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Staff Update

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# Transitional Services for Youth and Young Adults with Autism Spectrum Disorder

September 24, 2014

Legislative Program Review  
and Investigations Committee

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Connecticut General Assembly

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Legislative Program Review and Investigations Committee  
Connecticut General Assembly  
State Capitol Room 506  
Hartford, CT 06106



### 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 autism spectrum disorder (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 will be reviewed. In particular, the study will examine 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.

Since May, committee staff has had ongoing meetings with various state agency staff on a number of cross-cutting topics including but not limited to the State Department of Education (SDE) and the Departments of Developmental Services (DDS), Rehabilitation Services (DORS), and Mental Health and Addiction Services (DMHAS).

Interviews have also been conducted with representatives of several advocacy groups, parents of children with ASD, employers, service providers, and other interested stakeholders.

#### Main Points

- **Autism spectrum disorder (ASD)** refers to a group of **developmental disabilities** characterized by difficulties in social interaction, communication, and repetitive behaviors. ASD presents on a broad spectrum from **mild to very severe**.
- **ASD has no definitive cause or cure.** There has been significant increase in ASD prevalence since 2000. Recent CDC report estimates ASD occurs in 1 in 68 children.
- Conservative estimates suggest **expansive growth** in the **number of CT high school students with ASD** in the upcoming years.
- State agency involvement with ASD population varies by individual's age and existence of co-diagnosis.
- There is distinction between clinical diagnosis and educational classification of ASD.
- Mandated by both federal and state law, **transition services** are defined by the Individuals with Disabilities and Education Act as a **coordinated set of activities** focused on **preparing students** for employment, further education, and other **post-school adult living** objectives.
- **Secondary transition begins in the ninth grade.** After academic requirements have been met, students may remain to receive transition services up to age 21. After age 21, adult services are eligibility-based and offered within available appropriations.
- There are many challenges in secondary transition for ASD students:
  - ASD is a spectrum, with **individual transition needs varying greatly**.
  - During the secondary school years, **not enough emphasis** may be given to **preparation for life after high school**.
  - **Adult services** are **eligibility rather than entitlement based**, with long waiting lists.

#### Next Steps

Examine the services and programs available for the transition of youth and young adults with ASD.

Analyze potential gaps between transitional needs and resources.

Activities to inform these efforts will include:

- Surveys of secondary transition coordinators and parents
- Analysis of data collected by state agencies
- Research on other state models and approaches

# Acronyms

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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

\*Many of these terms are more fully defined in the attached Glossary.

## Glossary

### Transitional Services for Youth and Young Adults with Autism Spectrum Disorder Study

<b>ABA</b>	Refers to “applied behavior analysis”. A form of behavior therapy often used to treat individuals with autism spectrum disorder in which environmental stimuli are manipulated in order to produce a desired response. By breaking complex skills into small steps, individuals can systemically learn to respond and behave in socially appropriate ways.
<b>ADA</b>	Refers to “Americans with Disabilities Act”. A federal law that guarantees equal opportunity for people with disabilities in employment, public accommodation, transportation, government services and telecommunications.
<b>Adaptive Behavior</b>	The ability to adjust to new experiences, interact with new people and participate in new activities and experiences.
<b>Adaptive Skills</b>	Also referred to as “functional skills” used in daily living such as eating, dressing and toileting.
<b>ASD</b>	Refers to “autism spectrum disorder”. A group of developmental disorders now defined by the American Psychiatric Association’s Diagnosis and Statistical Manual of Mental Disorders (DSM-5) as a single disorder that includes disorders that were previously considered separate: ‘classic’ autism, Asperger’s syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (PDD-NOS).
<b>Asperger’s Syndrome</b>	A term used in prior editions of the DSM which is now subsumed into the definition of ASD. It is characterized by average to above-average cognitive function, deficits in communication and social language and, sometimes, a limited range of interests or obsessive interest in a particular topic.
<b>Autism</b>	Also known as “autistic disorder” or “classic autism” is now subsumed within ASD. It is generally classified by impairment in social interactions and communication and includes some restrictive or repetitive behaviors. Sometimes used interchangeably to refer to individuals with ASD.
<b>Competitively Employable</b>	Individuals able to qualify for jobs in the same settings where non-disabled persons are employed for pay at or above minimum wage.

