

Transitional Services for Youth and Young Adults with Autism Spectrum Disorder

Legislative Program Review and Investigations

Staff Findings & Recommendations

December 17, 2014

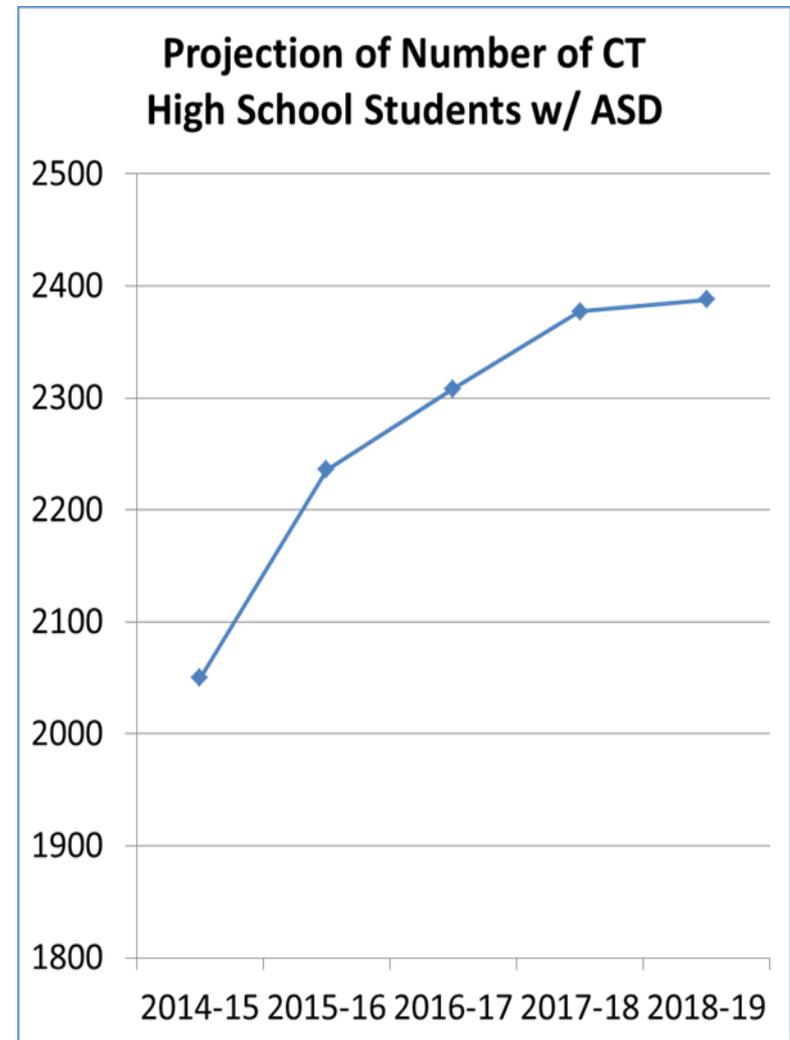
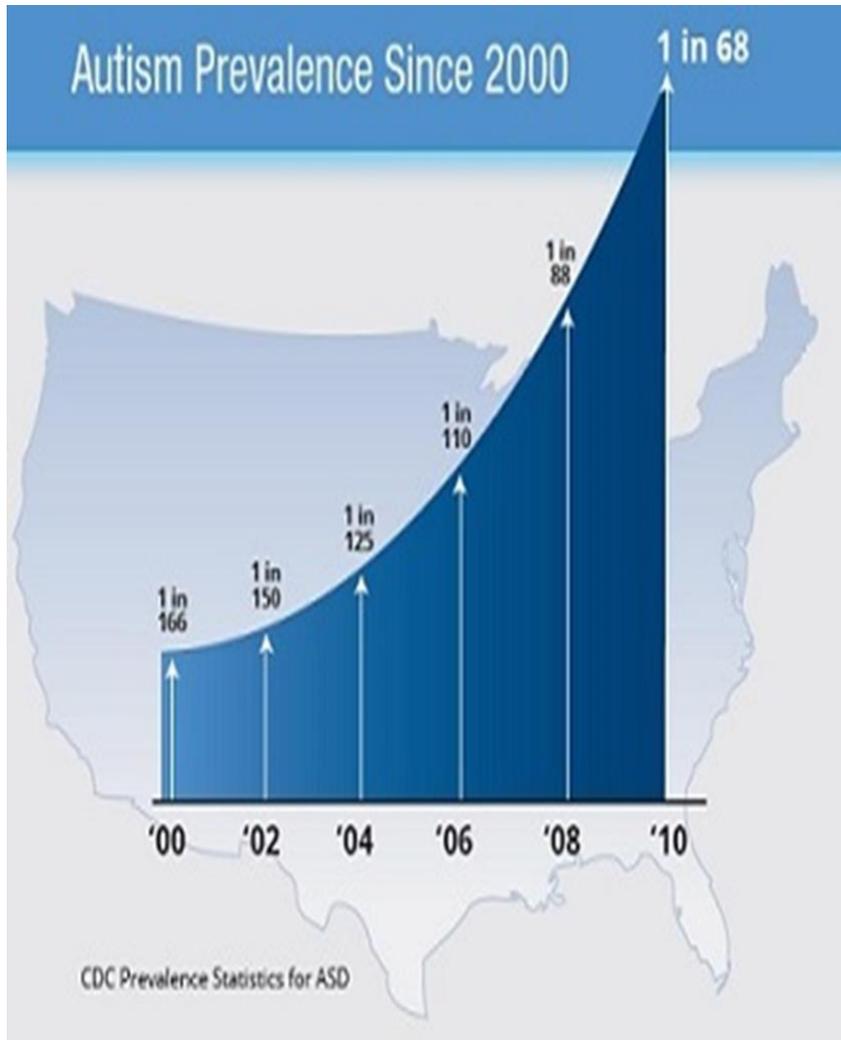
Study Focus

