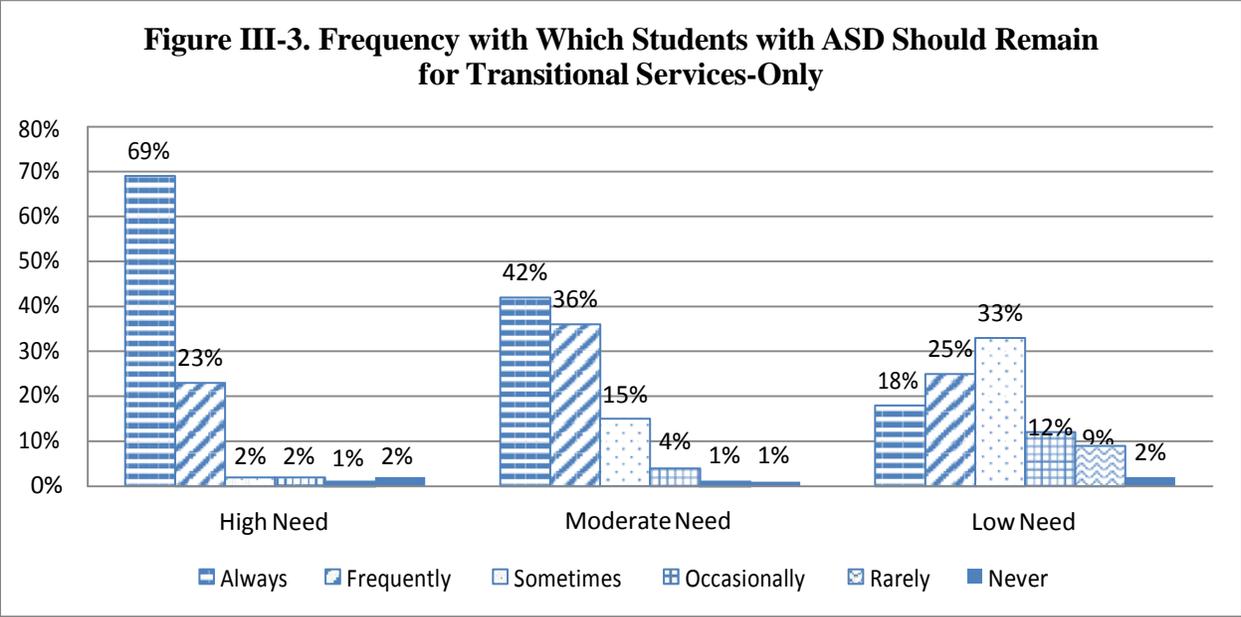


²⁴ “High need” was defined as students with ASD requiring substantial support, “moderate need” as students with ASD requiring moderate support, and “low need” as students with ASD requiring minimal support.

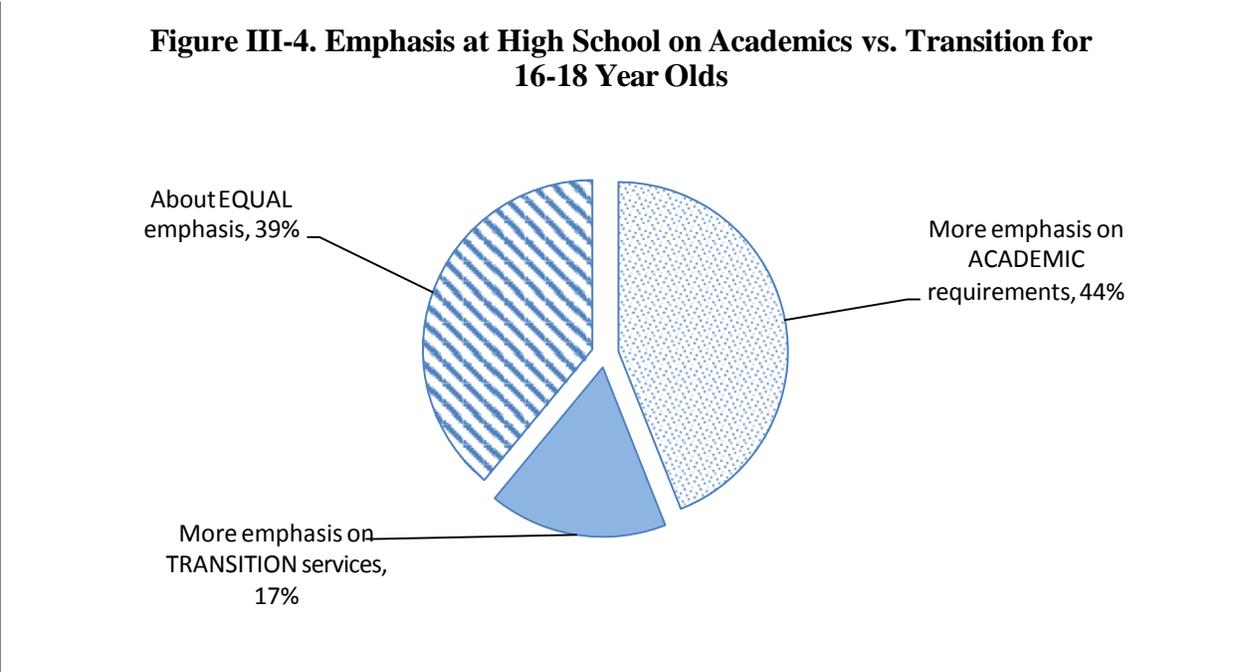
Likelihood of students with ASD remaining in high school for transitional services-only. Figure III-2 shows the likelihood of students with ASD remaining in high school for transitional services-only. Survey respondents believed it was very likely or likely that 83 percent of high need students with ASD, compared with 29 percent of low need students with ASD, would remain in high school for transitional services-only.



Benefits for students with ASD remaining for transitional services-only. Nine in ten survey respondents said high need students with ASD should remain for transitional services-only either always (69 percent) or frequently (23 percent) (Figure III-3). In contrast, less than half as many survey respondents said low need students with ASD should remain for transitional services-only either always (18 percent) or frequently (25 percent). Note, in comparison to the information provided in Figure III-2, there appears to be a slight tendency for respondents to believe students considered moderate or low need remain in high school for transitional services-only more often than is necessary (87 percent do remain vs. 78 percent should remain for moderate need; 53 percent do remain vs. 43 percent should remain for low need). Although the numbers are small, the three respondents who worked at private schools all said students with low needs should always or frequently remain for transitional services-only.

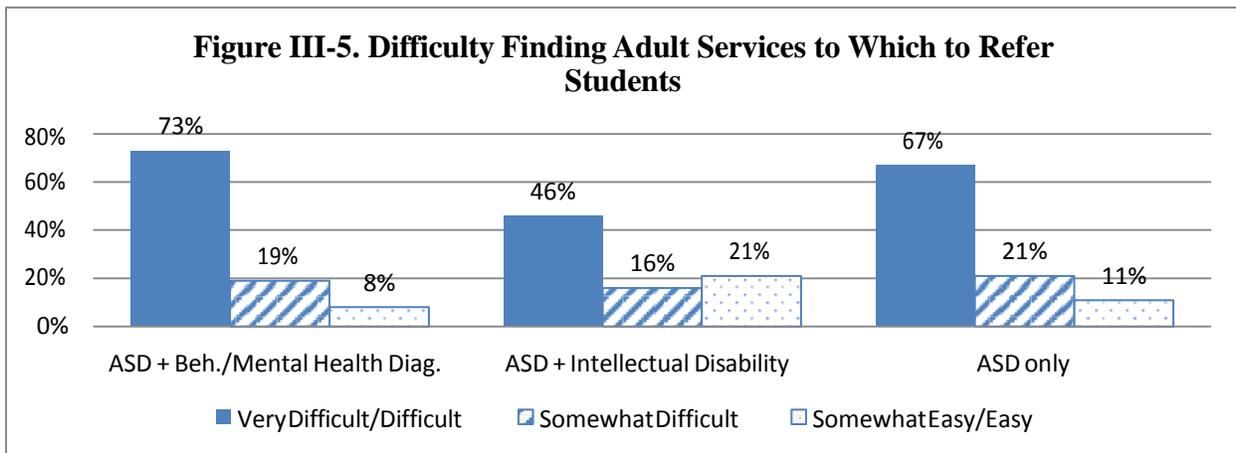


Emphasis on academic requirements vs. transition services for 16-18 year old high school students with ASD. The emphasis at high schools for students aged 16-18 years old with ASD was often on academics (44 percent) or academics and transition services (39 percent) (Figure III-4). Few students in this age range and population were believed to receive services focused solely on transition services (17 percent).

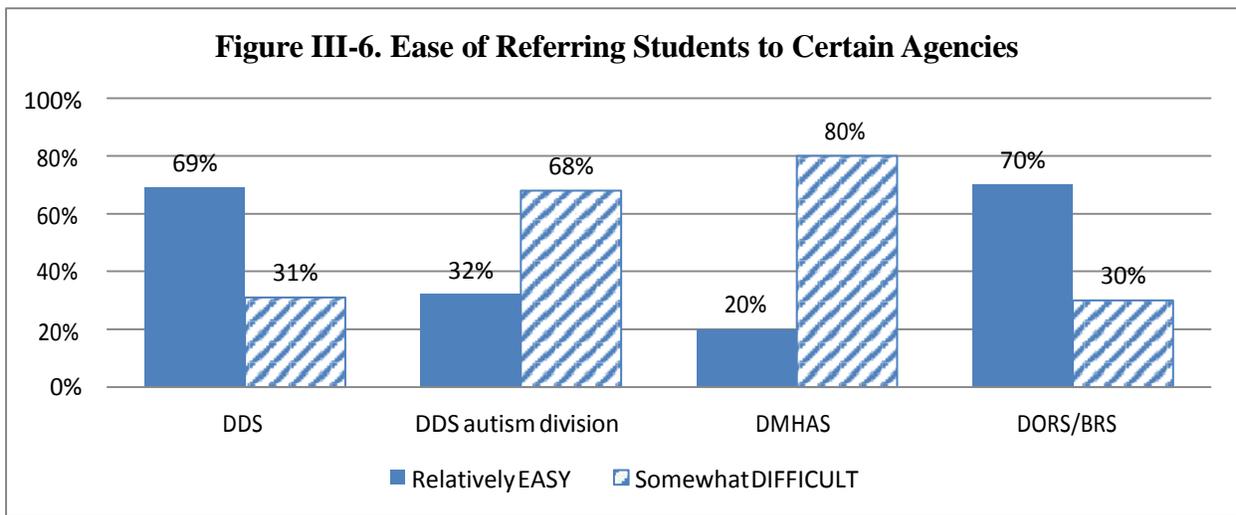


Referrals to adult service agencies. Respondents were asked to rate the level of difficulty in finding appropriate adult services to which they could refer special education students with certain disabilities (Figure III-5). Using a six-point scale (1=“very difficult” to 6=“very easy”), respondents reported that:

- compared with students who had both ASD and an intellectual disability, it was somewhat more difficult to find services to which to refer students if they had ‘ASD only’; and
- it was most difficult to find services to which to refer students if they had both ASD and a behavioral or mental health diagnosis.



Ease of making referrals to certain agencies. Of the four agencies most often considered for referrals for adult services, the majority of respondents found it relatively easy to make referrals to the Department of Developmental Services (DDS) and the Department of Rehabilitation Services Bureau of Rehabilitation Services (DORS/BRS), but somewhat difficult to make referrals to the DDS Division of Autism Spectrum Services and the Department of Mental Health and Addiction Services (DMHAS) (Figure III-6).



Planning and Placement Team (PPT) meeting attendance and outreach efforts by certain agencies. Three-quarters of respondents (75 percent) said DDS was likely to attend PPT meetings if invited, and two-thirds of respondents (63 percent) said the same about DORS/BRS. Conversely, approximately three-quarters of respondents (77 percent) said DMHAS and the DDS autism division did not attend PPT meetings.

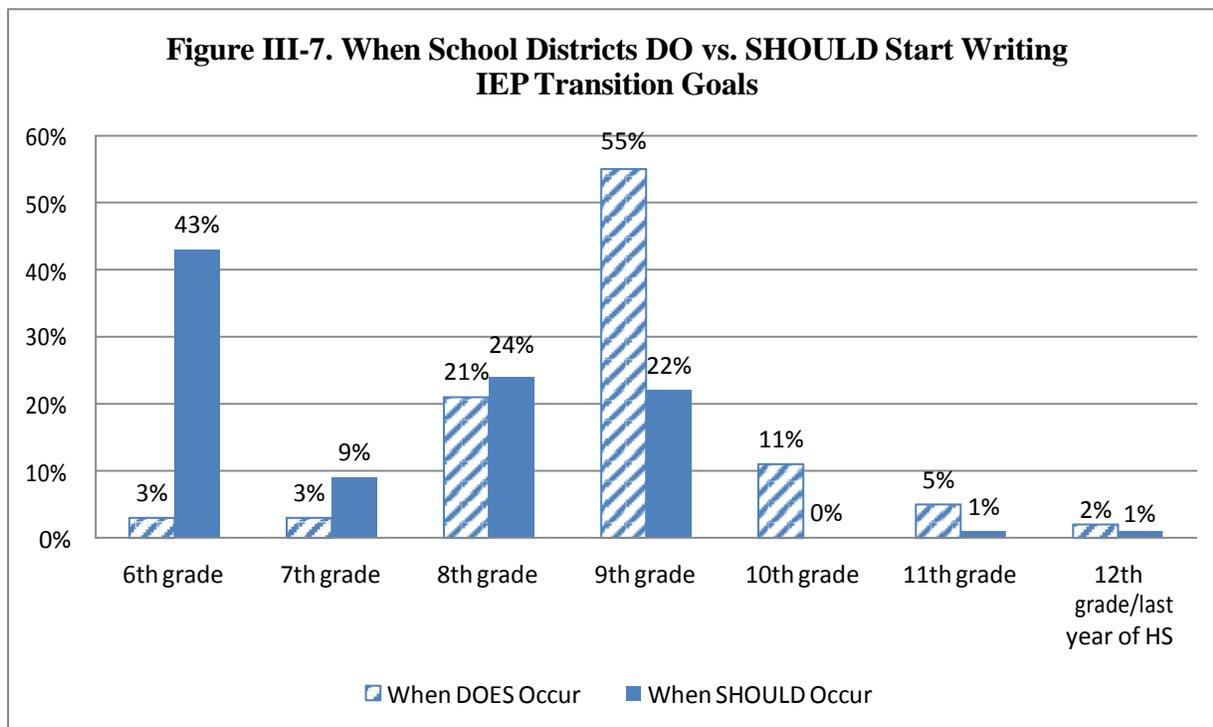
A similar pattern was found when respondents were asked about agency personnel making outreach efforts to students and families. Two-thirds of respondents (66 percent) said DDS staff was likely to make outreach efforts, and 61 percent said the same regarding personnel from DORS/BRS. On the other hand, 90 percent said DMHAS did not tend to make outreach efforts to students and families, and 82 percent said the same about personnel from the DDS autism division.

Assistance provided by school districts. Using a five-point scale (1=“always” and 5=“never”), Table III-2 shows the frequency with which survey respondents said courses or individual assistance were offered by the school district to high school students with ASD who needed the assistance. Survey respondents said approximately three-quarters of students were offered courses or assistance in career exploration, study skills, socialization skills, pre-employment activities, and organizational/executive functioning skills. Less likely to be offered were courses or assistance in household skills, such as cooking or laundry.

Table III-2. Courses/Assistance Provided to High School Students with ASD if Needed			
Area	Rating		
	Always/Frequently	Sometimes	Rarely/Never
Career exploration	77%	15%	8%
Study skills	74%	20%	6%
Socialization skills	78%	11%	11%
Pre-employment activities	74%	13%	13%
Organizational/executive functioning skills	73%	19%	8%
Finances	64%	24%	12%
Health and personal hygiene	59%	25%	16%
Household skills	51%	28%	21%

Source: PRI Transition Coordinator Survey.

Establishment of individualized education program (IEP) goals related to transition to adult life. The Individuals with Disabilities Act (IDEA) requires transition planning no later than age 16, or earlier if determined appropriate by the Planning and Placement Team (PPT) for all special education students. While over half of survey respondents (55 percent) said their school districts started writing IEP transition goals in ninth grade, many believed school districts should start writing these transition goals in an earlier grade (Figure III-7). Half of respondents, for example, believed the goals should be started in sixth and seventh grade. Only one-fifth (22 percent) believed transition goals should start to be developed in the ninth grade.



Regarding use of certain transition planning tools by school districts.

Secondary Transition Planning IEP Checklist. In collaboration with the Connecticut Interagency Transition Task Force,²⁵ the CSDE developed a tool called, “Secondary Transition Planning IEP Checklist.” The 25-item checklist is modeled after the instrument created by the National Secondary Transition Technical Assistance Center²⁶ that was approved by the Office of Special Education Programs (OSEP) as a rigorous, valid and reliable tool to assess performance on Indicator 13.²⁷ It is intended for use by the local education agencies or school districts to assess whether IEP goals and transition services are coordinated, measurable, and will reasonably enable a student to meet their postsecondary goals. Specifically:

- Items 1-11 deal with informing the student and parties of transition planning, needs and concerns, assessment results pertaining to vocation, and invitations to PPT;
- Items 12-16 pertain to outside agency participation and post-school outcome goal statements; and
- Items 17-25 continue post-school outcome goal statements, summary of performance, accommodations and modifications, and review of a copy of the Post-school Outcome Survey.

²⁵ The 42-member Connecticut Interagency Transition Task Force was formed in 1989 and serves as an advisory group to the CSDE Bureau of Special Education.

²⁶ The National Secondary Transition Technical Assistance Center is a national technical assistance and dissemination center funded by the U.S. Department of Education Office of Special Education Programs.

²⁷ See Chapter II for a description of Indicator 13.

Survey respondents were asked to estimate how often the checklist was used at some point during the secondary transition planning process. Almost one-third (31 percent) who answered the question estimated the checklist was always or often used, and 19 percent estimated the checklist was rarely or never used. Seventeen percent said it was used about half the time and seven percent at least one-quarter of the time. Twenty percent of respondents did not know how often it was used, and seven percent had never heard of the checklist.

Survey respondents were asked about possible reasons why the checklist was not always being used:

- three-quarters (75 percent) said the checklist was not always being used because it was not required;
- half (51 percent) said it was not always being used because it was too time-consuming; and
- just one in five (20 percent) thought the checklist was not being used because it was not helpful.

Student Success Plan. Legislation passed in 2011 requiring school districts to annually create Student Success Plans (SSPs) for every student in grade 6 through grade 12 beginning in the school year commencing July 1, 2012.²⁸ The SSP is an individualized student-driven plan that is intended to address all the students' needs and interests to help them stay engaged in school and achieve postsecondary education and career goals.

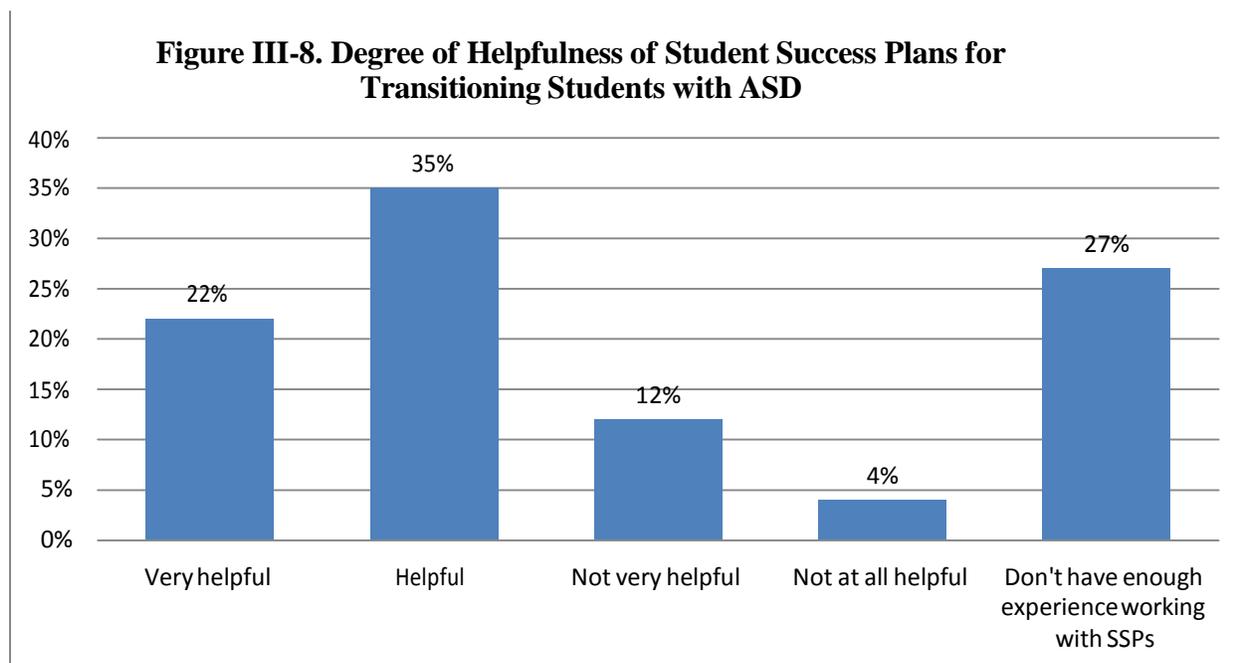
The SSP includes goal setting and related activities in three areas: academic growth; career exploration and planning; and personal, social/emotional and physical growth.

- SSP academic development includes:
 - experiential learning: job shadowing, internships, cooperative work, community service; and
 - opportunities for college credit while in high school.
- SSP career development includes:
 - interest and ability inventories;
 - career exploration activities; and
 - work-based learning experiences.
- SSP social, emotional and physical development includes:
 - identification of school and community resources; and
 - identification of accommodations, modifications and services a student with a disability might need in order to have equal access to activities or the opportunity to perform at the same level as peers.

²⁸ P.A. 11-135, An Act Concerning Implementing Dates for Secondary School Reform, Exceptions to the School Governance Council Requirements and the Inclusion of Continuous Employment in a Cooperative Arrangement as Part of the Definition of Teacher Tenure.

Survey respondents were asked to estimate the percent of students in grades 6 through 12 in their school districts who had Student Success Plans. About one-third (35 percent) didn't know how often it was used, and 41 percent said it was used for all (31 percent) or many (10 percent) of the students in grades 6 through 12. Other responses included: it was not used by any students or few students (10 percent), used by at least one-quarter of the students (six percent), used by about half the students (four percent), or they had never heard of the SSP (five percent).

Figure III-8 shows how helpful respondents thought the SSP would be in preparing students with ASD for life after high school. Over half (57 percent) thought the SSP would be very helpful or helpful in preparing students with ASD for life after high school.



Post-high school outcomes for students with ASD.

Available services/supports for former students with ASD. Considering students who graduated within the last five years and about whom they had at least some informal knowledge, survey respondents rated their agreement with 14 statements. A six-point rating scale was used for each item (1=“strongly agree” to 6=“strongly disagree”). Respondents could also check off “don’t know” and this occurred at least 10 percent of the time for the following six questions pertaining to post-high school:

- Services are available for too short an amount of time (20 percent);
- Services are limited in certain geographic areas (20 percent);
- Respite care is not readily available to the families (18 percent);
- There was no assessment of post-high school needs for these former students with ASD (16 percent);

- Private transition programs are not affordable for most of the families (11 percent); and
- Before and after program care services are a critical need for these families (10 percent).

Table III-3 shows the statements ordered from strongest to least agreement for respondents able to answer the question. Strongest agreement was found for limited housing options. Lowest agreement was found for no assessment of post-high school needs.

Statement	Strongly Agree	Agree	Total Strongly Agree + Agree
Housing options are very limited.	63%	23%	86%
Youth are referred to AVAILABLE services rather than to NEEDED services.	55%	22%	77%
Private transition programs are not affordable for most of the families.	53%	24%	77%
Transportation is a significant barrier to accessing services.	51%	26%	77%
College programs providing supports to students with ASD are necessary for success at this level.	40%	34%	74%
Before and after program care services are a critical need for these families.	45%	26%	71%
The level of services NEEDED and the level of services AVAILABLE do not match.	42%	29%	71%
Services are limited in certain geographic areas.	41%	30%	71%
Vocational programs are difficult to get into.	38%	22%	60%
Respite care is not readily available to the families.	36%	21%	57%
Services are available for too short an amount of time.	27%	24%	51%
There is a limited number of professionals with specific training in working with individuals with ASD.	26%	23%	49%
Programs teaching life skills/activities of daily living are rarely available.	20%	27%	47%
There was no assessment of post-high school needs for these former students with ASD.	12%	16%	28%

Source: PRI Transition Coordinator Survey.

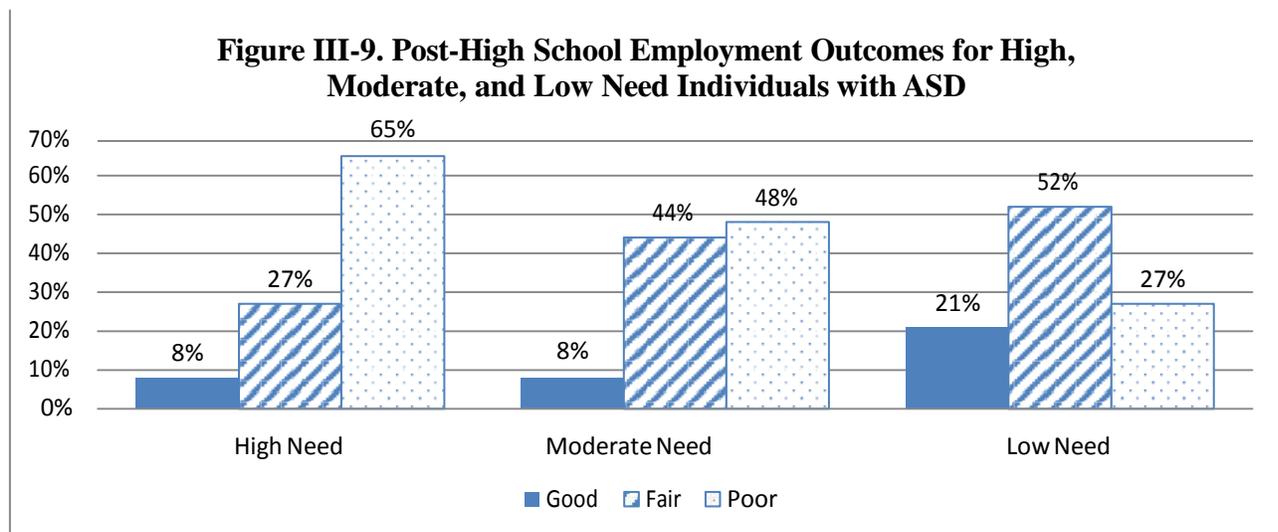
Outcomes for former students with ASD. Respondents were also asked to rate how well students with ASD were doing who had graduated within the last five years and about whom they had at least some informal knowledge.

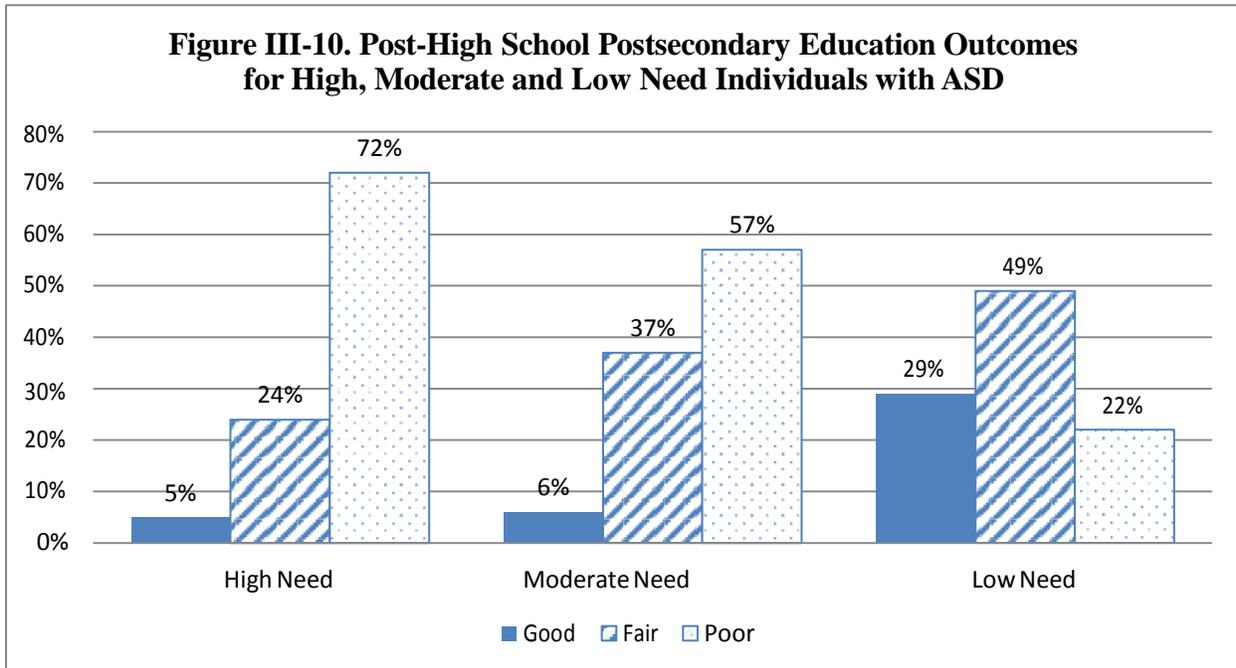
Ratings used for each area were “good,” “fair,” or “poor.” About one-quarter of the time respondents selected the option “don’t know.” Table III-4 shows the ratings separated by the degree of need (high, moderate or low) for the former students with ASD about whom the respondents had at least some knowledge.

In general, former students with high needs had more “poor” ratings than former students with moderate and low needs. Figure III-9, for example, shows the relatively higher ratings regarding employment for former students with low needs. However, even former students with ASD who were considered to have low needs tended to be rated in the various areas as doing “fair,” with only 14 percent given an overall rating of “good.” A similar pattern was found for postsecondary education ratings (Figure III-10).

Table III-4. Ratings of How Well Former Students Were Doing in Certain Areas			
Area	Good	Fair	Poor
Low Need Students with ASD			
Employment	21%	52%	27%
Postsecondary education	29%	49%	22%
Vocational training	24%	42%	35%
Social/recreation activities	13%	48%	40%
Overall rating	14%	53%	33%
Moderate Need Students with ASD			
Employment	8%	44%	48%
Postsecondary education	6%	37%	57%
Vocational training	14%	42%	43%
Social/recreation activities	5%	36%	59%
Overall rating	5%	51%	44%
High Need Students with ASD			
Employment	8%	27%	65%
Postsecondary education	5%	24%	72%
Vocational training	21%	27%	52%
Social/recreation activities	4%	34%	62%
Overall rating	8%	42%	50%

Source: PRI Transition Coordinator Survey.





Contributing factors to successful outcomes. Respondents were asked to rate the importance of certain factors in contributing to favorable outcomes for graduates with ASD. Table III-5 emphasizes the critical nature of having access to appropriate services after exiting high school. Also of great importance to more favorable outcomes, was parental advocacy during high school, proper evaluation of needs during high school, and student involvement in transition planning. A strong transition plan was seen as very important by two-thirds (65 percent) of respondents.

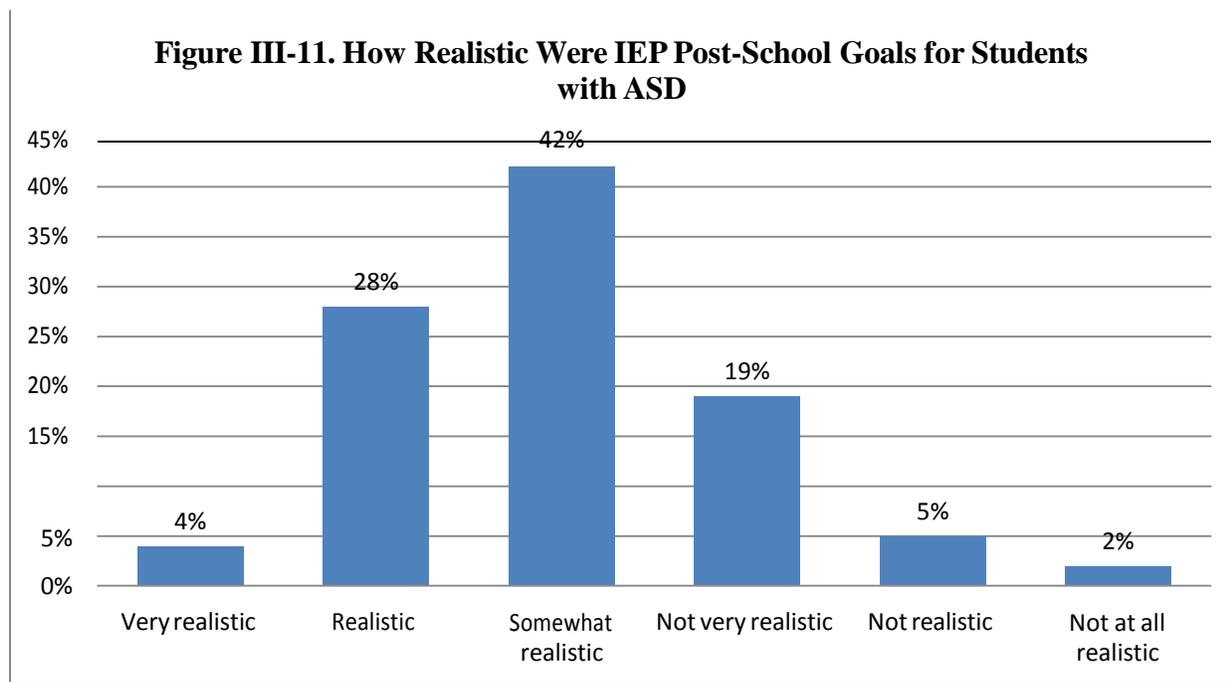
Factor	Very Important	Important	Total Very Important + Important
Access to appropriate services after exiting high school	82%	16%	98%
Parental advocacy during high school	72%	22%	94%
Proper evaluation of needs during high school	62%	33%	94%
Student involvement in transition planning	63%	29%	92%
Strong transition plan	65%	22%	87%
Less severe level of ASD	42%	34%	76%
Family financial ability	41%	32%	73%

Source: PRI Transition Coordinator Survey.

There were also 15 respondents who identified additional factors they considered important to favorable outcomes. These included:

- parent/family involvement and working together to reinforce and help the student generalize skills across a variety of environments including school, community, vocational and home, and not enabling the student;
- realistic goals and expectations by families based on the student’s level of functioning;
- teamwork between the school system, family and available state and community agency supports, with parents not expecting the schools to do everything;
- student involvement in activities that promote interaction and friendship between regular education students and students with special needs (e.g., “Best Buddies” club);
- person-centered services available to graduates so they can continue to use the skills they learned in high school; and
- availability of public transportation (if they have a job and can’t get to it after high school graduation, then they can’t keep working).

How realistic were IEP post-school goals for students with ASD. Respondents were asked how realistic were the IEP post-school goals developed for students with ASD (Figure III-11). The most prevalent response was “somewhat realistic,” suggesting that there is room to improve the IEP post-school goals and their relationship to what will be faced by the post-high school student.



The 14 comments regarding this question related to:

- challenge in developing goals which all parties agree are realistic (parents, student, transition coordinator, academic teacher);
- based on what agency help is available after the student reaches age 21;
- can depend on the relationship between the student and school personnel; and
- depending on level the student with ASD is performing at, the goals can either be realistic/too low or too challenging.

Level of success in achieving post-school outcome goals. When asked how successful students with ASD were in achieving their post-school outcome goals (or related annual goals and objectives), one-quarter of respondents answered “don’t know.” Of those who were able to answer, half (52 percent) said the students were “not very successful” and 43 percent said “successful” (2 percent said “very successful” and 3 percent said “not at all successful”).

Respondent suggestions for improvement.

Respondents were asked: “In your opinion, what, if anything, can be done differently to help students with ASD transition from high school?”

Comments were grouped into six categories:

1. secondary education changes/professional development;
2. more adult services provided by state agencies;
3. student skill development;
4. postsecondary education institutions;
5. depends on level of ASD; and
6. better partnership/relationship with parents/families.

Secondary education changes/professional development. Some respondents commented on the need for goals to be realistic, focusing more on transitioning the student to real life. More focus should be given to life skills and vocational opportunities and vocational exploratory courses, and students who would not be attending college.

More 18-21year old transition programs should be available to students, as they play a critical role in the student’s ability to go on to college, vocational institution, and work. Job coaches or vocational mentors are important for students transitioning to employment.

Professional development for teachers in the area of transition for ASD students was suggested by several respondents. Specifically mentioned was training for teachers and service providers to better understand all levels of ASD, and how to address socialization and behavioral training. Awareness of what postsecondary transition services are available was also mentioned.

More adult services provided by state agencies. Respondents commented on the need for more adult services designed for ASD individuals. The Department of Developmental Services (DDS)—and the DDS autism division in particular—and Department of Rehabilitation Services

Bureau of Rehabilitation Services (BRS) were the two agencies most frequently mentioned. Respondents commented on the need for more funding for agencies (“We build a bridge and there is no one on the other side [as students transition to adult life]”).

Respondents commented on the need for more involvement and outreach from the adult agencies during a student’s high school years. Better postsecondary services could start when the student is in high school, to bridge the programs seamlessly. There is a need for adult agencies to come to the table to help inform families about what should be done.

Needed adult services that were mentioned by respondents included transportation, day programs, subsidized supported living, respite services, long-term employment supports, and job coaching.

Student skill development. A number of respondents commented on the need for social skills for this population. Some respondents commented that social skills training should begin earlier, in elementary school, where students work on age-appropriate skills, one skill at a time. More emphasis on social integration, such as working with a group, was seen as beneficial. Another respondent suggested a mandatory social skills/anxiety survival class for every student with ASD every year (counting as their health credit), and another respondent suggested offering an after school support group for students with ASD.

Respondents also mentioned the importance of teaching skills of independence. One respondent suggested taking students out of their comfort zones while supports are still available. The need to have activities of daily living supports available in the community during a transition program (and post-high school) was mentioned as was giving students the opportunity for a fifth year/transitional services-only experience.

More job training and employment opportunities was suggested by several respondents. Others suggested that staff work with students to help students develop an understanding of their diagnoses. This understanding would help prepare students to advocate for themselves.

Postsecondary education institutions. Several respondents commented on the need for colleges to provide more supports for students with ASD. Mention was made of the need for programs that provide an immersion to social life in college and the expectations for academic rigor. The use of fifth year/transitional services-only as a bridge to community college (and for employment) was suggested.

Depends on level of ASD. Given the broad spectrum of autism, respondents commented on the need to provide different services, depending on the level of need of the individual. The more severe the ASD, the more services needed. More opportunities for low functioning students with ASD need to be provided. However, a number of respondents pointed out the lack of services for the higher functioning students with ASD (Asperger’s). Individuals who have ASD and an IQ of 70 or above were seen as not having services available to them. Needed services for higher functioning individuals with ASD included job coaching, interviewing, and socialization opportunities.

One respondent commented that students with severe limitations are strongly cared for, and higher functioning students can be successful in a supportive postsecondary education environment; however, the moderate functioning students seemed to struggle the most to get assistance.

Better partnership/relationship with parents/families. Respondents commented on the need for parents to have information about transition programs available and the transition planning process, particularly when their children are younger. Parents also need information about which agencies to turn to once their children turn 21.

Respondents commented on the need for parent involvement in transition in order for the student to be successful. One respondent commented on the need for parents (and teachers) to understand that even higher functioning students with ASD will need independent life skills training as part of their curriculum (e.g., understanding their health, transportation, social/emotional). Parents also need to begin giving their children more responsibility at home in order to carry over the skills learned in school or in a transition program such as doing laundry, cooking, money management and other independent living skills. Respondents also mentioned the need for parent outreach and support groups during the transition process. More detail on the comments may be found in Appendix H.

Respondents were also asked: “In your opinion, what resources or assistance do school personnel need to better serve students with ASD to prepare for adult life after high school?”

Comments were grouped into four categories:

1. more access/consistency from state agencies;
2. employment related services;
3. independent living/activities of daily living skills; and
4. more resources for high school.

More access/consistency from state agencies. Respondents mentioned a need for more consistent information and support from state agencies so transition coordinators can learn what is currently available for their students. Several respondents mentioned a need for more of a relationship with the adult agencies that will be picking up services for their students. More familiarity with adult service programs, perhaps through a resource list, was also suggested.

Greater access to personnel within state agencies such as the DDS autism division was recommended as a way for school personnel to help prepare students for adult life after high school. More adult services for people who do not meet the criteria for services from DDS, and the possibility of a state agency for ASD clients, were also mentioned. One suggested that DDS caseworkers come into the high schools to assist families in applying for DDS services as it is an overwhelming process, especially after age 18.

Besides recommendations pertaining to DDS, respondents suggested an increase in BRS personnel. Several commented on DMHAS needing to be more visible to school personnel and parents. One respondent suggested that DMHAS support staff should visit schools and offer workshops to staff on working with students with ASD. More information on mental health

services was another suggestion for assistance to school personnel to enable them to better serve students with ASD.

Employment related services. Respondents thought it would be beneficial to have additional funds for job coaches at the high school level. Mention of realistic employment goals and job development assistance while students are in high school were also suggested.

Some respondents commented on the need for students to practice working inside the school and outside in the community, job shadowing assistance, and work site visits. Having resources in the school such as a career center was also suggested.

One respondent commented that there should be exploration of vocational opportunities based on the skills of the student, not based on what is available, and encouraging school personnel to think outside the box. It is important to have students graduate with a skill that will allow them to become employed.

Independent living/activities of daily living skills. Respondents recommended that more functional skills be taught to students to prepare them for the real world. This may occur through spending more time in the community with less focus on academics. Alternatively, school personnel could look for opportunities to teach in authentic, community settings.

One respondent recommended incorporating activities of daily living into the requirements for general graduation rather than waiting to address them after academic requirements had been met. Funds for community mentors at the high school level was recommended as well as safety training and transportation planning.

Better options for residential services and the need for socialization groups were mentioned. Removal of dependency on one-on-one support staff was also suggested.

More resources for high school. In general, more resources for high school was recommended to help better serve students with ASD to prepare for adult life after high school. Respondents commented on the need for general education teachers to be given more training to better understand students with ASD. The general education teachers need to be aware of what effective modifications and accommodations would work best for students with ASD.

Respondents recommended that every school have transition specialists or transition coordinators. Also, that more professional development is needed for teachers and administrators to promote collaboration with the transition specialist.

Respondents recommended that a transition class be a requirement for graduation. One respondent reiterated the importance of every child having a Student Success Plan early on, even before sixth grade.

More detail on the comments may be found in Appendix I.

Summary

Legislative Program Review and Investigations Committee staff developed a survey for secondary education transition coordinators and other education professionals familiar with the area. It is estimated that the 174 survey respondents represent nearly half of all recipients of the transition coordinator survey (49 percent). Most of the respondents were affiliated with a public school district (84 percent). The 174 survey respondents most often identified themselves as either a transition coordinator (38 percent), special education teacher (20 percent), or director of special education (20 percent).

In analyzing responses regarding the services provided and experiences of students with ASD while in high school, it was found that:

- in comparison to students with ASD who were considered low need, students with ASD who were considered high need were more likely to: remain in high school past age 18; remain in high school for transitional services-only; and benefit from transitional services-only;
- the emphasis at high schools for students aged 16-18 years old with ASD is often on academics or academics and transition services—few students in this age range are believed to be focusing solely on transition services;
- respondents had the most difficult time finding appropriate adult services to which they could refer students who had both ASD and a behavioral or mental health diagnosis, followed by students with ‘ASD only’. Somewhat less difficult was making referrals for students with ASD who also had an intellectual disability;
- DMHAS and the DDS autism division were seen as somewhat difficult, and DORS/BRS and DDS relatively easy regarding: ease of referring students; likelihood of attending PPT meetings if invited; and outreach to students and families;
- approximately three-quarters of students with ASD were offered courses or assistance in career exploration, study skills, socialization skills, pre-employment activities, and organizational/executive functioning skills. Less likely to be offered was a course or assistance in household skills, such as cooking or laundry; and
- while over half of survey respondents (55 percent) said their school districts start writing IEP transition goals in ninth grade, many believe school districts should start writing these transition goals in an earlier grade. Half of respondents, for example, believe the goals should be started in sixth and

seventh grade. Only one-fifth (22 percent) believe transition goals should start to be developed in the ninth grade.

In reviewing use of two planning tools by school districts, it was found that both were used less than half the time:

- the voluntary secondary transition planning IEP checklist was always or often used less than one-third of the time during the secondary transition planning process; and
- about one-third of respondents could not say how often there were (statutorily required) Student Success Plans (SSPs), and 41 percent said it was used by all or many students.

Regarding post-high school outcomes for students with ASD, it was found that:

- many (86 percent) thought former students were faced with limited housing options, lack of affordability for private transition programs (77 percent), and transportation issues as a significant barrier to accessing services (77 percent)
 - three-quarters of respondents thought youth were referred to available services rather than to needed services;
- former students with high needs about whom respondents had some informal information, were more likely to be given “poor” ratings compared with former students with moderate and low needs:
 - at least half the time high need students with ASD were rated as doing poorly in the areas of employment, postsecondary education, vocational training, and social/recreation activities;
 - however, even former students with ASD who were considered to have low needs tended to be rated in the various areas as doing “fair,” with only 14 percent given an overall rating of “good.”
- respondents emphasized the importance of having access to appropriate services after exiting high school. Also of great importance to more favorable outcomes, are parental advocacy during high school, proper evaluation of needs during high school, and student involvement in transition planning. A strong transition plan was seen as very important by two-thirds of respondents.
- respondents tended to think IEP post-school goals for students with ASD were somewhat realistic, with less than one-third considering them very realistic or realistic.