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<b>Developmental Disabilities</b>	A group of chronic conditions caused by mental and/or physical impairments, manifesting in childhood and expected to persist indefinitely, substantially restricts the individuals functioning in several major life activities which result in functional limitations or impairments. Examples may include intellectual disability, autism, cerebral palsy, Down Syndrome, Fetal Alcohol Syndrome.
<b>DSM</b>	Refers to “Diagnostic and Statistical Manual” for Mental Disorders. A reference manual published by the American Psychiatric Association that lists the criteria, or characteristics, of many disorders. It is used widely by medical professionals in diagnosing and categorizing mental and developmental disorders. The most recent version is DSM-V which uses ASD as an umbrella term. Previous DMS versions classified certain autism disorders separately.
<b>Entitlement</b>	Services and programs that must be provided to qualifying individuals.
<b>Executive Functioning</b>	The ability to plan, organize and follow through, as well as the ability to inhibit actions, delay responses, make appropriate choices and shift attention. Individuals with ASDs, learning disabilities and other neurological conditions often have deficits in executive function, which is important to the attainment of goals.
<b>Fifth Year Bridge Option</b>	High school students 18-21 years old who have completed their academic requirements and are receiving transition services only.
<b>Functional Impairment or Limitation</b>	A limitation in the ability to do something that a member of the general population must do in order to live independently and obtain, maintain or advance educationally or vocationally.
<b>High Functioning Autism</b>	Although not officially recognized as a diagnostic category, it usually refers to individuals with ASDs who have near-average to above-average cognitive abilities and can communicate through receptive and expressive language.
<b>IDEA</b>	Refers to “Individuals with Disabilities Education Act”. A federal law that established the rights of all children with disabilities to get a free, appropriate public education in the least-restrictive environment.
<b>IEP</b>	Refers to “Individualized Education Program”. A yearly education plan prepared by teachers, therapists, psychologists, other providers and the parents outlining the supports and services specifically designed to meet the special educational needs of a student. For students 16 years or older, it must also contain a plan for the transition to postsecondary education, or the workplace, or to help the student live as independently

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as possible in the community.

<b>Inclusion</b>	The concept that students with disabilities should be integrated with their non-disabled peers; also referred to as mainstreaming.
<b>Intellectual Disability</b>	Disability involving significant limitations in intellectual functioning and in adaptive behavior, often defined as having an IQ lower than 70. About 40% of individuals with ASD also experience intellectual disability. Mental retardation is a clinically obsolete term for an intellectual disability.
<b>Medicaid Waiver</b>	Approval from the federal government to waive federal requirements allowing a state to provide designated services to individuals and still receive federal funds. Waivers are usually time limited and must be renewed. Home and Community Based Services waiver (HCBS) services are commonly used help people remain in their homes and communities, rather than be institutionalized.
<b>Neurotypical</b>	A term to describe individuals who do not have autism, intellectual disabilities or other developmental disorders. The term is particularly popular among members of the “neurodiversity movement,” who maintain that autism is just a variation of human experience that should not be considered something to be cured.
<b>“On the spectrum”</b>	A term used to describe any diagnosis that falls on the autism spectrum.
<b>OT</b>	Refers to “Occupational Therapy” or “Occupational Therapist”. A therapist that focuses on daily living skills, sensory integration, self-help skills, playing, adaptive behavior and fine motor skills.
<b>Person Centered Planning</b>	Approach that focuses on the unique values, strengths, preferences, capacities, needs, and desired outcomes or goals of the individual.
<b>PPT</b>	Refers to “Planning and Placement Team”. A group of individuals including parents, teachers, school administrators, the student (if over age 14), and other knowledgeable individuals who together determine the specific educational needs of the student and develop, review and revise the student’s IEP. This includes determining the environment(s) in which education will take place and the staff supports needed.
<b>Rehabilitation Act</b>	Section 504 of the Rehabilitation Act of 1973 is a national law that protects qualified individuals from discrimination based on their disability in a variety of settings including schools that receive federal funding. Other sections of the Act authorize funding for the State Department of Rehabilitation Services, which provides vocational rehabilitation services, including counselors assigned to each of the

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	school districts to assist high school students in their vocational needs.
<b>Respite Care</b>	Care provided by an individual or institution to a child with a disability so that the primary caretakers, usually the parents, can have a break. Sometimes respite care is funded by state agencies.
<b>Supported Employment</b>	Work done by people with cognitive, physical, or emotional challenges involving an adapted environment or additional support staff.
<b>Transition Services</b>	As defined by IDEA for secondary education students, a set of coordinated activities or services to prepare high school students for post-school, adult living.

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# **Transitional Services for Youth and Young Adults with Autism Spectrum Disorder**

Legislative Program Review and Investigations

Staff Update

September 24, 2014

# Update Outline

- Study Focus
- Overview of Autism
- Major State Agencies Involved
- Transition Planning
- Challenges and Barriers
- Next Steps

# Study Focus

# What is the Study Focus?

- To identify the needs of, and services available for, individuals with autism spectrum disorder transitioning from secondary school to young adulthood (up to age 25)

# Activities to Date

## Interviews with:

- State agencies
- Advocacy groups
- Community providers
- Legislators with specific interest in ASD including members of the I/DD caucus
- Parents of children with ASD
- Consultants working with ASD population in other states

## Other Activities:

- Attended Autism Day at Capitol
- Toured of Walgreens Employment Training Program
- Attended M.O.R.E. Special Education Work Group Meetings and reviewed documents
- Observed Autism Advisory Council Meetings