- 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)

Presentation Outline

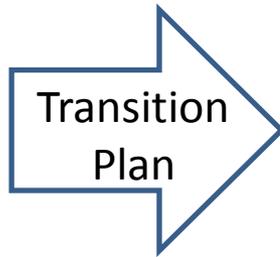
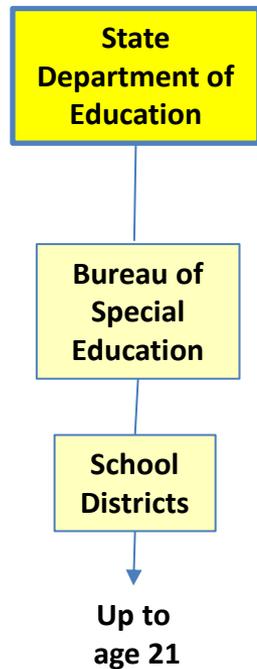
- Overview of trends, major agencies, study methodology
- Recommendation Areas:
 - Transitional Services During High School
 - Post-Secondary Education
 - Post-High School Employment/Vocational Services
 - Post-High School Independent Living
 - Supports for Independent Living
 - System Infrastructure

Prevalence of ASD

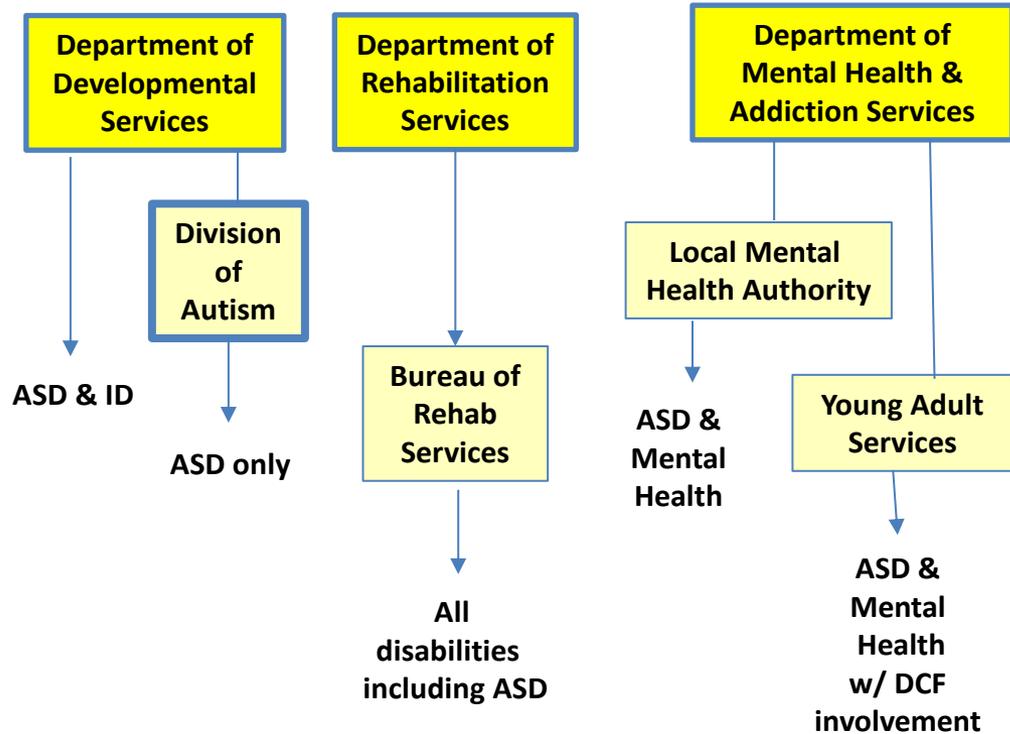


Major State Agency Involvement for ASD Population

ENTITLEMENT



ELIGIBILITY BASED ADULT SERVICES



Study Methodology

PRI staff sources of information:

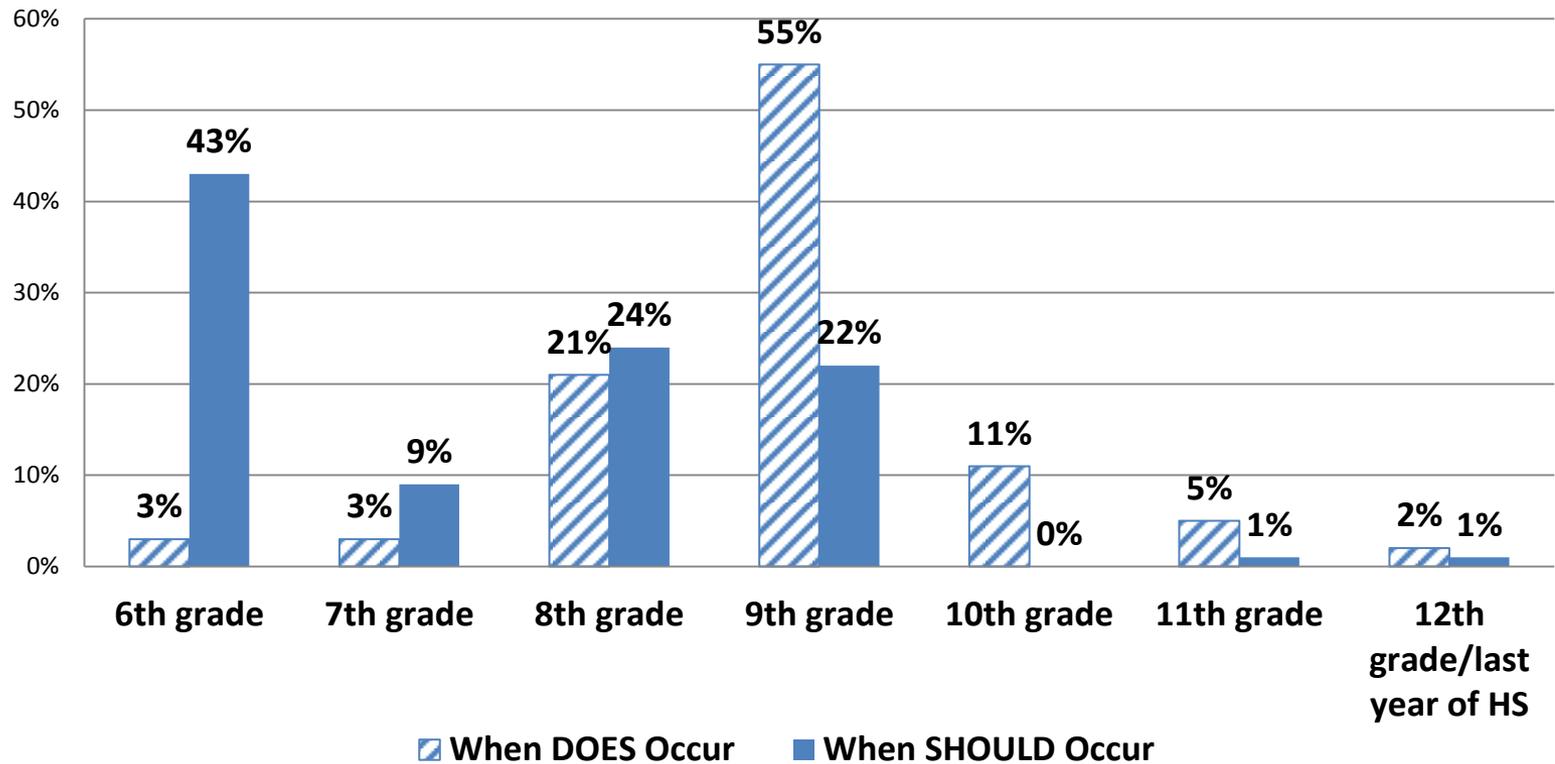
- Literature review
- Interviews w/ key stakeholders
- Public hearing
- Tours and visits
- Attendance at autism-related meetings and events
- **PRI Surveys:**
 - **Transition Coordinators (174)**
 - **Parents of transition-age youth (236)**
- CSDE
 - Special Education Parent Surveys
 - Post-School Outcome Surveys
- DDS
 - Client dataset
 - DDS & ASD Wait Lists
- DMHAS
 - Client dataset
- DORS
 - BRS case closure data

Transitional Services During High School

Rec. #1: CSDE promote best practice of earlier establishment IEP goals related to transition to adult life

Finding: Need earlier establishment of IEP transition goals.