There were a wide range of comments regarding suggestions for improvement in helping students with ASD transition from high school more successful. Comments fell into the general areas of:

- changes to secondary education (e.g., more professional development related to understanding all levels of ASD);
- more adult services provided by state agencies (e.g., more agency involvement and outreach during high school);
- student skill development (e.g., teaching independence);
- postsecondary education institutions (e.g., colleges) need to provide more supports for students with ASD;
- depends of level of ASD (e.g., different services needed depending on the level of need of the individual); and
- better partnership/relationship with parents/families (e.g., more parent involvement, and parent outreach and support groups during transition process).

There were also a wide range of comments regarding what resources or assistance school personnel needed to better serve students with ASD to prepare for adult life after high school. Comments fell into four general categories:

- more access/consistency from state agencies (e.g., need more consistent information from state agencies about what is currently available);
- employment related services (e.g., job coaches at the high school level);
- independent living/activities of daily living skills (e.g., more functional skills should be taught to students to prepare them for the real world); and
- more resources for high school (e.g., general education teachers need to be given more training to better understand students with ASD, and every school should have transition specialists or transition coordinators).

Chapter IV: Results of PRI Survey of Parents of Children with ASD Aged 15-25

Results of PRI Survey of Parents of Children with ASD Aged 15-25

Overview

A number of surveys of parents of children with disabilities have been conducted by CSDE and advocacy organizations; however, no findings have been reported that are specific to transitional services for youth and young adults with ASD. PRI staff determined that the best way to receive input from as many parents as possible was to develop and administer a survey relevant to the current study topic. The PRI survey of parents was especially important as it was an attempt to reach not only parents of children currently in high school, but also parents with sons and daughters up to age 25 years old who were no longer in high school.

PRI staff developed a survey for parents of children with autism spectrum disorder (ASD) between the ages of 15 to 25 years old. Drafts of the survey were reviewed and feedback provided by several parent advocates and professionals in the field. The survey was available online and in paper format (including a Spanish version of the survey). Most parents opted to complete the survey online. There were two versions of the survey: a survey for parents of children currently in high school including in a transitional program (17-item survey); and a survey for parents of children no longer in high school (25-item survey). The survey covered areas such as the services received during high school, transition, and post-high school, experiences with state agencies, and student outcomes.

Awareness of the survey was publicized through a variety of means including:

- Email announcements to members of:
 - Connecticut Autism Action Coalition (CAAC);
 - Autism Services & Resources Connecticut (ASRC);
 - Connecticut State Advisory Council on Special Education (SAC);
 - Connecticut Department of Developmental Services Division of Autism Spectrum Services waitlist;
 - North Central Community Collaborative;
 - Enfield Family Resource Center parents; and
 - Connecticut Parent Work Group.
- Website announcements on:
 - Connecticut Department of Developmental Services (DDS);
 - Connecticut Parent Advocacy Center (CPAC);
 - State Education Resource Center (SERC);

- Connecticut Council on Developmental Disabilities; and
- Southern Connecticut State University Center for Excellence on ASD website.
- private schools and programs notifying parents of children receiving transitional services;
- announcement at the CAAC Annual Meeting/luncheon; and
- PRI staff distribution of survey to interested parents at the November 1, 2014 ASRC Resource Fair.

A total of 236 parents responded to the parent survey during October and early November. One follow up reminder was emailed by CAAC approximately three weeks after their initial notification of the study survey.

Profile of Children of Survey Respondents

Table IV-1 provides some demographic information about the children of the 236 survey respondents. Parents with more than one child with ASD were instructed to answer the survey questions as they related to their oldest child with ASD who was in the 15-25 year old age range. The greater number of males and the percentage of children with intellectual disabilities are representation of this population.

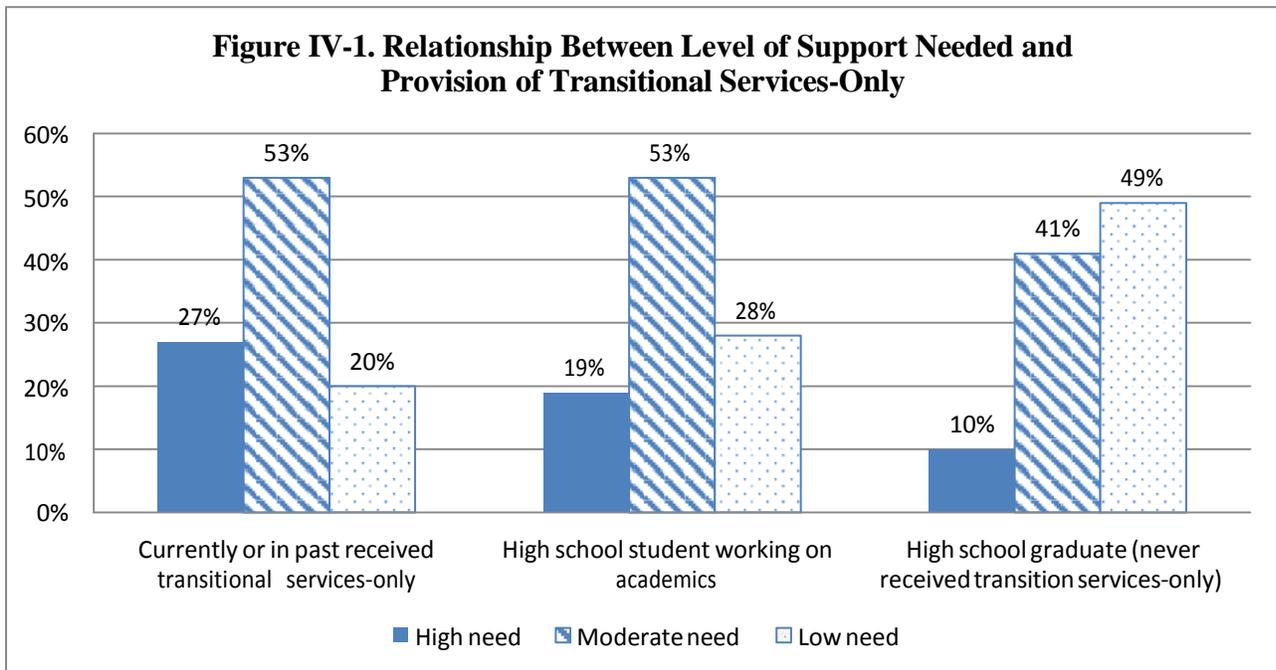
Table IV-1. Profile of Children being Parented by Survey Respondents	
Age of Child:	Percent:^a
15-17	31%
18-21	43%
22-25	25%
Gender of child:	
Male	82%
Female	18%
Estimated level of need of child:	
High need/requires substantial support	21%
Moderate need/requires moderate support	51%
Low need/requires minimal support	28%
Co-occurring Conditions:	
Intellectual disability	39%
Emotional/mental health disorder	37%
Other (e.g., ADD/ADHD, anxiety, OCD)	25%
Current status related to high school:	
High school student currently working on academic requirements (n=90)	38%
High school student who is currently being home schooled (n=1)	<1%
18-21 year old receiving transitional services-only (n=58)	25%
High school dropout (n=1)	<1%
High school graduate (n=86)	36%

^a Figures may not add up to 100 percent due to rounding.

Of the high school graduates, 43 percent of parents said their children had not received transitional services-only prior to exiting high school. The most frequent reasons given for not receiving transitional services-only by the 36 parents were:

- did not know this option was available (33 percent);
- child did not want to stay for transitional services-only (17 percent);
- transitional services-only were not required (11 percent); and
- child continued to work on academic requirements until age 21 (11 percent).

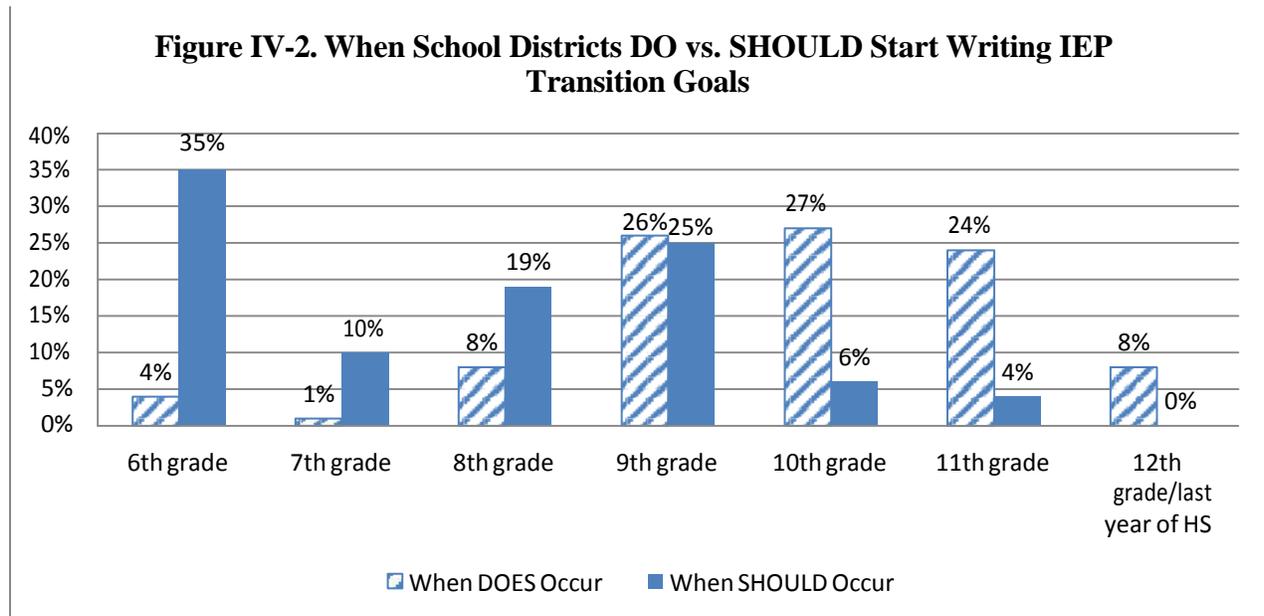
Students who are currently, or had previously received transitional services-only, were more likely to have high needs, and less likely to have low needs (Figure IV-1).



Overall Findings About Services Received During High School

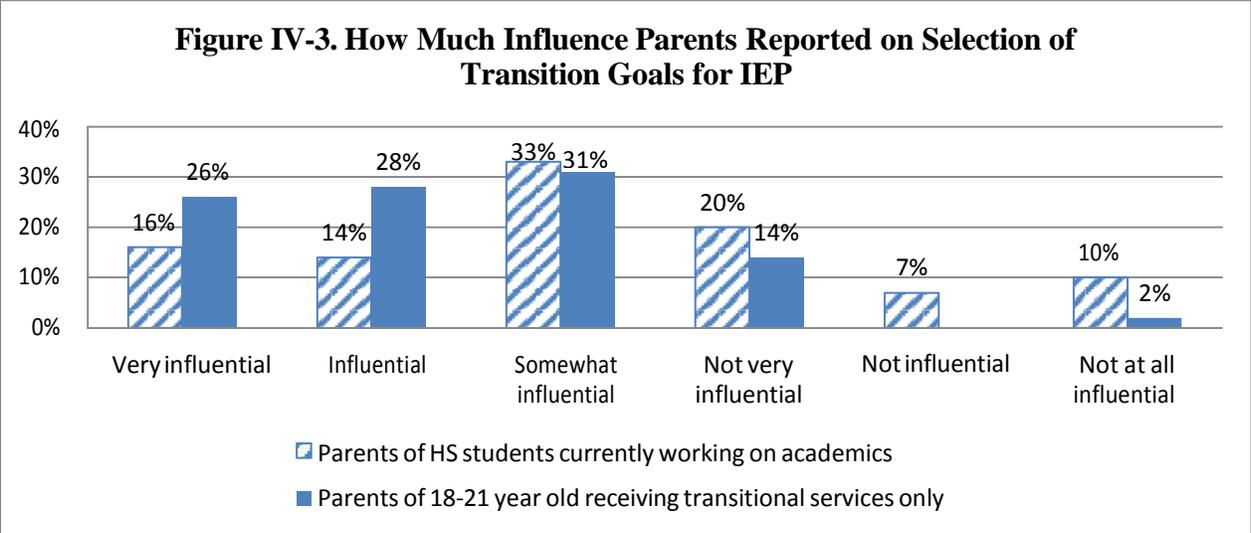
Establishment of individualized education program (IEP) goals related to transition to adult life. The Individuals with Disabilities Act (IDEA) requires transition planning no later than age 16, or earlier if determined appropriate by the Planning and Placement Team (PPT) for all special education students. Parents were asked to specify the grade that their children generally began having IEP goals related to transition to adult life. Excluding the 27 respondents who were not sure (14 percent of all survey respondents) and the three respondents who said after academic requirements had been completed but before the student left high school, Figure IV-2 shows the disparity between when the goals are written and when parents say the goals

should be written. While one-quarter say the IEP transition goals are written in ninth grade, one-third (35 percent) think they should start writing the goals in sixth grade.

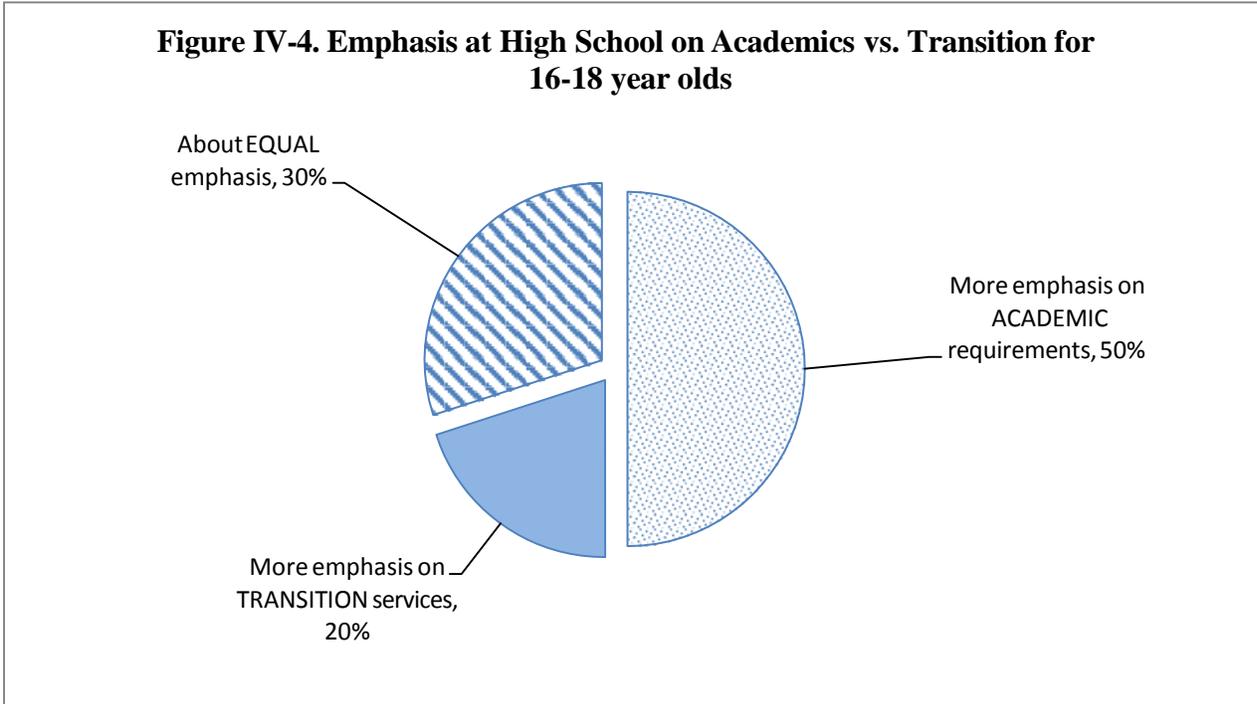


Parents were asked to choose a descriptor that described the transition goals on their child’s IEP. The most often chosen descriptor was “too broad” (28 percent) and 13 percent indicated “nonexistent.” Other responses included: “realistic” (12 percent); “agreed to by all the PPT members” (9 percent); “appropriate choices” (7 percent); and “unrealistic” (6 percent).

When parents were asked how much overall influence they would say they had on the transition goals chosen for their child’s IEP, the most often given response was “somewhat influential” (31 percent), followed by “influential” (28 percent), and “very influential” (26 percent). Figure IV-3 shows that parents of 18-21 year olds in transitional services-only believe they had more influence in the transition goals chosen compared with parents of students currently working on academics.



Emphasis on academic requirements vs. transitional services for 16-18 year old high school students with ASD. Half of parents said the emphasis at high schools for students aged 16-18 years old with ASD was on academics (50 percent) (Figure IV-4). Under one-third (30 percent) thought there was about equal emphasis, and 20 percent thought there was more emphasis on transition services.



Assistance provided by school districts. Table IV-2 shows the frequency with which survey respondents said courses or individual assistance was offered by the school district to

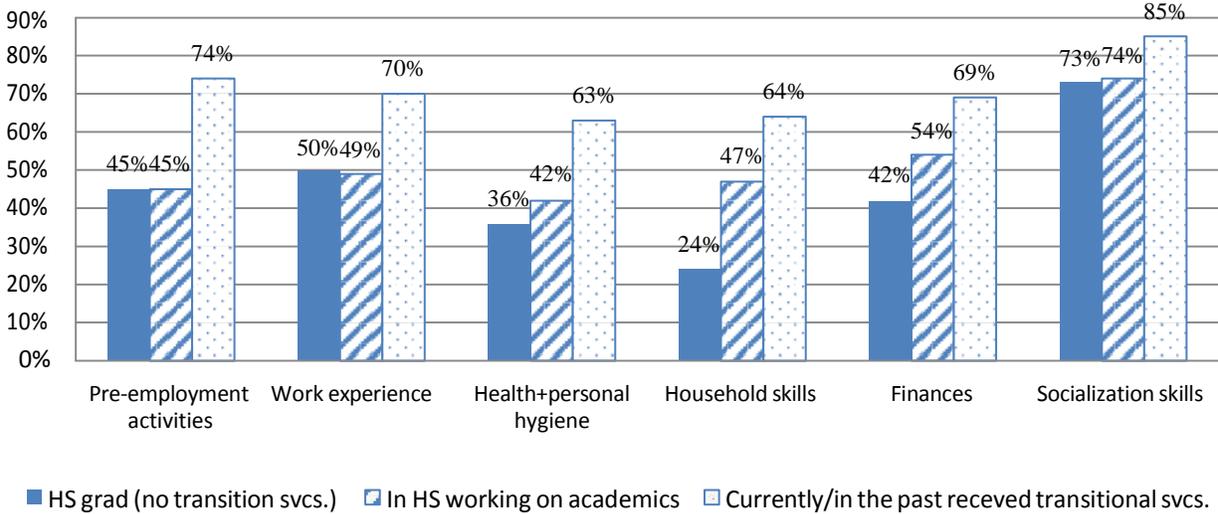
high school students with ASD who needed the assistance. Excluding the “don’t know” responses, answers are shown in Table IV-2. At least some assistance was provided at least half the time in all the areas. Socialization skills appeared to be offered the most often (78 percent), and health and personal hygiene the least often (51 percent).

Over one-third of parents said assistance in the following areas was not provided: household skills, such as cooking or laundry; work experience/internships; finances; and pre-employment activities.

High school graduates who had been in transitional services-only and 18-21 year olds currently in transitional services-only, were more likely to have received courses or assistance in six of the nine areas (Figure IV-5), including the four areas in which over one-third of parents said assistance had not been provided to their sons and daughters.

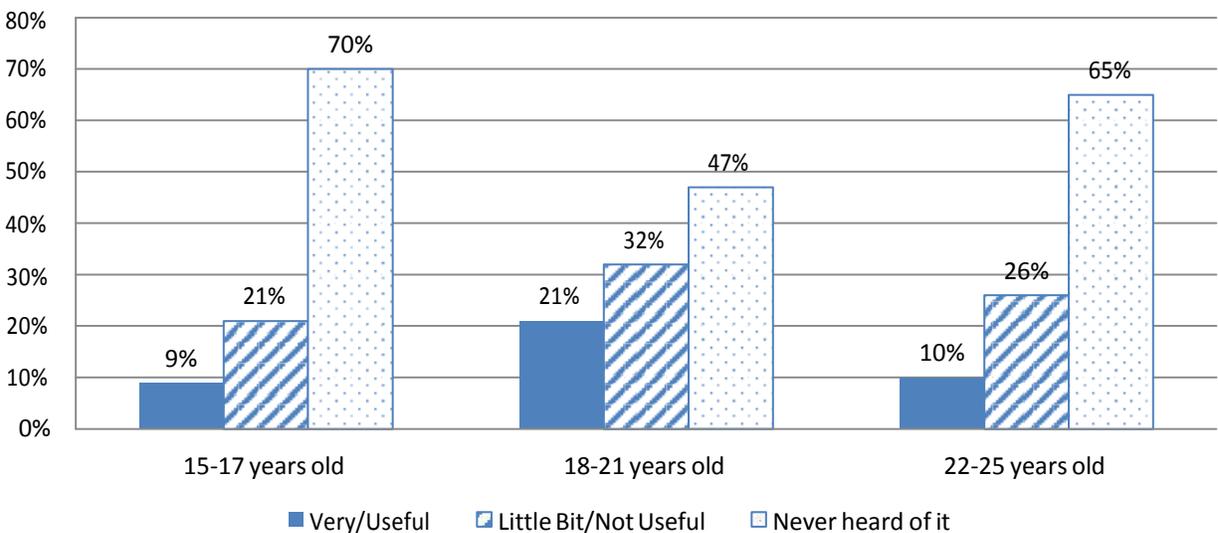
Area	Rating			Don't need
	Yes, quite a bit	Some assistance	No, not provided	
Socialization skills	20%	58%	20%	1%
Career exploration	12%	59%	27%	2%
Work experience/internship	16%	44%	39%	2%
Organizational/executive functioning skills	15%	54%	31%	0%
Study skills	14%	53%	29%	4%
Pre-employment activities	14%	46%	37%	4%
Finances	10%	49%	38%	2%
Household skills	12%	40%	40%	8%
Health and personal hygiene	12%	39%	32%	16%
Source: PRI Survey of Parents.				

Figure IV-5. Percent of Parents Reporting at Least Some Assistance in the Area



Over half (59 percent) the respondents had never heard of “Building a Bridge” or any other transition-related publications that could have been given to them by their school systems. This was less likely to occur for parents of children 18-21 years old (Figure IV-6). Regardless of age of child, relatively more parents questioned the usefulness of “Building a Bridge” or other transition-related materials they may have received from their school districts.

Figure IV-6. Usefulness of "Building a Bridge" or other Transition-Related Publications



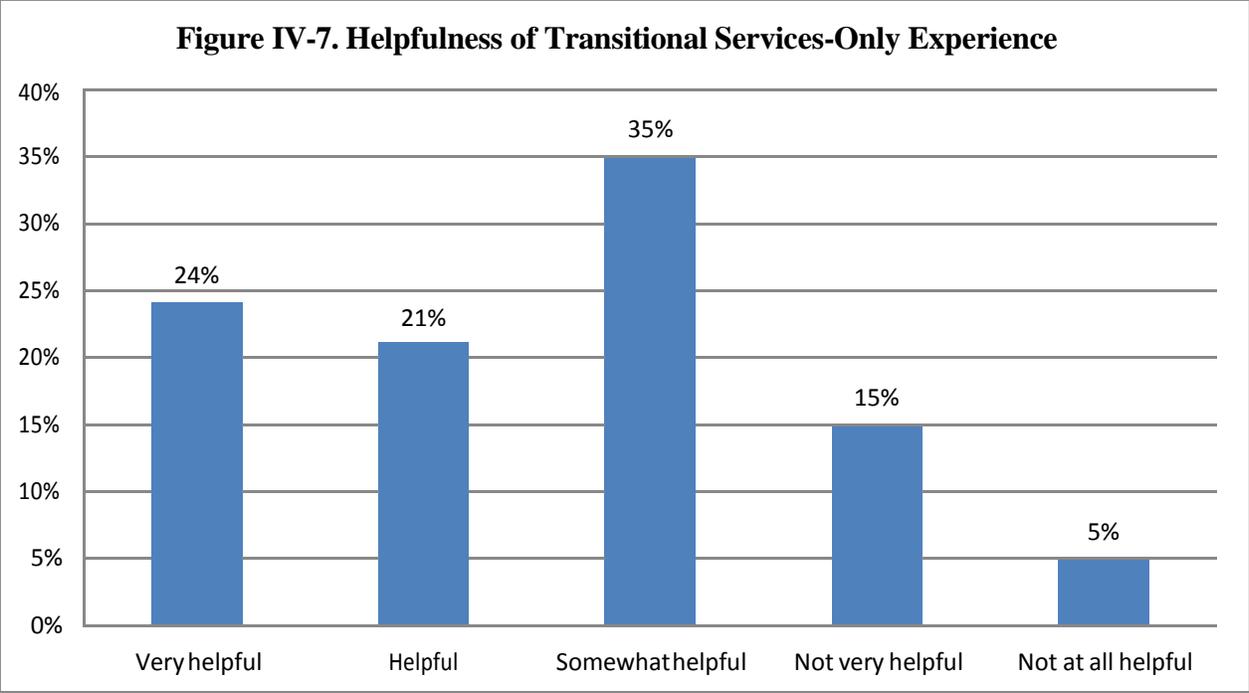
Findings of Factors Contributing to Successful Outcomes for Graduates

Respondents were asked to rate the importance of certain factors in preparing students with ASD for life after high school (Table IV-3). Factors considered important by almost all parents, regardless of whether their child was in high school, receiving transitional services, or had graduated, was access to appropriate services after exiting high school, proper evaluation of needs during high school, strong transition plan, and parental advocacy during high school. Parents also felt strongly about student involvement in transition planning and less so about the severity level of ASD.

Factor	Very Important	Important	Total Very Important + Important
Access to appropriate services after exiting high school	95%	4%	99%
Proper evaluation of needs during high school	88%	11%	99%
Strong transition plan	92%	7%	99%
Parental advocacy during high school	87%	12%	99%
Student involvement in transition planning	64%	22%	86%
Family financial ability	59%	22%	81%
Less severe level of ASD	43%	21%	64%

Source: PRI Parent Survey.

Of the parents with children who were currently receiving transitional services-only, or who's children had graduated from high school after receiving transitional services-only, Figure IV-7 shows their ratings of the helpfulness of transitional services-only in preparing their sons and daughters for life after high school. Four out of five parents (80 percent) said the experiences were at least somewhat helpful while the remainder (20 percent) said the experience was not very helpful or not at all helpful.



Post-High School Experiences for Parents and Children

Success in achieving IEP transition goals. Excluding the 14 parents who did not know or could not remember what their child’s IEP transition goals were (16 percent), two-thirds of the remainder (64 percent) said their son or daughter had been very successful or successful in achieving their IEP transition goals.

Familiarity with getting help/adult services after high school. Parents were asked how familiar they had been with getting help or adult services for their sons and daughters after exiting high school. Almost two-thirds (61 percent) were somewhat or very familiar, with the remainder not sure how to get assistance. Parents of children who had received transitional services-only were more familiar with how to get help or adult services for their children after high school (Figure IV-8).

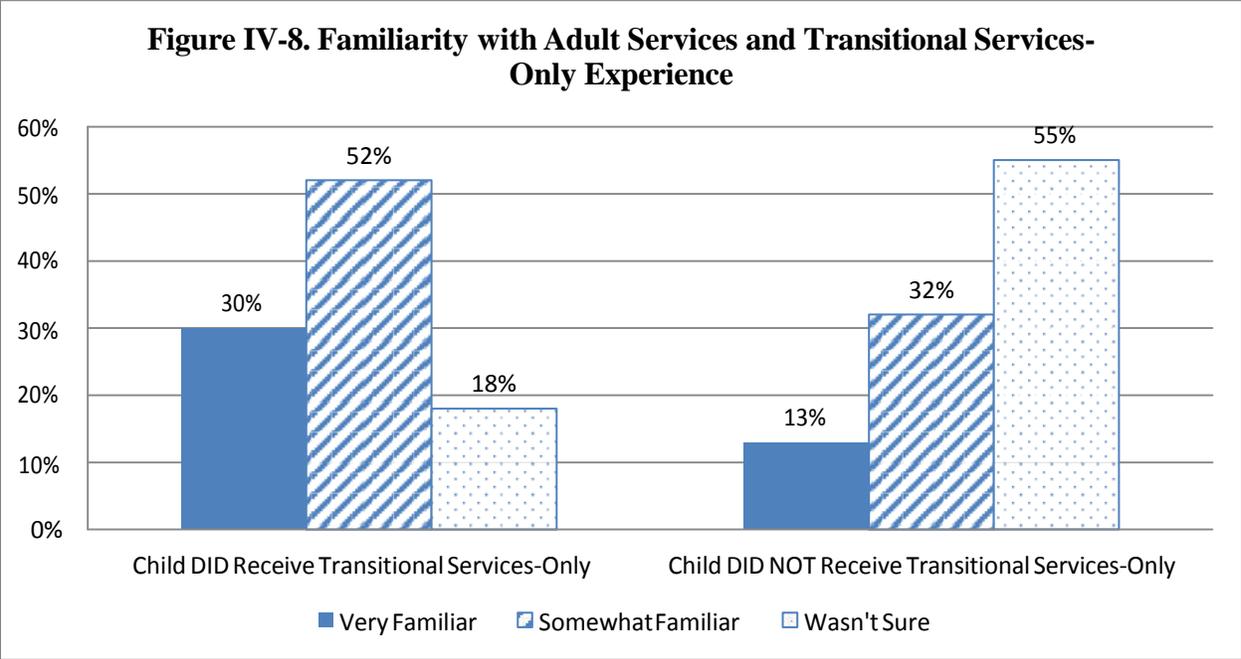
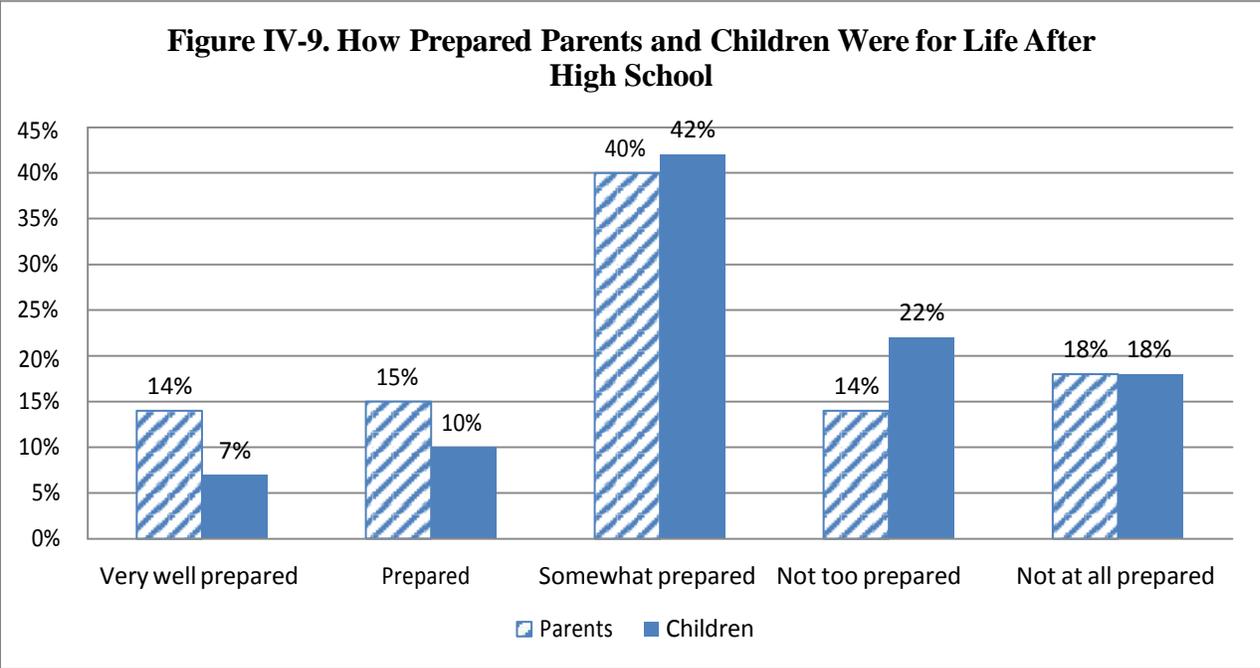
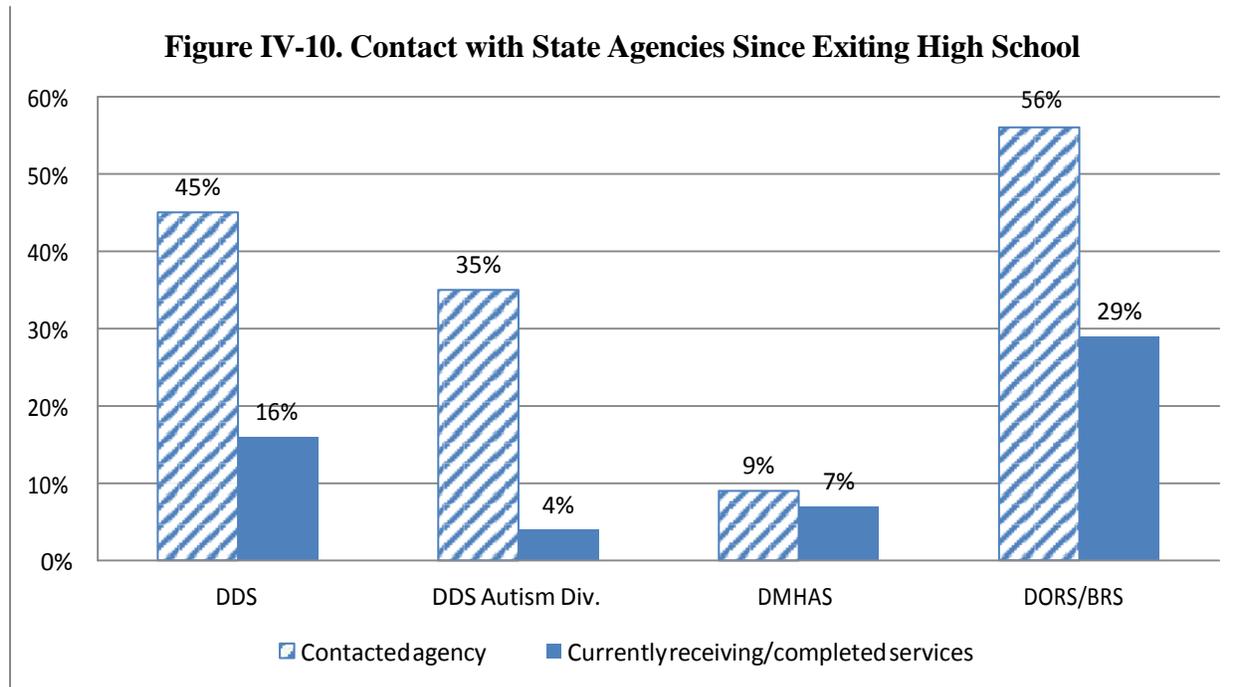


Figure IV-9 shows how prepared the parents said they and their sons and daughters were for what happened after leaving high school. “Somewhat prepared” was the most frequent response regarding both parents and children. While 29 percent of parents said they were very well or well prepared, the same rating was given for just 17 percent of the children. A total of 40 percent of parents said their children were not too prepared or not at all prepared for what happened after leaving high school.



Contact with state agencies since child exited high school. The Department of Rehabilitation Services Bureau of Rehabilitation Services was the state agency most likely to be contacted by families with children who had graduated from high school and the most likely to be providing services (Figure IV-10). While more than one-third (35 percent) had contacted the DDS Division of Autism Spectrum Services, just four percent were receiving services from the division.



Available services/supports for former students with ASD. In thinking about their current situations, parents were asked to rate their agreement with 12 statements. A six-point rating scale was used for each statement (1=“strongly agree” to 6=“strongly disagree”). Respondents could also check off “don’t know” and this occurred at least 10 percent of the time for the following six questions:

- Respite care is not readily available (26 percent didn’t know);
- Vocational programs are difficult to get into (23 percent didn’t know);
- Before and after program care services are a critical need (23 percent didn’t know);
- Programs teaching life skills/activities of daily living are rarely available (14 percent didn’t know);
- Housing options are limited (13 percent didn’t know); and
- Services are available for too short an amount of time (13 percent didn’t know).

Table IV-4 shows the statements ordered from strongest to least agreement. Strongest agreement was found for the critical need to have a high school transition coordinator with specific training and skills to do this work, and college programs providing supports to students with ASD. Lower agreement was found for transportation as a significant barrier to accessing services.

Table IV-4. Level of Agreement by Parents with Survey Statements Regarding Available Services and Supports			
Statement	Strongly Agree	Agree	Total Strongly Agree + Agree
It is critical to have a high school transition coordinator with specific training and skills to do this work.	83%	13%	96%
College programs providing supports to students with ASD are necessary for success at this level.	85%	10%	95%
Services are available for too short an amount of time.	69%	22%	91%
There is a limited number of professionals with specific training in working with individuals with ASD.	61%	26%	87%
Housing options are very limited.	74%	10%	84%
Private transition programs are not affordable for my family.	61%	21%	82%
Programs teaching life skills/activities of daily living are rarely available.	58%	24%	82%
Respite care is not readily available.	59%	22%	81%
Vocational programs are difficult to get into.	52%	28%	80%
Services are limited near where I live.	58%	17%	75%
Before and after program care services are a critical need.	48%	24%	72%
Transportation is a significant barrier to accessing services.	42%	19%	61%
Source: PRI Transition Coordinator Survey.			

Table IV-5 shows how well parents of children who had graduated high school said their sons and daughters were currently doing in a variety of areas including employment, postsecondary education, vocational training, and social/recreational activities. Becoming more independent and overall well-being were also rated by the parents.

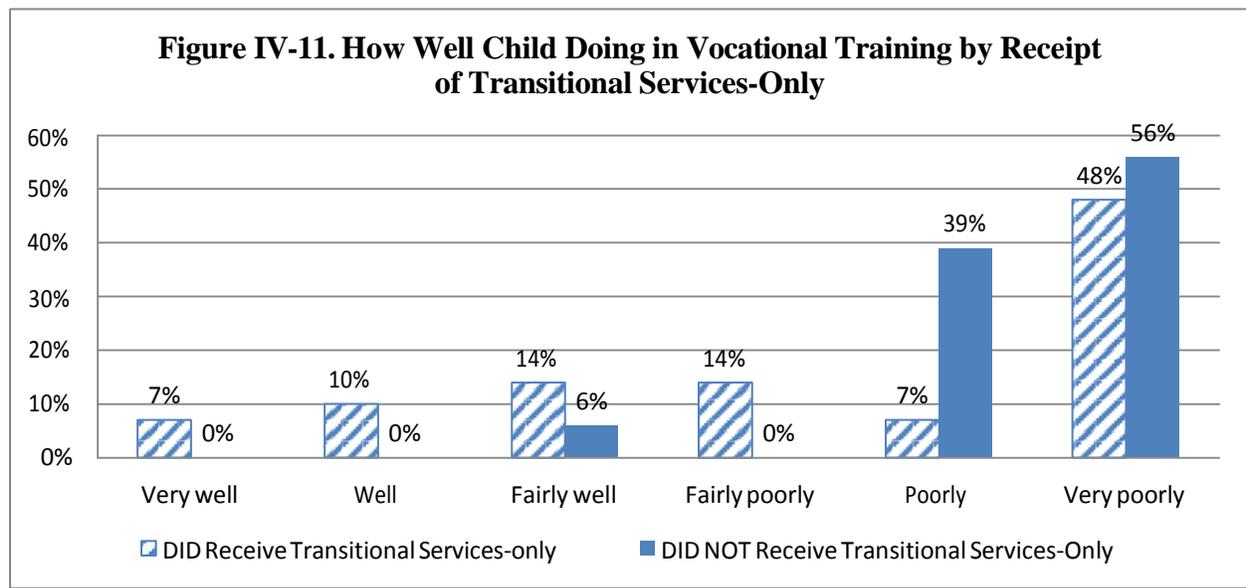
Area	Very well	Well/Fairly well	Fairly poorly/Poorly	Very poorly
Employment	8%	40%	18%	34%
Postsecondary Education	11%	34%	26%	28%
Vocational Training	4%	17%	28%	51%
Social/recreational Activities	6%	42%	27%	25%
Becoming More Independent	9%	49%	28%	14%
Overall Well-Being	5%	60%	23%	12%

Source: PRI Survey of Parents.

Two-thirds of parents thought that their children were doing at least fairly well overall, and more than half thought their children were becoming more independent. Over half of parents thought their children were doing fairly poorly to very poorly in the areas of:

- vocational training;
- postsecondary education;
- employment; and
- social/recreational activities.

Many students struggled in the area of vocational training. There was a greater likelihood, however, for former students who had received transitional services-only to do somewhat better in this area (Figure IV-11).



Summary

Legislative Program Review and Investigations Committee staff developed a survey for parents of children ages of 15 to 25 years old with ASD. A total of 236 parents completed the survey during October and November 2014.

Findings related to services received during high school were:

- Of the high school graduates, 43 percent of parents said their children had not received transitional services-only prior to exiting high school.
 - The most frequent reason given for not receiving transitional services-only by the parents was that they did not know this option was available.
- Students who are currently, or had previously received transitional services-only, were more likely to have high needs, and less likely to have low needs.
- Parents thought IEP goals related to transition to adult life should be developed earlier.
 - One-third thought they should be written starting in sixth grade.
 - Currently, over half the time, the goals are written beginning in tenth or eleventh grade.
- Parents of 18-21 year olds in transitional services-only believed they had more influence in the transition goals chosen compared with parents of students currently working on academics.
- At least some assistance was provided at least half the time for all skill areas queried including: socialization skills, career exploration, study skills, and organizational/executive functioning skills.
 - Over one-third of parents said needed assistance was not provided for household skills, work experience/internships, finances, and pre-employment activities.
 - Both high school graduates who had previously been in transitional services-only and 18-21 year olds currently in transitional services-only, were more likely to have received courses or assistance in many of the areas queried.
- Over half the respondents had never heard of “Building a Bridge” or other transition-related publications that could have been given to them by their school systems, although the parent respondents also questioned the usefulness of the document(s).

Findings related to factors contributing to successful outcomes for graduates were:

- Almost all parents, regardless of whether their child was in high school, receiving transitional service, or had graduated, considered the following factors important in preparing students with ASD for life after high school:
 - access to appropriate services after exiting high school;
 - proper evaluation of needs during high school;
 - strong transition plan; and
 - parental advocacy during high school.
- Parents also felt strongly about student involvement in transition planning, but less strongly about the role severity level of ASD played in preparing their children for life after high school.
- Four out of five parents with children who currently or had previously received transitional services-only said the experience was at least somewhat helpful.

Findings related to post-high school experiences for parents and children were:

- The majority of parents said their son or daughter had been very successful or successful in achieving their IEP transition goals.
- Parents of children who had received transitional services-only were more familiar with how to get help or adult services for their children after high school.
- Less than one-third of parents said they were very well or well prepared for what happened after their children left high school.
 - 17 percent of parents judged their children to be very well or well prepared; 40 percent of parents said their children were not too prepared or not at all prepared for what happened after leaving high school.
- The Department of Rehabilitation Services Bureau of Rehabilitation Services was the state agency most likely to be contacted by families with children who had graduated from high school, and the most likely to be providing services.
- Almost all parents agreed that it was critical to have a high school transition coordinator with specific training and skills to do this work, and to have college programs providing supports to students with ASD as necessary for success at this level.
- Two-thirds of parents thought their children were doing at least fairly well overall.
- Over half thought their children were becoming more independent.
- Over half of parents thought their children were doing fairly poorly or very poorly in the areas of:
 - postsecondary education;

- employment;
 - social/recreational activities; and
 - vocational training.
- Many students struggled in the area of vocational training. There was a greater likelihood, however, for former students who had received transitional services-only to do somewhat better in this area.

Chapter V: Transitional Services During High School

Description of Services Provided During High School

Services Provided by Connecticut State Department of Education (CSDE)

The primary provider of transition services during the high school years is the public school system. The Connecticut State Department of Education (CSDE) is required under the Individuals with Disabilities Education Act (IDEA) to provide transition services to students with disabilities. The Act defines transition services as a coordinated set of activities designed within a result-oriented process that:

- are focused on improving the academic and functional achievement of the student to facilitate the transition from secondary school to post-school activities such as vocational education, integrated employment (including supported employment), adult services, and independent living;
- are based on the needs of the individual student, and take into consideration strengths, preferences and interests; and
- includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and as appropriate, daily living skills and functional vocational evaluation.

The Bureau of Special Education within CSDE works with school districts to implement the various federal and state laws on special education. According to CSDE, the purpose of transition planning is to assist students in becoming the most independent, responsible, self-determined individuals they can be.²⁹ Secondary transition age is formally considered to be ages 16-21.