# Overview of Autism

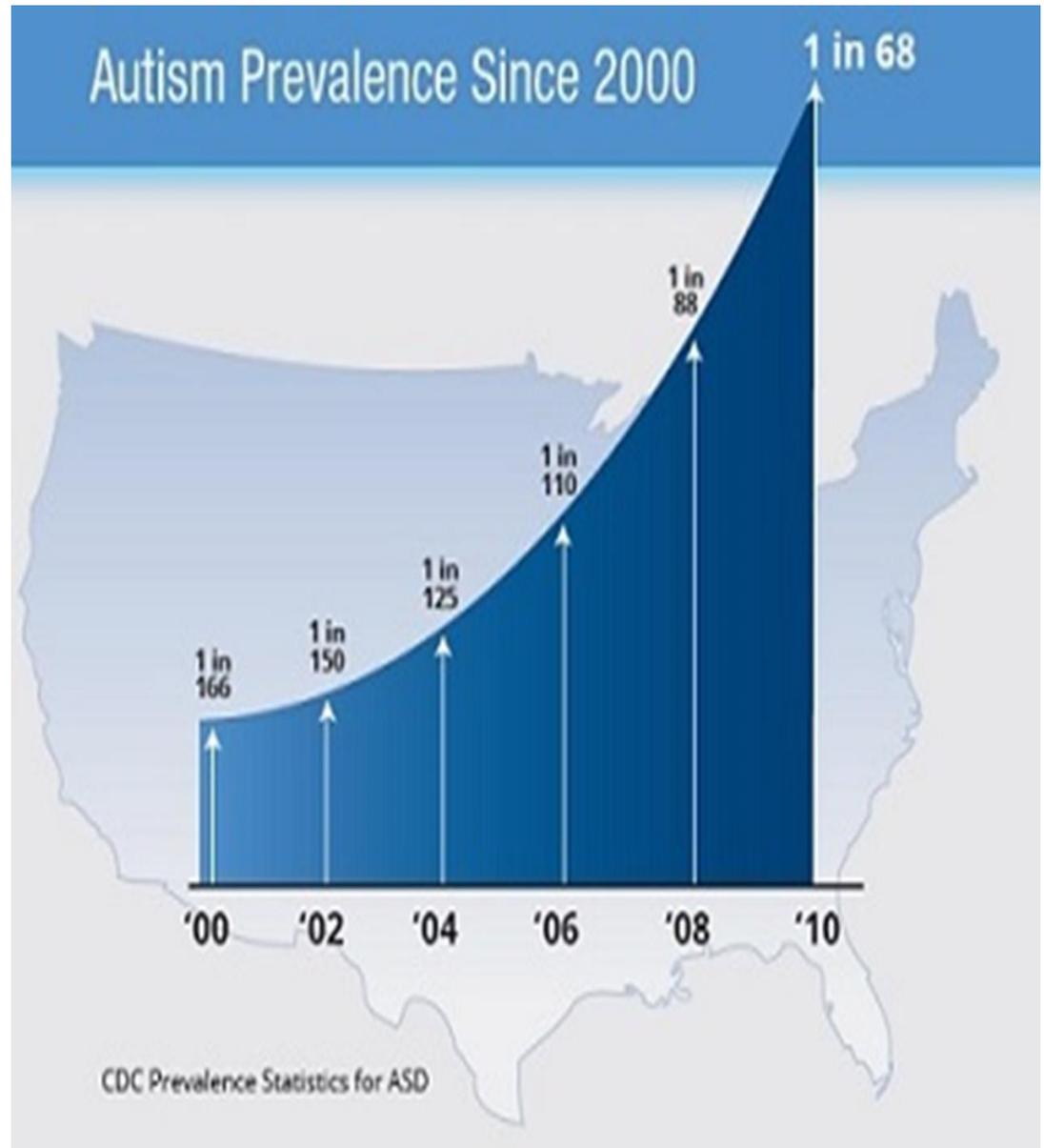
# What is Autism?

## Autism Spectrum Disorder (ASD)

- Refers to group of developmental disabilities
  - Autism disorder, PDD-NOS, Asperger's Syndrome
- Difficulty in three core areas:
  - Social interaction
  - Communication
  - Repetitive behaviors and interests
- Broad spectrum (mild to very severe)
- Lifelong condition

## How Prevalent is ASD?

- Significant increase since 2000
- Recent CDC estimates 1 in 68 youth
- Almost five times more common in boys
- Occurs in all racial, ethnic, and socioeconomic groups
- Cause unknown



# How is ASD Diagnosed?

- Clinical diagnosis vs. educational classification
  - Clinical refers to a medical/scientific diagnosis
  - Educational refers to the impact on an individual's ability to learn
- Diagnostic and Statistical Manual (DSM) is the primary clinical reference source
  - Recent change from DSM-IV to DSM-V

# How is ASD Diagnosed?

- ASD typically presents in childhood making early screening critical
- Formal diagnosis is done by a trained professional such as pediatrician
- Several screening tools and assessments
  - Varies by individual's chronological and developmental age
  - Based on observation of behaviors and abilities
  - Medical tests do not indicate autism but rather rule out other conditions
  - Harder to diagnosis in older individuals

# How is ASD Diagnosed?

- Often there are other co-existing conditions
  - Physical
    - e.g., sensory disorders such as hearing, sight, taste, touch
  - Intellectual disability (ID)
    - Approximately 40% of ASD individuals
  - Mental health
    - e.g., OCD, anxiety, depression
- Co-existing conditions may complicate diagnosis so multidisciplinary team approach is best

# Common Phrase in ASD Community

“If you’ve seen one individual with Autism,  
you’ve seen ONE individual with Autism.”