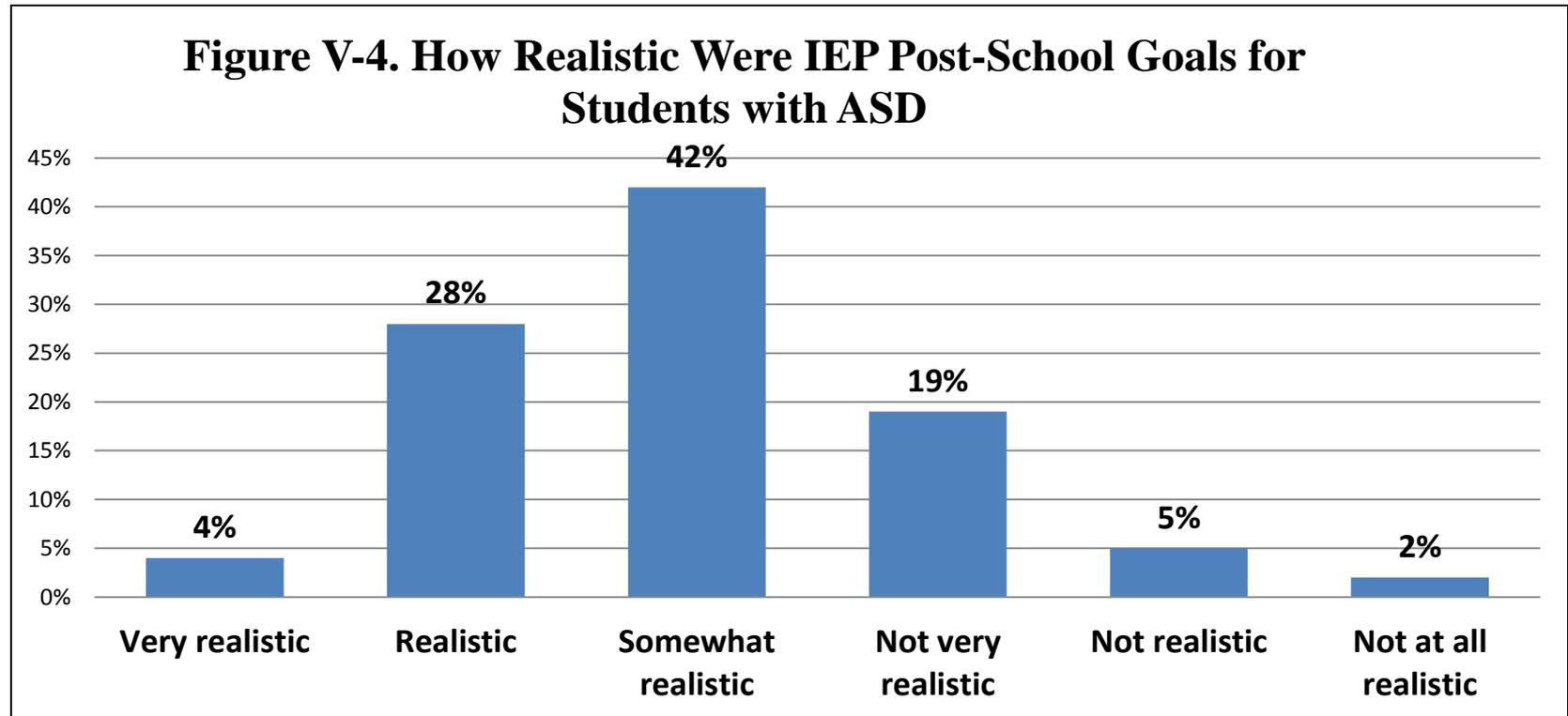
Figure V-3. When School Districts DO vs. SHOULD Start Writing IEP Transition Goals



Rec. #2: CSDE train transition coordinators on more realistic, specific IEP post-school goals

Finding: Need for more realistic, specific IEP post-school goals

- Parents most often described transition goals as “too broad”



Rec. #3: CSDE require schools to use the Secondary Transition Planning IEP Checklist