Efforts to provide transitional services are documented in the student's Individualized Education Program (IEP). As for all special education students, the IEP process must include transition planning no later than age 16, or earlier if determined appropriate by the Planning and Placement Team (PPT) (per section 300.43 of IDEA).

The IEP Manual and Forms of the CSDE Bureau of Special Education, Fifth Revision December 2013, states that IEP transition plans must have at least one post-school outcome goal statement (PSOGS)³⁰ related to postsecondary education or training, and at least one PSOGS related to employment. If independent living is appropriate, then another goal should be related to that outcome or preparation for that outcome. As required by IDEA and as stated in the CSDE IEP manual, the PSOGS are to be written as measurable statements that are to be achieved after leaving secondary school (IDEA 2004 Part B Regulations, 34 C.F.R. Sections 300.320(b)).

²⁹ Topic Brief on Post-School Outcome Goal Statements Frequently Asked Questions, July 2009, State Department of Education online library.

³⁰ Post-School Outcome Goal Statement is Connecticut's term for the "appropriate measurable postsecondary goals" required by IDEA for transition-age students.

Ideally, according to CSDE, implementing the transition plan will lead to the achievement of certain skills or abilities by the time the student graduates. Areas to be mastered relate to: self-determination/self-advocacy; social skills and behavior; career/vocational; and independent living (Figure V-1).

Figure V-1. Areas to be Mastered by High School Graduation for Transitioning Students

Related to Self-Determination/Self-Advocacy Skills:

- ✓ Assist with the development of IEP
- ✓ Attend, participate in and/or facilitate PPT meeting
- ✓ Explain disability
- ✓ Identify and ask for accommodations
- ✓ Know personal rights and responsibilities

Related to Social Skills and Behavior:

- ✓ Interact appropriately
- ✓ Maintain meaningful relationships

Related to Career/Vocational Transition:

- ✓ Access appropriate employment
- ✓ Access appropriate postsecondary education, training, or lifelong opportunities

Related to Independent Living:

- ✓ Take responsibility for independence and activities of daily living
- ✓ Access transportation

If agreed to by members of the PPT, students who have completed their academic requirements may delay their graduation to age 21 and receive transitional services-only. Transitional services-only are ideally provided in the least restrictive environment, in integrated, community settings. During transitional services, students aged 18 to 21 years old may gain employment preparation and work experience, postsecondary education or vocational preparation and experience, and learn skills needed to live independently such as cooking, laundry, and personal hygiene. In the 2013-2014 school year, there were approximately 118 students aged 18-21 years old with ASD who had completed their academic requirements and were focused solely on transition services.

Of the approximately 24 transitional services described in a directory published by CSDE,³¹ many take place at community colleges, state universities, and private universities such as Wesleyan University, Quinnipiac University, and the University of Hartford.

Assistance provided by school districts. Using a five-point scale (1=“always” and 5=“never”), Table V-1 shows the frequency with which PRI Transition Coordinator Survey

³¹ The Connecticut Transition Services in College, University and Community-Based Settings is in the process of being updated by CSDE and this revised directory is expected to be available in 2015.

respondents said courses or individual assistance was offered by the school district to high school students with ASD who needed the assistance.³² Survey respondents said approximately three-quarters of students were offered courses or assistance in career exploration, study skills, socialization skills, pre-employment activities, and organizational/executive functioning skills. Less likely to be offered was a course or assistance in household skills, such as cooking or laundry.

Area	Rating		
	Always/Frequently	Sometimes	Rarely/Never
Career exploration	77%	15%	8%
Study skills	74%	20%	6%
Socialization skills	78%	11%	11%
Pre-employment activities	74%	13%	13%
Organizational/executive functioning skills	73%	19%	8%
Finances	64%	24%	12%
Health and personal hygiene	59%	25%	16%
Household skills	51%	28%	21%

Source: PRI Transition Coordinator Survey.

In the CSDE Post-School Outcomes Survey results (Table V-2), money management skills were seldom taught, and self-advocacy skills were inconsistently taught—but were most often taught to students who went on to higher education or some other employment.³³

Agency	Percent of All Respondents (N=1,973)	Percent of Respondents with ASD (N=180)
Social Skills (getting along with others)	57%	55%
Self-Advocacy (ability to know why you need and ask for it)	51%	43%
Independent Living Skills (running a household, using transportation, taking care of your health and hygiene, managing your money)	32%	38%
Technology Skills (ability to use computers or other assistive tools)	46%	45%
Time Management/Organizational Skills	45%	44%
Money Management Skills	26%	28%
Study Skills/Learning Strategies	50%	48%
Work Experience	33%	38%
None	10%	10%

Source: CSDE and PRI staff analysis.

³² See Chapter III for complete results of PRI Transition Coordinator Survey.

³³ See Appendix B for complete results of CSDE Post-School Outcomes Surveys.

Parents responding to the PRI Survey of Parents of Children with ASD Aged 15-25 were also asked how frequently certain courses or individual assistance was offered by the school district to high school students with ASD who needed the assistance (Table V-3).³⁴

Area	Rating			Don't need
	Yes, quite a bit	Some assistance	No, not provided	
Socialization skills	20%	58%	20%	1%
Career exploration	12%	59%	27%	2%
Work experience/internship	16%	44%	39%	2%
Organizational/executive functioning skills	15%	54%	31%	0%
Study skills	14%	53%	29%	4%
Pre-employment activities	14%	46%	37%	4%
Finances	10%	49%	38%	2%
Household skills	12%	40%	40%	8%
Health and personal hygiene	12%	39%	32%	16%
Source: PRI Survey of Parents.				

Example of transitional services-only provided by a school district. A number of school districts either directly, or through contracts with RESCs, provide transitional services-only for some students with ASD who had completed their academic requirements for graduation, but remained up to June 30th of the year they turned 21 to receive additional assistance in preparing for the transition to adulthood. PRI staff visited one well-regarded program operated by the West Hartford school district. An overview of the ACHIEVE program and outcome data is now provided.

ACHIEVE Program (Transition Program for 18-21 Year Olds in the West Hartford School District)

Population served. The ACHIEVE program, which is run by the West Hartford school district, serves students ages 18-21 primarily from West Hartford with a diagnosis of ASD, learning disability, or speech and language disorder. Occasionally, out-of-district students are admitted to the program with an annual tuition cost of approximately \$40,500, which includes social work services.

The ACHIEVE program was started in 2007 in response to the increase in students with ASD. The program began with three students and currently has nine students. The goal of ACHIEVE is for the students to live as independently as possible within their community.

³⁴ See Chapter IV for complete results for PRI Survey of Parents of Children with ASD Aged 15-25.

Program/service description. The ACHIEVE program consists of three major components:

- functional academics;
- vocational/work; and
- community experiences.

Within these three components, students are learning skills such as:

- problem solving;
- self-advocacy;
- communication;
- building friendships;
- active learning;
- team work;
- decision making;
- small group instruction;
- meeting challenges; and
- taking ownership.

Activities of daily living, including managing personal needs, finances, and public transportation, are part of the ACHIEVE curriculum. Social skills that are worked on include acquiring self-confidence, achieving socially responsible behavior and maintaining good interpersonal skills.

Vocational experiences occur three to four days per week. The two transition coordinators for the ACHIEVE program work to find job sites for students so that they may gain work experience and also build stamina so that they are able to work more hours. In the second semester, there is also a college partnership where some students work on enrolling at community colleges, including linking with the college's disability coordinator.

In addition to the special education teacher and part-time transition coordinator, the staff for ACHIEVE includes one part-time supervisor, one special education teacher, two to three paraprofessionals, and one part-time social worker who works with the students in group sessions to help navigate systems and resolve peer disputes (individual sessions are also available).

Outcome data. Since the start of the program in 2007, there have been eight students with ASD who graduated from ACHIEVE:

- five graduates left with full- or part-time jobs in competitive employment:
 - two left working full-time;
 - two left working part-time; and
 - one left working two part-time jobs five days per week.

- two graduates left taking for-credit courses at Tunxis Community College; and
- one graduate left working with the Bureau of Rehabilitation Services to find a job (this graduate had previously been working full-time).

Although the number of graduates with ASD to date is relatively small, the program appears promising, as seven of the eight graduates with ASD (88 percent) are either competitively employed or attending college.

Services Provided by Other State Agencies

Department of Rehabilitation Services/Bureau of Rehabilitation Services. Federal funding for the Connecticut Department of Rehabilitation Services Bureau of Rehabilitation Services (DORS/BRS) is provided by the federal Rehabilitation Act of 1973. Section 103 of the Rehabilitation Act specifies that vocational rehabilitation services be provided to, among others, transitioning students with disabilities, with the purpose of facilitating the achievement of employment outcomes identified in an individualized plan for employment (IPE).

The Department of Rehabilitation Services has approximately 70 vocational rehabilitation counselors (VR counselors) assigned as liaisons to all 143 Connecticut school districts that provide secondary services. Most of the VR counselors each provide vocational assistance to 80-100 students at a time. The liaisons are responsible for working with the school, student, and family on the transition process.

While BRS may work with students as young as 14 years old, priority is given to students in the junior year or next to last year of high school.³⁵ The role of the counselors is to help the schools advise their students on what vocational assessment instruments to use. They also work with individual students to determine eligibility for BRS services and, if the student is eligible, develop individualized plans for employment (IPEs) that specify what services and supports BRS will provide directly upon graduation from high school. Although BRS does not pay for services until the student has graduated,³⁶ agency liaisons may be available to assist with transitional planning, including attending PPTs if already working with the student.

When it is time for a student to find employment, BRS can assist with job placement, additional training, job coaching, transportation assistance, and assessing a worksite for accessibility—these services are sometimes referred to as Vocational Rehabilitation.

As has occurred in previous summers, during the summer of 2014, DORS/BRS operated a jobs program for youth and young adults, described more fully in Chapter VII.

The Bureau has a Transition Committee that develops training, best practices, and better ways to engage schools. One member of the committee is the transition consultant from the State

³⁵ Technically, vocational rehabilitation counselors may work on transitions with students who are 14-24 years old, but they rarely deal with 14-year-old students.

³⁶ The summer jobs program is funded with state dollars as opposed to federal BRS money.

Department of Education. This individual's position is jointly funded by the state education and rehabilitation services departments, and provides consultation and technical assistance, coordinates transition planning between the two agencies, as well as outreach and identification strategies.

The Bureau also has an Autism Committee that reviews cases for persons of any age with ASD. Unlike the Transition Committee, the BRS Autism Committee is strictly about individual cases and does not develop or recommend general policies related to individuals with ASD.

Connecticut Department of Developmental Services (DDS). DDS currently has 12 transition advisors for ages 16-21 and 5 education advisors for ages 15-18. The Connecticut Department of Developmental Services transition advisors help students in high school obtain appropriate educational programs that focus on employment.

Connecticut DDS Division of Autism Spectrum Services. The Connecticut DDS Division of Autism Spectrum Services offers services to individuals on the waiver while in high school, such as behavior management, job coaches, and life skills coaches. They also provide community mentors, social skills groups, and transportation to some individuals.

Connecticut Department of Mental Health and Addiction Services. The Connecticut Department of Mental Health and Addiction Services (DMHAS) serves individuals with ASD while in high school if they are aged 18 and older and also have a co-existing mental or behavioral health condition. The department also has a program specifically for young adults; however, participants must also have had a connection or involvement with the Connecticut Department of Children and Families (DCF) in order to receive services from the young adult services program.

Services Offered by Private Providers

In addition to the services provided by state agencies, there are private agencies offering services to youth and young adults with ASD. A number of the private providers have been approved by the CSDE as "Approved Private Special Education Programs (APSEPs). At a March 20, 2014, presentation to the M.O.R.E. Special Education Working Group, it was reported that approximately 2,500 students were being educated in APSEPs (3.6 percent of the approximately 70,000 students aged 3-21 receiving special education services).

In order to become an APSEP, the organization must submit an application documenting that the program is being operated in accordance with the standards and approval principles set forth by the State Board of Education. Only schools in operation for at least one year with an enrollment of at least 10 students may request consideration for approval to become an APSEP. Approval is granted for a maximum of five years.

In the directory of APSEPs,³⁷ there are 57 schools listed, some of whom serve individuals with ASD. Chapel Haven of New Haven, Connecticut serves students with Asperger's (higher functioning autism) and individuals with both ASD and an intellectual disability. Oak Hill

³⁷ http://www.sde.ct.gov/sde/lib/sde/PDF/DEPS/Special/Priv_SpEd_Progs.pdf

Schools are operated in nine locations in the New Britain, Bristol, and Plainville areas, and provide services to individuals with ASD and other disabilities aged 13-21.

Another example is the Connecticut Center for Child Development, Inc. (CCCD), in Milford, Connecticut. CCCD is a private-nonprofit organization serving individuals aged 3-21 with autism, Asperger's syndrome and related disorders.

If part of the student's IEP, all or a portion of the expense to attend an APSEP may be paid by the home school district. Often it falls to the families to pay out-of-pocket for an APSEP. The availability of such providers may depend on several factors including location and the family's ability pay.

Services Offered by Advocacy Groups

There are various advocacy groups throughout Connecticut providing awareness and helping families navigate the medical, educational, and adult services systems. Some of the advocacy groups are broad, serving all disabilities (e.g., Connecticut Parent Advocacy Center (CPAC)), while others focus on ASD, such as Friends of Autistic People (Greenwich), and Connecticut Families for Effective Autism Treatment.

One of the larger advocacy groups focused on ASD is Autism Services & Resources Connecticut (ASRC). ASRC offers education and information on a comprehensive range of treatments and providers. Advocates and consultants who work for ASRC may be available to attend PPTs for transitioning youth. ASRC also has established parent support groups, organizes an annual resource fair, and advocates for various legislative changes.

The Connecticut Autism Action Coalition (CAAC) was formed in 2007 in an effort to bring the many autism groups together under one umbrella organization. Member organizations include a mix of state agencies, private providers, parent advocacy and support groups, and special education PTA (SEPTA). Each year, CAAC selects timely issues to work on, and the coalition is currently focused on transitional services.

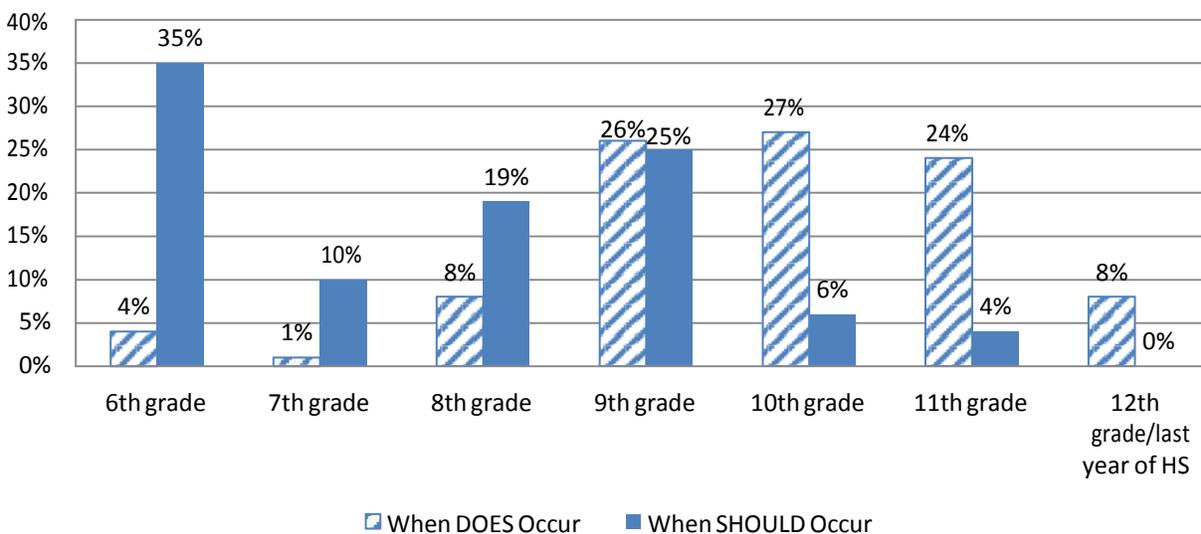
Challenges and Barriers

There are several challenges and barriers for transitioning high school students with ASD.

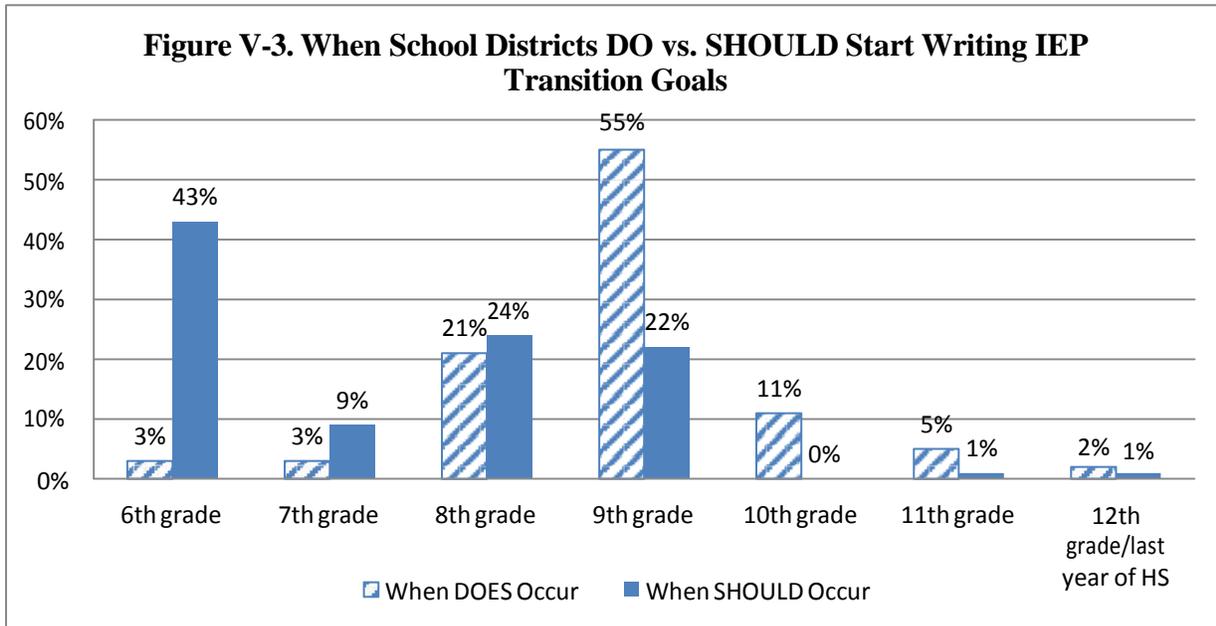
- **Need earlier establishment of individualized education program (IEP) goals related to transition to adult life.**
 - The Individuals with Disabilities Act (IDEA) requires transition planning no later than age 16, or earlier if determined appropriate by the Planning and Placement Team (PPT) for all special education students.
 - In the PRI Survey of Parents of Children with ASD Aged 15-25, parents were asked to specify the grade that their children

generally began having IEP goals related to transition to adult life. Excluding the 27 respondents who were not sure (14 percent of all survey respondents) and the three respondents who said after academic requirements had been completed but before the student left high school, Figure V-2 shows the disparity between when the goals are written and when parents say the goals *should* be written. While one-quarter say the IEP transition goals are written in ninth grade, one-third (35 percent) think they should start writing the goals in sixth grade.

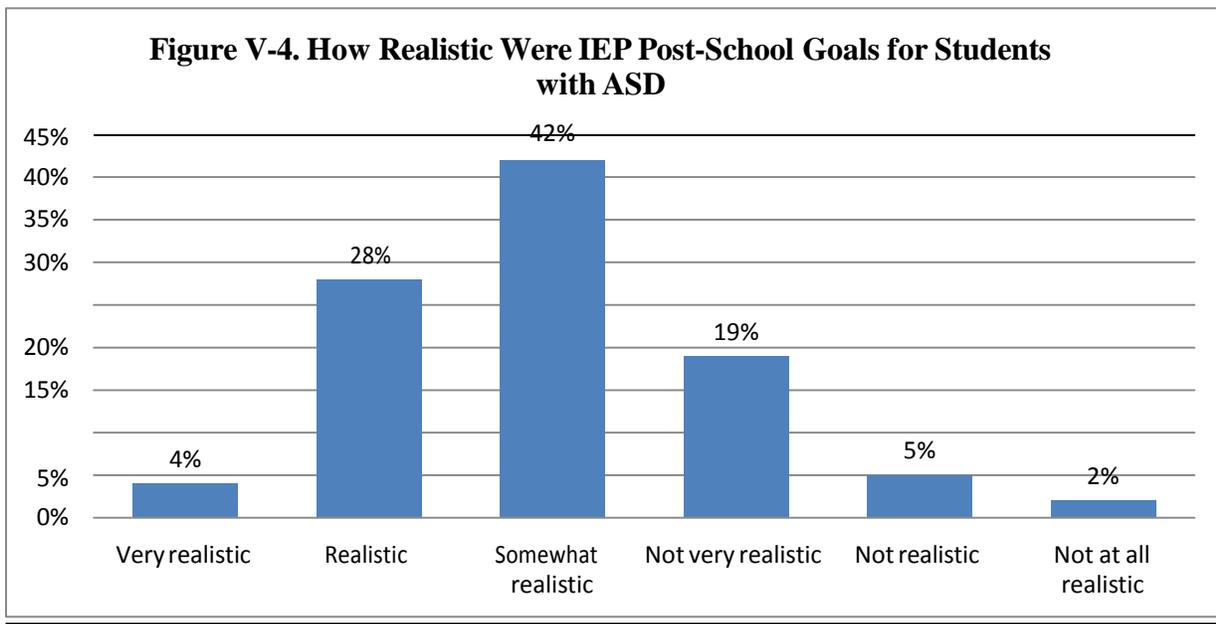
Figure V-2. When School Districts DO vs. SHOULD Start Writing IEP Transition Goals



- In the PRI Transition Coordinator Survey, transition coordinators were also asked when their school districts started writing IEP transition goals. While over half of survey respondents (55 percent) said their school districts started writing IEP transition goals in ninth grade, many believed school districts should start writing these transition goals in an earlier grade (Figure V-3). Half of respondents, for example, believed the goals should be started in sixth and seventh grade. Only one-fifth (22 percent) believed transition goals should start to be developed in the ninth grade.



- **Need for more realistic and specific IEP post-school goals for students with ASD.**
 - In the PRI Transition Coordinator Survey, respondents were asked how realistic they thought the IEP post-school goals developed for students with ASD were (Figure V-4). The most prevalent response was “somewhat realistic,” suggesting that there is room to improve the IEP post-school goals and their relationship to what will be faced by the post-high school student.



- Parents were asked to choose a descriptor that described the transition goals on their child’s IEP. The most often chosen descriptor was “too broad” (28 percent) and 13 percent indicated “nonexistent.” Other responses included: “realistic” (12 percent); “agreed to by all the PPT members” (9 percent); “appropriate choices” (7 percent); and “unrealistic” (6 percent).
- **Need for mandatory use of the Secondary Transition Planning IEP Checklist.**
 - In collaboration with the Connecticut Interagency Transition Task Force,³⁸ the CSDE developed a tool called, “Secondary Transition Planning IEP Checklist.” The 25-item checklist is modeled after the instrument created by the National Secondary Transition Technical Assistance Center³⁹ and approved by the Office of Special Education Programs (OSEP) as a rigorous, valid, and reliable tool to assess performance on Indicator 13.⁴⁰ It is intended for use by the local education agencies or school districts to assess whether IEP goals and transition services are coordinated, measurable, and will reasonably enable a student to meet their postsecondary goals.
 - Transition coordinator survey respondents were asked to estimate how often the checklist was used at some point during the secondary transition planning process. Almost one-third (31 percent) who answered the question estimated the checklist was always or often used, and 19 percent estimated the checklist was rarely or never used. Seventeen percent said it was used about half the time, seven percent at least one-quarter of the time, 20 percent did not know how often it was used, and seven percent had never heard of the checklist.
 - When survey respondents were asked about possible reasons why the checklist was not always being used, three-quarters (75 percent) said the checklist was not always being used because it was not required, and one in five (20 percent) thought the checklist was not being used because it was not helpful.

³⁸ The 42-member Connecticut Interagency Transition Task Force was formed in 1989 and serves as an advisory group to the CSDE Bureau of Special Education.

³⁹ The National Secondary Transition Technical Assistance Center is a national technical assistance and dissemination center funded by the U.S. Department of Education Office of Special Education Programs.

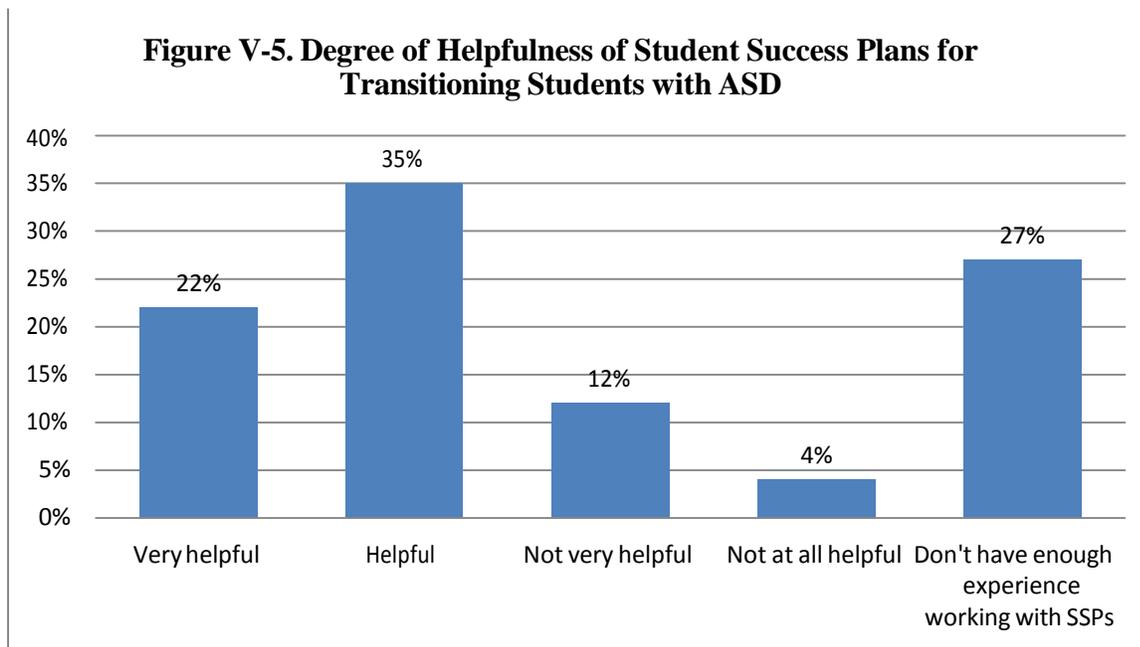
⁴⁰ See Chapter II for information about indicators required under the Individuals with Disabilities Education Act (IDEA).

- Use of the checklist would be expected to promote a strong transition plan, a factor considered important by 99 percent of parents, and 87 percent of transition coordinators in preparing students with ASD for life after high school/favorable outcomes for graduates with ASD.
- **Need to implement the Student Success Plan.**
 - One way to establish IEP secondary transition goals earlier and to have them be more realistic, is to implement the Student Success Plan. Beginning in the school year commencing July 1, 2012, legislation passed in 2011 requiring school districts to annually create Student Success Plans (SSP) for every student in grade 6 through grade 12.⁴¹ The SSP is an individualized student-driven plan that is intended to address all the students' needs and interests to help them stay engaged in school and achieve postsecondary education and career goals.
 - The SSP includes goal setting and related activities in three areas: academic growth; career exploration and planning; and personal, social/emotional and physical growth.
 - SSP academic development includes:
 - experiential learning: job shadowing, internships, cooperative work, community service; and
 - opportunities for college credit while in high school.
 - SSP career development includes:
 - interest and ability inventories;
 - career exploration activities; and
 - work-based learning experiences.
 - SSP social, emotional and physical development includes:
 - identification of school and community resources; and
 - identification of accommodations, modifications and services a student with a disability might need in order to have equal access to activities or the opportunity to perform at the same level as peers.
 - In the PRI Transition Coordinator Survey, respondents estimated the percent of students in grades 6 through 12 in their

⁴¹ P.A. 11-135, An Act Concerning Implementing Dates for Secondary School Reform, Exceptions to the School Governance Council Requirements and the Inclusion of Continuous Employment in a Cooperative Arrangement as Part of the Definition of Teacher Tenure.

school districts who had Student Success Plans. About one-third (35 percent) didn't know how often it was used, and 41 percent said it was used for all (31 percent) or many (10 percent) of the students in grades 6 through 12. Other responses included: it was not used for any students or few students (10 percent), used for at least one-quarter of the students (six percent), used for about half the students (four percent), or they had never heard of the SSP (five percent).

- Figure V-5 shows their responses to how helpful they thought the SSP would be in preparing students with ASD for life after high school. Over half (57 percent) thought the SSP would be very helpful or helpful in preparing students with ASD for life after high school.

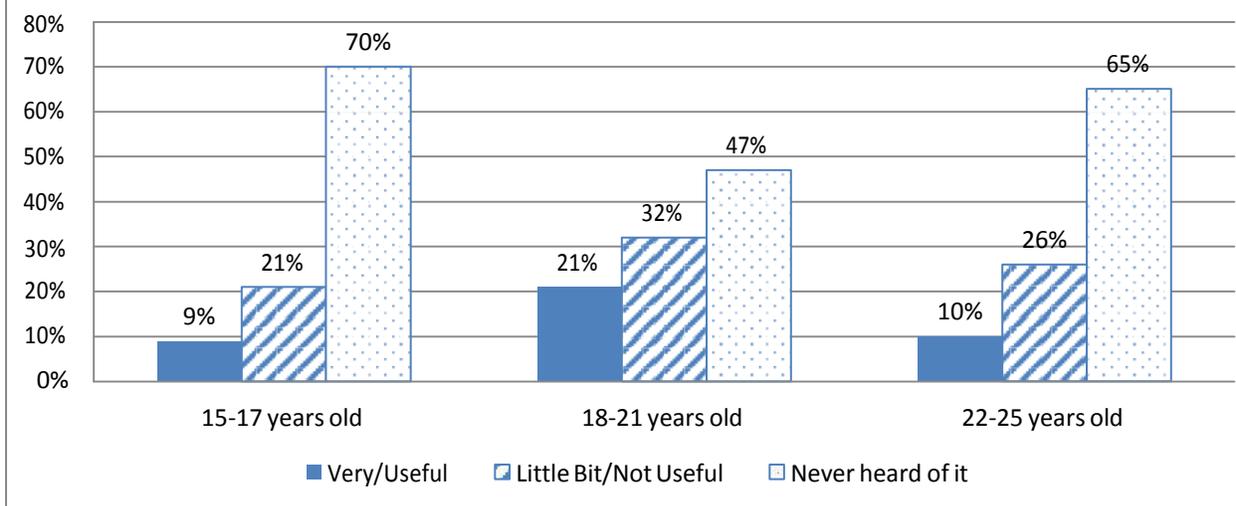


- **Need for better distribution of publications helpful to transitional services.**
 - In 2012, P.A. 12-173 (AAC Individualized Education Programs and Other Issues Relating to Special Education) required the school district to provide parents (effective July 1, 2012), with any CSDE info and resources relating to IEPs as soon as a student is identified as requiring special education. For students of transition age, the publication, Building a Bridge⁴² was recommended by CSDE.

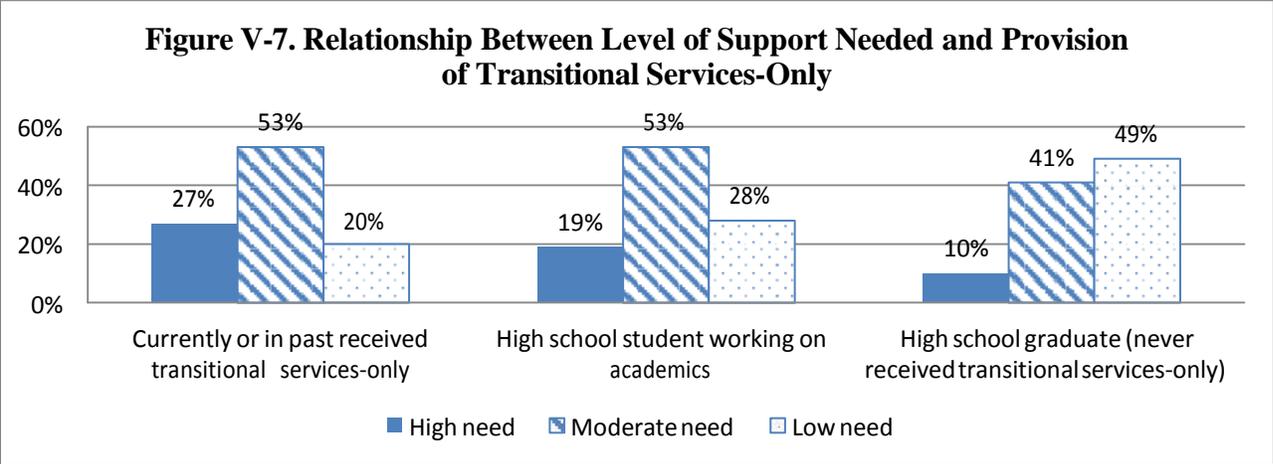
⁴² Building a Bridge from School to Adult Life: A Handbook for Students and Family Members to Help with Preparation for Life After High School, Revised 2009, prepared by the CT Transition Task Force.

- Over half (59 percent) the respondents to the PRI Survey of Parents of Children with ASD Aged 15-25 had never heard of “Building a Bridge” or other transition-related publications that could have been given to them by their school systems. This was less likely to occur for parents of children 18-21 years old (Figure V-6). Regardless of age of child, relatively more parents questioned the usefulness of “Building a Bridge” or other transition-related materials they may have received from their school districts.

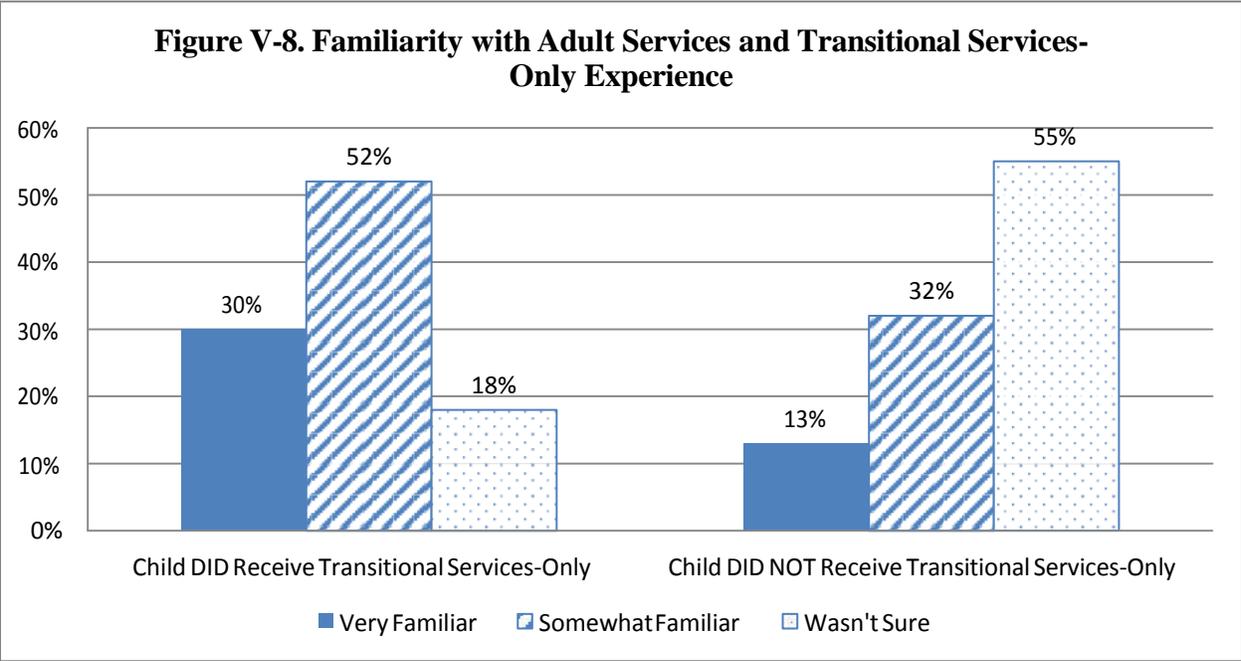
Figure V-6. Usefulness of "Building a Bridge" or other Transition-Related Publications



- **Need for greater awareness of transitional services-only option for qualifying students with ASD.**
 - According to parents with children who had already graduated high school, 43 percent of these respondents to the PRI Survey of Parents of Children with ASD Aged 15-25 said their children had not received transitional services-only prior to exiting high school. The most frequent reason given for not receiving transitional services-only by the parents was that they did not know this option was available. According to the parent survey respondents, students who are receiving, or had previously received transitional services-only, were more likely to have high needs, and less likely to have low needs (Figure V-7).



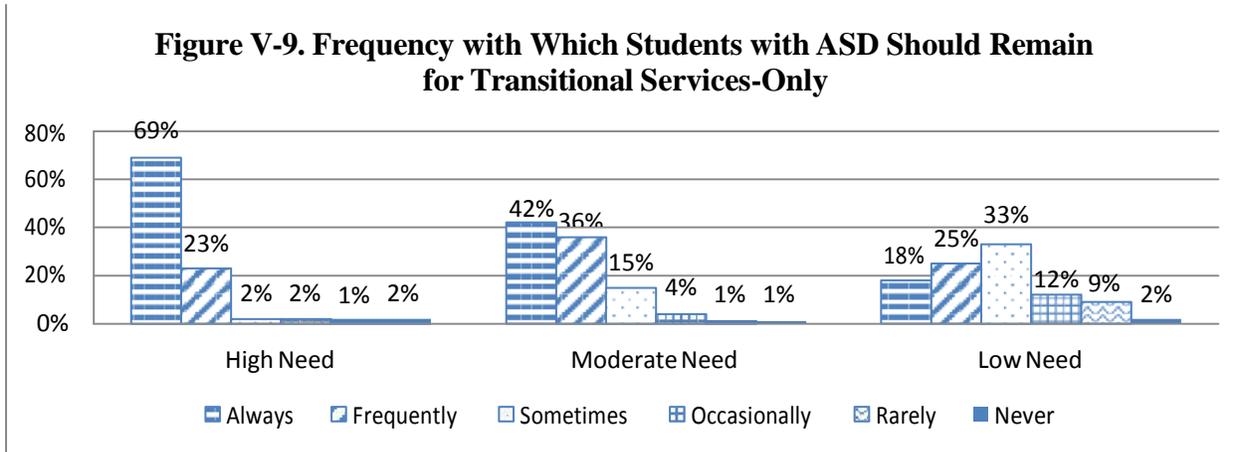
- In responding to the PRI Survey of Parents of Children with ASD Aged 15-25, parents of children who had received transitional services-only were more familiar with how to get help or adult services for their children after high school (Figure V-8).



- According to transition coordinators responding to the PRI Transition Coordinator Survey, students with ASD who were considered high-need were more likely to: remain in high school past age 18; remain in high school for transitional services-only; and benefit from transitional services-only.

- Nine in ten survey respondents said high need students with ASD should remain for transitional services-only either always (69 percent) or frequently (23 percent). In contrast, less than half as many transition coordinator survey respondents said low need students with ASD should remain for transitional services-only either always (18 percent) or frequently (25 percent) (Figure V-9).

Figure V-9. Frequency with Which Students with ASD Should Remain for Transitional Services-Only



- As described in Chapter III, although respondents to the PRI Transition Coordinator Survey were less likely to think lower need students with ASD should remain for transitional services-only, they also did not rate the students with low needs as doing especially well post high school. Clearly, students with high needs were more likely to be given “poor” ratings compared with former students with moderate and low needs; at least half the time, high need students with ASD were rated as doing poorly in the areas of employment, postsecondary education, vocational training, and social/recreation activities. However, even former students with ASD who were considered to have low needs tended to be rated in the various areas as doing “fair,” with only 14 percent given an overall rating of “good” (Table V-4). Social/recreation activities were flagged in the results of the CSDE parent survey for Indicator 8.⁴³ In comparing parents of high school students with ASD vs. other disabilities, parents of students with ASD were less likely to agree their child had the opportunity to participate in extracurricular school activities, and also less likely to agree the school provides supports

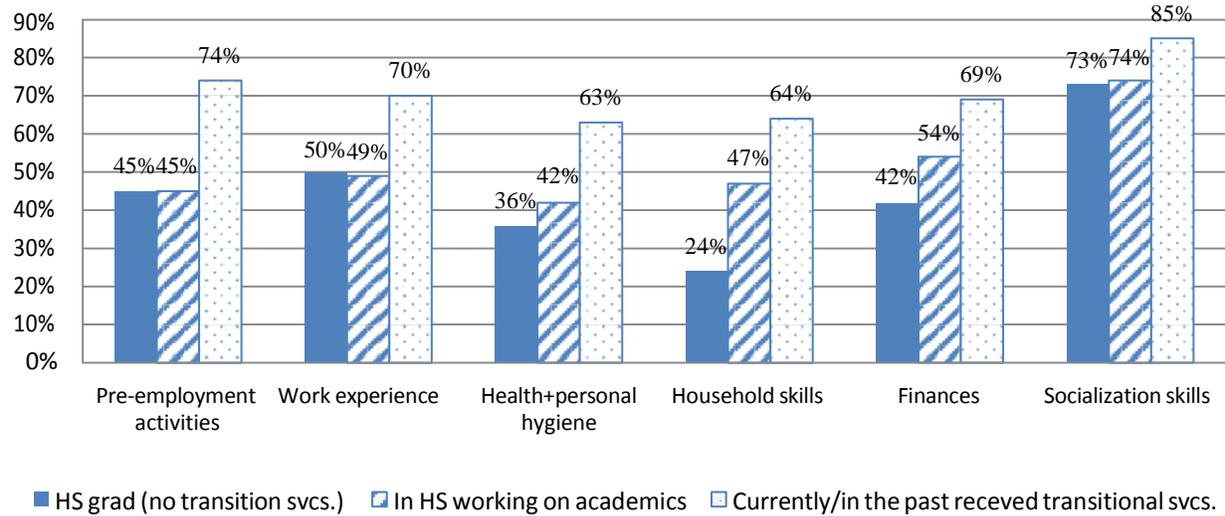
⁴³ See Chapter II for information about indicators required under the Individuals with Disabilities Education Act (IDEA).

necessary for their child to participate in extracurricular school activities.

- Support for the expanded use of transitional services-only comes from the parent survey. As described in Chapter IV in the PRI Survey of Parents of Children with ASD Aged 15-25, 40 percent of respondents said their children were not too prepared or not at all prepared for what happened after leaving high school.
- On the other hand, according to the respondents to the PRI Survey of Parents of Children with ASD Aged 15-25, high school graduates who had been in transitional services-only and 18-21 year olds currently in transitional services-only, were more likely to have received courses or assistance in six of nine areas (Figure V-10), including four areas where over one-third of parents said assistance had not been provided to their sons and daughters. One-quarter (24 percent) of high school graduates who received no transition services had been given at least some assistance in household skills.

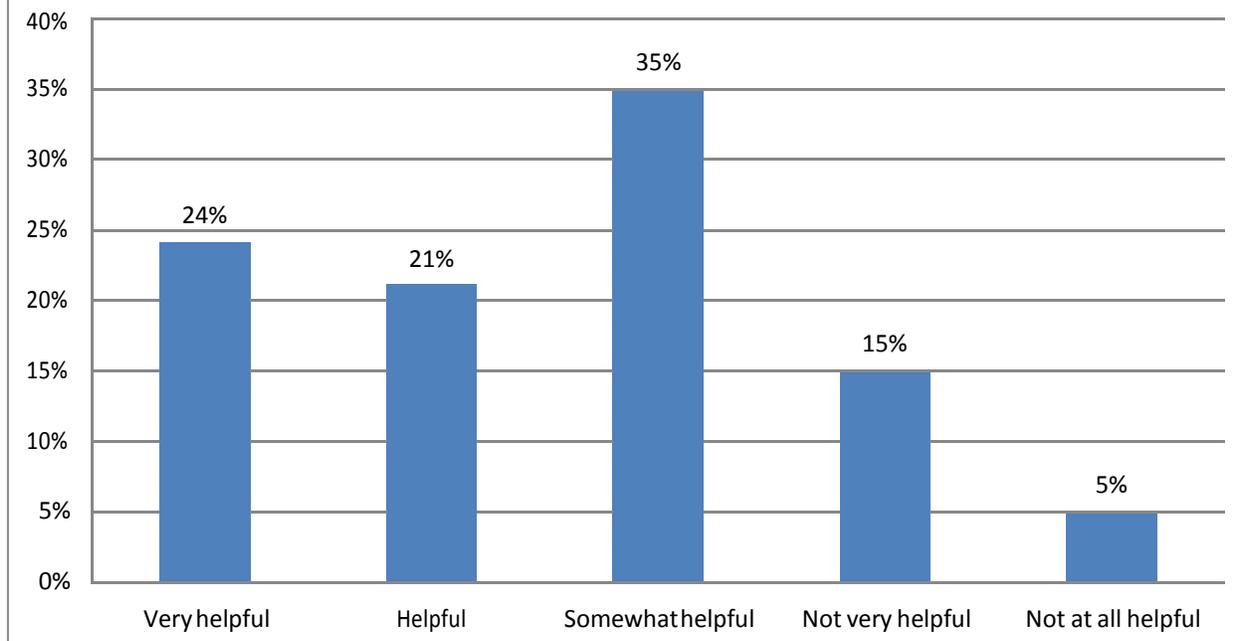
Table V-4. Ratings of How Well Former Students Were Doing in Certain Areas			
Area	Good	Fair	Poor
Low Need Students with ASD			
Employment	21%	52%	27%
Postsecondary education	29%	49%	22%
Vocational training	24%	42%	35%
Social/recreation activities	13%	48%	40%
Overall rating	14%	53%	33%
Moderate Need Students with ASD			
Employment	8%	44%	48%
Postsecondary education	6%	37%	57%
Vocational training	14%	42%	43%
Social/recreation activities	5%	36%	59%
Overall rating	5%	51%	44%
High Need Students with ASD			
Employment	8%	27%	65%
Postsecondary education	5%	24%	72%
Vocational training	21%	27%	52%
Social/recreation activities	4%	34%	62%
Overall rating	8%	42%	50%
Source: PRI Transition Coordinator Survey.			