# ASD Trends in Connecticut

Using the recent CDC prevalence rate and 2011 census data, the estimated number of CT residents with ASD:

- 52,636 across all ages
- 11,790 individuals under 18 years old

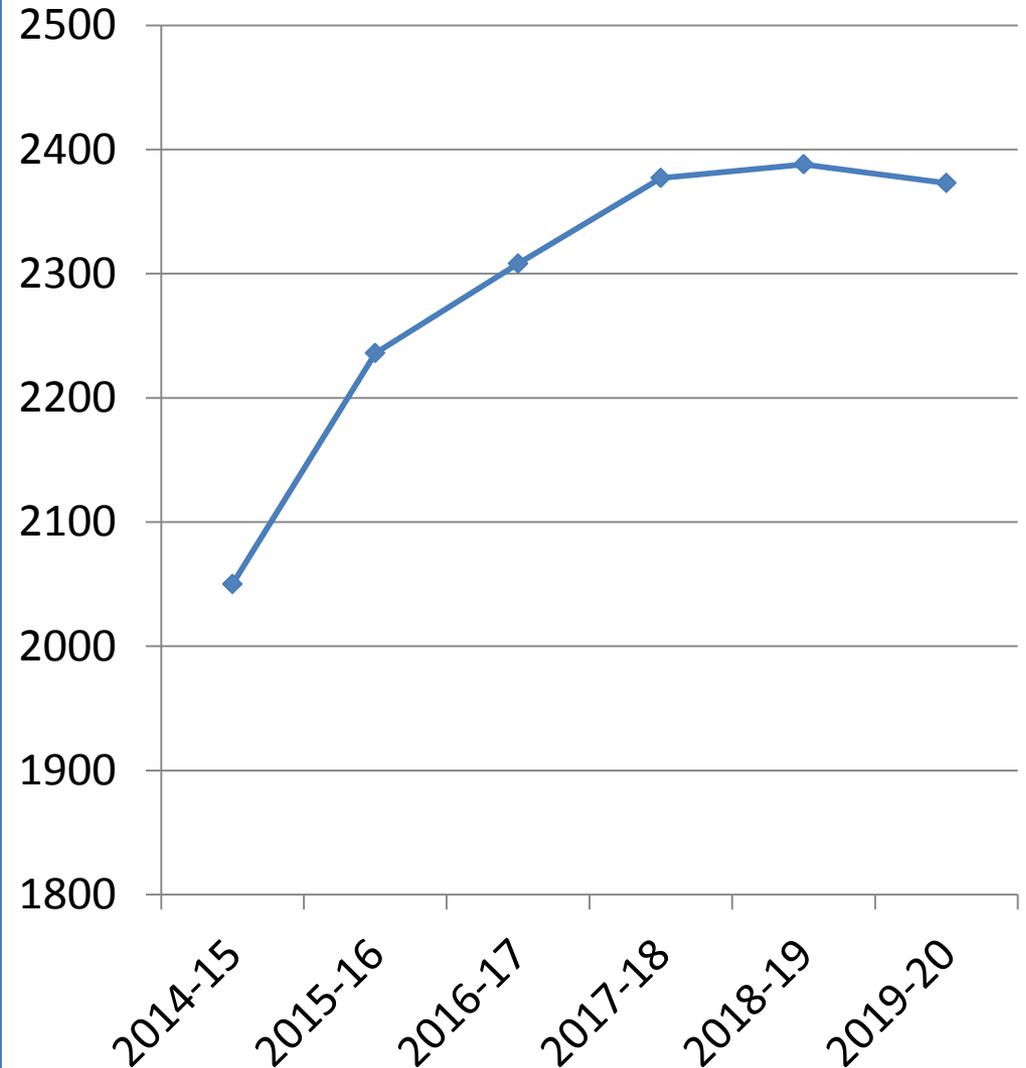
## Number of Connecticut Students with ASD

In 2013-14, there were 70,785 CT students with disabilities.

- 7,729 or (11%) had ASD
- 2,241 were in grades 9-12.
- 794 were in grade 12

Conservative projection based on existing CT student population data indicates significant increase of high school students with ASD in next few years.

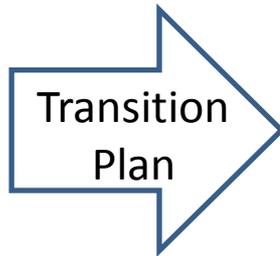
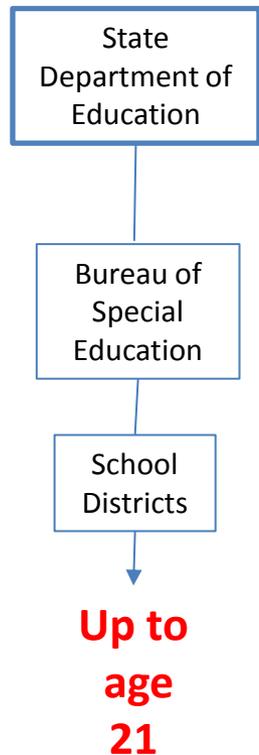
## Projection of Number of High School Students w/ ASD



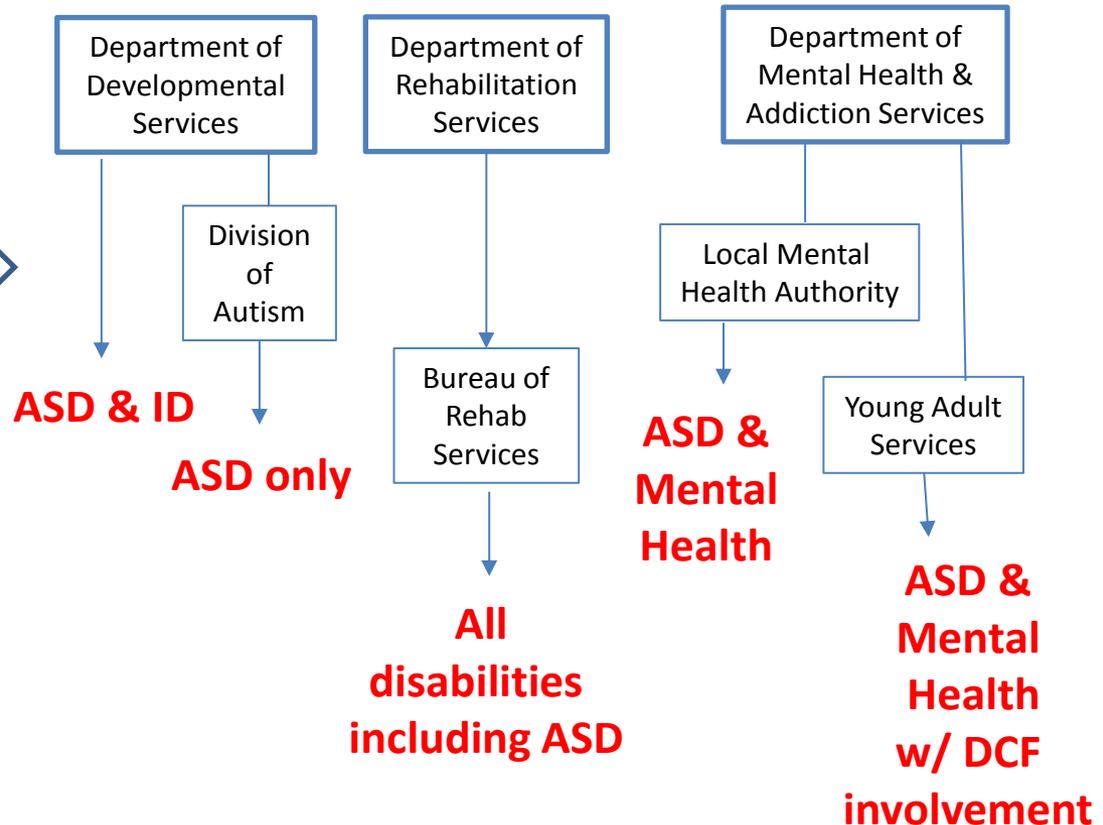
# Major State Agencies Involved

# Major State Agency Involvement for ASD Population

## ENTITLEMENT



## ELIGIBILITY BASED ADULT SERVICES



# State Department of Education (SDE)

- Bureau of Special Education within SDE works with school districts to implement various federal and state laws on special education
- Special Education students **entitled** to educational services up to age 21
- Must be provided in the least restrictive environment

# Department of Developmental Services (DDS)

- Provides various services to individuals with developmental and intellectual disabilities (i.e., IQ under 70)
- Serves ASD population in two ways:
  - Individuals with **both** intellectual disability (ID) and ASD
  - Individuals with ASD only
- Wait list for services to address residential needs is extensive
  - 682 people on wait list as of July 2014

# Division of Autism within DDS

- Serves individuals with ASD only
- Provides supports and services through Medicaid waiver
- Currently serves 114 clients
- Rapidly growing wait list
  - 283 in May 2014
  - 350 in July 2014
  - 366 in August 2014

# Department of Mental Health and Addiction Services (DMHAS)

- Serves individuals aged 18 or older with behavioral/mental health issues and co-existing ASD
- Young Adults Services (YAS) primarily for individuals with DCF involvement
- Applying for Medicaid waiver specifically for ASD and mental health

# Department of Rehabilitation Services (DORS)

- Provides employment assistance to disabled individuals who must be “competitively employable”
- 70 vocational rehabilitation counselors are liaisons to all CT high schools
  - Most have caseloads of 80-100 students
- Has summer job program for 14-24 year olds
  - This summer, approximately 200 of the 300 participants had ASD

# Who are Other Providers?

- Advocacy groups - various
- ASD specific providers
- Developmental disability providers
- Out-of-state providers

# Transition Planning

# Is There a Mandate to Provide Transitional Services?

- Both federal and state laws require transitional services for students with disabilities
- Transitional services are part of special education
- Special education must be provided from age 3 to graduation from high school or turn 21 years old

# What Federal Laws Impact Transitional Services?

- Individuals with Disabilities Education Act (IDEA)
- Rehabilitation Act
- Americans with Disabilities Act (ADA)

# What Federal Laws Impact Transitional Services?

## Rehabilitation Act

- Broadly defines “disability”
- Funds approximately 75% of vocational rehabilitation services
  - Requires they be provided to transitioning students with disabilities
- Section 504 of the Act protects the civil rights of persons with disabilities
- Requires reasonable accommodations for the disability in public schools