Figure V-10. Percent of Parents Reporting at Least Some Assistance in the Area



- Responses on the PRI Survey of Parents of Children with ASD Aged 15-25, support the expanded use of transitional services-only, with four out of five parents with children who currently or had previously received transitional services-only saying the experience was at least somewhat helpful (Figure V-11).

Figure V-11. Helpfulness of Transitional Services-Only Experience



- A report issued pursuant to Special Act 12-9, An Act Concerning Workforce Development,⁴⁴ noted that school districts often push to maintain high four-year graduation rates because every additional year a child remains in the public school system costs money, and poor four-year graduation rates result in the loss of incentives provided by the No-Child-Left-Behind Act. The report also noted there is little knowledge among parents about the fifth year bridge option, and only 20-25 percent of special education students remain in high school for an additional year.

- **Need for improved relationship between transition coordinators and the DDS Division of Autism Spectrum Services and DMHAS state agencies.**

- Of the four agencies most often considered for referrals for adult services, the majority of PRI Transition Coordinator Survey respondents found it relatively easy to make referrals to the Department of Developmental Services (DDS) and the Department of Rehabilitation Services Bureau of Rehabilitation Services (DORS/BRS), but somewhat difficult to make referrals to the DDS Division of Autism Spectrum Services and

⁴⁴ Report written by the Connecticut Women’s Education and Legal Fund for the Connecticut Department of Labor Office of Workforce Competitiveness, January 2013.

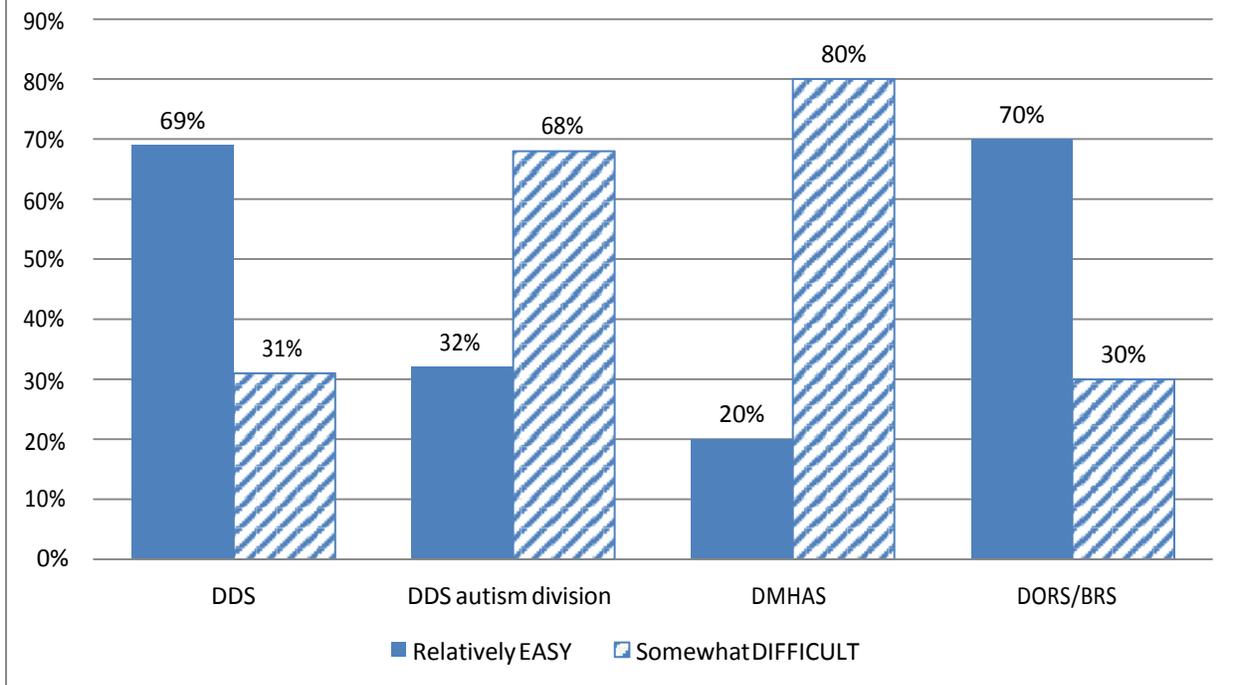
the Department of Mental Health and Addiction Services (DMHAS) (Figure V-12).

- In addition to ease of making referrals, attendance at planning and placement team (PPT) meetings followed a similar pattern. Three-quarters of transition coordinator survey respondents (75 percent) said DDS was likely to attend PPT meetings if invited, and two-thirds of respondents (63 percent) said the same about DORS/BRS. Conversely, approximately three-quarters of respondents (77 percent) said DMHAS and the DDS autism division did not attend PPT meetings.⁴⁵
- Also, when the PRI Transition Coordinator Survey respondents were asked about agency personnel making outreach efforts to students and families, two-thirds (66 percent) said DDS staff was likely to make outreach efforts, and 61 percent said the same regarding personnel from DORS/BRS. On the other hand, 90 percent said DMHAS did not tend to make outreach efforts to students and families, and 82 percent said the same about personnel from the DDS autism division.
- More access and consistency from state agencies (e.g., need more consistent information from state agencies about what is currently available) was mentioned by transition coordinators as a recommendation about what resources or assistance school personnel needed to better serve students with ASD to prepare for adult life after high school.
- In strategic planning currently underway by DORS,⁴⁶ participants identified providing a consistent message, and much better communication among/between agencies and schools, as central challenges. Strategic Objective B-2 requires development and communication of externally consistent messages about services.

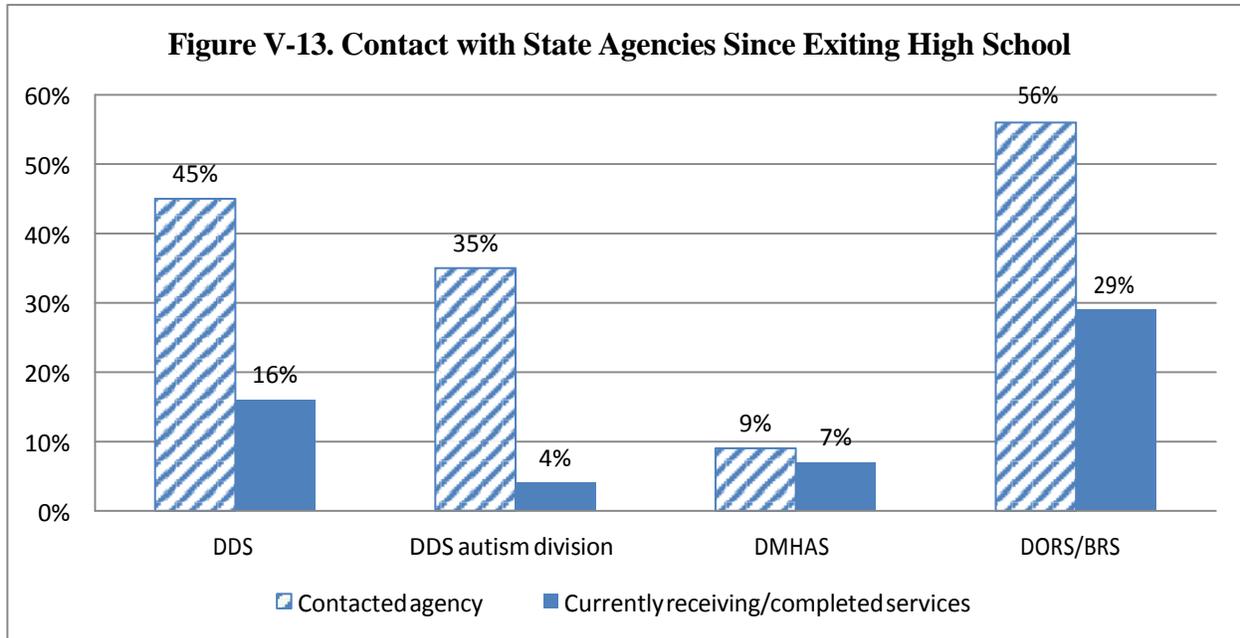
⁴⁵ Excludes situations where IEP states inviting adult agency was not appropriate, or the student/parent did not give written consent for agency to be invited to PPT.

⁴⁶ Connecticut Department of Rehabilitation Services Vocational Rehabilitation Services: Strategic Planning Meeting Summary, August 6-7, 2014. Prepared by TSI Consulting Partners, Inc.

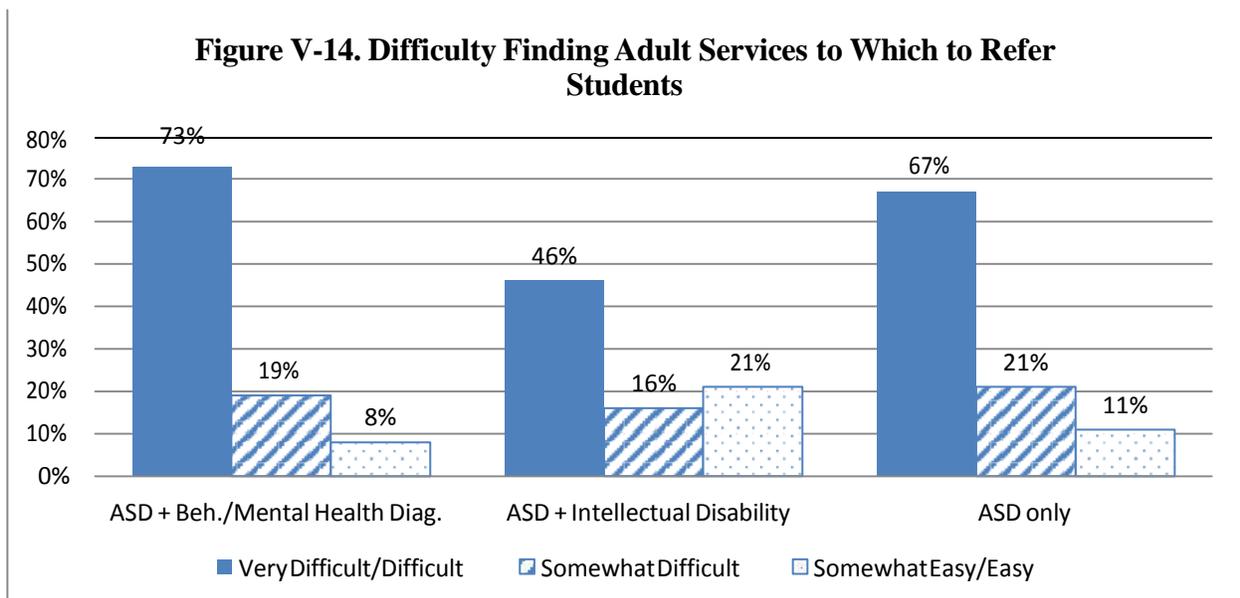
Figure V-12. Ease of Referring Students to Certain Agencies



- **Need for improved access to adult agency services post-high school.**
 - Besides the challenges faced by transition coordinators regarding these two agencies, parents also were less likely to receive services post-high school after contacting the DDS autism division and DMHAS (Figure V-13). For example, while more than one-third (35 percent) of parents responding to the PRI Survey of Parents of Children With ASD Aged 15-25 had contacted the DDS autism division, just four percent were receiving services from the division.



- According to responses to the PRI Transition Coordinator Survey, this difficulty in making referrals to, and receiving services from, is consistent with the relatively greater difficulty in finding adult services to which to refer students with ASD and a behavioral/mental health diagnosis (DMHAS) and ‘ASD only’ (DDS autism division) (Figure V-14).



- In ratings of level of importance of certain factors in preparing students with ASD for life after high school, 99 percent of parents said access to appropriate services after exiting high school was important. Similarly, 98 percent of transition coordinators said access to appropriate services was an important factor in determining favorable outcomes for graduates with ASD. Three-quarter of transition coordinator respondents agreed that youth were referred to available services rather than to needed services.

Other State Model or Approach

The possibility of other state models or approaches to providing secondary transition services and preparation were explored by PRI staff through interviews and a review of the literature. One model that may have applicability or relevance to Connecticut is now described.

Massachusetts. Massachusetts has instituted a law commonly referred to as the “Turning22Law.” This law requires students with severe disabilities to participate in a two-year planning and referral process prior to leaving the school district. A major component of the law is the requirement for a planning and referral process that identifies which state agency is best able to support the student after he or she exits high school. The determination is based on the student’s abilities, needs, intelligence quotient, and official diagnosis. By requiring this identification process, the student is helped to have a smooth transition, and state agencies are provided with advance notice of the volume of services required in upcoming years, helping the agency to more effectively petition for funding.

Massachusetts also passed a state law in 2008 (Chapter 2005 of the Acts of 2008) requiring school districts to begin special education transition planning and transition services at age 14, instead of at age 16 as required under IDEA. A form, called the Transition Planning Form, is completed annually, beginning with the IEP when the student turns 14, documenting the transition planning discussion.

PRI Staff Recommendations Related to Transitional Services During High School

Based on the discussion of the challenges and barriers, the **PRI committee staff makes the following recommendations:**

- **CSDE should promote a best practice of establishing individualized education program (IEP) goals related to transition to adult life sooner, prior to high school.** As expressed by both transition coordinators and parents, it would be beneficial to students with ASD (and other disabilities) to begin the transition process sooner.
- **CSDE should provide training to transition coordinators on the development of more realistic and specific IEP post-school goals.** As expressed by both transition coordinators and parents, it would be beneficial to have IEP goals that are both specific and realistic for transitioning students with ASD (and other disabilities).
- **CSDE should require school districts to use the Secondary Transition Planning IEP Checklist.** By using the checklist, local education agencies or school districts can assess whether IEP goals and transition services are coordinated, measurable, and reasonably calculated to enable a student to meet his or her postsecondary goals.
- **CSDE should formally monitor implementation of the Student Success Plan.** Unlike the IEPs, there is no formal mechanism for CSDE to monitor implementation of the Student Success Plans. Although Student Success Plans were required in statute to begin July 1, 2012, the plan has rarely been established for students. CSDE formal monitoring of usage of the plan will promote implementation of this statutory requirement.
- **CSDE shall monitor the requirement for parents of high school students with ASD (and other disabilities) to be provided with a copy/website link to “Building a Bridge” or other transition-related materials by their local school districts, and add this requirement to the Secondary Transition Planning IEP Checklist.** Although required in statute, many parents reported never hearing of these documents, and monitoring of implementation of this distribution will promote increased access to the materials.
 - **CSDE should assess reasons why parents are questioning the usefulness of “Building a Bridge” or other transition-related materials they may have received from their school districts, and revise the materials accordingly.**

- **CSDE shall develop and distribute a written Parents Bill of Rights to all parents of students with ASD (and other disabilities). This single-page document shall inform parents of the following:**
 - **They have the option to request consideration of provision of transitional services-only (18-21 programs) for their son or daughter**
 - **They are entitled to receive a copy of “Building a Bridge” or other transition-related materials**
 - **Their son or daughter is required to have a Student Success Plan beginning in sixth grade and parents must be given a copy of this plan (which addresses transition to adult life)**
 - **Their son or daughter will benefit from more realistic and specific IEP post-school goals**
- **The Autism Spectrum Disorder Advisory Council (ASDAC) should identify possible strategies to improve interactions between the DDS Division of Autism Spectrum Services, DMHAS, and DORS/BRS with both transition coordinators and parents.** These strategies could address better and more consistent communication, improved referral processes, and increased outreach efforts and PPT participation by adult service agencies.
- **CSDE should consider the feasibility of recommending a law similar to the Massachusetts “Turning22Law”, requiring the identification of which state agency is best able to support the student after he or she exits high school.** This exploration should include participation from representatives of adult state agencies.

Chapter VI: Postsecondary Education

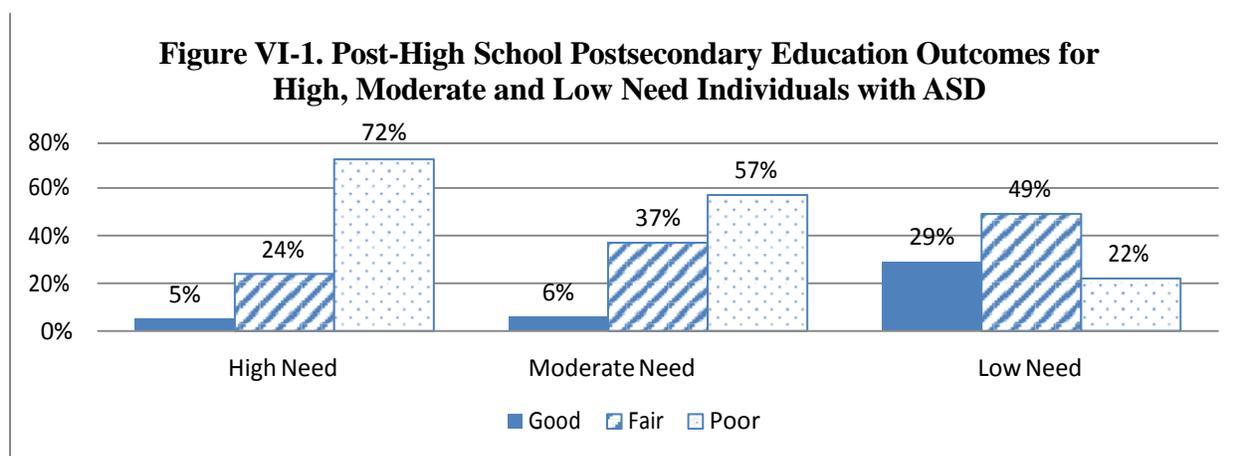
Description of Postsecondary Education

Attending college is considered a viable option for higher functioning students on the autism spectrum. Parents, students, and school personnel most often consider transition to college when a student has been successful academically at the high school level.

In the CSDE Post-School Outcomes Survey,⁴⁷ approximately half (52 percent) of high school exiters with ASD were in college one year later, and almost three-quarters (70 percent) were enrolled full-time. Two-thirds were attending a four year college—enrolled full-time 90 percent of the time, while those attending two-year colleges were more likely to be enrolled part-time (67 percent). Some (nine percent) of the high school exiters with ASD who responded to the survey were enrolled in some other education or training program such as: vocational, technical or trade school; short-term education or job training program; adult education; or postgraduate or college preparatory program. Examples of other education and training included fashion design program, floral design school, and computer program technology.

While statistics are not available on the college graduation rates for students with ASD, anecdotal evidence suggests that individuals with ASD face challenges in their transition to postsecondary education. In the PRI survey of parents of children with ASD,⁴⁸ half (54 percent) of respondents with children who had graduated high school said their children were doing very poorly (28 percent) or poorly/fairly poorly (26 percent) in postsecondary education.

PRI Transition Coordinator Survey respondents also provided some evidence that students with ASD who went on to postsecondary education may be struggling, especially those with higher needs⁴⁹ (Figure VI-1).⁵⁰



⁴⁷ See Appendix B for complete results of CSDE Post-School Outcomes Surveys.

⁴⁸ See Chapter IV for complete results of PRI Survey of Parents of Children with ASD Aged 15-25.

⁴⁹ “High need” was defined as students with ASD requiring substantial support, “moderate need” as students with ASD requiring moderate support, and “low need” as students with ASD requiring minimal support.

⁵⁰ See Chapter III for complete results of PRI Transition Coordinator Survey.

Services Provided by Transitional Services for 18-21 Year Olds

The IEP Manual and Forms of the CSDE Bureau of Special Education, Fifth Revision December 2013, states that IEP transition plans must have at least one post-school outcome goal statement (PSOGS)⁵¹ related to postsecondary education or training. For some students with ASD, preparation for life after high school includes transitioning to college.

The Building a Bridge resource manual contains a section on preparedness for college. Students are asked to answer a series of questions to help them decide if college is the best choice at this time. Questions include:

- How good is my academic background? (e.g., Am I enrolled in college prep classes that will prepare me for college-level course work?);
- Am I disciplined enough to manage my time and meet academic deadlines? (e.g., Do I deal well with unstructured environments?); and
- Do I have good problem-solving and decision-making skills? (e.g., Can I access community and college resources for assistance if needed?)

The Building a Bridge resource manual also provides information and guidance about the types of supports available at colleges, questions to ask a college disability services office, and transition goals and objectives relevant to postsecondary education or training.

The CSDE Bureau of Special Education published a directory in 2010 called, “Connecticut Transition Services in College, University and Community-Based Settings.”⁵² Based on information about the 24 programs listed in the directory as of 2010, there are 10 that include a specialty in working with students with ASD. Table VI-1 shows the programs that offer students college classes either for credit or not-for-credit. As described in Chapter V, of the 24 transitional services-only services for 18-21 year olds described in the directory, many take place at community colleges, state universities, and private universities.

In addition to providing exposure to postsecondary education through 18-21 year old transitional services-only, there are supports provided directly by colleges.

⁵¹ Post-School Outcome Goal Statement is Connecticut’s term for the “appropriate measurable postsecondary goals” required by IDEA for transition-age students.

⁵² The Connecticut Transition Services in College, University and Community-Based Settings is in the process of being updated by CSDE and this revised directory is expected to be available in 2015.

Table VI-1. Connecticut Transition Services in College, University and Community-Based Settings with a Specialty in Serving Students with ASD	
Offers college classes for credit	Offers college classes NOT for credit (audit)
<ul style="list-style-type: none"> • Farmington Valley Transition Academy at the University of Hartford (West Hartford) • ACHIEVE (West Hartford) (not reflected in 2010 directory) • Cedarhurst School Passage Program (Hamden) • Chapel Haven (New Haven) • Vista Vocational & Life Skills Center (Westbrook) (not reflected in 2010 directory) • Thames Academy at Mitchell College (New London) • Step Forward at Gateway Community College (New Haven) 	<ul style="list-style-type: none"> • Western Connection Program at Western Connecticut State University (Danbury) • Highlander Transition Academy at University of Connecticut (Torrington) • Students Transitioning to Age Appropriate Routes (STAAR) Program at University of Connecticut (Storrs) • Cedarhurst School Passage Program (Hamden) (Both credit and not-for-credit) • Step Forward at Gateway Community College (New Haven) (Both credit and not-for-credit)
Source: CSDE Bureau of Special Education Connecticut Transition Services in College, University and Community-Based Settings, September 2010.	

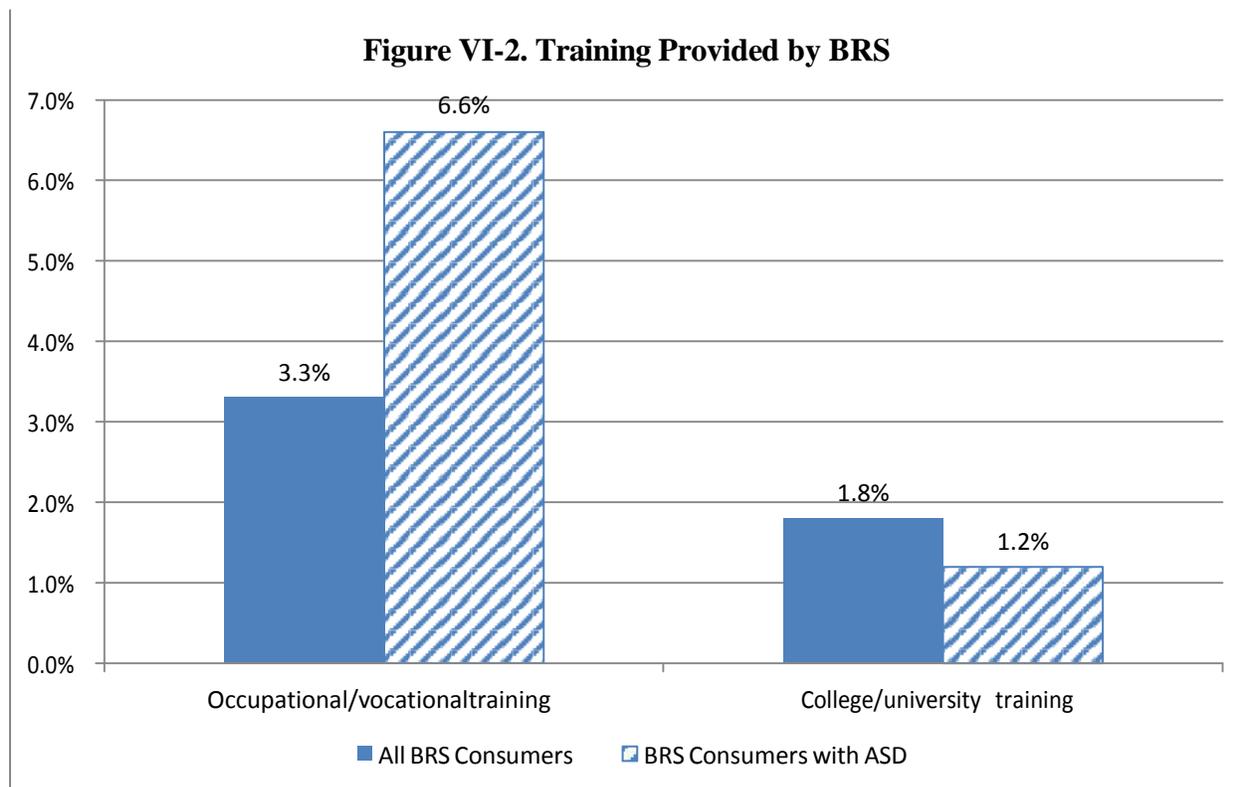
Services Provided by Connecticut Department of Rehabilitation Services/Bureau of Rehabilitation Services (DORS/BRS)

The primary focus of DORS/BRS is on employment. However, in some instances, consumers benefit from postsecondary education or vocational training as a means to employment. There is one category of BRS services that is related to postsecondary education or vocational training:

College or university training. Under this category, training includes full-time or part-time academic training that is beyond high school level training. This type of training is expected to lead to a degree including associate, bachelors, graduate, or professional degree. This type of training also includes earning a certificate or other recognized educational credential. The setting for the training is: four-year college or university, community college, junior college, or technical college. During FFY 2011-2013, a total of 205 consumers received college or university training as part of their BRS services. As shown in Figure VI-2, based on BRS Case Closure Data,⁵³ a smaller percentage of consumers received college/university training compared with occupational/vocational training.

⁵³ Appendix E contains a complete description of the analysis of data provided to PRI staff by the Connecticut Department of Rehabilitation Services Bureau of Rehabilitation Services from their case management system.

None of this type of training is provided directly by BRS. Rather, public or private colleges provide this education to the BRS consumers. The median cost for this type of training in FFY 2011-2013 was \$5,109.



Services Provided by Department of Developmental Services

The Department of Developmental Services and the DDS Division of Autism Spectrum Services provide services to 18-25 year old youth and young adults with ASD. While emphasis is more often on supported employment options, attendance at a college or vocational training may occur for 18-21 year old individuals receiving transitional services-only.

Services Offered by Department of Mental Health and Addiction Services

The Department of Mental Health and Addiction Services (DMHAS) serves some individuals with ASD who are aged 18-25 and have a co-occurring mental or behavioral health disability. According to their website,⁵⁴ eligible inpatient youth who are transitioning to adulthood through DMHAS are encouraged to take an active role in their education. The website notes youth are invited to attend their educational planning meetings, where future goals are explored and established. Two of the future goals mentioned for DMHAS inpatient youth

⁵⁴ <http://www.ct.gov/dmhas/cwp/view.asp?a=2902&q=335288>

transitioning to adulthood include attending a two- or four-year college, and an employment goal requiring vocational training.

Model Initiatives Offered by Connecticut Colleges

In the PRI Survey of Parents of Children With ASD Aged 15-25, almost all respondents either strongly agreed (85 percent) or agreed (10 percent) with the statement, “College programs providing supports to students with ASD are necessary for success at this level.” Three-quarters of respondents to the PRI Transition Coordinator Survey either strongly agreed (40 percent) or agreed (34 percent) with the same statement.

PRI staff had the opportunity to tour and/or interview directors of college programs for students with ASD. The following are some examples of such programs at a Connecticut community college (Gateway Community College), state university (Southern Connecticut State University), and the University of Connecticut (Storrs campus).

Gateway Community College: Step Forward I and II Programs (Transition Programs for 18-21 Year Olds)

Step Forward I Program

Population served. The Step Forward I program at Gateway Community College in New Haven, Connecticut, is intended for individuals considered to have mild cognitive abilities (IQs between 70-85). Although not considered intellectually disabled, these individuals are too low functioning to attend Gateway Community College without some support.

Most of the participants are currently enrolled in Connecticut high schools and have the Step Forward I program as part of their IEPs. Beyond funding from local school districts, Step Forward I may also be self-funded for students who have already graduated high school. The cost of the 10-month Step Forward I program is \$21,000.

The majority of Step Forward I program participants have ASD. Of the seven new students enrolled in Step Forward I in the Fall 2014, four have ASD.

Program/Service Description. Step Forward I began in 2005. It is a non-credit program that focuses on interpersonal communication skills, career exploration and workplace readiness. Goals for the students include the ability to function in a job, reduced reliance on accommodations that were previously available in the high school setting, and more control over their lives.

Some of the areas program participants work on include:

- ready-to-work and job search essentials;
- personal finances and budgeting;
- how to be appropriate (interpersonal and workplace communications);

- leadership, self-advocacy and disability awareness;
- living on one's own; and
- socializing.

The Step Forward I program participants work on these areas on campus three days per week, and in internships on campus or in their home communities, two days per week. Participants receive four weeks of coaching during their internships, which is then gradually tapered off (“faded out”).

Step Forward I participants also attend social events at the college. A parent component of the program keeps parents informed about the program and what they can do to promote independence and attainment of program goals in the home environment.

Step Forward II Program

Population served. The Step Forward II Program is a transition program designed for students who have successfully completed Step Forward I. Higher functioning students with ASD who are academically qualified to enroll in classes at Gateway Community College may enroll directly in Step Forward II, receiving an additional level of support and case management beyond what would be required under the federal Americans with Disabilities Act (ADA). The cost of the 8-month Step Forward II program is \$21,000, and may be paid by the student's home school district or self-pay.

Program/service description. Step Forward II began in 2010 with a focus on career objectives. Each participant receives individualized academic and disability-related advising, and case management. For half the day on Mondays and Wednesdays, students can take one to two classes at Gateway Community College. Participants not yet ready to be in the college classroom can do online programs and courses in a teacher-supervised computer lab using Metrix and Connectibility software.

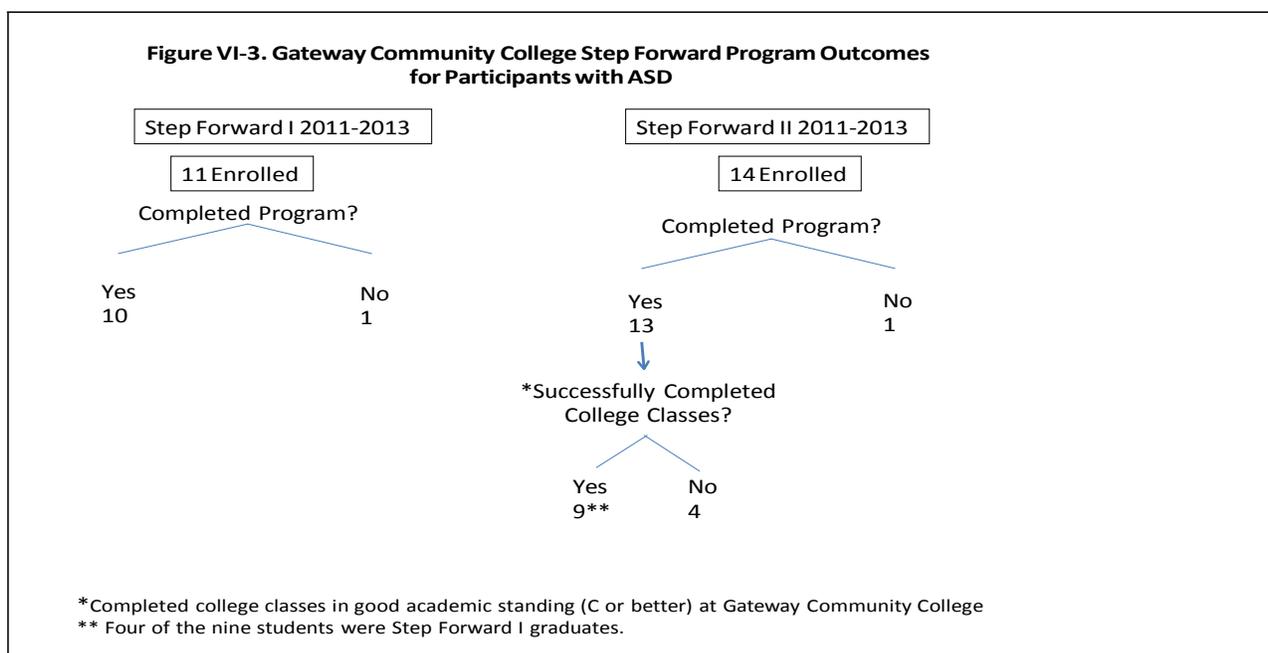
On the other half of the day on Mondays and Wednesdays, students attend a college 101 seminar run by the Step Forward II program, covering such topics as:

- goal setting and strategies for success;
- self-advocacy;
- time management;
- effective study skills;
- understanding college expectations; and
- interpersonal communication and social skills.

Work experience within individual fields of interest may occur on Tuesdays and Thursdays in the students' home towns. Intensity of experience depends on the student and his/her previous work history. Fridays are used to practice social skills during a community activity.

Case management includes Step Forward II staff speaking with college course instructors weekly. Students are required to sign up for tutoring for courses. Any needed accommodations must be arranged by the students themselves. As with the Step Forward I program, there is also a parent component to ensure that both staff and parents are working together toward shared goals for the students. An important element of the program is the need for students to be able to fail in a safe environment, and learn from the experience.

Step Forward I and II: Outcome data. Figure VI-3 shows the outcomes for Step Forward I and II participants with ASD during 2011-2013. Nearly all students enrolled in Step Forward I and II completed the programs. Nine of the 14 students (64 percent) enrolled in Step Forward II successfully completed college classes at Gateway Community College in good academic standing (grade of “C” or better).



Southern Connecticut State University Disability Resource Center

Population served. The Disability Resource Center (DRC) at Southern Connecticut State University (SCSU) is available to all undergraduate and graduate students at SCSU who self-identify as having a disability that substantially impacts them in an educational setting. Services are provided free of charge regardless of whether the student is full- or part-time, and matriculated or non-matriculated.

In addition to the growing number of students with ASD, the Center also serves students with a variety of disabilities including learning disabilities, attention deficit disorder, and emotional/psychological disabilities. Prior to receipt of services, students must provide current documentation of their disabilities.

Students may receive services from the DRC for one semester or throughout their time at SCSU. Students usually receive approved services during their first term and choose to use their approved accommodations off and on in future semesters, based on the nature of their classes or by personal choice. Students are encouraged by DRC staff to use their accommodations each semester.

Program/service description. The DRC is staffed by a full-time director, assistant director, disability specialist, several university assistants, a secretary, student workers and math tutors. The DRC staff has advanced degrees and/or extensive experience (there is one graduate student intern who also meets with a few of the students).

The center provides what it refers to as “wraparound” services to students. These include weekly one-on-one meetings for a half-hour with a staff person. The purpose of these meetings is to help the student adjust to college and stay successful.

The wraparound services also include assistance with course selection. For example, there are special math sections open to students with ASD or any other disability. The course uses the same syllabus, tests and grading system as the traditional on-campus math class; however, there may be one additional meeting per week. There is also a tutor available, and the course is taught by a professor who is experienced in teaching math to students with disabilities.

Another aspect of the wraparound service is a foreign language substitution component. Instead of a foreign language, which is challenging for many students with ASD or a learning disability, participating students can substitute two other approved other classes in lieu of the foreign language requirement.

Additional services provided by the center include assistance with:

- compensatory strategies such as time management, study skills, and identifying strengths and weaknesses;
- self-advocacy, goal setting, and career development;
- assistive computer technology and alternate formats;
- additional time for tests and exams;
- taking tests and exams in less distracting, alternative environments; and
- note-taker services.

Outcome data. Table VI-2 provides information for nearly four calendar years on the SCSU students with ASD who came to the Disability Resource Center for assistance. The table shows the number of students who discontinued enrollment at SCSU due to academic or non-academic reasons (e.g., dropped out or were academically dismissed) as well as the number who remained. Retention from one semester or one year to the next is a prerequisite for graduating college.

Although DRC staff was unable to follow the same student from year to year or semester to semester, this preliminary data shows DRC to be a promising model for retention of college students with ASD.

Table VI-2. Outcomes for SCSCU Students with ASD Served by the Disability Resource Center (DRC)				
Calendar Year	Total DRC students with ASD served during calendar year*	DRC students with ASD who discontinued enrollment at SCSU due to academic or non-academic reasons	DRC students with ASD who remained at SCSU through the calendar year	DRC students with ASD who graduated from SCSU
2011	28	2	26	1
2012	27	0	27	2
2013	25	0	25	4
2014**	24	2	22	6
Average for 2011-2014	26	1	25	Total: 13***
* Students may receive services across multiple calendar years				
**Partial year (January 1, 2014-November 14, 2014)				
***Total, as students would graduate one time				
Source: SCSU DRC staff.				

University of Connecticut Beyond Access Program

Population served. The Beyond Access Program at the University of Connecticut (UConn) main campus at Storrs, Connecticut, is intended for any student who is interested in working on meeting academic and personal goals. Program participants do not need to have a disability in order to apply to the program; however, the director reported that all but one of the 46 students this semester has a disability. Of the 46 students, nine (20 percent) have a diagnosis of ASD.

Most students who participate in the Beyond Access Program do so when they are first admitted to UConn. Beyond Access is housed within the UConn Center for Students with Disabilities, and many of the program participants first came to the center to request academic accommodations. In addition to students with ASD, Beyond Access also serves students with other types of disabilities including psychiatric, physical, and learning disabilities.

According to the director of the Beyond Access Program, participants with ASD tend to stay with the program for most of their time at UConn, choosing to participate every semester. Some students, however, opt to leave the program after receiving initial assistance during their first year, and then return for additional help in their senior year, focusing on career-related issues such as exploration of appropriate work environments, review of unwritten rules in the

workplace, resume writing and mock interviewing, and life skills (e.g., post-graduation living arrangements, financial planning).

Program/service description. Beyond Access began as a pilot program in 2008 and was adapted from a program developed at the University of Minnesota. Beyond Access has two tracks:

- Track I, where students meet with a strategy instructor for three hours per week (cost: \$3,400 per semester); and
- Track II, where students meet with a strategy instructor for one hour per week (cost: \$1,700 per semester).

Students are given the option to participate in whichever track they feel best meets their needs. Many students will choose to participate in Track I during their first semester, and Track II for the remainder of their participation in the program. In the current Fall 2014 semester, there are 46 students in Beyond Access, with eight of the students participating in Track I and 38 participating in Track II.

Since every student's program is customized to meet his/her individual goals, the skills and strategies used are personalized to match the student's goals and learning styles. When the students are meeting with a strategy instructor, they are working on developing skills such as:

- time management and organization;
- study skills;
- stress management;
- self-advocacy;
- memory and concentration;
- social skills;
- career preparation;
- health and wellness; and
- reading and writing skills.

The Beyond Access team has a program director who oversees the program and supervises the strategy instructors, who are graduate students working toward their master's and doctoral degrees. Prior to serving as strategy instructors, they attend a comprehensive summer training program where they are provided with pertinent information, including training related to working with students served in Beyond Access. There are currently four strategy instructors for the program.

According to the director, keys to students getting the most out of the Beyond Access Program are:

- scheduling the meeting with the strategy instructor as if it was a course time, and meeting with the same strategy instructor each week at that same time;

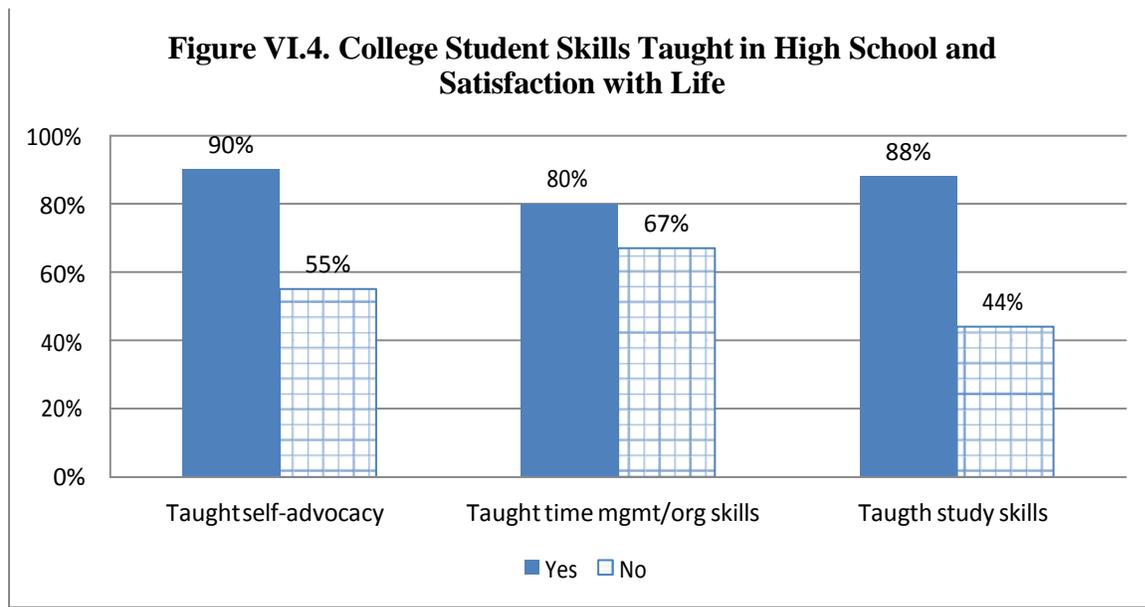
- appreciating and taking advantage of the fact that the program is individualized, with staff tailoring the assistance to the type of disability the student has; and
- treating the participants like adults (“they’re in the driver’s seat”) and maintaining constant, honest communication about what is and is not working.

Outcome data. Since the inception of the Beyond Access Program in 2008, there have been 38 students served with a formal diagnosis of ASD. Of the 38 students, 36 went on to graduate from UConn (95 percent graduation rate). The director noted that one of the students who did not graduate from UConn left because the school was too large for him/her, and the other student who did not graduate transferred to another college that had a larger academic program in his/her area of interest.

Challenges and Barriers

There are several challenges and barriers for individuals with ASD seeking postsecondary education.

- **Need adequate preparation for college during high school.**
 - Preparation for college while students are still in high school is viewed by many as the preferred strategy as opposed to waiting to assist students once they arrive at college. In the CSDE Post-School Outcomes Survey, higher levels of satisfaction with life after high school for students with an outcome of higher education occurred more often when students had been taught the following skills in high school: self-advocacy; time management/organizational skills; and study skills (Figure VI-4).



- Need to learn self-advocacy skills for success in college.
 - Students with ASD, as well as students with other disabilities, are not automatically entitled to disability-related services and supports; they must meet eligibility requirements through the documentation of a disability. Most, if not all, universities and colleges have a documentation policy or procedure for determining eligibility for services.
 - Transitional services-only can teach students how to contact the college's disability coordinator. One transitional services-only academy, for example, will initially go with the student to meet with the disability coordinator, to model the skill and help to make the experience of taking their first college courses a success. Through reasonable accommodations, such as an adjustment to a course, teacher selection, program or activity, a qualified person with a disability has an equal opportunity to receive a college education.

- Need to learn time management/organizational skills for success in college.
 - Executive functioning and organizing deficits are considered a hidden disability for individuals with ASD. While in high school, teachers, paraprofessionals, and parents are available to provide the organizing and time management needed to complete academic work. Often when the student moves on to college, this structure is absent, and becomes a barrier to success in college.
 - There are some colleges that offer specialized programs geared to serving students with ASD. Some colleges offer a mixed/hybrid model where students with disabilities are involved in social activities and/or academic classes (audited or for credit) with students without disabilities. Others offer a substantially separate program, where students are on campus but are in classes only with other students with disabilities; however, socializing with all students is part of the model. Also, there is an inclusive individual support model where students receive individualized services, such as an educational coach or tutor, and are enrolled in college classes, certificate programs, and/or degree programs. In this type of model,

students are integrated into the existing college structure, rather than in a distinct program.

- Need to learn study skills for success in college.
 - For students who plan to attend college, there are courses at community colleges that students can take while still enrolled in high school to learn study skills necessary for success at the college level. Learning in college is not the same as learning in high school, and academic success at the high school level is not necessarily an indicator of success at the college level for students with ASD. For example, when students attend college, there are more requirements and higher expectations.
- **Need to decrease reliance on supports provided in high school.**
 - To more closely mirror what will occur when a student enrolls in college, it was recommended that there be a decrease in supports previously available to a student during high school. Others have gone so far as to recommend the final year of high school mimic the freshman year of college. Although some accommodations will be available for students seeking such support, they are unlikely be as comprehensive or intense as what the student may have experienced in high school.
 - The need to taper off supports must be a belief shared by all parties involved. For example, parents of students who want their children to go to college, but who also want their children to continue having one-on-one assistance, can promote a successful transition to college by working with the school district to ease reliance on the one-on-one, a support that will not be available at the college level. Parents need to understand that, if they want their children to attend college, then they must begin backing away from accommodations, to establish more college-like expectations.
 - A consultant who works with many families in transitioning children with ASD on to college, emphasizes the need to carefully wean students from accommodations that were put in place when the students were younger. This change is considered critical to the success of students with ASD who are planning to attend college. In addition to tapering off the use of aides, students can begin to use timed testing, asking teachers for clarification, and using assistive technology. They may also take a more active role in PPT meetings, schedule their own appointments, and refill their own medications.

- **Need for intense, immersion to college experience.**
 - Sometimes referred to as a summer bridge program or boot camp, some colleges offer incoming students with ASD (and other disabilities) an immersion experience to help them adjust to college life. One college, for example, offers a summer boot camp designed to provide students with high functioning ASD with the communication and social skills they are going to need to function effectively on a college campus. The more informed students are about the changes in responsibility and the demands of college, the smoother the transition will be from secondary to postsecondary education.

- **Need college programs providing supports to students with ASD.**
 - There are some colleges that have specific programs to help students develop and master skills such as time management, studying, decision making, socializing, and independent living tasks. Colleges may have programs linking students with ASD with neurotypical students to help serve as social navigators while adjusting to the heightened social demands of college. A college peer mentor can offer help with social skills, making a big difference in the success of a college student with ASD.

 - The Step Forward programs at Gateway Community College, Disability Resource Center at Southern Connecticut State University, and Beyond Access at the University of Connecticut all appear to be helpful in providing supports to students with ASD.

 - Sometimes referred to as buddies or mentors, another option is to have college students with ASD use life coaches. Life coaches are available to help the person with ASD problem-solve, organize and negotiate during parts of their life, such as college. The life coach model has successfully been used with individuals with Attention Deficit Disorders.

 - In the CSDE Post-School Outcomes Survey data pertaining to students with an outcome of higher education, students who accessed their college disabilities office were more satisfied with life since exiting high school than college students who did not access their college disabilities office (Figure VI-5). The same pattern held for students with ASD who had an outcome of higher education (Figure VI-6).

Figure VI-5. Level of Agreement About Satisfaction with Life Since Exiting High School for Respondents Who Had an Outcome of Higher Education and Whether Accessed College Disabilities Office

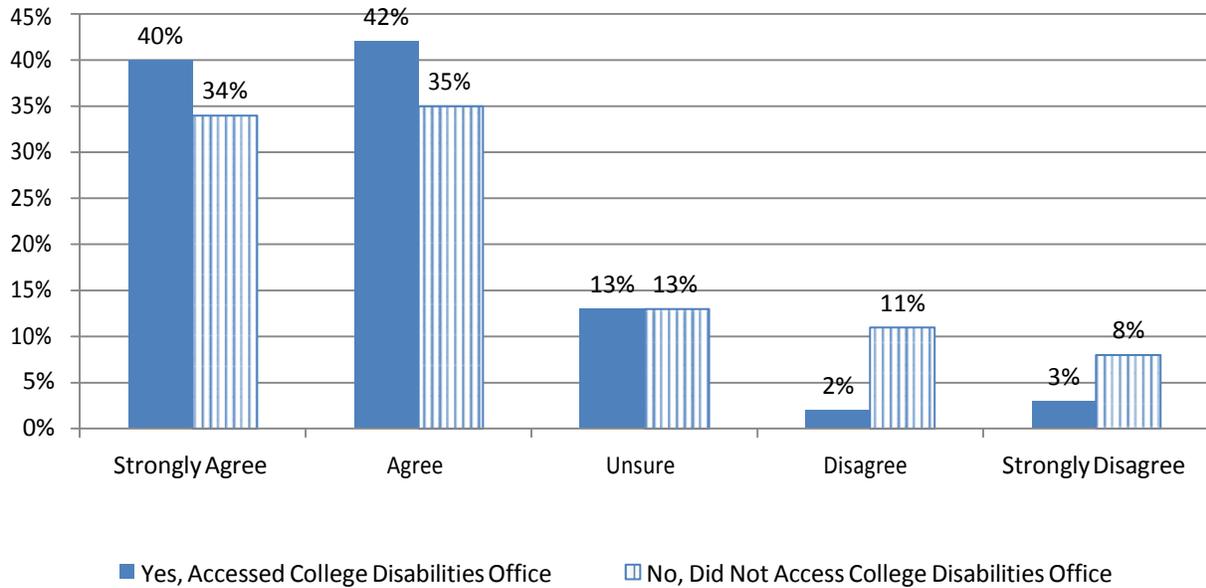
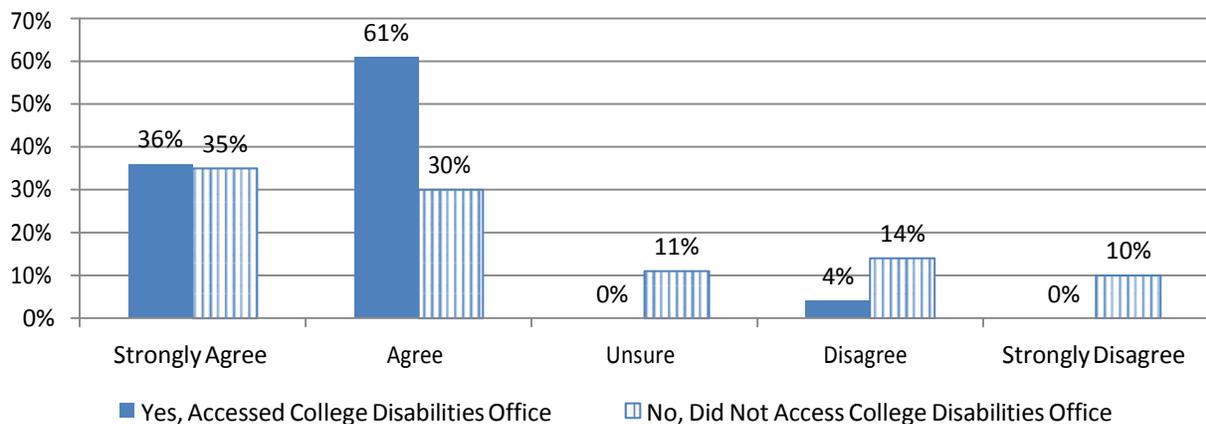


Figure VI-6. Level of Agreement About Satisfaction with Life Since Exiting High School for Respondents with ASD Who Had an Outcome of Higher Education and Whether Accessed College Disabilities Office



- In PRI Transition Coordinator Survey respondent comments regarding what could be done differently to help students with ASD transition from high school, there were several comments on the need for colleges to provide more supports for students with ASD. Mention was made of the need for programs that provide an immersion to social life in college and the expectations for academic rigor. The use of fifth year/transitional services-only as a bridge to community college (and for employment) was suggested.

Other State Models or Approaches

In addition to the Connecticut programs described in this chapter, there are other state models or approaches in colleges and universities across the country. The College Supports Program at Eastern Michigan University is an example of a full-service program for students with ASD.

Autism Collaborative Center at Eastern Michigan University College Supports Program. This program is available to students with Asperger’s Syndrome and related social communication disorders. Considered one of the most comprehensive autism support programs for college students, services include academic assistance, life and social skills, counseling, peer mentoring, time management and daily monitoring, parent support, and on campus living support. Goals of the program include: teaching the student how to be independent; learning the skills necessary to enter a competitive workforce; and facilitating a positive environment for academic achievement. There are currently 16 students participating in the program. The additional cost of the program to participants ranges from \$5,000 to \$8,000 per person per semester.

PRI Committee Staff Recommendations Related to Postsecondary Education

Based on the review of the challenges and barriers, the **PRI committee staff makes the following recommendations:**

- **CSDE should offer training to transition coordinators on the development of IEP transition goals related to self-advocacy (including accessing college disabilities office), time management/organization, and study skills for college-bound high school students with ASD.** The acquisition of these skills is associated with improved outcomes for college students with ASD.

- **For college-bound students with ASD, CSDE should consider incorporating decreasing reliance on supports prior to high school graduation into IEP or Student Success Plan.** The reduction in supports while in high school more closely mirrors what will occur when the student enrolls in college.
- **CSDE should publicize the advantages of a college immersion experience.** Participation in summer bridge programs or college boot camps prior to entering college may prove beneficial for students with ASD transitioning from secondary to postsecondary education.
- **The Board of Regents should consider replicating the Step Forward programs at other Connecticut community colleges.** The demonstrated success of the program could be helpful to students at the other Connecticut community colleges.
- **The Board of Regents should consider replicating the Disability Resource Center model at Southern Connecticut State University to other Connecticut State Universities.** The demonstrated success of the program could be helpful to students at the other Connecticut state universities.
- **The University of Connecticut should consider replicating the Beyond Access Program at other University of Connecticut campuses.** The demonstrated success of the program could be helpful to students at the other University of Connecticut campuses.

Chapter VII: Post-High School Employment/ Vocational Services

Description of Post-High School Employment/Vocational Services

As described in Chapter II, the federal and state laws mandating transition planning have a focus on both postsecondary education or training, and employment/career (independent living is a third optional goal of transition planning). In secondary transition IEPs, at least one post-school outcome goal must relate to employment. Also, the recently legislated Student Success Plan (SSP) requires students, beginning in the sixth grade, to have a comprehensive plan to help students stay engaged in school and achieve postsecondary education and career goals.

This chapter begins with a review of overall issues and considerations relevant to post-high school employment and vocational services. It then describes services and efforts to promote employment for high school exiters with ASD including preparatory services offered at local high schools. Information about employment-related services available through DORS/BRS, the state agency responsible for administering a number of employment programs under federal legislation including the Rehabilitation Act, and other state agencies both during and post-high school, are also provided.

Overall Issues and Considerations Relevant to Post-High School Employment and Vocational Services

There is a multi-agency initiative focused on competitive employment. CSDE recently developed a “Transition Community of Practice.” This team focuses on secondary transition in general and competitive employment in particular. Multiple agencies are represented on this team including DDS. Goals of the Transition Community of Practice are: 1) development and use of a statewide transition website; 2) development of a transition calendar of events and proposals for the development of a statewide transition conference; 3) identification of existing transition training opportunities statewide and development of cross-agency training; and 4) development of a directory of transition resources including a web-based transition timeline.

Different state agencies define “competitive employment” differently. Different state agencies define “competitive employment” in different ways. The State Performance Plan, for example, defines outcome categories for students exiting high school. The “competitive employment” category is defined as youth who have worked for pay at or above the minimum wage in a setting with others who are nondisabled, for at least 20 hours a week, for at least 90 days at any time in the year since exiting high school. This includes military employment.⁵⁵ The State Performance Plan also defines “other employment” as working in a setting that does not fully meet the requirements for competitive employment, including earnings below minimum wage, working fewer than 20 hours per week, and/or work in a non-integrated setting such as a sheltered workshop.

⁵⁵ The Rehabilitation Act/Department of Rehabilitation Services does not require a minimum number of hours to be worked as part of its definition of “competitive employment.”

The Rehabilitation Act, under which the Department of Rehabilitation Services Bureau of Rehabilitation Services is funded, defines competitive employment as working in an integrated setting for minimum wage or higher. It does not require a minimum number of hours worked in its definition of competitive employment. The difference in definitions across state agencies stems from inconsistencies in definition at the federal level (Figure VII-1).

Also, the State Performance Plan indicator allows only one outcome per student. So, for example, if a student is both attending college and working in a competitive employment setting, according to the rules, the higher education category will be selected.

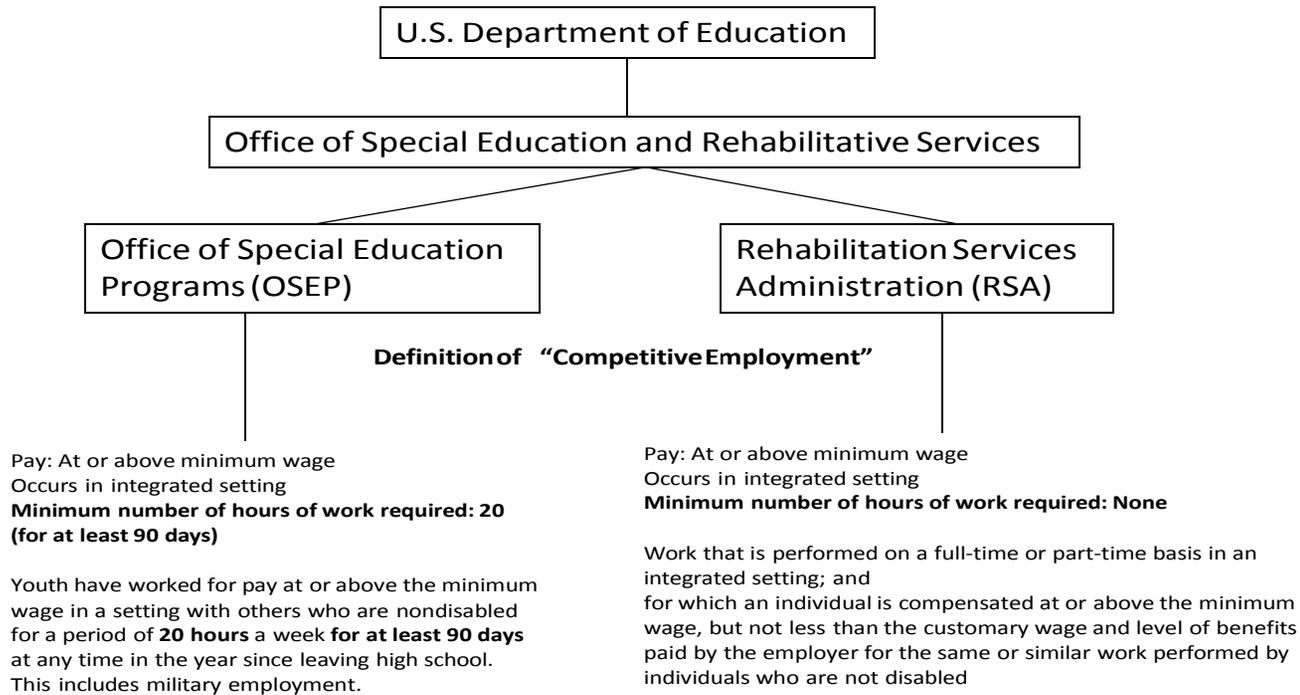
Depending on the definition of competitive employment, the number of individuals employed can vary significantly. Based on data from the CSDE Post-School Outcomes Surveys,⁵⁶ Table VII-1 shows the respondents who are working in competitive employment, including those in college, and those working less than 20 hours per week. With this expanded definition, competitive employment is found for 41 percent of the survey respondents, a figure more than triple the reported 13 percent competitively employed. A similar pattern is found for respondents with ASD.

Table VII-1. Expanded Definition of Competitive Employment				
	All Respondents (N=1,973)		Respondents with ASD (n=180)	
	Number	Percent	Number	Percent
Considered competitively employed by CSDE				
Considered by CSDE to have an outcome of competitive employment	255	13%	14	8%
Considered competitively employed by CSDE, but categorized as higher education due to their enrollment in a 2- or 4-year college	280		19	
Subtotal	535	27%	33	18%
Considered competitively employed by BRS				
Working less than 20 hours per week	272		21	
Total (of 1,973)	807	41%	54	30%
Source: CSDE and PRI staff analysis.				

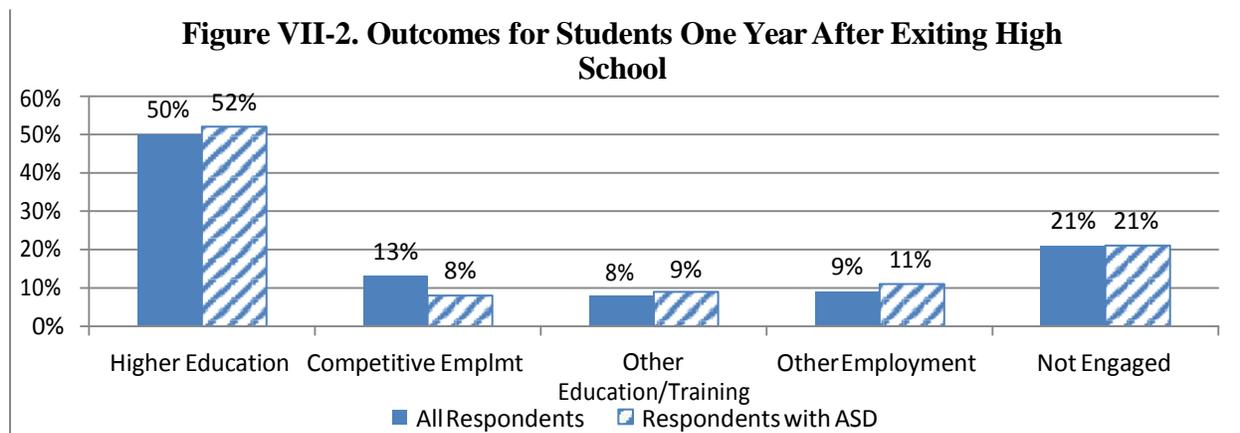
Relatively fewer high school exiters with ASD are competitively employed compared with all students with disabilities. The CSDE Post-School Outcomes Survey asked respondents to identify an outcome one year after exiting high school. Figure VII-2 shows the outcomes for all respondents and respondents with ASD. Compared with all former students who had received special education services, students with ASD were relatively less likely to be competitively employed (13 percent vs. 8 percent). Slightly more (9 percent) were categorized as having an outcome of “other education/training.” This category included exiters enrolled in an education or training program such as: vocational, technical or trade school; short-term education or job training program; adult education; or postgraduate or college prep program. Examples of other education and training included in the current data set included fashion design program, floral

⁵⁶ See Appendix B for complete results of CSDE Post-School Outcomes Surveys.

Figure VII-1. Federal Variations in Definition of “Competitive Employment”



design school, computer program technology, and transition/life skills residential program. For the most part, the other education or training appears linked to vocational training or education to prepare students for employment.



In a national longitudinal transition study on post-high school outcomes of young adults with disabilities,⁵⁷ the percentages of young adults who were employed at the time of the interview ranged from 30 percent to 67 percent depending on type of disability. At the low end of the range, 30 percent of young adults with ASD were employed at the time of the study interview.

Employed high school exiters are more likely to be working part time. In the CSDE Post-School Outcomes Survey, there was a trend for respondents with ASD who were competitively employed to be working part-time (71 percent) compared with the overall figure (48 percent) for all survey respondents.

Support for working fewer hours was also found in the national longitudinal transition study on post-high school outcomes of young adults with disabilities. The study reported differences in the number of hours worked per week by type of disability. While young working adults with learning disabilities, emotional disturbances, speech/language impairment, or traumatic brain injuries, for example, averaged 34-38 hours of work per week, young adults with autism averaged the lowest number of hours per week (24 hours per week).

Regardless of the number of hours worked, high school exiters who were competitively employed expressed greater satisfaction with life. Table VII-2 shows level of agreement for each of the five outcome categories in the CSDE Post-School Outcomes Survey. Apart from higher education, students who were competitively employed one year after exiting high school expressed the greatest satisfaction with life, followed by students now in some other postsecondary education or training program, followed by those in some other employment.

⁵⁷ From the Post-High School Outcomes of Young Adults with Disabilities Up to 8 Years After High School: A Report from the National Longitudinal Transition Study-2 (NLTS2), September 2011 from U.S. Department of Education Institute of Education Sciences (IES).

Outcome Category	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
Higher Ed	36%	36%	13%	8%	7%
Competitively Employed	31%	32%	15%	14%	7%
Some Other Postsecondary Education or Training Program	24%	35%	20%	10%	10%
Some Other Employment	12%	39%	22%	16%	11%
Not Engaged	9%	26%	22%	24%	20%
Total*	26%	34%	16%	13%	10%

*Percents do not total to 100% due to rounding.
Source: CSDE.

There is evidence that post high school, former students with ASD are struggling in the areas of employment and vocational training (i.e., “some other postsecondary education or training program”). In addition to information from the CSDE Post-School Outcomes Survey, over half of parents who responded to the PRI Survey of Parents of Children with ASD Aged 15-25⁵⁸ said their children who had graduated high school were doing fairly poorly to very poorly in the areas of employment and vocational training (Table VII-3).

Area	Very well	Well/Fairly well	Fairly poorly/Poorly	Very poorly
Employment	8%	40%	18%	34%
Postsecondary Education	11%	34%	26%	28%
Vocational Training	4%	17%	28%	51%
Social/recreational Activities	6%	42%	27%	25%
Becoming More Independent	9%	49%	28%	14%
Overall Well-Being	5%	60%	23%	12%

Source: PRI Survey of Parents.

Services Provided by Local School Systems

Given that at least one post-school outcome goal in the secondary transition IEP must relate to employment, high schools are responsible for providing at least some pre-employment preparation. Chapter V provided information about the expected achievement of certain skills or abilities by the time the student graduates. Feedback on the receipt of such skills during high school and progress in attaining employment is now presented from several sources: CSDE Post-School Outcomes Survey; PRI Transition Coordinator Survey,⁵⁹ and PRI Survey of Parents of Children with ASD Aged 15-25.

⁵⁸ See Chapter IV for complete results of the PRI Survey of Parents of Children with ASD Aged 15-25.

⁵⁹ See Chapter III for complete results of PRI Transition Coordinator Survey.

Feedback from respondents to the CSDE Post-School Outcomes Survey. Table VII-4 shows which skills were reportedly taught by the respondent’s high school, depending on the outcome category. Related to competitive employment and other employment, according to the CSDE Post-School Outcomes Survey respondents:

- self-advocacy skills were inconsistently taught, but were most often taught to students who went on to higher education or some other employment;
- independent living skills were not often taught, although nearly half who went into some other employment received training in this skill; and
- work experience in high school most likely occurred for students who went on to some other employment post-high school (56 percent)
 - less than half who went on to competitive employment post-high school reported receiving work experience during high school (46 percent).

Table VII-4. Skills Taught in High School for Outcome Categories								
Outcome Category	Skill							
	Social Skills	Self-Advocacy	Indep. Living Skills	Tech. Skills	Time Mgmt/Org. Skills	Money Mngmnt Skills	Study Skills	Work Experience
Higher Ed	56%	60%	27%	49%	58%	23%	65%	26%
Competitively Employed	55%	46%	37%	51%	40%	33%	42%	46%
Some Other Postsecondary Education or Training Program	53%	43%	29%	41%	39%	21%	43%	33%
Some Other Employment	73%	50%	48%	45%	33%	32%	31%	56%
Not Engaged	58%	35%	35%	39%	24%	26%	30%	31%

Source: CSDE and PRI staff analysis.

Feedback from respondents to the PRI Transition Coordinator Survey. Respondents to the PRI Transition Coordinator Survey said approximately three-quarters of students were always or frequently offered courses or assistance in career exploration, and pre-employment activities, if needed.

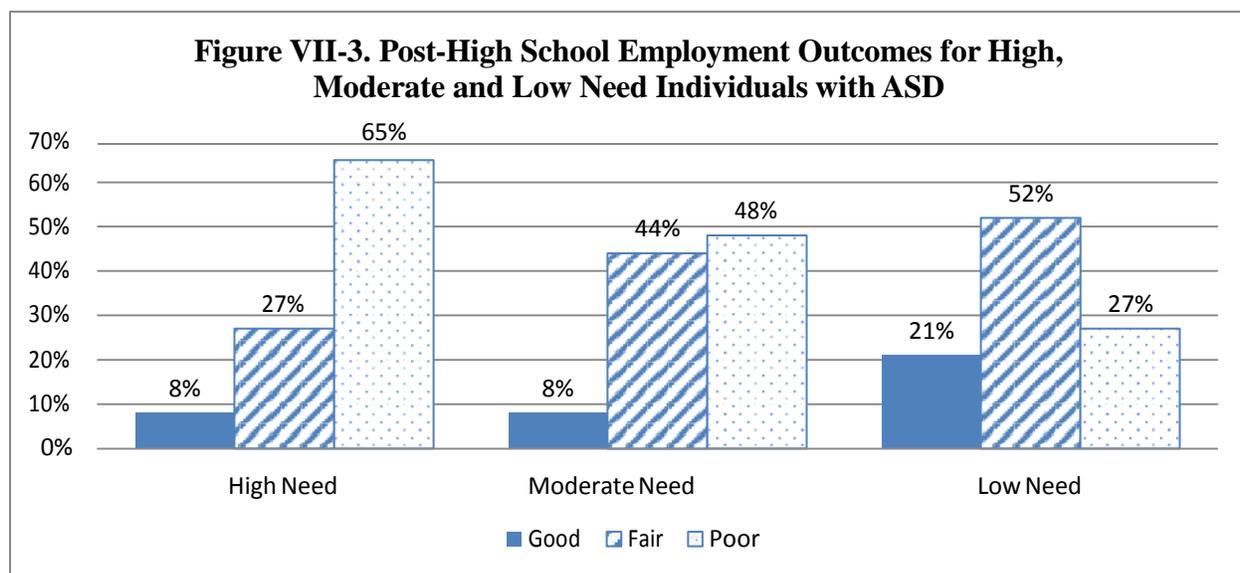
The PRI Transition Coordinator Survey respondents were asked to describe what resources or assistance school personnel need to better serve students with ASD to prepare for adult life after high school. A number of comments related to employment services:

- Respondents thought it would be beneficial to have additional funds for job coaches at the high school level. Mention of realistic employment goals and

job development assistance while students are in high school were also suggested.

- Some respondents commented on the need for students to practice working inside the school and outside in the community, job shadowing assistance, and work site visits. Having resources in the school such as a career center was also suggested.
- One respondent commented that there should be exploration of vocational opportunities based on the skills of the student, not based on what is available, and encouraging school personnel to think outside the box. It is important to have students graduate with a skill that will allow them to become employed.

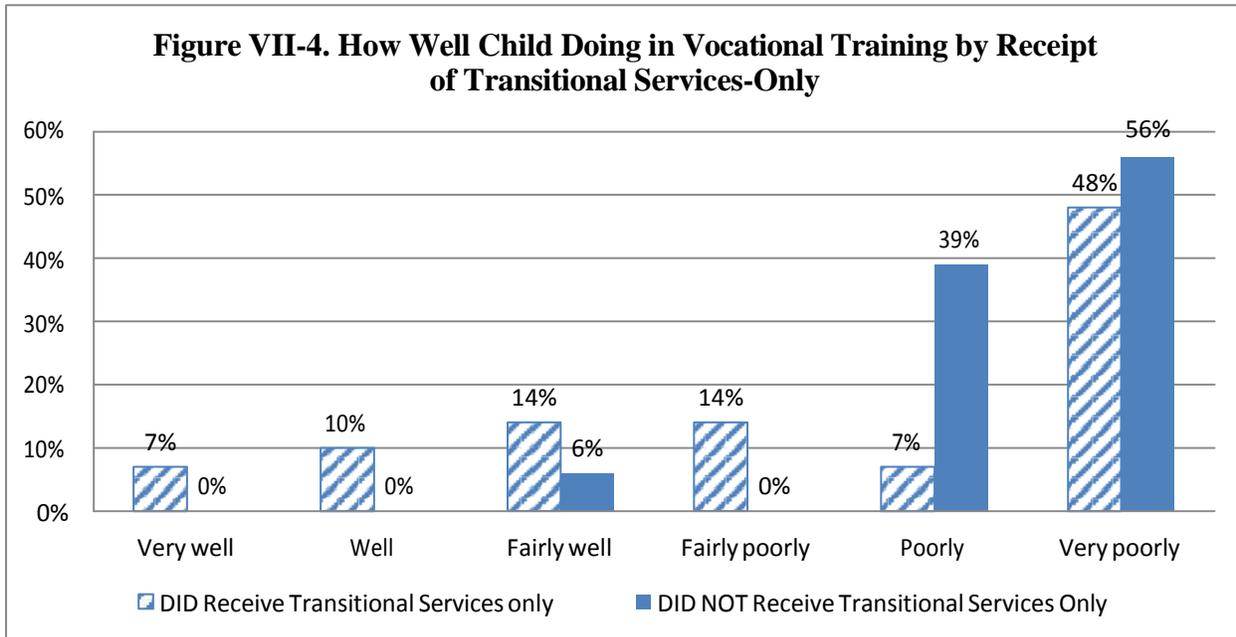
Based on responses on the PRI Transition Coordinator Survey, former high need students with ASD struggled the most regarding employment compared with former students considered to be of moderate or low need (Figure VII-3).⁶⁰



Feedback from respondents to the PRI Survey of Parents of Children with ASD Aged 15-25. Respondents to the PRI Survey of Parents of Children with ASD Aged 15-25 gave a similar answer when asked about the offering of certain courses or assistance by the high school to students with ASD. Quite a bit (12 percent) or some assistance (59 percent) was provided for career exploration, and quite a bit (14 percent) or some assistance (46 percent) was provided for pre-employment activities.

Based on the responses to the PRI Survey of Parents of Children with ASD Aged 15-25, many students struggled in the area of vocational training. There was a greater likelihood, however, for former students who had received transitional services-only to do somewhat better in this area (Figure VII-4).

⁶⁰ “High need” was defined as students with ASD requiring substantial support, “moderate need” as students with ASD requiring moderate support, and “low need” as students with ASD requiring minimal support.



Services Provided by Connecticut Department of Rehabilitation Services/Bureau of Rehabilitation Services (DORS/BRS)

The Connecticut Department of Rehabilitation Services Bureau of Rehabilitation Services (BRS) provides assistance to individuals with significant disabilities who want to find or keep employment. There is no financial means test for BRS services. A person with a physical and/or mental impairment that is a substantial barrier to employment, and who could benefit from vocational rehabilitation services to ultimately become competitively employed, is eligible for services. The BRS process is described in Appendix J.

DORS/BRS assistance to high schools. As noted in Chapter V, DORS has approximately 70 vocational rehabilitation counselors (VR counselors) assigned as liaisons to all 143 Connecticut school districts that provide secondary services. The role of the counselors is to help the schools advise their students on what vocational assessment instruments to use. They also work with individual students to determine eligibility for BRS services and, if eligible, develop individualized plans for employment (IPEs) that specify what services and supports BRS will provide directly upon graduation from high school.

In collaboration with school districts, BRS may provide pre-employment transitional services such as:

- job exploration counseling;
- work-based learning experiences;
- counseling on comprehensive transition or postsecondary education;
- workplace readiness training; and
- instruction in self-advocacy.

When it is time for the student to find employment, BRS can assist them with planning and coordinating employment services, job placement, additional training, job coaching, transportation assistance, and assessing a worksite for accessibility—these services are sometimes referred to as Vocational Rehabilitation. The vocational rehabilitation counselor will also periodically review the progress of individuals, and determine whether a program should be continued, modified, or discontinued, as appropriate.

Increased emphasis on transition services. The recent reauthorization of WIA (called WIOA, or Workforce Innovation and Opportunities Act), emphasizes an increase in services to youth 14-24 with disabilities. It requires state vocational rehabilitation agencies (e.g., DORS) to make pre-employment transition services available, and to set aside 15 percent of federal funds for transition services.

BRS State Plan. The Bureau of Rehabilitation Services (BRS) will submit a new State Plan to the Rehabilitation Services Administration (RSA) regarding the provision of vocational rehabilitation and supported employment programs in Connecticut for federal fiscal year 2014. Based on a draft of the 2014 state plan, there is a goal to increase employment outcomes for individuals with disabilities, particularly those individuals from unserved or underserved populations. Among the priority areas identified are individuals with autism spectrum disorders. Additionally, the draft includes an objective (2.5) to develop more responsive services for individuals with autism spectrum disorders. The strategies associated with this objective include a review of recommendations from the Autism Task Force, and utilization of the Autism Spectrum Disorder Advisory Committee (ASDAC).

Supportive Employment Program (EOP). Although the program is housed in BRS, the Supportive Employment Program (EOP) is not considered a BRS program. Unlike the federally-funded short-term services provided by BRS, the EOP program long-term services are funded by the State of Connecticut. Over the years, there has been a decrease in funding, from a high of \$1.5 million to the current \$700,000 allocated to EOP. The long-term services or supports, which can be for up to 10 hours per month, are provided indefinitely while the individual remains employed and requires such services. The EOP program is intended for individuals who have no other means of receiving required long-term employment supports. When the DDS Division of Autism Spectrum Services was created, individuals with ‘ASD only’ were no longer eligible for the EOP program because the division became a potential resource for long-term employment supports.

Summer Employment Program for Youth with Disabilities. Started approximately three years ago, the BRS-run summer youth employment program is for 14-24 year olds with disabilities that impact their potential ability to become competitively employed. These paid jobs allow participants to receive three months of work experience.

The participating youth receive up to five hours of orientation in the form of a meeting or interview with the provider paid to work with the student, the student, and the potential employer. The summer program requires a minimum of 135 hours during July-September, with a minimum of 15 hours worked per week. This past summer, the program targeted youth with ASD, mental health disabilities, and youth who were mono-lingual, and deaf/hard of hearing.

As has occurred in previous summers, during the summer of 2014, DORS/BRS operated a jobs program for 310 youth and young adults aged 14 to 24 year olds, focusing on underserved youth. According to DORS, 117 of the 310 participants (37 percent) were identified as having ASD. The total cost to serve the 117 participants with ASD was \$772,377, with the major expenses being for wages to participants, job coaches, and on site evaluations.

Who may receive assistance from BRS? Any individual who would require short-term supports to attain and remain competitively employed is eligible for BRS services. The distinction between need for short-term vs. long-term supports are shown in Figure VII-5. The following points should be noted:

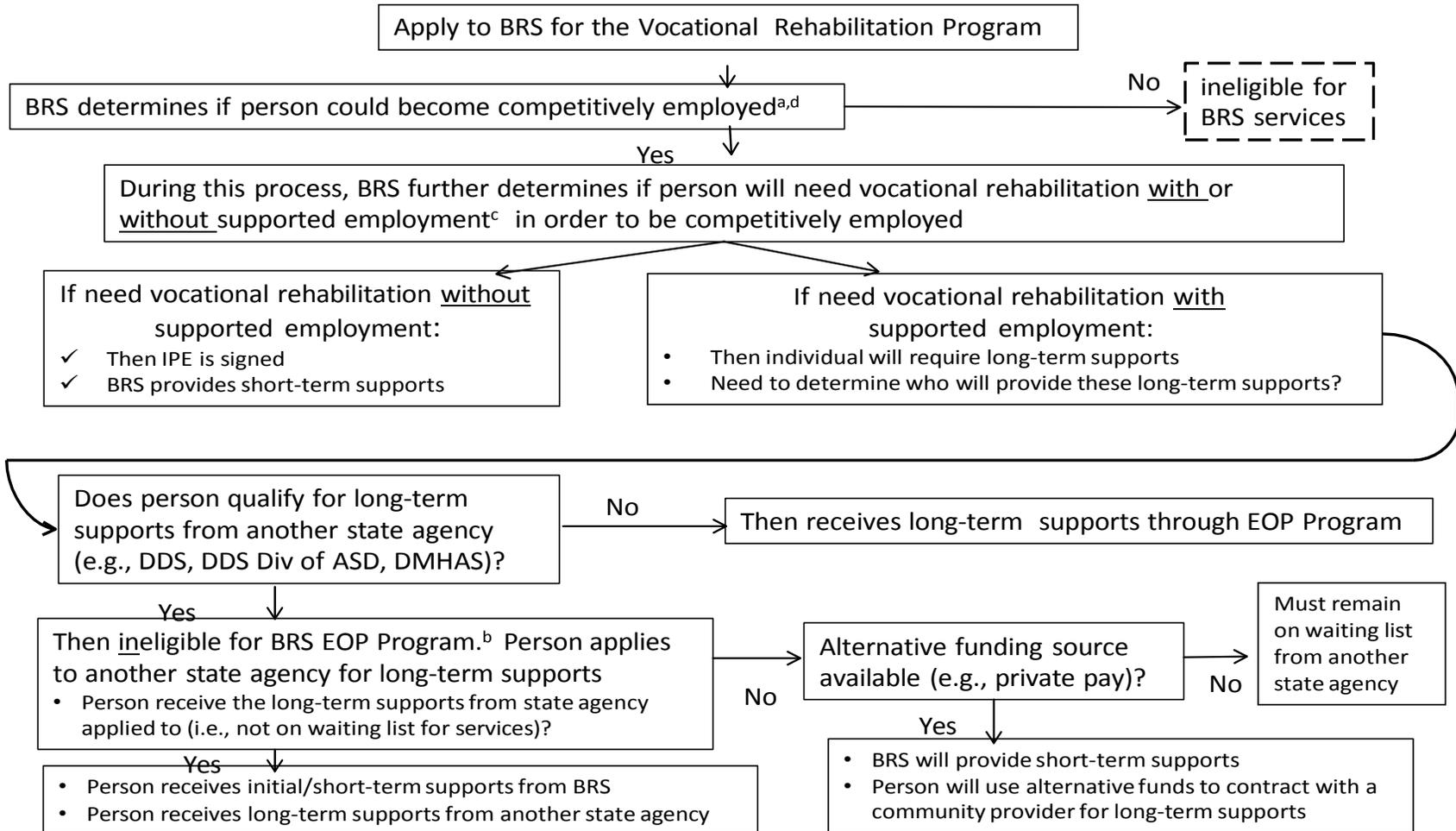
- As dictated by federal law, *BRS may only assist individuals who can become competitively employed.*⁶¹
 - Competitive employment refers to the *setting* where the employment takes place
 - Competitive employment is unrelated to *supported employment*
 - Supported employment refers to the individual's need for long-term supports to maintain employment, regardless of whether it is in a competitive employment setting
 - With the exception of the EOP program, *BRS only provides short-term (time-limited) vocational rehabilitation for individuals who can become competitively employed*
 - If the individual needs long-term supports to become competitively employed, then a source for this support must be identified before BRS can provide the initial short-term (time-limited) vocational rehabilitation

Other DORS/BRS efforts related to Autism. DORS has a Transition Committee that develops training related to secondary transition. The committee also works on best practices and better ways to engage schools.

Additionally, DORS has a BRS Autism Committee that reviews cases for individuals of any age with ASD being served by DORS. The committee does not develop or recommend general policies related to individuals with ASD.

⁶¹ Recall the BRS definition of competitive employment is working in an integrated setting (has both employees with and without disabilities) for minimum wage or higher.

Figure VII-5. BRS Decision Tree



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^a Competitively employed defined by BRS as working in an integrated setting for minimum wage or higher.

^b Employment Opportunities Program (EOP) is a state-funded program housed in DORS.

^c Vocational rehabilitation offers short-term assistance that is gradually faded out; supported employment requires support to be in place long-term, often for the duration of the employment.

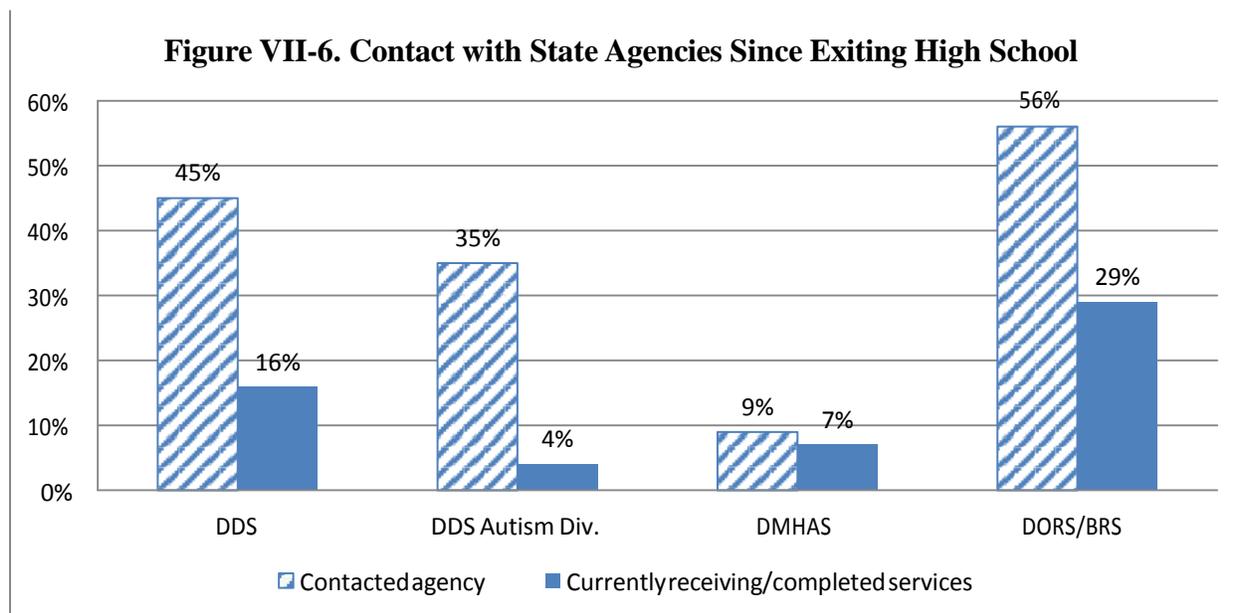
^d Assumes person met eligibility requirements: 1) disability present, 2) disability an impediment to employment, and 3) can benefit from BRS assistance

Services received by BRS clients with ASD. Based on the BRS Case Closure Data,⁶² among the 11,126 BRS cases that closed during FFY 2011-2013, there were 563 with a primary or secondary impairment of ASD (five percent). Table VII-5 shows the relatively younger age of BRS cases with ASD.

Table VII-5. Cases Closed by Age of Consumer				
	All Closed Cases		Cases with ASD*	
	Number	Percent	Number	Percent
15-25	3,449	31%	468	83%
26-35	1,559	14%	40	7%
36-45	1,849	17%	23	4%
46-55	2,386	21%	25	4%
56+	1,879	17%	7	1%
Total	11,122***	100%	563	99%**

*ASD as primary or secondary impairment
 **Percent may not total to 100% due to rounding.
 *** This information was missing for four of the cases.
 Source: BRS and PRI staff analysis.

Based on PRI Survey of Parents of Children with ASD Aged 15-25, the Department of Rehabilitation Services Bureau of Rehabilitation Services was the state agency most likely to be contacted by families with children who had graduated from high school and the state agency most likely to be providing services (Figure VII-6).



⁶² See Appendix E for complete results of the BRS Case Closure Data.

Consistent with the finding that consumers aged 15-25 had their cases open longer than other age groups, and that individuals served with ASD tended to be younger than other groups of individuals with disabilities, the average number of months their cases remained open was higher than for other disability groups served by BRS (Table VII-6).

Disability Type	Number of Months Case Open
ASD	25.2
Intellectual Disability	20.6
Specific Learning Disability	18.8
Depressive and Mood Disorders	17.1
Schizophrenia and other Psychotic Disorders	16.3
Physical Disorders/Conditions	15.1
Total	17.3

Source: BRS and PRI staff analysis.

Figure VII-7 provides a timeline for the process, from application to closure for all applicants.

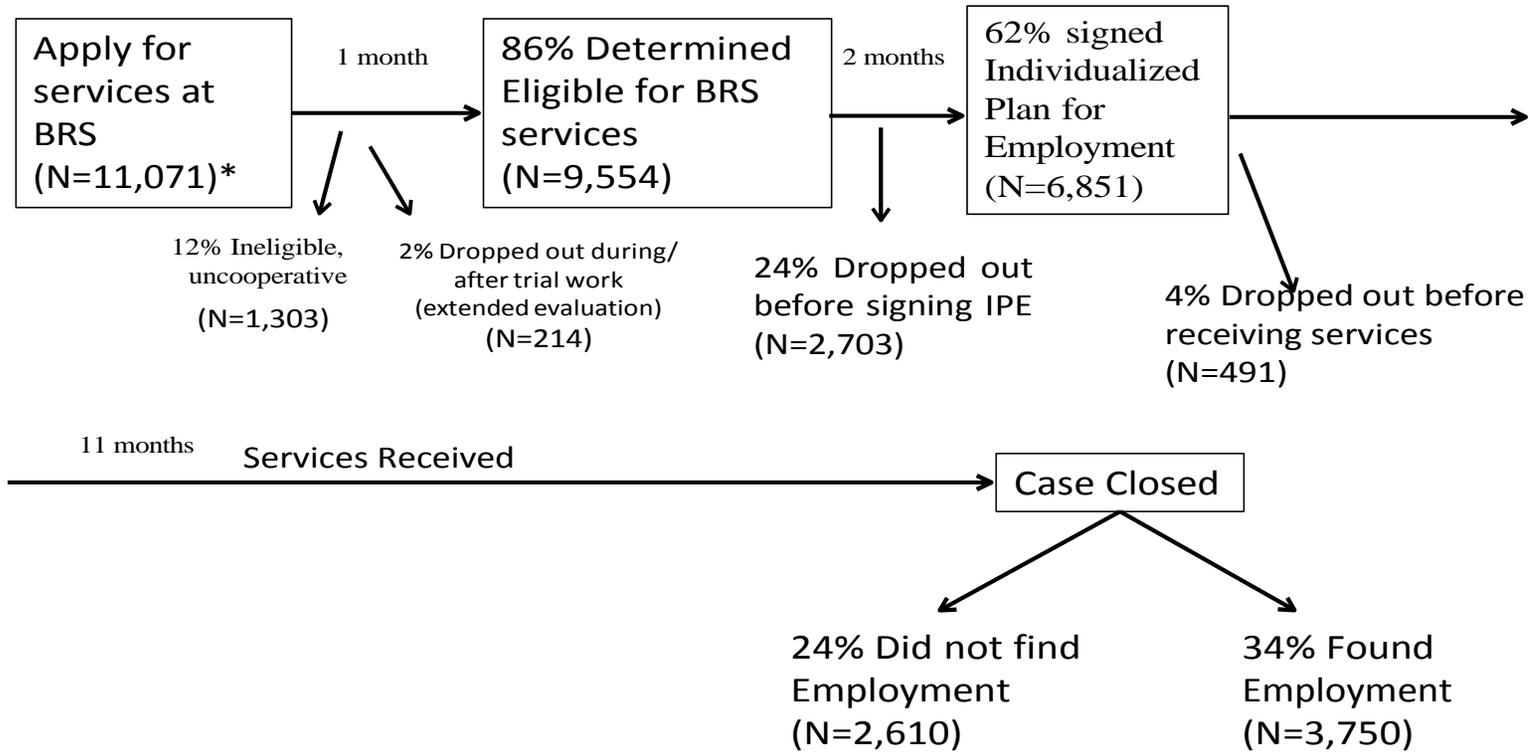
Table VII-7 shows the percent of the 11,126 closed cases that received certain BRS services. All individuals received vocational rehabilitation counseling and guidance, defined as vocational counseling and guidance necessary for an individual to become employed. Counseling ranged from medical and vocational to family areas.