# What Federal Laws Impact Transitional Services?

## Americans with Disabilities Act (ADA)

- Prohibits discrimination on the basis of disability in public schools and private nonsectarian schools
- Prohibits discrimination on the basis of disability in employment
- Requires reasonable accommodations for eligible students in job training or community-based placements

# What Federal Laws Impact Transitional Services?

## Individuals with Disabilities Education Act (IDEA)

- Referred to as the Federal Special Education Law (P.L. 108-446)
- Specifies certain disabilities
- Provides some funding for special education
  - Approximately \$120 million in FY 13
- Requires provision of transitional services

# What are Key Aspects of IDEA?

- Free Appropriate Public Education
- Least Restrictive Environment
- Team Decision making
- Individualized Education Program/Transition Plan

# One of the Goals of IDEA

*...to “lead productive and independent adult lives, to the maximum extent possible”*

(U.S.C. 1400(c)(5)(A)(ii)).

# How Does IDEA Define Transition Services?

- Coordinated set of activities
- Focuses on improving academic and functional achievement for transition to post-school activities (e.g., acceptable behavior at work)
- Is individualized
- Includes instruction, community experiences, employment and other post-school adult living objectives

# What Does CT/State Department of Education Say About Secondary Transition?

- According to State Law, secondary transition planning starts in 9<sup>th</sup> grade
- Secondary transition age is formally considered to take place during ages 16-21
  - Option for special education students who completed academic requirements to remain for transition services only
- Creates a vision of what life will look like in the future after high school
- Transition is not a program; is a set of services to assist student in meeting postsecondary goals

# What Does CT/State Department of Education Say About Secondary Transition?

- Transition plans are developed as part of the student's Individualized Education Program (IEP)
- The plan requires Post-School Outcome Goals Statements in the areas of:
  - Postsecondary education or training
  - Employment
  - Independent living (optional)

# What Areas Should Transitioning Students Master by Graduation?

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

# What Areas Should Transitioning Students Master by Graduation?

Related to Career/Vocational Transition:

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

Related to Independent Living Skills:

- ✓ Take responsibility for independence and activities of daily living
- ✓ Access transportation
- ✓ Access appropriate healthcare
- ✓ Access community resources

# Transition Services for Students 18-21 Years Old

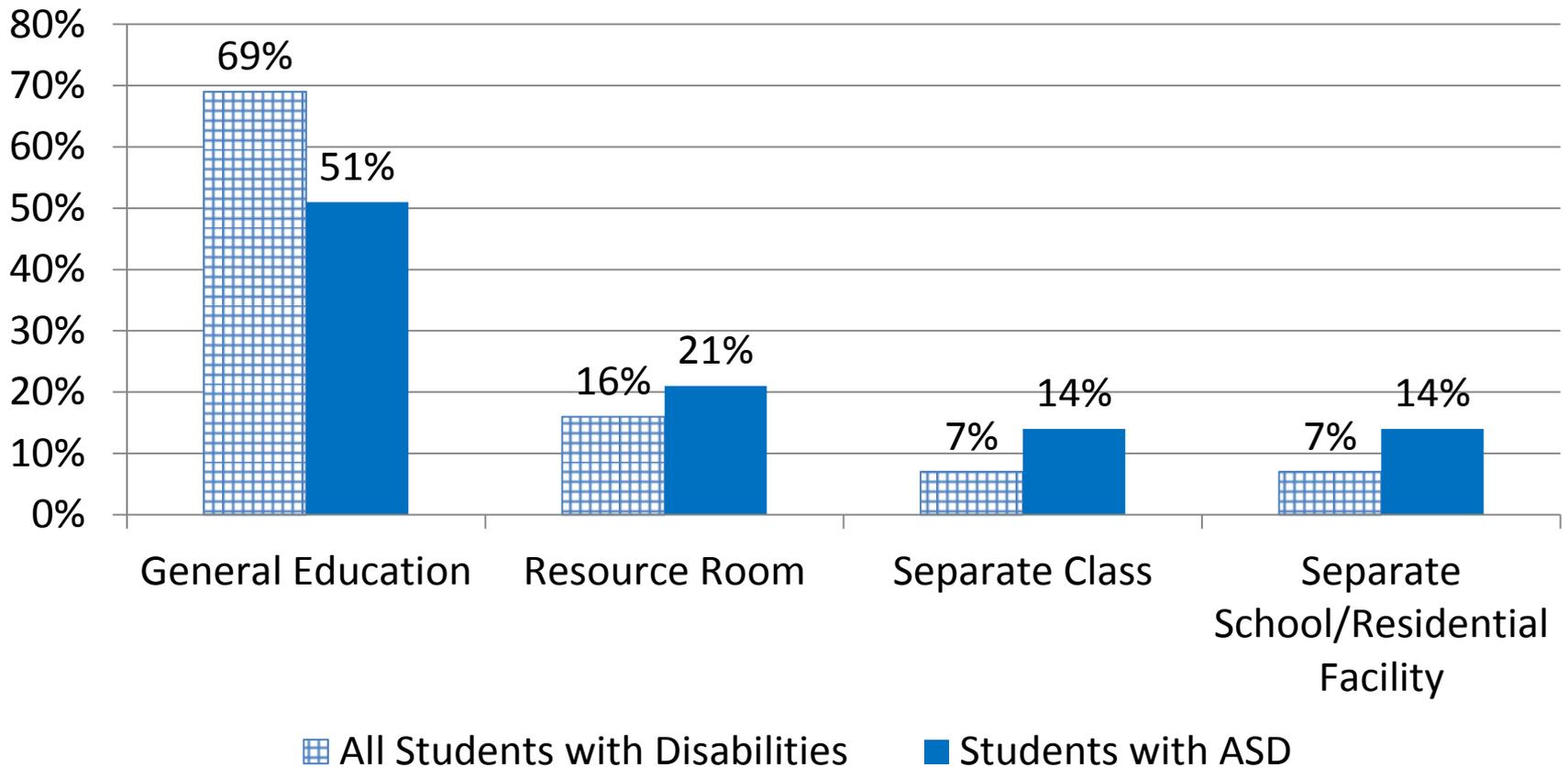
- Take place outside high school, in the community
  - In 2013-2014, 118 students with ASD participated
- Are approximately 40 Community-Based Transitional Services settings for students 18-21 located at:
  - Colleges
  - Church basements
  - Organizations in the community