Service	All Cases	'ASD Only'
Counseling	100%	100%
Assessment	61%	74%
Diagnosis/Treatment	35%	21%
Info and Referral (for services from other agencies)	27%	24%
Job Placement Assistance	20%	33%
Job Readiness Training	12%	21%
On the Job Supports Short-Term (e.g., job coaches and follow-up services)	12%	35%
Job Search Assistance	9%	13%
Rehabilitation Technology (e.g., selection and provision of assistive technology devices)	7%	<1%
Transportation (including training in use of public transportation)	7%	6%
OJT in specific job skills by prospective employer	4%	7%
Occupational/Vocational Training	3%	7%

Source: BRS and PRI staff analysis.

Assessment services pertained to activities needed to determine eligibility for vocational rehabilitation (VR) services and deciding the types of services to be included in the individualized plan for employment (IPE). Trial work experiences and extended evaluations were also included under assessment services. Three-quarters of BRS clients with ASD received assessment services.

Figure VII-7. Median Number of Months for BRS Process From Application to Closure



* Excludes 53 closures from an order of selection waiting list and 2 missing cases.

Diagnosis and treatment services were somewhat less likely for BRS clients with ASD. These services included diagnosis and treatment for mental and emotional disorders, physical or occupational therapy, and prosthetic devices.

Job placement assistance (i.e., referral to a specific job resulting in an interview, regardless of interview outcome), was more likely to be received by BRS consumers with ASD. Job readiness training (e.g., appropriate work behaviors and appearance) was also more likely to be received by BRS consumers with ASD. Also more likely to be received by BRS consumers with ASD was job search assistance, which included resume preparation assistance, interview skills and contacts with potential employers on behalf of the consumer.

On the job supports were provided nearly three times more often for individuals with ASD. These services were provided to individuals who had been placed in a job and were used to stabilize the placement and promote job retention. Examples of on the job supports included job coaching and follow-up services to retain the employment.

Occupational, vocational, or job skill training is provided by a community college and/or business, vocational/trade or technical school. The purpose of the training is to prepare consumers for competitive employment in a particular occupation; the training does not lead to an academic degree or certification. During FFY 2011-2013, there were 369 consumers who received occupational, vocational, or job skill training. Although the percents are small, according to the BRS Case Closure Data, the consumers with ASD were twice as likely to receive this type of training compared with all BRS consumers.

Less than one percent of this type of training is provided directly by BRS. Rather, rehabilitation programs in the private sector, or some other private source provide the occupational, vocational, or job skill training.

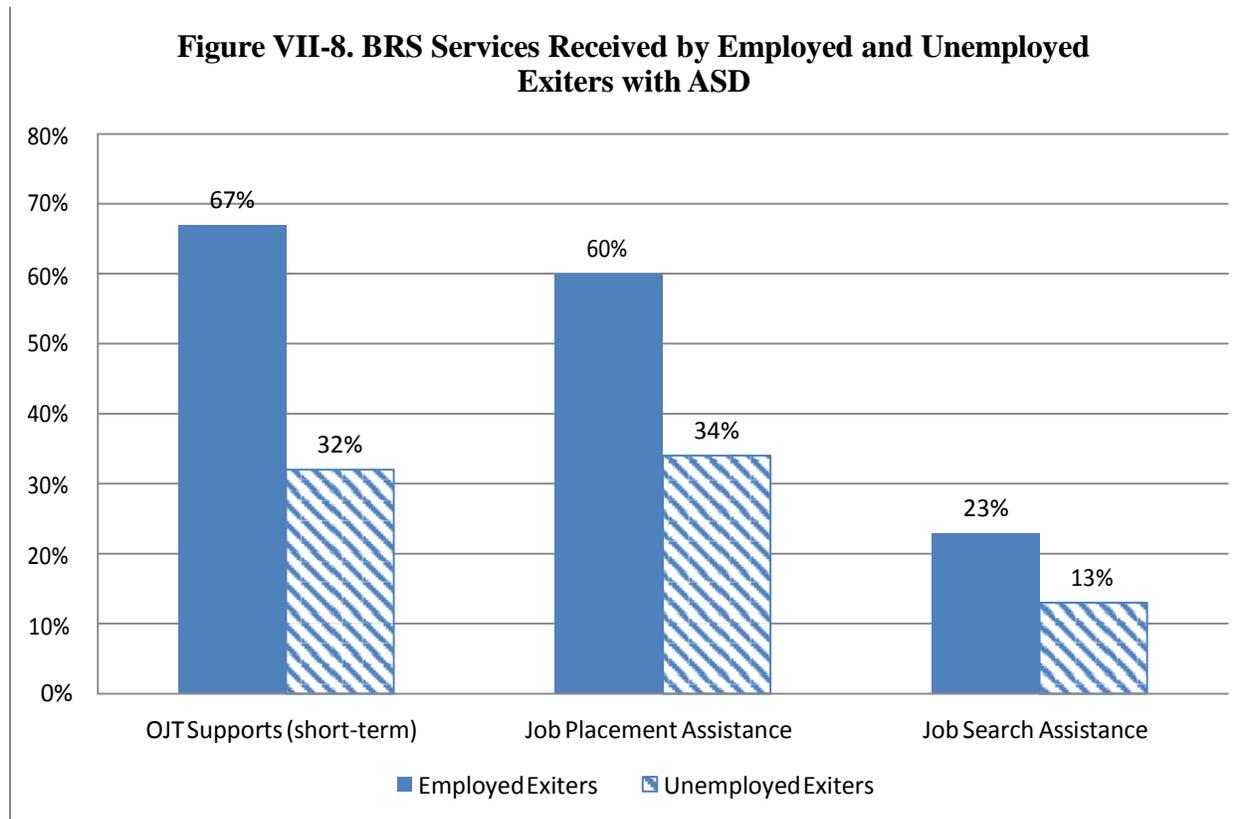
Table VII-8 shows the percent of closed cases by disability that received some of the more frequently offered services. BRS consumers with intellectual disabilities and BRS consumers with ASD had a similar pattern of receipt of services.

Service	Total	ASD	Depressive/ Other Mood Disorders	Physical Disorders/ Conditions	Specific Learning Disabilities	Intellectual Disability	Schizophrenia/ other Psychotic Disorders
Assessment	61%	74%	59%	67%	60%	72%	60%
Job Readiness	12%	21%	14%	5%	16%	17%	12%
Job Placement	20%	33%	23%	11%	25%	33%	26%
Job Search	9%	13%	11%	4%	11%	14%	10%

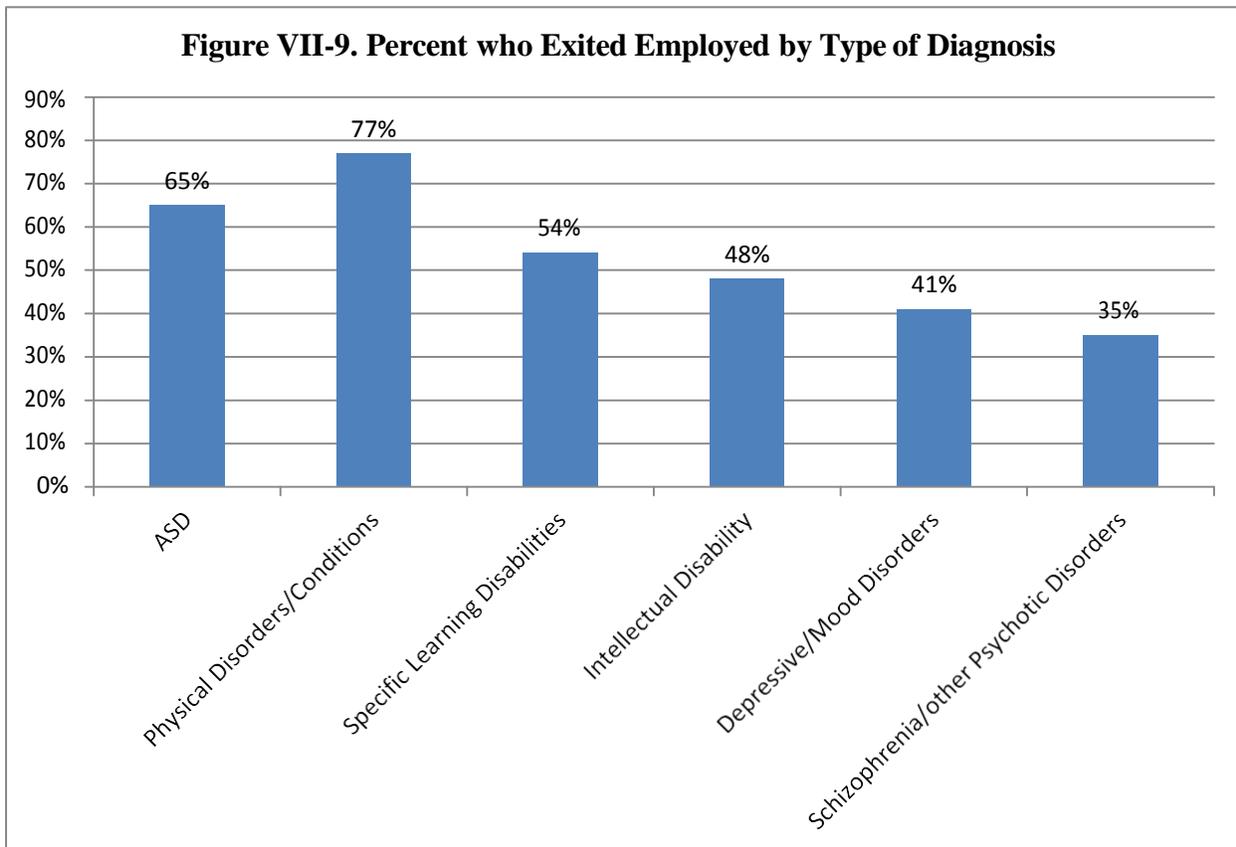
Source: BRS and PRI staff analysis.

Employed exiters with ASD were more likely to have received certain services during their time with BRS. Employed exiters with ASD were more likely to have received on the job

supports (short-term), job placement assistance, and job search assistance compared with unemployed exiters with ASD (Figure VII-8).

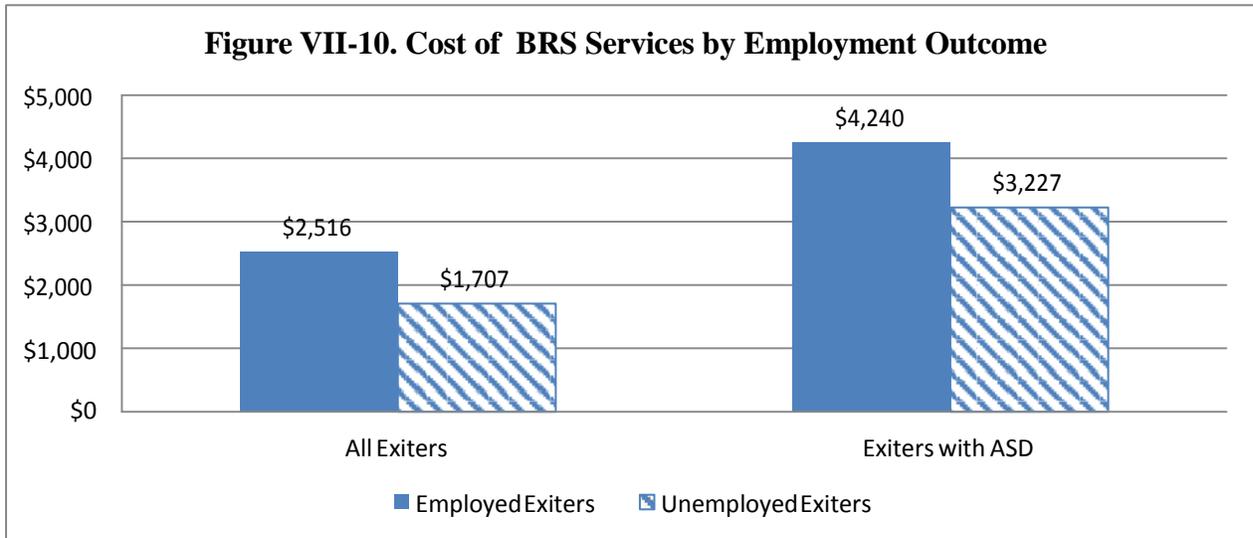


The percent of employed exiters varied by type of diagnosis. Figure VII-9 shows the percent who exited employed by the type of diagnosis. With the exception of consumers with physical disorders or conditions, those with ASD had a relatively higher percent exiting with an outcome of employment. Approximately two-thirds of consumers with ASD (65 percent) who received BRS services exited with an outcome of employment.



More money was spent by BRS to purchase services for consumers who exited employed (after receiving BRS services). Figure VII-10 shows the greater cost to BRS for employed exiters and for employed exiters with ASD:

- For all exiters who received BRS services, the median costs were 47 percent higher for employed exiters.
- For exiters with ASD who received BRS services, the median costs were 31 percent higher for employed exiters.
- Median costs for exiters with ASD who received BRS services were greater, regardless of outcome.



As noted earlier, some consumers applied to BRS in need of some type of job retention support. Removing these consumers who were already employed at the time of application, Figure VII-11 shows somewhat high median costs.

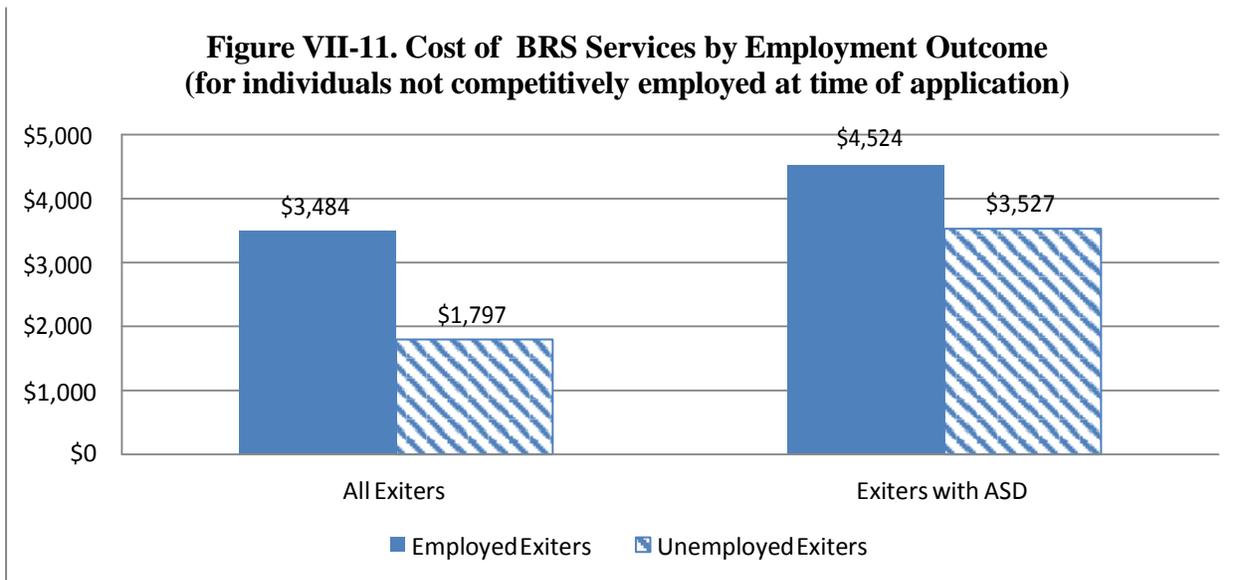
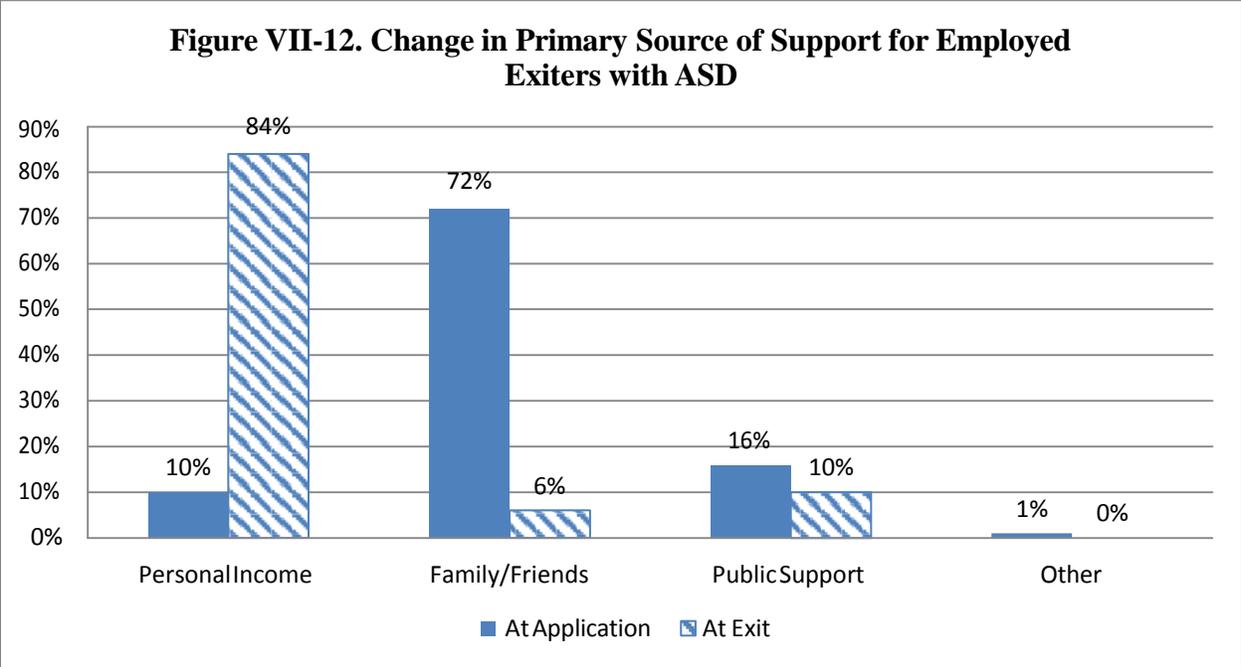
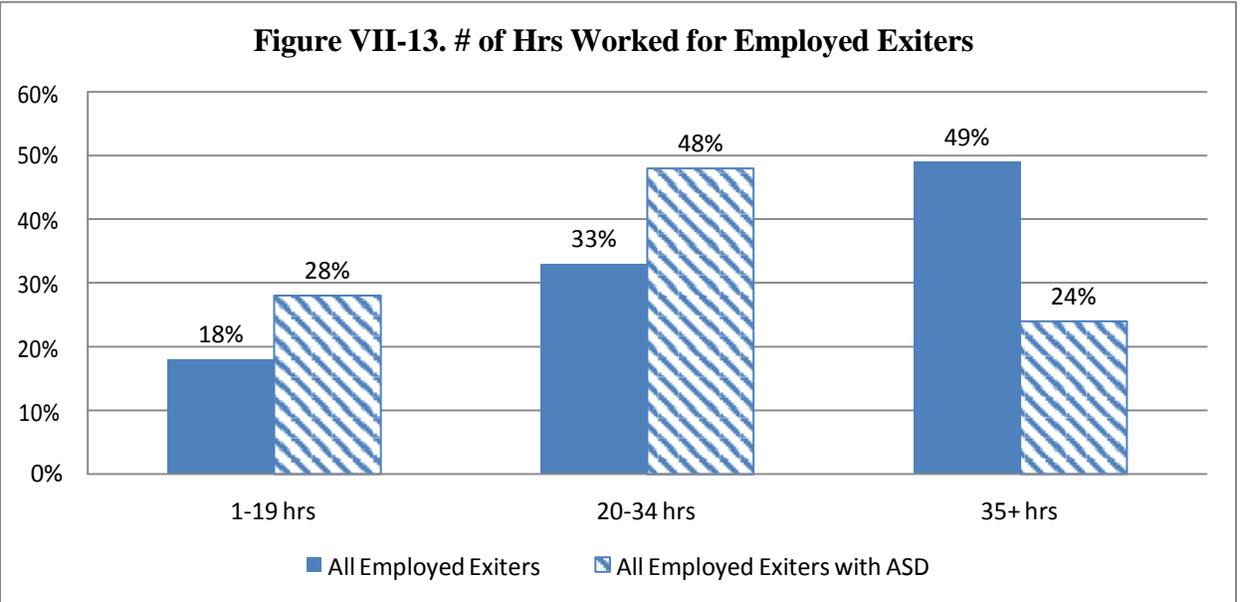


Figure VII-12 shows the increase in personal income as the primary source of support for employed exitters from BRS with ASD.



Employed exiters with ASD worked fewer hours than employed exiters without ASD. Figure VII-13 shows the number of hours worked in competitive employment. Nearly half of all employed exiters worked full time (at least 35 hours per week); however, just one-quarter of employed exiters with ASD worked full time. Employed exiters with other types of disabilities who were also less likely to work full time were those with intellectual disabilities (18 percent) and schizophrenia/other psychotic disorders (15 percent).



Employed exiters with ASD were more likely to have employment with supports in an integrated setting compared with all BRS employed exiters (24 percent vs. 8 percent of all employed exiters). The remaining 76 percent of employed exiters with ASD were categorized as having employment without supports in an integrated setting (vs. 91 percent of all employed exiters).

Services Provided by Department of Developmental Services

CT DDS transition planning and employment services. CT DDS describes transition planning as a coordinated set of activities designed to assist the student to develop skills, strengths and preferences in certain areas, including employment. The goal is to become employed in a fully integrated setting, and if the goal is achieved, DDS will continue to work with the client to maintain employment and consider additional career or advancement opportunities.

According to an October 2011 DDS document, all DDS regions have transition coordinators who may be able to help families navigate the transition planning process, including employment preparation or opportunities. At the September 24, 2014 PRI public hearing, the DDS commissioner testified that in 2012, eighteen DDS employees were re-assigned to new transition advisor positions to help students obtain appropriate educational programs that focus on employment. The commissioner further noted that DDS had created six employment/self-determination positions (two per region) to help enhance employment outcomes in the regions, and that case managers received technical assistance by the employment/self-determination personnel to help individuals on their caseloads find and keep competitive employment.

The DDS also publishes a document called, “Great Expectations.” The document contains information to help parents prepare their children for employment. Some of the topics covered are: impact of wages on benefits; skill building in the family home; and the importance of real work experiences.

CT DDS five year plan. The Connecticut Department of Developmental Services has a five year plan (2012-2017)⁶³ that contains two goals related to employment.

Goal 1: Increase the number of individuals who are gainfully employed, including self-employment and double the number of people who are competitively employed. The report notes that the total number of DDS clients working in competitive employment has not increased. Efforts to promote greater employment include a comprehensive assessment of DDS by the national Supported Employment Leadership Network (SELN)⁶⁴ with recommendations to include promotion of employment, and combining the Community of Practice Employment Committee with the DDS employment steering committee to promote greater consumer and family participating in employment steering committee activities. A recent technology grant

⁶³ http://www.ct.gov/dds/lib/dds/report/5yrplan/dds_5_year_plan_update_7_2014.pdf

⁶⁴ The SELN is a membership-based network of state developmental disability agencies that is committed to making employment changes in their service systems.

award was expected to help improve employment outcomes through promotion of the use of iPads.

Goal 2: Decrease the number of individuals in sheltered workshops and non-work day habilitation programs that are typically called day support options (DSO). As of October 1, 2012, admission to sheltered workshops was closed. Included in the status update on this goal is the establishment of a committee of current sheltered workshop providers and other stakeholders to develop a process to reduce the number of persons in sheltered workshops. New definitions of prevocational services supports taking place in small business enterprises and prevocational enclaves were also drafted.

Recommendations by the Supported Employment Leadership Network. Results of the comprehensive assessment of DDS by the national Supported Employment Leadership Network (SELN) included the following potential focal areas in the draft/preliminary report referenced under Goal 1:

- CT DDS should consider moving forward to create a full time position at the central office level that is focused on employment;
- CT DDS should consider setting a goal that focuses, not specifically on decreasing group employment, but on increasing individual employment; and
- clarify the definitions of employment used by CT DDS and stakeholders so that the goal is clear, and that CT DDS and stakeholders have a clear understanding of outcomes and system performance.

Employment definitions used by CT DDS. CT DDS defines *competitive employment* as the individual being employed and supervised directly by the employer, and paid prevailing wages. The individual may require no or minimal ongoing employment support, and if needed, the support is provided through DDS. The department has not adopted a competitive employment definition that requires a minimum number of hours be worked.

Employment First initiative. Nearly every state has an Employment First initiative. Employment First is a philosophy that all individuals can and should work. It reminds clients that work is an expectation rather than an option. Connecticut DDS began its Employment First initiative in June 2008, and adopted an Employment First Policy stating that employment opportunities in fully integrated work settings are the first priority for individuals with intellectual disabilities (I.C.5.PO.001). While Employment First applies to all clients, it is currently being implemented by having case managers develop individual plans for consumers who are 18-21 years of age with a level of need of 1-3. The plans include an employment outcome that references minimum or competitive wages.

The key features of Employment First in Connecticut are:

- Real work: work performed in a competitive and integrated setting that is both needed and valued;

- Real wages: wages are paid by the employer and are similar to what someone without a disability is being paid;
- Integrated work environments: the work setting includes many co-workers who do not have disabilities and who come into regular contact with the employees who do have disabilities; and
- On-going support: supports are tailored to the needs of the individual and vary widely by type and frequency. It is assumed that these individuals will require long-term support either through the employer, co-workers or adult service agency such as DDS.

As part of the Employment First initiative, the commissioner of DDS sent a memo on October 12, 2011 alerting Regional Planning and Resource Allocation Teams that they have the authority to sign off and commit to appropriate requests for long-term DDS support for individuals applying for BRS vocational rehabilitation services that require supported employment after the initial short-term support is provided. If no long-term support is needed, then the person can just work with DORS/BRS. Recent changes in Medicaid allow job coach services to be considered an impairment related expense. With this change, a client can use his/her own money (e.g., from SSI) to pay for a job coach.

Services Offered by Department of Mental Health and Addiction Services

The Department of Mental Health and Addiction Services (DMHAS) serves some individuals with ASD who are aged 18-25 and have a co-occurring mental or behavioral health disability. According to their website,⁶⁵ through their DMHAS Special Education Services, eligible inpatient youth who are transitioning to adulthood are encouraged to take an active role in their education. The website notes youth are invited to attend their educational planning meetings, where future goals are explored and established. Two of the future goals mentioned for DMHAS inpatient youth transitioning to adulthood include attending a two- or four-year college, and an employment goal requiring vocational training.

The DMHAS Young Adult Services (YAS) program also provides some assistance pertaining to employment. For example, DMHAS subcontracts with various providers to assist youth and young adults with pre-employment and soft skills. DMHAS looks for individuals to become employed in an inclusive, integrated setting at a pay of at least minimum wage.

Employment and education are a focus of the YAS program. The YAS program has 16 employment specialists to help young adults identify interests, strengths, and career/vocational needs. The employment specialists may also assist with job searches and job development, including encouraging employers to hire clients.

DMHAS Employment Services. DMHAS has an Employment Services department or division. As noted on their website, meaningful employment has been found to promote recovery from mental/behavioral health-related disorders. The Department contracts with more than 30

⁶⁵ <http://www.ct.gov/dmhas/cwp/view.asp?a=2902&q=335288>

agencies to provide services such as: career planning, job search assistance, and on- and off-the-job coaching.

Activities listed under DMHAS Employment Services are:

- **Mental Health Supported Employment Services:** DMHAS continues to implement the Evidence-based Supported Employment Practice (EBP) for persons with serious and persistent psychiatric disorders. This includes embedding employment staff in clinical treatment teams to promote integration, where employment becomes “everyone’s business.” Employment staff is also responsible for helping people choose, find and keep “integrated competitive employment,” that is, jobs that are open for all to apply and pay competitive wages.
- **Peer Employment Services:** Peer staff can assist individuals and treatment teams with employment planning and supports while serving as role models for recovery.
- **Bureau of Rehabilitation Services (BRS):** DMHAS employment providers have teamed with their local BRS offices to develop a blended continuum of employment services and leverage the resources of both systems.
- **Family Advocacy for Employment:** DMHAS is committed to increasing the active involvement of family members, significant others and family advocacy groups in employment planning.
- **Recovery Oriented Employment Services:** Currently addiction employment services are available in three of the DMHAS five regions to assist individuals reenter the workforce through such efforts as vocational assessment and evaluation; vocational counseling; and support groups.

Challenges and Barriers

There are several challenges and barriers for individuals with ASD seeking post-high school employment or vocational services.

- **Need for greater accessibility/availability of vocational programs for individuals with ASD.**
 - In both the PRI Transition Coordinator Survey and the PRI Survey of Parents of Children with ASD Aged 15-25, respondents reported challenges in accessing vocational programs.
 - Based on responses on the PRI Transition Coordinator Survey, for example, 38 percent strongly agreed, and 22 percent agreed with the statement: “Vocational programs are difficult to get into.” The parents responding to the PRI Survey of Parents of Children with ASD Aged 15-25 even more often strongly

agreed (52 percent) or agreed (28 percent) with the same statement.

- **Need to clarify eligibility for BRS services.**
 - During PRI staff interviews, a number of people expressed confusion about who was eligible for BRS services. PRI staff also had multiple exchanges with DORS/BRS personnel to better understand who may access their services.
 - Points of confusion/inconsistent messages from BRS include:
 - A community provider was told by BRS that they cannot serve clients until they are higher on the DDS ASD waiver list.
 - Before you can apply to BRS, you must first apply to the DDS autism waiver program.
 - If a client is on an agency waiting list such as the DDS Autism waiver list, then they are ineligible to apply for short-term BRS vocational rehabilitation services.
 - There are different expectations by agencies (e.g., DDS, DMHAS) on what the person is capable of, and schools and agencies may incorrectly anticipate denial of BRS services for student and clients, preventing them from receiving short-term vocational rehabilitation services.
 - One experienced transition coordinator said that BRS and DDS Division of Autism Spectrum Services have a disconnect, providing inconsistent and conflicting information.
 - Inconsistency of information/message from DORS/BRS was seen by some respondents to the PRI Transition Coordinator Survey, as a barrier to better serving students with ASD to prepare for adult life after high school.
- **Need to provide transitional services for students interested in vocational training and competitive employment.**
 - Over half of parents who responded to the PRI Survey of Parents of Children with ASD Aged 15-25 said their children who had graduated high school were doing fairly poorly to very poorly in the areas of employment and vocational training.

- Based on the responses to the PRI Survey of Parents of Children with ASD Aged 15-25, there was a greater likelihood for former students who had received transitional services-only to do somewhat better in this area.
- Based on responses on the CSDE Post-School Outcomes Survey related to employment:
 - self-advocacy skills were inconsistently taught, but were most often taught to students who went on to higher education or some other employment;
 - independent living skills were not often taught, although nearly half who went into some other employment received training in this skill; and
 - work experience in high school most likely occurred for students who went on to some other employment post-high school (56 percent)
 - Less than half who went on to competitive employment post-high school reported receiving work experience during high school (46 percent).
- **Need to promote advantages of working part-time vs. not at all.**
 - In the CSDE Post-School Outcomes Survey, there was a trend for respondents with ASD who were competitively employed to be working part-time (71 percent) compared with the overall figure (48 percent) for all survey respondents.
 - In the national longitudinal study described earlier, young adults with autism averaged the lowest number of hours worked per week (24 hours per week) compared with young adults with many other types of disabilities.
 - Evidence that individuals with ASD are more likely to be employed part time rather than full-time was shown in the BRS Case Closure Data. While nearly half of all employed BRS exiters worked full time (at least 35 hours per week), just one-quarter of employed exiters with ASD worked full time.

- **Need to understand impact of employment on benefits.**
 - One deterrent to employment is the confusion regarding how employment would impact federal and state benefits.
 - Many parents are concerned that encouraging their children to work and earn an income will affect their child’s eligibility for needed public benefits, such as Social Security and Medicaid.
 - As noted by the DDS commissioner at the September 24, 2014 PRI public hearing, there is a need for ongoing training on employment and benefits, especially during any period of transition.
 - When someone receives cash or other benefits from the government, there are various work rules, sometimes called “work incentives” that allow them to keep some or all of their benefits as they transition to work. In most situations, people can start to work, see how things go, and still have their benefits to fall back on.

- **Need for parents/families to play a role in (parent buy-in) supporting students in their job/employment efforts.**
 - One of the findings from a multi-agency pilot project conducted to promote increased employment for graduating students with disabilities, was that families were not prepared for their child’s employment schedule (often nights or for only a few hours each day).
 - In another pilot done a few years ago in one of the BRS regions with local school districts, it was found that there was a disconnect between what parents thought would happen at age 21 and what actually happened. The two main barriers to transitioning to employment were that families were unprepared to support students in their jobs, especially transportation to and from work.

- **Need to encourage summer employment while in high school.**
 - One of the best predictors of future employment is having a job during high school/summer job.
 - The National Collaborative on Workforce and Disability for Youth recommends summer jobs as a great way for youth to

gain valuable work experience and prepare for work when they are older.

- **Despite increasing emphasis on employment for DDS clients, there is currently no position dedicated to the promotion of employment.**
 - Although CT DDS is placing increasing emphasis on employment for its clients, there is no one person or department dedicated to promoting this effort.
 - In an evaluation of CT DDS by a national employment network, it was recommended that CT DDS consider moving forward to create a full time position at the central office level that is focused on employment.
- **Need to understand what is meant by competitive employment**
 - Different state agencies define “competitive employment” in different ways.
 - Depending on the definition of competitive employment, the number of employed individuals can vary significantly.
 - As a state, there needs to be a shared definition if progress on increasing competitive employment is to be assessed for individuals with ASD and other disabilities.

Model Initiative: Walgreens Distribution Center. The Walgreens Distribution Center, located in Windsor, Connecticut, opened approximately six years ago. The Center was modeled after a highly successful Walgreens distribution center in South Carolina, which had decided about 10 years ago to have employees with disabilities make up one-third of the distribution center’s workforce. The Windsor distribution center currently has 48 percent of its 680 member workforce made up of individuals with disabilities.

A total of 11 percent of Walgreens Distribution Center employees in Windsor have ASD. Other employees have disabilities ranging from bipolar disorders to learning disabilities. According to the Center’s outreach coordinator, all employees work full-time, at least 40 hours per week, and are held to the same standards, receiving equal pay for equal benefits, regardless of presence or absence of disability. While all employees must be able to lift 35-50 pound boxes, accommodations were made in workplace design such as the use of touchscreens and pictures in addition to numbers to identify work stations.

Some potential employee referrals are received from the BRS, DDS and BESB transition programs. The Center partnered with Community Enterprises⁶⁶ to provide an onsite training program. Training occurs on machines and in a setting that is the same as, or very close to, what the individuals would actually face if they became employed at the distribution center. The onsite training is unpaid and lasts for nine weeks. The training also includes job and social skills, safety, and company culture including core values, work ethic and appropriate behavior.

At the end of the nine weeks of training, the majority (e.g., 10 of 12 trainees) are offered spots at the next level, called the transitional work group. At this level, the individuals are paid as temps, going through the temporary employment agency operated by Community Enterprises (CE). CE supports the individuals on the floor, for example, acting as job coaches. Upon successful completion of this nine week phase, individuals are officially hired by Walgreens, and job coaching and other supports provided by CE are eliminated for almost all individuals. The distribution center's outreach coordinator estimates almost every completer is offered a job (98 percent success rate).

While the supports provided by CE are no longer available to employees, function/department managers are trained to interact with disabled employees. Also, all employees at the distribution center go through internal training called "Inclusion University." During this disability training, employees learn how to create job aids and other strategies.

According to the Walgreen Distribution Center outreach coordinator, the Windsor center is now considered the most successful Walgreens distribution center, assessed in terms of accuracy, employee turnover, safety, and productivity or number of boxes shipped.

PRI Committee Staff Recommendations Related to Post-High School Employment/Vocational Services

Based on the discussion of the challenges and barriers, **the PRI committee staff makes the following recommendations:**

- **The Autism Spectrum Disorder Advisory Council (ASDAC) should explore ways to increase accessibility/availability of vocational programs for individuals with ASD.** A key to employment for some individuals with ASD is gaining access to vocational programs. The ASDAC could assess current barriers to this service, capacity of existing programs, and possible ways to increase their accessibility/availability for individuals with ASD.
- **DORS should develop an information campaign clarifying who may be eligible for BRS services.** This campaign would provide written information that clearly and succinctly outlines who may apply for services. The campaign will explain the differences between short-term vocational rehabilitation, supported employment, and the Employment Opportunities Program (EOP). The campaign will also encourage schools and agencies to leave the determination of eligibility for these services to BRS.

⁶⁶ Community Enterprises of Northampton, Massachusetts, works with corporations to develop customized classroom curriculum, simulated work room training and transitional work group practices and standards.

- **Local school districts should provide transitional services for students interested in vocational training and competitive employment.** Secondary transition coordinators can assist in the identification of vocational opportunities. Students may especially benefit from transitional services-only to advance these vocational opportunities as the next step post-high school, and should include assistance in self advocacy, independent living, and expanded use of work experience in high school.
- **DORS should promote the advantages of at least part-time employment.** Because it can be anticipated that a substantial proportion of individuals with ASD will require part-time rather than full-time employment, part-time employment should be promoted in transitional and post-high school plans as a preferable alternative to no employment.
- **In collaboration with other state agencies, DORS should take the lead on developing an informational campaign regarding the impact of employment on benefits.** Areas to be covered include social security work incentives, and programs that allow beneficiaries to retain certain benefits (referred to as the Section 301 provision) while employed.
- **CSDE should work with transition coordinators on the need to address advantages and logistics of youth employment with parents/caregivers.** Transition coordinators need to understand the importance of partnering with and preparing families to take on the responsibilities and added burdens created by their son/daughter's employment schedule and related transportation needs. Parents and caregivers need to understand the importance of this step in the transition to adulthood for their children.
- **CSDE and BRS should encourage families and students with ASD to experience summer employment while in high school.** Transition coordinators can work to identify and publicize summer employment opportunities to schools and families. BRS can consider increasing the number of students participating in its summer youth employment program, pending satisfactory outcome data.
- **DDS should consider establishing a full-time position dedicated to the promotion of employment.** The position would serve as a centralized point-person for all employment efforts, as a dedicated resource to improving the number of DDS clients (with and without ASD) who are employed.
- **Develop a shared definition of "competitive employment" across state agencies.** A shared definition by CSDE, BRS, DDS, and DMHAS would allow statewide monitoring of progress in this area for employment of individuals with ASD and other disabilities.

Chapter VIII: Post-High School Independent Living

Post-High School Independent Living

Living independently is a goal of young adults generally and is one of the optional goals under the federal laws for transition planning. Housing is a significant concern for many families of individuals with special needs as they transition into adulthood. They share many of the same concerns of anyone seeking housing – affordability, proximity to work and family/support system, and/or accessibility of transportation. Of particular concern for some is what will happen when the primary caregiver can no longer provide care necessitating another living arrangement. This may include an aging caregiver or an inability to handle increasingly challenging behaviors at home.

This chapter provides a discussion of the residential needs for young people with ASD as they transition out of high school; a description of the current residential models; and some of the existing challenges and barriers.

Residential Needs for Individuals with ASD

The basic housing needs of individuals with ASD transitioning from secondary school are the same as for any young adult. However, some people with ASD are able to live relatively independent lives while others may have more severe challenges and need a lifetime of support. This is partly due to deficits in executive functioning which include skills such as organizing, planning, sustaining attention, and inhibiting inappropriate responses. The broad range of the ASD spectrum necessitates a variety of considerations for residential options including:

- Supports and services needed – the person’s level of independent functioning for activities of daily living (personal care, grooming), money management (budgeting and paying bills), general life skills (cooking, cleaning, ability to handle emergencies). Problems with executive functioning may impact these necessary skills.
- Location – the need for public transportation, access to community activities (shops, leisure or recreation areas), proximity to job, family and natural support system. Travel training is a critical component for independent living that is sometimes lacking for individuals with ASD.
- Interests and preferences – requires separate bedroom/bathroom, prefers to live alone, environmental adjustments for sensitivity lighting and noise; has pets; accommodations for particular hobbies/interests. Allowances may be necessary for certain ASD characteristics such as resistance to changes in routine or environment, sensitivity to sensory stimulation, and intense and focused interests.

- Financial considerations - steady source of income, good credit history, monthly ongoing expenditures. As noted earlier, employment is often difficult to find and retain for young adults with ASD, and those who are employed are often paid minimum wages.

Residential Models

According to research literature, young adults with ASD are more likely to remain at home with parents or a caregiver, and are less likely to have lived independently after finishing high school than people with other disabilities.⁶⁷ Some families opt for self-funded housing where the residence is purchased by the family and/or individual using their private money. Another option is to reside in a dwelling owned by a private provider who is either paid by a government entity or by the individual who self-pay. Some provider agencies may package residential and day services together or separately. There are also a select number of residential services offered and delivered by state agencies for specific populations.

Generally speaking, a range of residential models exists from full independent living to 24-hour supervision and care in a restricted setting. Among the variations in models is the level of supervision required, whether the housing and support services are provided together or separately, and who pays for the service. The following descriptions are generalizations of residential models; many permutations exist as well as terminology among different agencies or providers for similar concepts.

Supported living. Supported living programs allow individuals who are able to live independently either on their own or in a family home in the community. Under this model, the individuals may receive in-home supports. This may be minimal assistance that allows the individual to remain in a private residence and be integrated into the community. Typically, the individual directs the specific supports and instruction they need.

Supervised living. Supervised living offers more oversight and guidance to individuals than in supported housing. Settings could be a private residence or a set of apartments in building or complex. Individuals may live alone or with others, with more structured services provided by staff. Although there is greater staff accessibility, this is still a less restrictive environment than a group home. In supervised living, individuals may live in the community usually with a small number of individuals. Staff may provide some functional life skills such as budgeting, shopping, cooking, and going to doctor appointments.

Group homes. These are usually homes located in the community designed to serve individuals with higher needs requiring more continuous supervision. Group homes are typically licensed by the state, must adhere to various regulations, have available trained on-site staff round-the clock and serve a larger number of individuals (generally up to six). The group homes may be owned by a private provider or the state that set guidelines and rules for residents.

⁶⁷ Anderson, K., Shattuck, P., et al., 'Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder', *Autism* (2013)

Congregate/Institutional settings. These are facility-based settings that provide the most intensive care and support. Programs may be large congregate settings or community-based group homes. This model usually serves individuals with complex needs and who are medically fragile and/or multi-challenged.

State Agency Options

While there are certain state and federal housing agencies (discussed below) that provide assistance to people with low incomes, there is no state agency at this time that provides residential services for persons with ‘ASD only.’ DDS and DMHAS offer residential services for the population with ASD when it co-occurs with an intellectual disability or mental/behavioral health condition. Each agency funds a continuum of residential options designed to provide a different level of support for the individuals from in-home supports to congregate settings. As noted earlier, several options seem similar and are labeled slightly differently in the agencies.

DDS Residential Services

DDS provides several residential services for individuals with intellectual disabilities, some who may also have ASD. Currently, the department does not offer any residential placements for individuals with ‘ASD only’ - without intellectual disabilities - served by the department’s autism division. (This is discussed later in this chapter.) The following residential service options are available for the dually-diagnosed (ID/ASD).

Individualized Home Supports (IHS). These support services are provided by an agency or private person hired by the individual allowing them to remain in their own or family’s home in the community. Some of the IHS services may include assistance with basic skills, money management, and shopping. IHS is an intermittent support that is less than 24-hour a day support. The individual’s level of need (LON) and individual plan dictates the number of service hours received.⁶⁸

All providers or persons hired must receive training in DDS policies and procedures including; abuse/neglect, incident reporting, individual rights and confidentiality and the prevention of sexual abuse. They must also have specific training to address behavior, medical or other identified needs.