# How Do We Know If The Goals of IDEA Are Being Achieved?

Requires state performance plans that measure performance in achieving IDEA

- 20 indicators
- Least Restrictive Environment (Indicator #5)
- Parental Involvement (Indicator #8)
- 2 indicators specific to Transitional Services (#13, #14)

# 2013-14 Educational Setting for CT Students with ASD vs. All Students with Disabilities (Indicator 5)



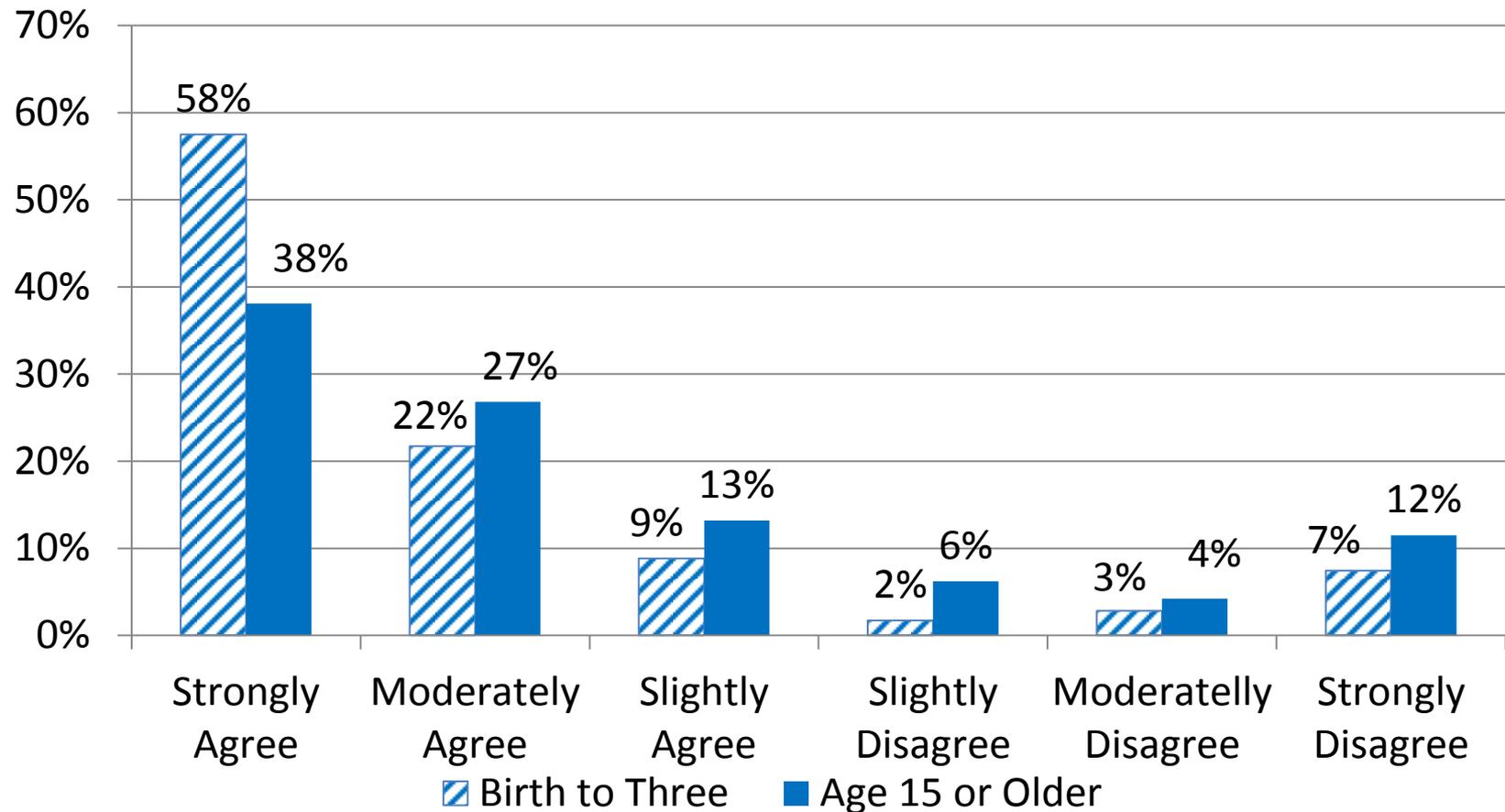
Source: CT State Department of Education.

Figures based on students identified with disabilities under IDEA.

# How Do We Know If The Goals of IDEA Are Being Achieved?

## Indicator 8:

% of Parents Agreeing School Facilitated Parent Involvement



Source: Connecticut Special Education Parent Survey 2012-2013.

# How Do We Know If The Goals of IDEA Are Being Achieved?

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

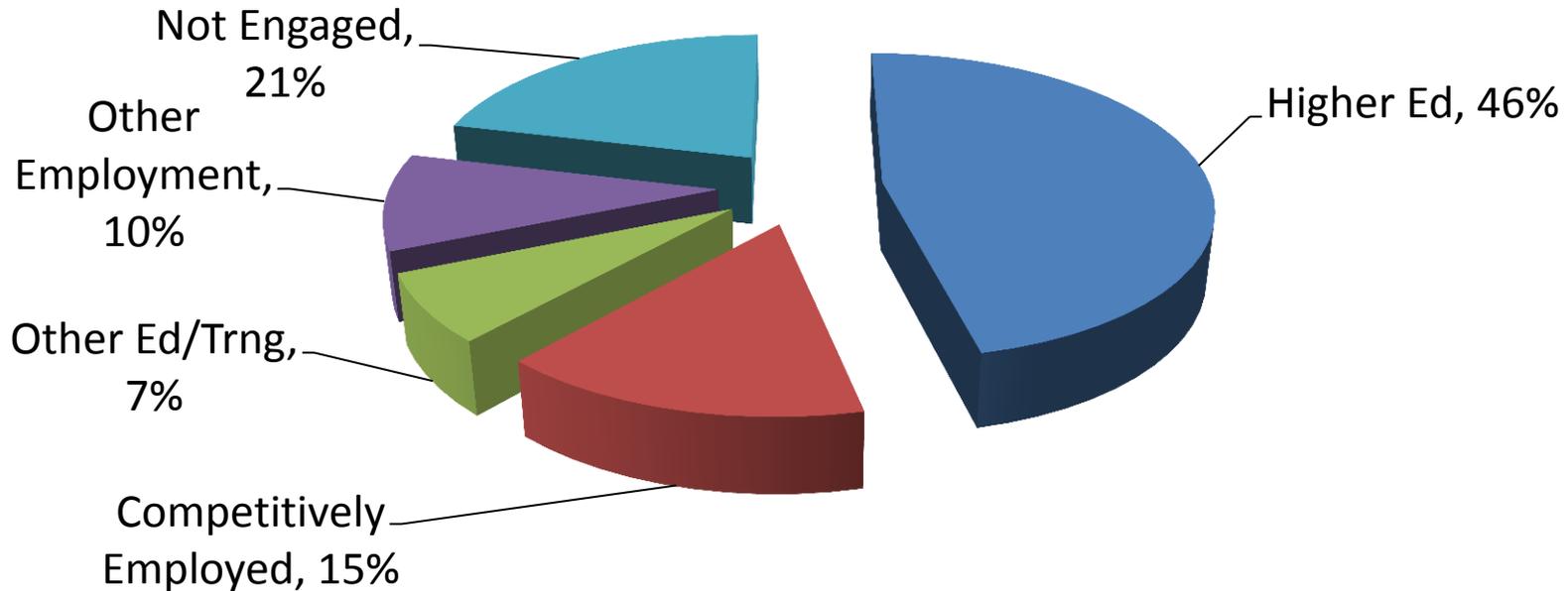
For 2011-2012 found:

- 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

# How Do We Know If The Goals of IDEA Are Being Achieved?

- Indicator 14: One year after leaving high school, percent of youth in college or employed

## Outcomes for 2008-2009 Exiters



# Challenges and Barriers

# What are Some of the Challenges in Transitioning for Youth and Young Adults with ASD?

- ASD is a spectrum—needs vary greatly and are quite individualized
- Emphasis on academics vs. functional areas
- Focus may not have been on next steps

# What are Some of the Challenges in Transitioning for Youth and Young Adults with ASD?

- Reliance on education system not readily replaced when student graduates
- Isolation
- Transportation
- Training and credentialing of providers

# What are Some of the Challenges in Transitioning for Youth and Young Adults with ASD?

- Agencies potentially able to provide assistance at the next step are eligibility based
  - Entitlement vs. Eligibility
- Program and services funding
  - Limited number of waiver slots
  - Long waiting lists
- Cost

# Next Steps

# What are the Next Steps?

- Examination of the Services and Programs
  - Employment/Financial Support
  - Education/Vocational Training
  - Residential
  - Life Skills
- Continued Data Collection From Key Stakeholders
  - Survey of transition coordinators
  - Survey of parents
  - Data requests from agencies
- Research on Other State Models and Approaches

# **Transitional Services for Youth and Young Adults with Autism Spectrum Disorder**

Legislative Program Review and Investigations

**Public Hearing**

Today at 1 pm in Room 2D

For copies, see PRI Study Page: [www.cga.ct.gov/pri/2014\\_ASD.asp](http://www.cga.ct.gov/pri/2014_ASD.asp)