Community Living Arrangements (CLAs). CLAs are a type of community group home operated by either DDS or private agencies usually serving six or fewer individuals. Medicaid reimbursement is available for CLAs. The homes must be licensed by DDS and certified by the Department of Public Health (DPH) under federal standards. A few of the privately operated CLA are ICF/MR certified. DDS reports 873 CLAs with a licensed capacity of 3,928.

Continuous Residential Supports (CRS). Individuals and/or families may combine their resources to establish a shared living arrangement for three or fewer DDS individuals. Unlike CLAs, CRS is not licensed but must be reviewed by DDS prior to occupancy. The

⁶⁸ A description of the DDS Level of Need (LON) is provided in Appendix C.

individuals may pool their funding to hire sufficient ongoing support staff and clinical supports. Currently, there are 414 CRS locations with 687 active slots.

Community Companion Home (CCH). This residential model serves three or less individuals in a private family home licensed by DDS. Residents of a CCH share responsibilities and receive the necessary daily living skills to be as independent as possible. Similar to CLAs, CCHs must adhere to range of regulatory and training requirements. There are 292 licensees with 493 beds (3 are pending).

Regional centers. DDS operates five regional centers with 186 beds located throughout the state that provide congregate care. These centers are certified by DPH as intermediate care facilities for the mentally retarded (ICF/MR) and are eligible for Medicaid reimbursement. Some of the centers also provide respite services upon availability.

Training school. In the past, this approach provided residential facilities on a campus-like setting to serve individuals with significant developmental disabilities. Since deinstitutionalization, this approach has been slowly phased out in favor of more community-based setting. DDS has one training school in Southbury which is no longer taking clients.

Out-of-state placements. There are a number of clinically complex cases exhibiting intense behavior challenges that require hospitalization. In some instances, the individuals require highly specialized hospitalization available only out-of-state. Connecticut has few in-state psychiatric hospital beds with specialized care for individuals with ASD. Currently, there are 58 DDS clients with intellectual disabilities and a co-occurring ASD in nine other states; of these 19 are 18-21 years old.

Utilization of DDS Residence Types

Using a DDS dataset, PRI committee staff examined the residential locations of DDS clients with a co-occurring diagnosis of ASD (ID/ASD). Table VIII-1 summarizes the residential placement of the ID/ASD population. (Appendix C contains a full data summary.)

Residence Type	Under 15	15-25	Over 25	Total
Family Home	241	843	451	1,535
Community Living Arrangement (CLA) Group Home	4	135	677	816
Continuous Residential Supports (CRS)	4	76	79	159
Independent Living/Own Home	0	23	103	126
Training School	0	0	76	76
Residential School (SCR)	8	44	11	63
Community Training Home (CTH)	1	6	43	50
Regional Center	0	1	34	35
Skilled Nursing Facility	0	0	9	9
Other (Hospital, MH facility)	1	1	5	4
TOTAL	259	1,129	1,488	2,876
Source: PRI staff analysis				

As the table demonstrates, the vast majority of DDS clients of all ages with intellectual disabilities and a diagnosis of ASD reside in the family home. This is followed by residence in Community Living Arrangements, and continuous residential supports. The results are the same for transition-aged individuals (15 to 25).

DDS wait list for residential services. The demand for DDS residential services has existed for several years resulting in a significant wait list. The wait list includes individuals who receive no residential supports and require supports either in their own home, with their family, with a host family or in a residential setting. DDS uses certain criteria to categorize the wait list into individuals who need immediate residential placements (Emergency) and individuals who need placement within one year (Priority One).

The emergency list consists of individuals who have no home, who have an elderly caregiver that is ill, or who have behaviors that cannot be managed in their own homes. The Priority One list includes individuals who have a pressing need for services.

Based on the DDS database (Table VIII-2), the DDS wait list of 669 individuals seeking residential services contains 124 DDS clients with intellectual disabilities and an ASD diagnosis, approximately 19 percent of the whole wait list population. Most are found in the Priority 1 category (117) and more than half of those are over the age of 25.

Status	Clients with ID Only – No ASD	Clients with ID and ASD			
	Total	Under 15	15-25	Over 25	Total
Emergency	23	0	3	4	7
Priority 1	522	3	47	67	117
Total	545	3	50	71	124
Grand Total	669 (as of October 2014)				

Source: PRI staff analysis

Aged caregiver. As mentioned above, having an aged caregiver is one of the factors that may place a DDS client on the emergency list. Table VIII-3 shows the number of DDS clients who currently have an elderly caregiver over 70. Of the 4,950 DSS clients with an aged caregiver, 13 percent have both an intellectual disability and a co-occurring ASD diagnosis.

Diagnosis	Under 15	15-25	Over 25	TOTAL
ID only – No ASD	2	81	4,215	4,298
ID/ASD	0	29	623	652
Total	2	110	4,838	4,950

Source: PRI staff analysis

Autism Spectrum Waiver services. As explained earlier, DDS does not offer residential placement for individuals with ‘ASD only’ who are served by department’s autism division. According to division staff, the 95 individuals receiving Autism Spectrum Waiver services either live with their families or are relatively independent. The waiver was developed with an annual cap of \$60,000 per person. Any residential services sought must be ones that could be reasonably provided within the cap. Given the limited cap, it does not allow for much residential support as well as other support needs. (The Autism Spectrum Waiver is described in more detail in the next chapter.)

DMHAS Residential Options

DMHAS’ primary focus is on individuals with mental health and substance abuse issues aged 18 and over. The department only serves individuals with ASD if they also have a co-occurring mental or behavioral health need (MH/ASD). DMHAS funds several programs and services to support the various living arrangement needs of its clients.

Supported and supervised housing. DMHAS provides specialized case management in supported housing. These individuals are usually in their own residence but without support may be at risk of losing their housing. The department also has contracted for supervised housing which provides more extensive staff access usually 24-hour either in the same building or in a nearby location. There are approximately 400 beds for this category which is the most common type of DMHAS residential model. This model is generally used for individuals recently released from the hospital, who are in need of supports, and are looking to re-enter the community.

Congregate settings. DMHAS also offers a mix of more congregate settings (e.g., group homes, 24-hour supervision). Group homes are typically used as a step-down from psychiatric care for individuals with severe mental illness coming out of a hospital setting. There are about 200 beds that are managed by the LMHAS. The group homes are licensed by DPH, not by DMHAS. Most group homes are viewed as transitional housing with an expectation that the individual will be able to move to more independence in supervised or supported housing within one or two years. This is a policy change from years past when many individuals placed in group homes remained indefinitely. Now, there are only a few individuals who use group homes as a permanent living situation.

YAS residential options. YAS offers comprehensive mental health and substance abuse treatment and support for clients who need a high level of care. Many of the YAS participants have no family support and rely on the state as their sole support. Many are identified and referred by DCF or have DCF involvement.

For the YAS participants, DMHAS has supervised apartments in 33 sites with a 71 bed capacity. There are eight group homes with total of 41 beds. The program also uses scattered site apartments in two sites that accommodate 19 beds.

Living Arrangements for DMHAS Clients with ASD

DMHAS provided PRI committee staff with a database of clients with a co-occurring ASD diagnosis. (A summary of the PRI staff analysis of this database is found in Appendix D.) As Table VIII-4 shows, the largest number of DMHAS clients with a co-occurring diagnosis of ASD lives in a private residence owned or leased by a relative or friend. The second largest group lives independently where they own or hold the lease on the residence. Congregate setting (e.g., group homes) is the third most common living arrangement where 70 individuals reside. The ranking is similar for the transition-aged group (18 to 25). Both age groups also have a sizable number in supported or supervised housing.

Residence Type	AGE		TOTAL
	18-25	Over 25	
Private residence (friend or relative owns the residence or lease)	101	73	174
Independent Living (Private residence client owns/holds lease)	35	95	130
Congregate (group setting, 24-hour supervision)	42	28	70
Supported/Supervised Housing (Private residence community provider owns or holds lease)	20	22	42
Private residence unspecified	3	21	24
Residential Care Home/Board and Care	12	9	21
Homeless (shelter)	9	4	13
Inpatient (Psychiatric/Substance Abuse/Medical)	2	8	10
Skilled Nursing/ICF/Nursing home	0	2	2
Other (correctional, respite)	9	8	17
Unknown or Missing Info	82	127	209
Total	315	397	712
Source: PRI staff analysis			

Out-of-state placements. DMHAS currently has approximately 42 individuals who are placed in eight out-of-state facilities because they require specialized therapies or approach not available in Connecticut. Of these, sixteen have a co-occurring diagnosis of ASD. However, none of the placements are due to the ASD condition but rather mental and behavioral health issues.

Living arrangement at DMHAS discharge. DMHAS was also able to provide some discharge information for its clients with a co-occurring ASD diagnosis. A review of the data shows the same distribution and ranking for living arrangements. For the 259 individuals discharged who had a co-occurring ASD, the top three living arrangements remain the same: private residence of a family or friend, independent living, or in congregate setting such as a group home.

Table D-8. Living Arrangement of DMHAS Clients with ASD Upon Discharge			
Residence Type	18-25	Over 25	Total
Independent Living (Private residence client owns/holds lease)	20	18	38 (15%)
Private residence, friend/relative owns the residence or lease	33	27	60(23%)
Congregate (group setting, 24 hour supervision)	17	5	22 (8%)
Supported/Supervised Housing (Private residence community provider owns or holds lease)	7	2	9 (3%)
Inpatient (Psychiatric/Substance Abuse/Medical)	1	4	5 (2%)
Homeless (shelter)	3	3	6 (2%)
Residential Care Home/Board and Care	1	4	5(2%)
Other (correctional, SRO, ICF, unspecified private residence)	8	7	15 (5%)
Unknown or Missing Info	55	44	99 (38%)
Total	145	114	259
Source: PRI staff analysis			

DMHAS wait list. According to DMHAS, all residential options have a wait list of approximately three to six months. Unlike DDS, there is no universal assessment tool providing a composite score used to inform the type of residential placement.⁶⁹ Decisions regarding housing re-locations are determined by a committee of various professionals, community providers, and DMHAS staff at weekly meetings. The committee looks at factors including client preference, risk of homelessness, and availability.

According to DMHAS, exceptions may be made when a critical incident/event occurs. This may include engaging in behavior that is injurious to self or others.

Department of Public Health (DPH)

Connecticut Medical Home Initiatives. Medical homes are available to children and youth under age 22, regardless of income, who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. This initiative is administered through the Department of Public Health in five regions. DPH reports 1,200 of the 8,000 youth served through medical homes have ASD. Of these, 136 are aged 15 or older.

Department of Housing (DOH)

Low-income housing programs. Federal and state funds are available for eligible low-income individuals through programs of the state Department of Social Services (DSS) or the federal Department of Housing and Urban Development (HUD). Among these programs are rental vouchers and subsidies such as Section 8 or Rental Assistance Programs as well as funding and grants through Community Development Block Grants to build and support affordable housing. Rental vouchers and subsidies are limited and often subject to wait lists or are sometimes closed for long periods of time. None of these agencies track or monitor housing services provide to individuals with ASD.

Community and/or Private Provider Options

There are also additional residential approaches available to the population with ASD that are privately operated and primarily accessible to those can afford to self-pay.

Cooperative living/Ownership. Similar to the group home model except that the home is owned by a group of families or individuals who have formed a cooperative agreement. Staff support is hired by the owners either with their own funds or with individual budget from waiver funds. Under this model, families can pull together and leverage private and public resources. PRI committee staff could not ascertain an exact number for this type of living arrangement. However, different state agencies and advocacy groups were aware of families looking to pursue this model.

⁶⁹ In the past year, a new initiative known as “VI-SPDAT” or Vulnerability Index was established and used to prioritize those homeless people who are at greatest risk and need of housing.

Transitional residential models. Transitional residential programs provide a residential experience for a relatively short period of time (e.g., few months to two years) with the objective of transitioning the individual to either a new residence or previous residence after completing the program. Typically, these programs may offer one or more of the following: intensive evaluation and intervention focusing on behavior disorders; intensive life skills instruction preparing the individual for independent living; and college support services. These programs also often offer separate supported housing in their community after the individual graduates from the transitional program. Examples of this model would be residential school programs such as Vista in Westbrook or Chapel Haven in New Haven. These programs are discussed in more detail further below.

Agricultural autism community. Also known as farmstead communities, this model incorporates an agricultural employment component with a residential living arrangement. It may include one home or individual apartments located either on-site or in a nearby location. This model has been established in England and few cities in the U.S. One Connecticut ASD advocacy group, Friends of Autism, is currently working on creating a Farm Academy in southwestern part of the state.

Examples of Transitional Residential Models

PRI committee staff toured and visited two transitional residential models in Connecticut. Below are descriptions of the programs and outcome data requested by the PRI committee staff.

VISTA ENTRANCE PROGRAM IN WESTBROOK, CT

Population served. The Vista Entrance transition program can serve up to 38 clients. Students are usually 18-21 years old and typically have learning disabilities, neurological impairments, such as seizures, traumatic brain injury, or ASD. Many Vista clients with ASD also have co-occurring diagnoses such as anxiety disorder, depression, and intellectual disability. Some have moderate, but not significant, behavior disorders.

Half of the Entrance students are from Connecticut. Vista works with approximately 20 school systems from across the state as well as several out-of-state school systems in New York and New Jersey. In FY 15, the Vista transition program cost \$70,620 per year.

Program/Service Description. The Entrance program lasts approximately two to three years. As a tuition-based residential program, students may reside in the two-year dormitory (26 students) in Westbrook or in the one-year transition apartments in Guilford (12 students). Participants usually start out living in a dormitory with 24-hour support. The program uses an individualized approach to work on four areas:

- work/vocational skills (e.g., internships, community-based supported employment, classes, and job shadowing);
- cognitive/social development (e.g., counseling with a teaching, modeling, and supporting focus, decision-making, problem-solving, self-advocacy, and relationship building);

- community involvement (e.g., clubs, diversity awareness, and comprehensive dormitory experience); and
- life skills (e.g., money management, travel, time management, medication and food management).

Each student is partnered with a program counselor. Some take college courses at Gateway Community College or Middlesex Community College. Vista works with over 120 employers, generally small businesses. There are also in-house businesses, referred to as Vista Ventures, such as commercial cleaning or landscaping, and contracts for competitive employment doing assembly work for an institution of higher education.

Outcome data. Upon completion of the Entrance program, most students continue into the Vista Outreach program that offers fee-for-service menu of selective supports for individuals living independently. Graduates who continue on in Vista’s Outreach program are often employed. (Currently, 99 out of 152 are employed (65%); 31 employed by Vista Ventures, and 68 by community employers).

Outcomes for Vista Students		
Outcome	FY 13-14	FY 09-13
Number of students enrolled in the Vista Entrance Program	31	75
Number of students graduated from the Vista Entrance Program	8	56
Number who graduated with a college degree	0	0
Number graduates who enrolled in post-secondary education	0	3
Number of program graduates transitioning into the Vista Outreach Program	7 (88% of 8)	46 (82% of 56)
Number of Outreach Program participants competitively employed	1 (14%)	16 (35%)
Number of Outreach Program participants in paid supported employment	0	11 (24%)
Number of Outreach Program participants non-paid vocational activities (e.g., volunteering, internships, day program)	6 (86%)	19 (42%)
Source of Data: Vista		

CHAPEL HAVEN IN NEW HAVEN, CT

Population Served. Chapel Haven serves individuals with ASD aged 18-21 in two residential programs: Asperger Syndrome Adult Transition (ASAT) program; and the Residential Education at Chapel Haven (REACH) program. ASAT serves students with an average or higher intellect and with a primary diagnosis of Asperger Syndrome or related social disability. The REACH program serves students with autism and intellectual disabilities (IQs of 60-80). Chapel Haven is not a therapeutic milieu and is not an appropriate fit for individuals with significant co-occurring mental health issues.

Program/Service Description. The ASAT program is a 24-month residential program for individuals at least 18 years old. The program also offers day services and an extensive supported living program for adults with some ability to live independently. Students live in two-three bedroom apartments, with each person having a private bedroom. The annual cost of the ASAT program in 2014-2015 was \$86,400.

ASAT focuses on four areas: social communicative competency; self-determination; independent living; and supports for college/work. Many young adults come to ASAT after having completed some college; others are still in high school and just beginning the college experience. Chapel Haven is within close proximity to Southern Connecticut State University and Gateway Community College, along with a variety of other colleges. ASAT provides college supports such as help with planning, time management and executive functioning to help make the college experience successful.

ASAT students also explore career and employment opportunities through a rotating series of work experiences in the New Haven community. This part of the curriculum helps students understand the routine, responsibility and social implications of employment. Job developers help students to find employment, provide supports directly to students, and explore volunteer opportunities.

The REACH program is for individuals at least 18 years old, and lasts for up to two years. The program has 30 slots and students live in shared apartments with 24-hour staff support available. The annual cost of the REACH program in 2014-2015 was \$65,400.

REACH program has five components: life skills; education; employment; recreation; and social communicative competency. The life skills component is imbedded in the residential setting. Students are taught household maintenance skills (e.g., cooking, cleaning, laundry), mobility, managing finances (e.g., banking and budgeting), self-care (e.g., medication administration, hygiene), and learning how to live with roommates.

The education component of REACH covers subject areas such as: language arts; math and science; social studies; life skills; vocational skills; wellness; personal enrichment; and an array of continuing adult education classes. The employment component offers students progressively more challenging opportunities to work at 30 agencies and companies in the area, in either supported or competitive employment.

Outcome Data. The table below provides information for the most recently completed school year. Almost half the ASAT students participated in internships and volunteer experiences, and nearly one quarter (23 percent) were employed. Almost two-thirds (62 percent) had met their postsecondary education and career goals, and several were enrolled in college.

At least 80 percent of both the ASAT and REACH graduates were able to transition to greater independence in the Chapel Haven Supported Living Community program. In this higher level program, graduates and others who have the skills to live independently with limited professional support (up to eight hours per week) reside within walking distance of the Chapel Haven campus.

Table 1. Outcomes for Chapel Haven Students	
Outcomes for the 15 ASAT Students Served in FY 13-14	
Outcome	FY 13-14
Students with paid employment	23%
Average hours worked per week	4.5 hours
Students with internship/volunteer experience	46%
Average hours interning per week	4 hours
Students enrolled in post-secondary education	15%
Postsecondary education/career goals met	62%
Number of graduates	4
Percent of graduates who transitioned into Chapel Haven Supported Living Community	80%
Outcomes for the 20 REACH Students Served in FY 13-14	
Outcome	
Number of graduates	9
Percent of graduates who transitioned into Chapel Haven Supported Living Community	89%
Source of data: Chapel Haven	

Table 2 provides some information about the individuals in the Chapel Haven community programs during the past two years.

Table 2. Information About Chapel Haven Community Programs		
Chapel Haven Supported Living Program (SLP)	FY 13-14	FY 12-13
Population served: Chapel Haven residential graduates and adults able to live independently with limited supports	110	115
Average hours of weekly support (ranges .5-16 hrs per week)	3.17	3.10
Employment information for Participants in the SLP, SAIL and Bridge Community Programs		
Number Employed	69 (50%)	66 (47%)
Average Hours Worked per Week	9.6 hours	10.35 hours
Total Number of Clients on Crews	68	71
Total Number in Individual Jobs	26	27
Source of data: Chapel Haven		

Other State Models or Approaches

PRI committee staff searched for other state approaches to residential issues for the population with ASD. The results reveal that other states are facing similar housing dilemmas as Connecticut. In some states, the wait lists for developmental disabilities are much larger and offer much less than Connecticut.

With regards to the housing concerns for the ASD population, PRI staff identified only two states that have tackled this problem – Pennsylvania and Massachusetts. Both states have commissioned studies to explore and develop specific strategies for this group.

Pennsylvania. In September 2008, the Department of Public Welfare’s Bureau of Autism Services appointed the Housing Options Committee and charged them with the task of identifying and assessing housing options that will meet the varying needs, preferences and abilities of adults living with ASD at different points in their life cycle.

The committee included representatives from state and county agencies, statewide disability organizations, elected officials, nonprofit housing developers, and individuals with ASD and their family members. The long-term goal was to expand the number of viable housing options and models to maximize the choice and independence. The committee work was facilitated by a consultant and staff from the Bureau of Autism Services.

The final report developed guiding principles; described the characteristics of the target population and their unique housing needs; identified barriers that adults with ASD encounter in accessing housing or creating new housing opportunities; developed criteria for reviewing and selecting housing models for inclusion in the report; and reviewed numerous existing housing models for people with disabilities. The state is still working towards accomplishing the report’s recommendations.

Massachusetts. In its 2014 Autism Omnibus Bill, Massachusetts established a commission on autism to investigate and study the present, and anticipated future, of statewide affordable supportive housing needs for the state’s population of persons with ASD. The commission must develop and conduct a statewide housing survey to determine the current status of affordable supportive housing stock for adults with ASD and make recommendations. Additionally, the commission must use estimates for the prevalence of ASD to project the number of adults with ASD in the coming decades. This information shall be used to recommend an action plan to address the resulting need for affordable supportive housing for those individuals. The report must be completed by June 30, 2015.

Challenges and Barriers

There are several challenges and barriers for individuals with ASD and families seeking housing solutions.

- **Wait lists exist for all residential services offered by state agencies.** The government funded housing options that exist in DDS or DMHAS either have significant wait lists or only become available under immediate crisis situations. Government housing programs for the general low-income population (e.g. housing vouchers) also have large numbers of individuals competing for limited resources. Without a government subsidy, individuals must either remain in their family home undermining independence and self-esteem or self-pay for residential options available through community and/or private providers, sometimes at extremely expensive rates.

- **Limited state residential supports are available for ‘ASD only’ population.** The segment of individuals with an ‘ASD only’ diagnosis has the fewest housing options from state agencies. Existing options offered through state agencies are limited to individuals with intellectual disabilities or mental health who have co-occurring ASD diagnosis. The one government-funded waiver service for ‘ASD only’ has restricted circumstances for residential support that must be paid within a limited cap of \$60,000 and must cover any other number of support services the individual may need.
- **The broad range of ASD spectrum needs may require new and different residential models to be considered.** The huge demand for residential housing and the limited resources designated for particular segments of the population necessitate exploration of alternative housing solutions. The range of residential models and supports necessary for the ASD population will vary as much as the ASD spectrum. The ASD spectrum is so diverse, one size can fit many but not all. Examples of the creative approaches the ASD community is pursuing are cooperatives and agricultural homesteads.
- **Families need information and guidance on traditional and alternative residential options.** Often families are surprised to learn that the eligibility-based adult system involves significant wait lists sometimes up to five or more years, especially if it involves waiver services. Many of the residential models appear similar and can be confusing for individuals without knowledge of how to search for housing resources. In addition, families may be unfamiliar with how to proceed with options though they may have the financial means to do. Families seeking to develop their own housing solutions face many challenges including: how to purchase and structure ownership without jeopardizing any benefits for their child; how to oversee the property management; navigate any licensing or other regulation requirements; how to coordinate or best leverage staff supports and resources.
- **Without options, the demand for residential services will likely reach crisis level.** As the research literature shows and the state agency data indicates, many of individuals with ASD remain at home for a variety of reasons. However, it is a likely expectation that as the prevalence of ASD continues new generations of adults with ASD will emerge and alternatives will be needed for aging primary caregivers or those no longer able to manage challenging behaviors in their home.

New State Initiatives or Recent Developments

Below is a summary of some new state initiatives and recent developments that will have a positive impact on the residential demand for individuals with ASD and their families.

Additional DDS funding. In 2014, Connecticut budgeted \$4 million dollars to provide residential support and services for 100 individuals on the DDS wait list. The funds are designated for Priority One individuals who have a primary caregiver who is at least 70 years old. This only will assist individuals with an intellectual disability and co-occurring ASD diagnosis.

Additional psychiatric beds. Pursuant to an ASDAC subcommittee proposal and a recommendation of the recent children’s behavioral health taskforce report, a budgetary request for proposal (RFP) is being developed for up to three specialized inpatient hospital beds for individuals experiencing the most acute and complex ASD and co-occurring psychiatric disorders.

DMHAS project. DMHAS is currently working together with a community partner, FOCUS, to convert an existing FOCUS operated housing complex that formerly housed three clients with ASD into supervised apartments. The new configuration and modifications will allow for servicing two to three additional individuals with ASD.

Rental vouchers. During the summer of 2014, the state Department of Housing announced that applications for a housing voucher lottery would be available. Five thousand applications will be chosen by lottery for the Section 8 wait list while three thousand will be selected for RAP.

Federal legislation. Currently, federal legislation known as the ABLE Act is being considered that would allow families to take advantage of tax-free savings accounts for ASD expenditures without jeopardizing a child’s benefit. (This is discussed in more detail in Chapter IX.) If enacted, this would allow families to be able to support residential options for individuals using family funds without loss of benefits.

PRI Committee Staff Recommendations Related to Post-High School Independent Living

Based on the discussion of the challenges and barriers, the PRI committee staff makes the following recommendations:

- **DDS should consider establishing a housing coordinator position for the autism division.** Although residential funding is not currently available to the division’s ‘ASD only’ clients, this position would help to identify and plan for ASD residential needs in two different ways. First, the coordinator could, upon request and availability, assist individuals on the wait list locate resources in the community. Secondly, the coordinator would be instrumental in preparing a long-term housing plan for this population (further described below). Specifically, the housing coordinator would collaborate with other state and federal housing authorities such as the federal HUD, state Department of Housing, public housing authorities, rental subsidy programs, and other state agencies such as DMHAS to explore opportunities for partnerships.
- **Within available resources, the housing coordinator should assist the resource specialists working with wait list families to develop an individual housing plan** that help envision where the individual with ASD sees themselves in three to five years as well as in the immediate future. The coordinator should also develop informational sessions on housing plans and options for individuals with ASD and perhaps facilitate potential roommate matching services. Workshops or informational seminars, in collaboration with other entities, could

be conducted for parents seeking to develop their own housing solutions including what is required and the programs and services they may avail themselves of.

- **The autism division should establish a one-stop housing resource for individuals with ASD** as they prepare to move from the family home. This should include a web-based directory of the different types of housing that may be available for individuals with ASD. The division's webpage should link to other Connecticut resources that provide information about housing for people with disabilities. It should provide guidance in navigating through the maze of different housing and funding options. It should also provide information to help people make housing choices to fit their needs and personal goals.
- **The ASDAC council should establish a subcommittee on housing to produce a report on the present and future ASD residential needs, best practice guidelines, and plan of action proposals** similar to studies commissioned by Pennsylvania and Massachusetts. With the assistance of the housing coordinator, the subcommittee should review housing concerns and issues and seek ways to leverage existing agency resources for more supported/supervised housing. The group should examine the array of housing options that work for the full spectrum of individuals with ASD. The housing coordinator should survey the types and extent of the needed supports for individuals on ASD wait list to anticipate service demand. The subcommittee should seek the collaboration of state housing officials, developers, and other housing representatives to explore public/private partnerships to fund assisted living facilities. Among the possible issues to examine is whether: 1) the existing DDS residential models used for the ID population are appropriate for the needs of individuals with 'ASD only'; 2) the existing regulatory structure discourages or restricts development of new models or expansion of existing ones; and 3) more flexibility is possible or needed in waiver programs to facilitate use of options such as transition residential models. The group should also consider the needs for individuals with ASD as they continue to enter old age.

Chapter IX: Supports for Independent Living

Supports for Independent Living

Individuals with disabilities and their families may require various types of assistance in order to accomplish different tasks or meet basic needs. These are usually referred to as supports. Supports may be provided through government-funded agencies, natural supports such as family and friends, or paying out-of-pocket to private providers.

This chapter first identifies and discusses certain support services that are of particular need to the population with ASD. It then describes the use of various government-funded waiver services and state programs to provide support to individuals with ASD and their families. Finally, it summarizes the gaps and barriers found with potential and evolving solutions.

ASD Service Needs and Challenges

Supports can take on a variety of forms and cover a broad range of areas. In addition to therapeutic treatment and interventions, the supports needed by individuals with ASD and their families may include but not be limited to in-home supports, life skills, respite care, social and recreation activities, and transportation. A general description of the each support area and the issues and challenges for individuals with ASD and their families are discussed below.

In-home supports. In-home supports are individualized and help persons with ASD to remain home in the community and avoid out-of-home placement and reduce crisis interventions such as emergency room visits and hospitalization. The advantage to home-based supports is that it allows treatment and assistance to take place onsite in the home so individuals may learn therapeutic techniques in their everyday environment, develop routines, and learn new behaviors.

Life skills. Life skills are instruction in daily living and self-help including meal preparation, laundry, housecleaning, home maintenance, managing finances, hygiene, showering, dressing, and appropriate social interactions. The assessment and development of life skills is critical to foster an individual's level of independent living. The development of these skills is often challenging because caregivers have difficulty relinquishing control, sometimes unconsciously or not, over doing the chores or tasks for the individual. Therefore, the attainment of life skills must be a joint effort between caregivers, individual, and provider.

A number of state agencies and private providers have developed or adopted instruments to assess functioning level and independent living skills. DDS has a formalized assessment tool, known as Level of Need (LON), which measures needed supports and is used by DDS regions for funding and services. DMHAS has recently developed a learning inventory of skills training (LIST) that scores an individual's strengths and weaknesses in a number of domains. Life skill training is offered by several community-based providers. The use of a life skills coach is covered as part of most waiver services.

Respite care. Respite care provides unpaid caregivers temporary relief from the work associated with care giving. Caregiver burnout is high among families with a child/adult with ASD especially as the youth physically grows and the caregiver ages. Families often have a hard time finding respite care away from the dependent child/adult in order to engage in their own social lives, reduce family stress, or simply accomplish chores that cannot be done when the dependent child/adult is present.

Frequently families rely on their own natural support system (e.g., siblings, extended family members, neighbors and friends). Some families benefit from community support networks. For individuals with complex health or behavioral needs, DDS operates Respite Centers providing scheduled 24-hour and overnight respite on weekends and for 8 full weeks throughout the year including full weeks during the summer and some school vacations. Priority is given to families who are not receiving other in-home supports, personal supports or certain other types of services from the department. DMHAS also has contracted approximately 50 beds for respite care. This provides a temporary residential option with staff oversight for people having difficulty with their current living situation. Respite care is also a covered service under most Medicaid waivers, permitting individuals to contract for their own respite arrangements.

Social/Recreation activities. The ASD deficits in communication and social interaction (e.g., difficulty with eye contact, limited emotional and social reciprocity, and an inability to correctly perceive or read faces) often makes social functioning difficult.⁷⁰ As a result, persons with ASD are less likely to socialize with peers or engage in extracurricular activities leading to isolation and loneliness. Therefore, it is important for individuals with ASD to actively participate in community life including social and recreational activities.

While still in school, youth and young adults with ASD have the school environment to develop friends and relationships. However, chances for socialization diminish greatly after graduating or leaving the school setting. A recent ASDAC council subcommittee concluded that there are a limited number of opportunities for social recreation for persons with ASD across the state. The ones that exist are either geographically clustered or not effective in meeting the needs of all individuals with ASD.⁷¹

There are some community providers and advocacy groups that offer socialization and recreation events for individuals with ASD. One proven method of expanding inclusive recreation and socialization opportunities is through peer mentoring. In addition to fostering peer relationships, it also promotes role models in a natural environment. DDS provides funds to several groups such as the Connecticut Family Support Network, Best Buddies, and Special Olympics to help individuals participate in inclusive recreation activities. However, these are usually focused on individuals with intellectual disabilities. Funding for social skills groups specific for individuals with ASD is available under the Autism Spectrum Waiver.

⁷⁰ Nora Friedman, Marji Erikson Warfield and Susan L. Parish. (2013) Transition to adulthood for individuals with autism spectrum disorder: current issues and future perspectives, *Neuropsychiatry*, 3(2), 181-192.

⁷¹ ASD Council Sub-committee Report of the Socialization, Recreation and Respite across the Lifespan Workgroup (2014) p2.

Transportation. Transportation is another critical component of independent living. It is a cross-cutting issue as it impacts choices in housing, employment, access to services, social life, and community interaction. Some options for persons with ASD range from driving a car, relying on family and friends to drive, arranging for ride shares, or taking public transportation. Some of the options, depending on locations, are not always readily available or accessible.

Certain providers and organizations, such as the Kennedy Center, offer travel training to teach individuals with disabilities how to use public transit. Travel training is available to individuals with disabilities and can be part of the transition IEP. Autism Spectrum Waiver services allow for non-medical transportation and specialized driving assessment that provide a pre-driving evaluation to determine if an individual can safely operate a motor vehicle.

State Waiver Services

Waiver services are a Medicaid option available to states to provide Home and Community-Based Services (HCBS) to qualified Medicaid recipients. It is important to note that Medicaid and Medicaid waiver services are different benefits. Waiver services allows for particular types of services that are not funded in regular Medicaid programs. Waiver services are not an entitlement. All waiver programs have limited capacity and limited funding. The availability of waivers depends on state appropriations. There is no guaranteed entry into a waiver, even if someone meets all the eligibility criteria for a particular waiver. Some waiver programs have waiting lists. The provision of any new services would have to be through additional state funding or if individuals exit the waivers no longer needs waiver services through death, institutionalization, or for other reasons.

DDS waivers. DDS currently has five HCBS waivers. The first three are designed for individuals with intellectual disabilities who may or may not have a co-occurring ASD diagnosis:

- *Intellectual Disability Comprehensive Support Waiver (COMP)* – is for services delivered in licensed settings, and it provides employment support, vocational, and in-home support services needed for people who require an intensive level of support to remain in their own home or in their family home.
- *Intellectual Disability Individual and Family Support Waiver (IFS)* – provides in-home, employment, vocational, and family support services for people who live on their own or in their family home who need less extensive supports.
- *Intellectual Disability Employment and Day Supports Waiver (EDS)* - provides day, vocational, and family support services for people who live on their own or in their own home and have a strong natural support system.

There are two relatively new waivers specifically serving children and adults with a diagnosis of ‘ASD only’ without an intellectual disability:

- *Autism Spectrum Waiver* – provides a range of support services (described below) to individuals with ‘ASD only’ aged three and up to live and remain in their community. The waiver is in the second of a five year approval.
- *Early Childhood Autism Waiver* – DDS’ newest waiver provides young children aged three to four who have ASD and significant deficits in adaptive behaviors and severe maladaptive behaviors. Services are focused on improving communication skills, social interaction, and activities of daily living while reducing inappropriate or problematic behaviors. This waiver was approved February 2014 with the goal of filling the gap between Birth-to-Three and Kindergarten programming.

Once approved for waiver services, an individual will receive a budget allocation that includes all the services and supports that best meet the individual’s level of need within the DDS rates and cost standards. Table IX-1 lists and compares the services available under each waiver.

ASD Enrollment in DDS Waivers

Using a DDS dataset (as of October 2014), Table IX-2 breaks down the current enrollment in the various DDS waivers of individuals with an ASD diagnosis by age group. With the exception of the Autism Spectrum Waiver which is for individuals with ‘ASD only’, all persons enrolled in the other DDS waivers also have an intellectual disability.

Table IX-2. Enrollment of the ASD Population in DDS Waivers by Age Group				
DDS Waiver	Under 15	Age 15-25	Over 25	TOTAL
Autism Spectrum Waiver (ASD only)	18	33	44	95
HCBS Comprehensive (COMP)	18	203	798	1,019
Individual and Family Support (IFS)	130	385	359	874
Employment and Day Services (EDS)	4	84	23	111
Other Agency Waivers (DSS) ⁷²	1	1	2	4
Total	172	706	1,224	2,102
Source: PRI staff analysis				

⁷² *Katie Beckett* waiver allows parents to access Medicaid services for their child with a severe disability or medical needs without having to financially qualify for Medicaid. *Money Follows the Person* is a federal demonstration program designed to help states rebalance their long-term care systems to better support people living in institutions who want instead to live in the community.

As the table illustrates, DDS currently serves over 2,000 individuals with an ASD diagnosis through waiver services. Of these, 95 are diagnosed ‘ASD only’ and served through the Autism Spectrum waiver. The demand for this limited waiver is significant. (See Autism Spectrum Waiver wait list below.)

The largest waiver for all ages is the Comprehensive waiver (1,019) followed by the IFS waiver (874). As described above, this means most enrolled in the Comprehensive waiver are receiving extensive supports usually in a licensed setting. Those enrolled in the IFS waiver are receiving in-home supports.

A closer examination of the 15 to 25 age group (this study’s target population) shows most are served through IFS (385) and Comprehensive (203) waivers. This group also uses the employment and day services waiver more (84) than the over 25 age group (23).

Employment and day activities. PRI committee staff examined the employment and day activities for the current population with ASD in DDS (Table IX-3). Employment includes having a competitive job, individual supported employment, or group supported employment. The day options may include participation in individualized day programs, sheltered workshops, local education agencies, or a residential school day program.

Table IX-3. Participation in Employment/Day Programs by DDS Clients w/ ID & ASD			
Employment/Day Program	15-25	Over 25	Total
Day Support (DSH& DSO)	245	782	1,027
Competitive Employment	0	14	14
Group Supported Employment (GSE & GSH)	153	379	532
Individualized Day Non-vocational	38	78	116
Individualized Day Vocational	27	26	53
Local Education Agency (LEA)	552	3	555
Individual Supported Employment (SEI)	12	44	56
Sheltered Employment (SHH)	4	45	49
No Day Program (medical reason, refused, no program)	5	30	35
Residential School Day Program	10	5	15
DDS School (Early Connections)	2	0	2
Other Day	4	3	7
Source: PRI staff analysis			

As the table shows, day supports is most common activity for all ages (1,027), followed by enrollment in a local education agency program (555), or group supported employment (532). For the group aged 15 to 25, the same categories were in the top three; however, enrollment in LEA (552) was the most common.

The most common activity, day supports, help participants to acquire, improve, and/or retain skills and abilities to prepare for work and/or community participation, or support meaningful socialization, leisure, and retirement activities. This may include independent functioning skills including but not limited to sensory-motor, cognition, personal grooming,

hygiene, toileting, assistance in developing and maintaining friendships and skills to use in daily interactions; the development of work skills; opportunities to earn money; opportunities to participate in community activities.

Other supports in DDS regions. For the DDS clients with intellectual disabilities, each of the three DDS regions has its own Helpline, Individual and Family Support Resource Team, and family grant program. These resources are available to individuals with intellectual disabilities who reside at home with their families, regardless of whether or not they have a DDS case manager or receive waiver services.

The resource team members include a family support worker, behaviorist and/or psychologist, nurse, and educational liaison, and a transition advisor. Team members may provide family training, information sharing and referral, crisis support, collaboration with local school districts and agencies, and community development. Resources are not entitlements and are subject to availability in the region.

Currently, under certain circumstances, DDS provides family grants to individuals with intellectual disabilities who may or may not have ASD. Families who are not receiving DDS waiver services and have children who live in their homes can request one-time Individual and Family grant funding for disability-related expenses that cannot be covered by other resources. The grants are intended to pay for items and services that support care in the home. This may include but is not limited to: respite, transportation, recreation, support coordination, crisis support, and assistance to access community supports. These funds are subject to availability. Grant amount may range from \$600 to \$1,000 per year. These supports are not available to ‘ASD only’ individuals seeking or receiving waiver services from the autism division within DDS.

Autism Spectrum Waiver

Approved by the federal Centers for Medicare and Medicaid Services (CMS) in 2012, the Autism Spectrum Waiver targeted two groups: 1) adults who were receiving services through the Autism Pilot Program⁷³; and 2) youth and young adults receiving services through the Department of Children and Families (DCF) Voluntary Services Program. The five-year waiver is currently in its second year and includes a limit on the number of individuals who can enroll and be served.

To be eligible, participants must:

- Be a Connecticut resident at least three years of age
- Have a diagnosis of ASD (without an intellectual disability)
- Live in a family/caregiver/own home
- Be Medicaid eligible

⁷³ In 2006, the legislature authorized a pilot program to provide coordinated support and services, including case management, to people with ASD who did not also have mental retardation (i.e., IQs above 70). The pilot served up to 50 people until 2008 after which an evaluation would be completed.

The DDS level of need (LON) tool is used with other appropriate assessments to determine the resources to be assigned. Waiver funding is capped at \$60,000 annually per participant. According to DDS, waiver services for children average \$42,000 and \$30,000 average for adults. The Autism Spectrum Waiver covers services and supports in community companion homes (formerly Community Training Homes), live-in companion, respite, assistive technology, clinical behavioral supports, community mentor, individual goods and services, interpreter, job coaching, life skills coach, non-medical transportation, personal emergency response system (PERS), social skills group, and specialized driving assessment.

As of November 21, 2014, there were 126 individuals with ‘ASD only’ receiving case management services through the DDS autism division. Of these, 95 were actively receiving Autism Spectrum Waiver services while the remaining 31 were not yet enrolled - primarily younger children waiting to be enrolled in early childhood autism waiver. Approximately 35 of the 95 active waiver participants are young adults from the DCF Voluntary Services program.

Utilization of ‘ASD only’ services. Table IX-4 presents the types of services received by the ‘ASD only’ population by age group under the Autism Spectrum waiver. As the table shows, the highest utilization of services for all ages and by the 15 to 25 year olds is life skills coach, community mentor, and behavior management. The table reports the information contained within the DDS database provided to PRI committee staff which is a snapshot of activity.

Waiver Service	Under 15	15-25	Over 25	TOTAL
Behavior Management	18	21	25	64
Community Mentor	16	28	27	71
Job Coach	0	7	18	25
Life Skills Coach	16	30	40	86
Social Skills Group	1	12	25	38
Transportation	0	0	8	8
Source: PRI Staff Analysis				

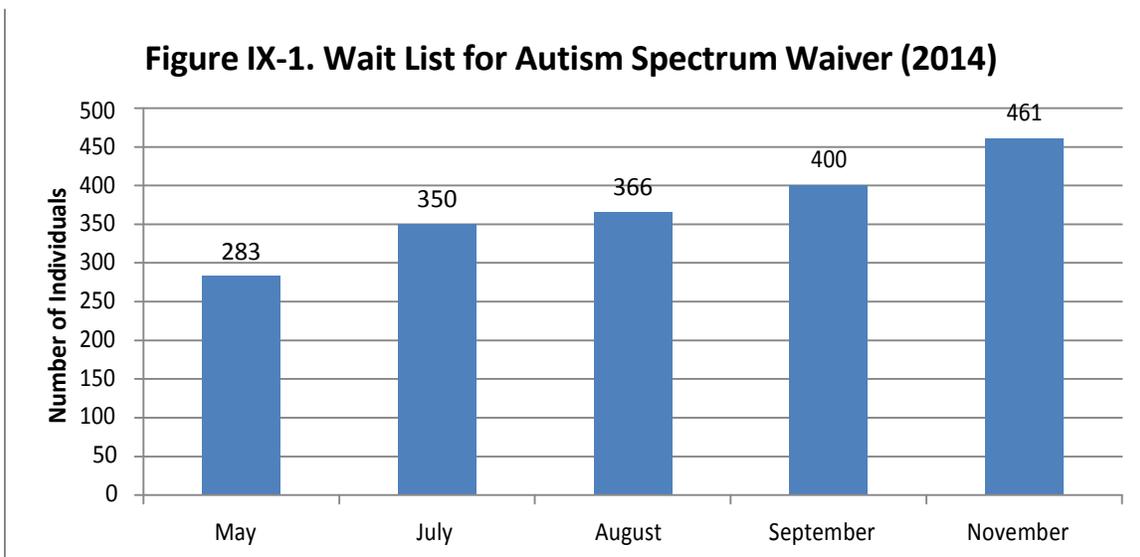
DDS also routinely prepares a Management Information Report (MIR) that captures information over a period of time. The MIR statistics for the Autism Spectrum Waiver participants for June 2013 and 2014 is presented Appendix C. However, it is important to note that the MIR information reflects duplicated counts of participants.

Autism Spectrum Waiver wait list. As noted earlier, the Autism Spectrum Waiver is in the second of its five year CMS approval period. The enrollment cap increases every year of the waiver with an established number of unduplicated “slots”. The number of enrollees allowable under the waiver is shown in Table IX-5. The division fills slots as they become available and have

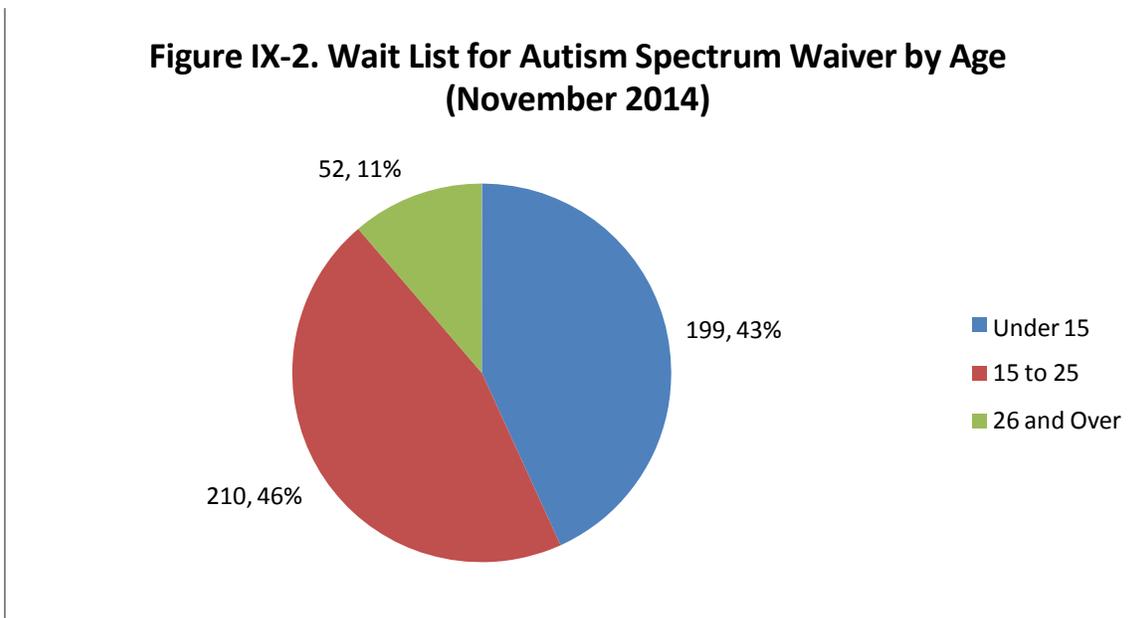
Year 1	100
Year 2	115
Year 3	122
Year 4	129
Year 5	136
Source: DDS	

created a wait list for those seeking waiver services. As mentioned previously, the waiver now actively serves 95 individuals, the remaining number are pending approval for waiver services or Medicaid eligibility.

The demand for the Autism Spectrum Waiver has expanded dramatically as illustrated in Figure IX-1. During a seven-month period, the number of individuals placed on the wait list grew by 63 percent. The current wait list number (461) is four times greater than the existing allowable enrollment capacity of the waiver.



The autism division captures general information regarding individuals on the Autism Spectrum Waiver wait list. All applicants are served on a first-come, first-served basis. The figure below provides a snapshot of the wait list by age group as November 21, 2014.



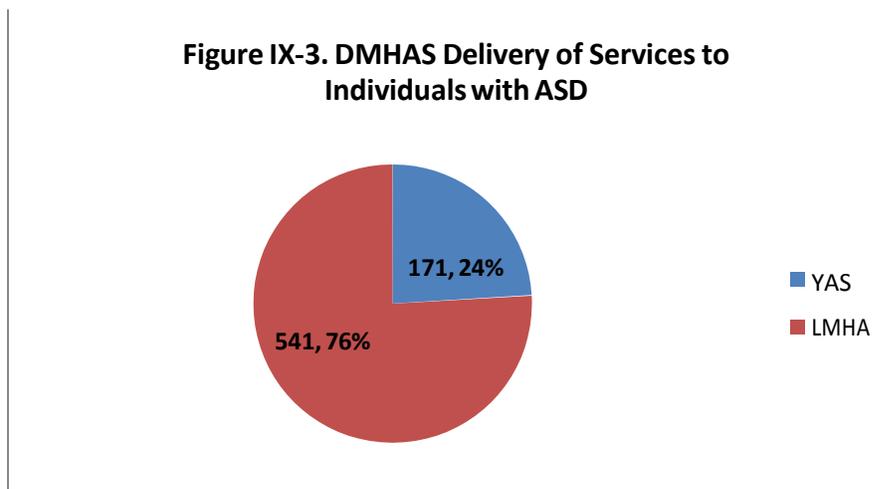
As Figure IX-2 demonstrates there is about an equal number and percentage of applicants found in 15 to 25 year old group (46%) and in the younger (under 15) group (43%). The number and percentage of wait list applicants over the age of 25 (11%) is significantly lower. The fewer number of older applicants may be due to individuals in this age bracket already being “settled” in their support environment or aging-in-place and not seeking new services. In addition, younger individuals may be more likely to become aware of waiver services through schools, advocacy groups, or family networks. A review of the distribution of applicants across DDS regions found a fairly proportionate number of applications from the three DDS regions with the expected clusters in the major cities. (See Appendix C for further analysis.)

In September 2014, DDS reported that the Autism Spectrum Waiver wait list included 188 youth and young adults between the ages of 15 to 25. By November 21, 2014, the applicants in this age group grew by 12 percent to 210 individuals.

Autism resource specialists. In FY 14, DDS hired two autism resource specialists to work with individuals and families waiting for Autism Spectrum waiver services. The specialists have been conducting home visits, upon request, and generally assisting individuals on the waiting list as well as performing outreach activities at resource fairs, schools, and transition events. According to the specialists, daily communications via phone and emails are received from people on the wait list seeking assistance and guidance. As of July, the specialists report having conducted approximately 50 home visits. Planning is underway for a self-advocate series, more training events, and to provide more networking opportunities.

DMHAS Support Services

DMHAS provides an array of support services across the state through a number of state facilities as well as private providers, and non-profit entities. DMHAS serves clients through the Young Adult Services programs (clients aged 18-25) as well as the Statewide Services Division within a network of local mental health agencies (LMHAs) and facilities. According to DMHAS database, there are 712 DMHAS clients with a co-occurring diagnosis of ASD. As Figure IX-3 shows, the majority of those clients (76%) receive services through the LMHA network.



Young Adult Services (YAS). The YAS program receives its funding through state appropriation. It is not a waiver program although participants are Medicaid eligible. YAS offers psychiatric services, individual and group psychotherapy, case management, clinical services, nursing, trauma and crisis services, assessment and consultation services, rehabilitation services, linkage to vocational and educational services, and residential or housing support. Services are provided through a network of state operated and contracted private non-profit agencies.

DMHAS waiver. DMHAS also operates the Connecticut Mental Health waiver which provides adult day, health, community support, supported employment, assisted living, brief episodic stabilization, community living support, home accessibility adaptations, home delivered meals, non-medical transportation, overnight recovery assistant, peer supports, PERS, recovery assistant, specialized medical equipment, and transitional case management for individuals with mental illness ages 22 and older. The waiver is administered through DMHAS Statewide Services and the network of LMHAs and facilities.

ASD Utilization of DMHAS Services and Programs

DMHAS information for FY 14 shows the primary type of program services sought by the 712 clients with a co-occurring ASD is mental health services (Table IX-6). To reiterate, the primary focus of DMHAS services and programs is on mental and behavioral health and not ASD. Services range from inpatient hospitalization, outpatient services, social rehabilitation, residential and housing supports, crisis services, employment supports, community supports, and a number of other case management, prevention, and specialized services.

Service Type	18to25	Over 25	Total
Outpatient Services	126	186	312
Social Rehabilitation	54	122	176
Residential Services	60	44	104
Crisis Services	26	4	30
Employment Services	8	6	14
Intake	11	6	17
Inpatient Services	2	11	13
Community Support	5	6	11
Other (ACT, forensic community-based, prevention, case management, recovery support, consultation)	23	12	35
Source: PRI staff analysis			

As the table demonstrates, the majority of DMHAS clients with an ASD diagnosis receive outpatient services. This is followed by social rehabilitation and residential services. For the transition-age group (18 to 25), those categories are also the most common services. In addition, this younger group utilizes crisis services more than the older population.

The client information provided above is not historic information; it is a point-in-time. As a snapshot, this information only represents the primary/first-coded services DMHAS clients received during the time period. It does not necessarily reflect whether an individual has received multiple services currently or in the past.

Challenges and Barriers

The following is a summary of the identified challenges and barriers to support services for the population with ASD in Connecticut. PRI committee staff compiled the information from various sources including interviews and anecdotal evidence from state agency staff, educators, service providers, professionals working with ASD population, parents, and advocacy groups. Information was also collected from the PRI committee surveys (Chapter III and IV) as well as materials and documents prepared by other taskforce or work groups.

- **The biggest barrier to support services for the ‘ASD only’ population is the limitation of resources to expand waiver services.** While individuals with intellectual disabilities and a co-occurring ASD diagnosis have a few more available options for waiver services, transition-age youth and young adults (individuals age 15 to 25) with an ‘ASD only’ diagnosis have just one option – the Autism Spectrum Waiver which has over 400 individuals on the wait list.
- **Individuals with ASD may require long-term supports for independent living.** Persons with ASD may be cognitively and verbally proficient yet unable to live independently. Difficulties in executive functioning contributes to the challenges individuals with ASD have in obtaining the skills needed to live independently or with lower levels of supervision. Specifically, individuals with ASD have difficulty dealing with new situations and processing complex information as well as problem-solving through planning. These skills are necessary for managing everyday occurrences. For the transition-aged youth (15 to 25), transitioning from a family home to another home setting may be difficult and take time.
- **A ‘one size fits all’ approach for support services would exclude and ignore the needs of large segments of the population with ASD.** Flexible support options must be established to serve the wide range of needs of persons on the ASD spectrum. Individuals with ID tend to present with a more even level of functioning across all settings of daily living (home, work, day program, community). Individuals with ‘ASD only’ may exhibit a more splintered set of skills and may have more difficulties functioning in some settings or occasions due to deficits in communication or social skills. Services and evidence-based interventions should be accessible to all groups across the spectrum.

- **Individuals with a diagnosis of ‘ASD only’ have the largest gap in state services.** While all individuals on the autism spectrum have service delivery impediments, the largest gap in services is apparent for individuals who have diagnosis of ‘ASD only’. Individuals with ASD and co-occurring conditions must rely on general developmental disability services and mental health care that may not address their autism specific needs or provide them with the necessary level of care. Outside of waiver services, individuals with ‘ASD only’ must rely on general population services despite specialized needs. They may also access some services designed for other special needs groups, but they must meet the eligibility requirements of the agency providing the service.
- **Social recreation opportunities for youth and young adults with ASD are limited.** After leaving school setting, there are fewer opportunities for adult recreation and socialization than for the school-aged population who access to school-based resources. Social and recreation opportunities must be developed for the various lifespan phases and include a mix of integrated as well as separate activities with peers. Without socialization, youth and young adults may experience isolation leading to anxiety, depression, and other mental health issues. Socialization skills are also critical for community integration and for obtaining or maintaining employment.
- **The lack of transportation may negatively impact an individual’s ability to live independently.** Transportation is one challenges of the most frequently mentioned by families, providers and professionals as an obstacle for school, employment, and community involvement. Often there is limited or no funding to assist families in transporting their child to and from a day service or work site. Depending on where one lives in Connecticut, the availability of public transportation can vary.
- **The financial burden is significant for families caring for individuals with ASD.** Families unable to enroll in waiver services must often incur the financial burden of self-paying for private provider services. Family contributions could jeopardize eligibility status for those currently and those potentially receiving waiver services who must remain Medicaid eligible. In addition, a parent’s ability to work is often compromised due to the dynamic and extensive nature of their child’s care needs.
- **Ongoing training and awareness of ASD issues must be provided to state agency personnel and contracted service providers who interact and work with individuals on the spectrum.** The prevalence of individuals with ASD has resulted in adult services agencies newly encountering a growing number of clients with ASD. With each encounter, the personnel must be aware of the specific needs and issues surrounding working with individuals with ASD. This is particularly critical for agencies newly experiencing an increase in ASD clients. For example, DMHAS is currently applying for an autism waiver for its client population yet training offered on ASD issues is not mandatory.
- **Individuals with ASD and their families could use the support of a professional case coordinator or manager.** Families often must navigate the various medical, educational, social services systems on their own. This journey is further complicated when seeking to

bridge or transition from the entitlement system to the adult eligibility system. Applying for benefits or services is a complicated but often necessary process. Enrollment processes may take long time, requires numerous documentations, and must be mindful not to exceed income limits or create conflicts that jeopardize benefits. In addition, there are challenges in accessing and finding available and appropriate services and resources as well as alternatives if ideal services are unavailable.

New State Initiatives or Recent Developments

There are a number of new state initiatives and recent developments currently being explored or implemented that would affect the availability of supports for the ASD population in Connecticut. The most critical change is the new Medicaid State Plan Amendment.

Medicaid State Plan amendment. In July 2014, the Centers for Medicare and Medicaid Services (CMS) clarified to states that Medicaid programs must cover a full menu of services for individual with ASD up to age 21 under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit if they are medically necessary. In response, DDS and DSS, the state's Medicaid administrator, prepared a state plan amendment that was developed with the assistance of several other state agencies including DCF, DMHAS, CSDE, and OPM.

The new Medicaid state plan amendment will allow coverage for a range of services previously not funded by Medicaid including certain types of ASD services provided by unlicensed individuals in independent practice settings.⁷⁴ In the past, Medicaid only allowed coverage in this category if it was rehabilitative (meaning to restore function that previously existed) but not for habilitative services to acquire missing skills as many youth with ASD require.

The proposed plan details how services will be provided, target populations, who can render the services, authorization standards, and the medical necessity review process. Another key component of the plan is care coordination to assist individuals and families navigate the service system with timely information, home visits, or phone contact. Currently, the ASDAC council is providing input to the amendment. Once completed, the plan amendment will be submitted to CMS for review and approval.

It is important to note that the proposed changes only apply to Medicaid coverage and do not apply to Connecticut's Children's Health Insurance Program (Husky B)⁷⁵ or to all commercial insurance plans.⁷⁶ In addition, the state agencies are still figuring out what, if any, is the impact of the Medicaid State Plan Amendment on the delivery of existing waiver services.

Care coordination. The plan amendment covers individuals with ASD up to age 21; however, the DDS proposal extends care coordination and/or family navigator services to adults age 21 and over. These services will be provided through clinical and non-clinical professionals

⁷⁴ There is no specific license for autism specialists but there is a board certification as a Behavior Analyst or an Assistant Behavior Analyst from the Behavior Analyst Certification Board.

⁷⁵ Unlike Medicaid, EPSDT does not apply to Husky B.

⁷⁶ Connecticut law (C.G.S. §38a-514b) requires commercial insurance plans to cover ABA services but this coverage is not readily available for many individuals in self-funded insurance plans.

to facilitate access to services, ensure coordination between all service providers, provide support to the family or caregiver, and conduct home visits, evaluate member experience, and if more assistance is needed with health related needs.

ASDAC council proposals. There are several council proposals currently being considered for implementation that would impact the quality and delivery of support services.

Credentialing/Training. The credentialing subcommittee is currently making efforts to improve and expand access to qualified professionals and effective services. The council's training committee is also working to improve and expand access to training, consultation and learning opportunities for providers, professionals, and families.

Resource guide. The council has a subcommittee proposal to improve and expand access to a comprehensive service resource guide.

In-home supports. The council is proposing and seeking funding to develop two pilot programs. One pilot would identify youth with escalated behaviors and develop successful team-based in-home and in-school intervention plans that include crisis management to reduce hospitalization, emergency room use, and out-of-home placements.

The second pilot would increase social/recreational/respite capacity for individuals with ASD by: 1) identifying opportunities for school extracurricular activities that match an ASD student's strengths and areas of interest and require minimal support; and 2) developing activities and groups, if none exist, based on the pilot participant's interest and abilities. All support will be provided by trained high school peers.

Socialization, recreation and respite. The council has a subcommittee on optimizing access to social, recreational participation for individuals with ASD of all ages. According to an examination by an ASD council sub-committee, there are few opportunities for socialization for individuals with ASD and particularly, outside of the Connecticut River valley. The subcommittee's preliminary research found social recreation opportunities seem to cluster in the central portion of the state with fewer offerings in the northeast and northwest regions.

The subcommittee proposes the creation and expansion of peer mentor programs in schools and community agencies. Specifically, this would be accomplished through: conducting an inventory of existing peer mentoring programs (e.g., Best Buddies, Circle of Friends); preparing a presentation with training materials aimed at school administrators, park and recreation staff, community centers, and service clubs such as Boy Scouts; and establishing a Peer Mentoring Association network.

A second proposal is a pilot program for adults with ASD using short-term mentors to accompany and support participation in existing community activities. Another component of this proposal includes conducting a survey and interviews of adults with ASD to determine effective social recreation approaches that individuals would respond to.

New waiver services. DMHAS is in the process of applying for a new Medicaid Home and Community-Based Services waiver for individuals with neurodevelopment disabilities

including young adults with autism within the Young Adults Services. The new waiver would allow DMHAS to receive additional federal funds to service this population and permit federal reimbursement for services that are currently funded by the state. The department anticipates the waiver to be approved sometime next year.

Federal legislation. Currently, the federal government is considering passage of the Achieving a Better Life Experience (ABLE) Act that would allow families to establish tax-free savings accounts for disability-related expenditures without jeopardizing an individual's benefits provided by Medicaid, Social Security, private insurance, or other sources. Withdrawals would be allowed for qualified disability expenses such as education, housing, transportation, employment support, health prevention and wellness, assistive technology and personal support. The concept is similar to the flexible accounts allowed for college savings.

In 2014, Massachusetts passed its own state version of the federal ABLE act permitting the creation of tax-free savings account for people with disabilities to pay for education, housing, medical, transportation and other needs.

Community First Choice. Among the options available through the Affordable Care Act is the Community First Choice option in the Medicaid plans allowing states to receive more money to use for home and community-based services. Through this option, more access to personal care assistance services would be available including assistance with activities of daily living, independent living skills, health-related tasks, learning skills, and supervisory help with prompts and cueing. Only a few states currently use this option. According to DDS staff, the department will be pursuing the Community First Choice option in 2015.

TransitNet. In October 2014, The Arc Connecticut, a lead advocacy organization for individuals with intellectual and developmental disabilities, launched a new transportation information and resource website known as "TransitNet". Funded through a combination of partnership of federal and community agencies, the website does not provide actual transportation, but rather offer links and contact information to transportation resources. This provides individuals a starting point of where to seek assistance and begin to navigate Connecticut's existing systems. According to The Arc, it will also reveal where in the state transportation options are limited. The goal is to establish an inclusive coordinated transportation system that incorporates the suggestions and ideas of users and improves community transportation services for the target population.

Other State Models or Other Approach

PRI committee staff contacted the National Conference of State Legislatures (NCSL) to gather information on ASD services in other states. In general, eligibility for waiver services varies from state to state. Most states include individuals with ASD in one or more of their HCBS programs for persons with intellectual and/or developmental disabilities (sometimes referred as a related condition.) Few states offer waivers specifically for adults with ASD. Most states with ASD specific waivers are primarily for children. Pennsylvania and Maine are two states often mentioned as having model approaches. In addition, Massachusetts recently passed an Autism Omnibus act in 2014. Table IX-7 provides a summary of these state efforts.

Table IX-7. Other State Models and Approaches

Pennsylvania

Adult Autism waiver Implemented in 2011, provides day habilitation, residential habilitation, respite, supported employment, supports coordination, therapies, assistive technology, behavioral specialist services, community inclusion, community transition services, environmental modifications, family counseling, family training, job assessment/finding services, nutritional consultation, temporary crisis services, and transitional work services for individuals ages 21 and older with autism.

Adult Community Autism Program (ACAP) program designed specifically for adults with ASD age 21 and older. Comprehensive services and supports are individually tailored to each person's strengths and individual goals and integrate health care, improve social skills, support vocational and leisure activities, and assist families and caregivers. Services are flexible and can be readily modified as a person's needs change over time.

Autism Mini-Grant Program provides up to \$500 each to support individuals with ASD or their families who are not able to access existing services. The grants may be used for things such as respite care, community inclusion, summer programs and home safety modifications.

Maine

Maine Waivers. Maine has separate division for ASD services and two waivers for adults with ID/ASD.

- 1) Implemented in 2010, provides services including community support, home support, work support, communication aids, consultation, counseling, crisis assessment, crisis intervention, employment specialist services, home accessibility adaptations, non-traditional communication consultation, non-medical transportation, non-traditional communication assessment, specialized medical equipment and supplies, and speech therapy for individuals 18 and older with autism and intellectual disability.
- 2) Implemented in 2011, provides community support, respite, work support, employment specialist services, home accessibility adaptations, and transportation for individuals ages 18 and older with autism and intellectual disability.

Massachusetts

Omnibus Autism Bill (2014) In addition to the coverage of autism services under Medicaid, the new law creates a 35 member commission to address the long-term needs of individuals with ASD. The commission must report on progress made with periodic benchmarks and cost estimates for a coordinated, system-wide response for people of all ages on the autism spectrum.

The law also created a special commission to study the supportive housing needs and the employment needs and opportunities of adults with autism and to make recommendations to the legislature.

In addition, MassHealth, the state agency for Medicaid and the Children's Health Insurance Program (CHIP) in Massachusetts, is required to cover medically necessary autism services including applied behavior analysis (ABA), with no age or dollar caps. The new law expands to public insurers the coverage requirements found in Massachusetts' 2010 law for private insurers.

The law also establishes a tax-free savings account patterned after the federal ABLE Act legislation to allow all disabled families to save for expenses including education, housing, and any other needed supports and services. This will not take effect immediately due to the need for federal participation.

PRI Staff Recommendations Related to Supports for Independent Living

When implemented, the new state initiatives and recent developments described above will go far to improve and expand the needed services for the population with ASD. PRI committee staff also considered a few additional options, discussed below, to address the current demand for ASD services.

In order to expand waiver services to the ‘ASD only’ population, there are two options which are both costly and likely to be controversial. One option is to increase the state appropriations to expand the capacity of the Autism Spectrum Waiver. The second option is to expand the DDS eligibility definition to include ASD as part of the general intellectual disability population; thus, allowing the ‘ASD only’ individuals access to the programs and services currently available to just the ID population, some who have a co-occurring ASD. These options are discussed below.

Cost to expand the Autism Spectrum Waiver. Significant financial resources would be required to address the demand of the existing Autism Spectrum wait list. During the 2014 legislative session, DDS prepared some information on fully funding the Autism Spectrum Waiver wait list. At that time, the wait list had 231 individuals. Based on the average cost of waiver services of \$30,000 per year for adults and \$42,000 per year for children, DDS estimated \$8 million was needed to address the wait list. This would provide coverage at the existing level of waiver services and did not include case manager positions.

As of November 2014, there were 461 individuals on the ASD wait list. Using up-to-date wait list information, PRI staff estimates that approximately \$16.2 million in additional funding would be needed to meet wait list demands (Table IX-8). It is important to note that this would be at existing service level and does not include any residential or housing options.

Cost to Expand Autism Waiver	Under 15	15 and older
Number on Wait list (Nov. 2014)	199	262
Average cost of waiver services	\$42,000	\$30,000
Additional Expenditures	\$8,358,000	\$7,860,000
Total	\$16,218,000	
Source: PRI staff analysis		

Expansion of DDS eligibility definition. Many individuals with ASD do not have an IQ lower than 70 (required for DDS eligibility for services) but do have significant functioning limitations (e.g., self-care issues, mobility, unable to live independently, learning issues). One possible option to increase access to services is expanding the existing eligibility definition for DDS services to include individuals with ASD who meet conditions for substantial functional limitations. This would allow individuals with ‘ASD only’ access the same service delivery system as those with intellectual disabilities. There are a few challenges with such potential expansion. First, the ID system is already struggling to meet the needs of the existing population, in particular for residential services. Adding another population will only further stress that system. Without a corresponding change in resources, any expansion in eligibility means serving more people fewer services. Secondly, there are mixed responses from families and advocacy groups regarding combining the populations. Many feel individuals with ASD have different or distinct needs given the broad spectrum of ASD that requires a separate service delivery system.

Expand ASD coverage to non-Medicaid insurance plans. As noted earlier, the expansion of ASD coverage under the Medicaid State Plan amendment will not apply to HUSKY B or to all commercial insurance plans. To provide greater ASD coverage to the non-Medicaid populations in these plans would require legislative action and in particular, for the HUSKY B program, significant additional financial resources. To ensure all youth and young adults have comparable access to ASD coverage, PRI committee staff recommends **the Department of Social Services, in coordination with the DDS autism division, examine the feasibility of providing children served in the HUSKY B program with the same coverage being considered under the Medicaid State Plan amendment.**

Survey of Autism Spectrum Waiver wait list. The dramatic increase of individuals signing up for the Autism Spectrum Waiver wait list suggests that there is significant demand that is not being met. Although DDS compiles basic information regarding the individuals on wait list, the autism division has not asked or monitored what particular services are being sought. Interviews with agency staff indicate that a survey of wait list individuals is under discussion. PRI committee staff concurs with the department staff and recommends **a survey of the individuals and families on the autism waiver wait list be conducted to compile basic information regarding their immediate and upcoming needs and their levels of existing resources and support.** While committee staff recognizes and acknowledges that immediate funding may not be available to assist many on the wait list, the survey results may help plan for future services and perhaps prioritize assistance.

Additional ASDAC Council subcommittees. As described earlier, the ASDAC council has established five subcommittees focused on expanding and improving services in a number of areas. The subcommittees have developed a number of proposals that will require continued work for implementation. Going forward, the PRI committee staff recommends, **the ASDAC council consider establishing additional subcommittees on transportation and life skills.**

A transportation subcommittee should examine, among other things, opportunities to build coalitions with groups with similar transportation needs (e.g., elderly or physically disabled) such as TransiNet to ensure the needs of individuals with ASD are considered; explore

ways to ease Department of Motor Vehicles experience testing; and offer ASD awareness training for public transportation employees.

Given the board range of the ASD spectrum and anticipated prevalence of young adults with ASD, the autism division, in consultation with the ASDAC council, should examine the independent living skills most needed by youth and young adults and establish criteria and best practices for life skills training for individuals with ASD.

Family financial support. Individuals with ASD may require a diverse array of medical, therapeutic, behavioral and educational services. Beyond medical costs, many families utilize non-medical services with high out-of-pocket spending resulting in significant financial burden for families. Acknowledging the significant amount of resources needed to meet the demands of the existing Autism Spectrum Waiver wait list, PRI committee staff recommends **DDS consider creating an interim family grant program for the ‘ASD only’ population similar to the one already established for individuals with intellectual disabilities to help offset disability-related expenses.**

Similar to the mini-grant program in Pennsylvania (see Table IX-7), this would offer a stop gap funding source for families and serve as an interim step until additional resources to expand ‘ASD only’ waiver services becomes available. As with the families of individuals with intellectual disabilities, temporary grants can be lifeline for many families.

Financial planning. Besides financial support, families with individuals with disabilities also need assistance with financial planning. At present, the typical financial planning vehicle used by families of individuals with ASD is the special needs trust (SNT). A SNT is established for a disabled beneficiary under the age 65 to legally shelter assets used for the benefit of a disabled person. Generally, the purpose of a SNT is to provide supplemental and extra care above what the government provides while allowing the individual to continue to qualify for government programs such as SSI or Medicaid that have strict asset limits.

Another way to assist families with financial planning is the creation of the tax-free accounts for disability-related expenses, as currently under consideration on the federal level. According to most sources, there is bipartisan support for the federal ABLÉ legislation and it is anticipated that it will pass in the near future. At least one state, Massachusetts, has enacted its own version of the ABLÉ act earlier this year. The law will not go into effect until the federal provisions are enacted. PRI committee staff believes, that like Massachusetts, the **Connecticut legislature should consider passing its own ABLÉ act.**

Additional staffing for the DDS autism division. As described previously, the autism division has recently hired two resource specialists to assist individuals on the Autism Spectrum Waiver wait list. To date, the specialists have been able to conduct 50 home visits. In addition, the specialists are also performing several outreach activities. The sheer volume of the growing 400 plus individuals on the wait list makes it untenable for two staff to manage requests for assistance as well as outreach events. Therefore, PRI committee staff recommends **DDS shall, within available appropriations, consider hiring additional ASD resource specialists.**

One essential component of the proposed Medicaid State Plan amendment will be to include and extend care coordination and family navigator services for individuals over the age of 21. If approved, this will definitely increase access to available services for individuals with ASD and their families. Nevertheless, PRI committee staff finds the DDS autism division would also benefit from certain elements of the resource team approach used in the DDS regions. Specifically, **the autism division should have access to education and transition advisors for the ‘ASD only’ population. Upon request and within availability, these advisors could provide guidance or referral to other state and/or community-based supports to individuals and families on the wait list.**

Chapter X: System Infrastructure

System Infrastructure

Transition planning will not be effective without active interaction between all the necessary services and service providers. Transition efforts involve coordination and communication between different parties including, but not limited to, the state agencies for education, vocational rehabilitation, developmental disabilities, mental health and addiction services. There may also be involvement with public and private providers, universities and other educational institutions, or private-sector employers and businesses. In addition, advocacy groups and families also have influential roles.

This chapter provides an overview of the existing system infrastructure serving the transition-aged youth and young adults with ASD. It also identifies some barriers and gaps in the delivery of services for individuals with ASD and makes recommendations for strengthening collaboration and communication.

Current System

When the transition out of secondary education is going to be discussed, representatives of outside agencies may be invited, especially those well-informed about adult resources and services in the community. As outlined in Chapter I, Connecticut provides different services to individuals with ASD and their families in multiple systems. The major state agencies (and divisions) serving the population with ASD in educational, vocational, developmental, and behavioral and mental health services include:

- Connecticut State Department of Education (CSDE)
 - Bureau of Special Education
- Department of Rehabilitation Services (DORS)
 - Bureau of Rehabilitation Services (BRS)
- Department of Developmental Services (DDS)
 - Division of Family and Community Services (ASD with IQs under 70)
 - Division of Autism Spectrum Services ('ASD only' aged three and up)
- Department of Mental Health and Addiction Services (DMHAS)
 - Young Adult Services (YAS)
 - Statewide Services and Local Mental Health Authorities (LMHAs)

Other state agencies provide services to other special needs individuals (e.g., physically disabled, low-income) or the general population, and may serve individuals with ASD. These include the Departments of Social Services (DSS), Housing (DOH), Public Health (DPH), and Labor (DOL). In addition, there are a number of community, non-profit and private providers, educational institutions, and advocacy groups who interact with the population with ASD.

Role of Division of Autism

In 2007, the Division of Autism Spectrum Services was established within DDS. Initially, the division was created to manage a pilot program providing services to adults with ASD who did not also have intellectual disabilities (i.e., IQ under 70). The pilot ended in 2009 and participants were incorporated into an ongoing Medicaid Autism Spectrum Waiver program.

By state law, the DDS division serves as the “lead agency for combating autism” and is responsible, within available appropriations, for the development and provision of services to individuals with ASD.⁷⁷ The division has made significant strides in establishing a new additional waiver for early childhood services and is preparing proposals on a number of critical issues in collaboration with the ASDAC council (*see below*).

Presently, the division staff consists of a division director, a case management supervisor, six case managers, two resource specialists, and an administrative assistant. Case management staff works with the waiver participants while the primary focus of the resource specialists is to work with individuals and families waiting for services.

ASDAC council. The ASDAC council was established in 2013 to advise DDS on matters related to ASD including services, policies, programs, and implementing recommendation from a 2011 autism feasibility study. The 23 member council includes representation from families, advocates, providers, state agencies, and researchers. The council currently has five subcommittees that have produced proposals for agency consideration including: credentialing, training, creating a resource guide, social/recreation pilot programs and in-home behavioral support pilot programs.

Roles of Other Involved Entities

Role of other state agencies. Other agencies may serve as one-time or ongoing providers to address educational, vocational rehabilitation, intellectual disabilities or mental health for individuals with ASD. Each of the major state agencies (CSDE, DORS, DDS, DMHAS) has transition coordinators/advisors to assist youth and young adults with ASD within their own agency mission. As described in the previous chapters, each group has its own set of goals and expectations regarding transition of youth on both the individual level and for statewide action or programs. They must adhere to their own regulations and requirements.

Role of advocacy groups. There are several advocacy groups for the population with ASD. Some have a specific focus on ASD while others cover all disabilities including ASD. One group, the Connecticut Autism Action Coalition, brings together a number of advocacy groups and stakeholders to share information. However, there are other groups scattered throughout the state providing awareness and helping families navigate the various medical, educational, and adult services systems. In particular, support groups for parents are the most common and exist in several locations around the state. However, the level and scope of activity for the groups vary. Some groups can help individuals find services, share ideas and approaches to common problems, and help families deal with frustrations.

⁷⁷C.G.S.§17a-215c

Role of community and private providers. Community and private providers often fill in gaps when government-funded services are not available. They can facilitate links to the community and promote integration. There are ASD specific providers as well as providers who provide services for individuals with all developmental disabilities, including ASD. Community providers such as recreation centers and programs (e.g., YMCA) may offer youth development activities. Families may also use private providers or out-of-state providers for treatment, vocational or housing supports. The availability of other providers may depend on a number of factors including geography and/or the family's ability to self-pay.

Role of employers. Private employers and businesses are an important component of the infrastructure. They can offer insight into the expectations that the business community has for future workers and help develop training and job opportunities. Some have established successful employment training models such as the Walgreens distribution center.

Role of universities. A number of universities have programs, projects, or offer services in different areas for the population with ASD including but not limited to: Southern Connecticut State University, University of Connecticut, University of Saint Joseph, and Yale University. In some instances, there are formal or informal ties to state entities. For example, DDS collaborated with state universities to conduct the evaluation of the autism pilot project and to examine the level of need tool for individuals with autism. In addition, a few representatives from higher education are members of the ASDAC council. These alliances are mutually beneficial for teaching and research and provide opportunities for peer mentoring as well as recreational opportunities for individuals with ASD for who may be college bound.

Role of families. Family members bring unique insight and experience and are usually prepared to advocate on behalf of their relative with ASD. Family members can serve as system navigators, consultants and advocates, and be active participants on committees and councils. Partnerships between families, professionals, and community members can help youth and young adults with ASD reach current and future goals. These partnerships are a means of fostering a comprehensive coordinated and more family/person-centered system of care.

Interagency Groups

Interagency coordination and collaboration is a key element to transition programming. Some agencies have formal agreements to work together on certain issues while others have informal arrangements. A number of state teams and group projects exist that are focused on the needs of transition-aged disabled individuals including, those with ASD. For example:

- There is an interagency group consisting of DMHAS, DDS, DCF and the Court Support Services Division (CSSD) of the judicial branch which regularly meet to consult on individual cases.
- There is also an interagency group that includes representatives from DORS, DDS, and CSDE to improve employment outcomes for students with disabilities.

- DDS and DORS have a memorandum of agreement requiring periodic meetings on improving employment supports for individuals served by both agencies.
- DDS also has workgroup with CSDE, known as “Collaborating Across the Lifespan” to examine issues in service delivery that lead to competitive employment for individuals of various ages.
- CSDE established a “Transition Community of Practice” group focused on secondary transition and employment to determine better ways to improve post-school employment outcomes for all youth with disabilities. The group is working on: development and use of statewide transition website; web-based calendar of transition events; and proposal for a statewide transition conference; identification of existing transition training and cross-agency training; and a directory of transition resources including a web-based transition timeline.
- For two years, there has been an ongoing sustainability initiative that meets to identify ways that collaboration can be improved in order to better meet the transition needs of students with disabilities. Members of this initiative include: DORS, CSDE, the six Regional Educational Service Centers (RESCs), the State Education Resource Center (SERC), the Connecticut Parent Advocacy Center (CPAP), with invited members including DDS to develop effective working partnership between DORS and the local education agencies.

Barriers and Gaps

While much progress has been made since the state’s first Autism Pilot Program in 2007, Connecticut still does not have a comprehensive or coordinated service system to address the needs of individuals with ASD or their families.

- **There is a fragmented system of care.** Currently, services are available through special education programs at varying levels in individual school districts, in limited programs in different state agencies for specific subgroups of the ASD spectrum, and through private practitioners with disparate credentialing and in some instances restricted access. As a result, there are inconsistencies in approach and quality, and services do not necessarily meet the level of demand.
- **The state’s lead agency on ASD is still evolving.** The DDS autism division was established to assume the responsibilities of the autism pilot program. Since that time the division’s primary focus is overseeing the Autism Spectrum Waiver program. The division works with a 23 member advisory council to expand and improve statewide service delivery. Through five subcommittees, the council has examined and developed proposals on issues regarding credentialing, training, socialization and recreation, an ASD resource guide, and in-home supports. While these efforts will have a definite and significant impact, additional work remains to be done. The role of the division must continue to evolve as a stronger centralized entity with a distinct leadership role.

- **There is no centralized entity to coordinate services and promote cooperation among the various entities involved with a particular individual.** There is fragmentation in bureaucratic responsibility for ASD services that involve numerous providers across multiple settings. Because of this, potential gaps and overlaps may occur, as different agencies may work at cross purposes, responsibility may be passed around, and opportunities for consistent services delivery are missed. This lack of coordination could result in scarce funds not being used in the most efficient manner. There must be a seamless, comprehensive service system that helps coordinates physical and mental health, education, family needs, and individual goals.
- **System navigation tools must be improved and made readily available.** Connecticut's system for ASD is complicated, disjointed, and may be confusing for families already overwhelmed by demands of caregiving. It usually falls to the caregiver to coordinate services across systems with fundamentally different missions. This lack of coordination is problematic for individuals with ASD of all ages. However, it is particularly evident when trying to cross from the entitlement to eligibility-based systems. The splintered system places the burden on families to seek information on ASD, learn what services are available, apply for those services, and once receiving them, coordinate services from different sources. Families and caregivers should have easy access to appropriate information to answer questions, address concerns, and navigate a road map to resources and supports.
- **Limited access to scarce funding necessitates leverage of resources.** Opportunities must be identified to leverage limited resources to provide efficient and effective services. This should be part of the leadership charge for the autism division. However, the division is not adequately staffed to assume additional responsibilities. Ideally, this division would coordinate potential ASD funding across agencies and seek out opportunities for additional grants, financing, or reimbursements. It could also conduct more outreach to the array of advocacy groups, community providers, educational institutions, employers and others who provide services, programs or assistance to the population with ASD. Families of individuals with ASD should have access to multiple resources for necessary services.
- **A shortage of qualified workforce exists in the ASD field.** The complexity of needs associated with ASD requires multiple interventions and practitioners. Staff and support systems are often challenged to meet the varied needs of people with ASD. The growing demand and problems in the supply of trained and licensed ASD specialists may create access barriers for individuals with ASD. The autism division and the ASDAC council are working on credentialing and training programs to address these concerns.
- **There is limited data collection and a lack of outcome monitoring.** Program evaluation and outcome data is essential to improve the quality of existing programs and establish best practices for ASD. However, information is not readily collected, tracked, or analyzed. Outcome data is not easily available. Agency data is not usually monitored for individuals with ASD as they are typically part of a larger population dataset or not collected at all. More systemic data collection is needed. Outcome data from a variety of

sources (e.g., transition programs, employers, contracted providers) should be centralized and evaluated to produce reliable data to inform practice and policy.

- **There is a proliferation of state teams, group projects, and interagency committees.** During the course of interviews with a broad range of stakeholders and interested parties, PRI staff became aware of large cadre of working groups for a variety of ASD issues. While these groups undoubtedly have their own purpose and goals, it would be mutually beneficial for all involved if information and efforts are shared and perhaps streamlined.

Recent Developments and New Initiatives

Several recent developments and new initiatives are currently underway that will address many of the barriers and gaps discussed above. A summary of these is provided here:

ASDAC council proposals. As discussed throughout this report, the council has a number of proposals under consideration. The following address some of the barriers and gaps mentioned above.

Credentialing. The ASDAC credentialing subcommittee continues its work to improve and expand access to qualified professionals and effective services. This becomes more important as demand for services will increase with the new Medicaid state plan amendment. In addition, insurance reimbursement is unlikely if treatment and supportive services are not provided by appropriately licensed personnel.

Training. Using survey results of over 1,500 of families and professionals who serve individuals with ASD, a council subcommittee examined the training needs for four core groups including: educators; parents; community providers (e.g., job coaches, job developers, day treatment); and medical/clinical professionals. The council has proposed and is seeking funding for the following training initiatives:

- *Educators* - trainings on interventions and supports for persons with ASD
- *Parents* - series of training geared towards navigating the various service systems categorized by age group (young children, teens/tweens, and adults)
- *Community providers* - training for autism specific credentialing
- *Medical/clinical providers* - developing a curriculum of interventions and supports for different provider types (i.e., physicians, psychologists and clinical social workers)

Resource guide. A council subcommittee is also working on the development of a resource guide, putting it online and training 2-1-1 helpline staff to use the guide to answer questions for individuals and families.

DDS website. DDS recently launched a new website specifically designed for individuals and families linked to DDS services and supports. The website features services aimed at the stages of an individual's lifespan including the Transition to Adulthood. For each phase, the site

asks and answers questions regarding a range of areas such as healthy living, education, community connections, finance and benefits, planning for the future. The department also has an employment page with information on transition and employment. The department sees the website as an evolving process that will continue to improve over time.

Community of Practice. Connecticut is one of five states recently selected for a national grant to participate in a five-year Community of Practice study.⁷⁸ The goal is to identify and implement policies and practices that support individuals with intellectual and developmental disabilities and their families across the lifespan. The expectation is that that these will serve as a national framework. Community of Practice committees has recently formed that include ASD representation and will meet monthly.

Living the Mission project. In 2013, DDS partnered with eight private provider agencies to shift agency culture and help management re-think processes to ensure a person-driven system that promotes meaningful opportunities for individuals to fully participate in their communities.

Transition Interagency Strategic Planning. Recognizing the number of workgroups and committees regarding transition and transition-related issues, DORS recently began an initiative to bring together the various stakeholders and representatives to align interests and goals. In August 2014, a two-day meeting was convened to outline the issues and develop work tracks focused on strategic planning for transition. Currently, members of the group include DORS, CSDE, DMHAS, DDS, school district personnel, and parent advocacy groups.

The goal of the initiative is to build a coordinated system to improve employment outcomes for youth and young adults. The expectation is to incorporate and build upon the work already being done (e.g., Community of Practice). The group's first meeting will be in January 2015 to discuss three priorities: 1) support students and families in navigating the transition landscape; 2) promote meaningful collaboration across agencies and schools; and 3) build outreach and engagement across the state. There is no established deadline except for two agreed upon checkpoints at six months and one year. A determination will be made whether this group will be the mechanism to continue implementation of goals or if another existing group will continue its work.

Multi-disciplinary teams. Pursuant to the recommendations of the recent Children's Behavioral Health taskforce report, DDS will establish one to three multidisciplinary teams of specially trained practitioners to assist in the transition of individuals with ASD out of treatment facilities back into the home/school environment.

PRI Committee Staff Recommendations Related to System Infrastructure

DDS, through its autism division, should continue its ongoing efforts to establish and maintain a seamless and comprehensive system for the delivery of quality and effective services for the population with ASD. As the designated autism agency for Connecticut, the DDS autism division, should be the lead entity for coordinating, where possible, the functions of the several

⁷⁸ Among the grant partners are the National Association of Councils on Developmental Disabilities and the National Association of State directors for Developmental Disabilities Services .

state agencies responsible for providing services to individuals with ASD. It should be the central entity functioning to carry out and continually update the visions and strategies set by state policy. Specifically, the PRI committee staff recommends that **the DDS autism division, as the state's lead agency for autism, should:**

- **Establish and maintain an integrated confidential data system that facilitates shared agency information.** Reliable data must be regularly collected, reviewed and analyzed to inform improvements to the system. A workgroup of state agency representatives and ASD professionals should be convened to determine the data that can be collected and establish benchmarks for monitoring progress. At a minimum, the system should track utilization of services, funding, and outcome data. To the extent possible, it should also try to align information being collected by multiple ASD organizations.
- **Serve as a one-stop resource regarding statewide resources, assessments, lifespan services, waivers, healthcare, housing, transportation, employment, education, and community supports for individuals with ASD.** The division should continue its outreach efforts to compile information about appropriate resources for all individuals on the spectrum including populations that are currently underserved. Once the division develops the proposed family resource guide for ASD, it should be routinely updating information that provides options with alternative solutions to facilitate informed choices. It should continue developing its website as a one-stop resource with an online navigator tool to help people know where to go for assistance in various domains.
- **Keep exploring opportunities to further develop and strengthen the system infrastructure through coordination of state-level work on ASD.** Whenever possible, the division should align with other interagency efforts to assist in coordination and to promote collaboration of service delivery across the lifespan. The division could examine the possibility of increasing the development and use of formal interagency and collaborative agreements. In particular, agreements that clarify roles and coordination of service delivery between health care, education, employment, and social services.
- **Identify funding sources that are flexible, diversified (public and private, state and federal), and sustainable that can be used in a variety of ways to meet the ASD population's unique, diverse, and evolving needs.** Meeting the needs of individuals with ASD is a complex and expensive undertaking that will require new funding. The division should be able to educate policy makers about the return on investment of funding across the spectrum and across the lifespan. When appropriate, it should encourage the legislature to explore new funding sources.
- **Promote outreach activities that bring together significant stakeholders and interested parties.** Better collaboration with all Connecticut public and private institutions of higher learning need to occur. Currently, the division has established good working relationships with the state university system. However, more

partnerships should be considered with private educational institutions such as Yale, which is currently developing ASD programs and services. The division could also establish more of a presence at regional interagency transition teams to identify what transition services exist in the community or are needed. Additional efforts should be made to reach job developers and potential employers as part of the planning efforts.

- **Continue to develop an ASD training infrastructure** that: 1) provides a statewide mechanism for disseminating best practices and promotes professional development for individuals working with people with ASD (e.g., educators, paraprofessionals, mental health providers, child care providers) to ensure that services are consistent and of high quality; and 2) offers education and training to increase awareness of ASD topics to community entities and persons who may interact with the ASD population (e.g., family members, law enforcement/judicial staff, employers, emergency personnel, public housing providers). In particular, it should develop a required training course that jointly serve educational personnel, vocational rehabilitation counselors, support staff at adult service agencies and contracted community providers interacting with the transition age (15 to 25) ASD population.
- **Prepare an annual progress report listing accomplishments and activities of the division and council.** At a minimum, the report should include information on: the number of children and adults with ASD who are served by the state agencies, the number of children and adults with ASD on the DDS wait lists for waiver services; the type of waiver services currently used by children and adults with ASD; the unmet service needs; measurable outcome data, potential longitudinal cost estimates both to individual and the state; and descriptions of new initiatives and proposals under consideration.