Finding: While not often used, the Secondary Transition Planning IEP checklist would promote stronger transition plans

- Checklist intended for use by schools to assess whether IEP goals and transition services are coordinated, measurable, etc.
- More than one-quarter couldn't say how often it was used
 - Two-thirds who could estimate said it was used no more than half the time
 - 75% said the checklist wasn't always being used because it was not required

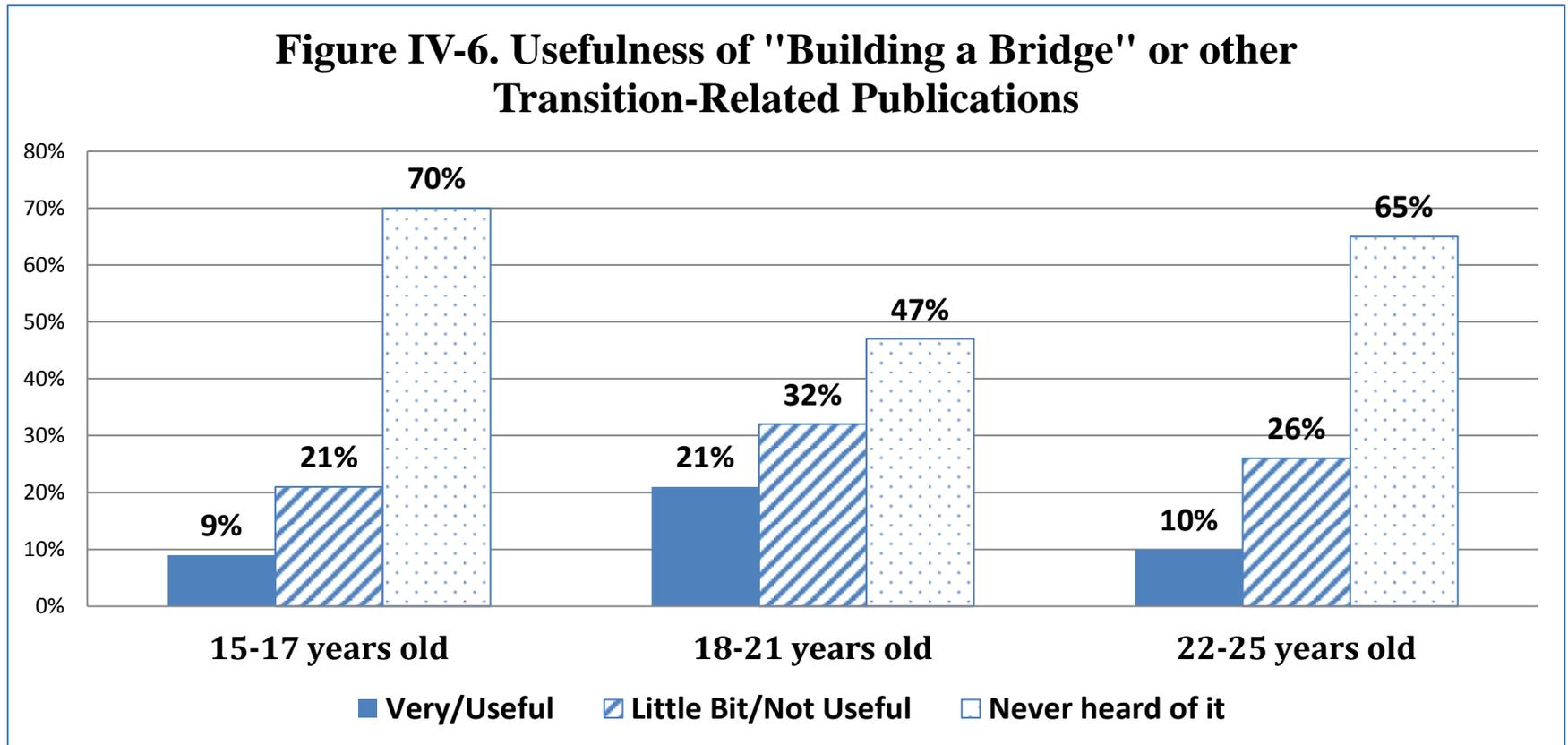
Rec. #4: CSDE monitor implementation of the Student Success Plan

Finding: Need to implement the Student Success Plan

- Beginning 7/1/12, every student in grades 6-12 required to have a Student Success Plan (SSP)
 - Plan addresses academic and career development, and social, emotional and physical well-being
- One-third of survey respondents didn't know how often SSP was being used
 - 41% said it was used for all or many students in grades 6-12
- Over half though the SSP would be helpful in preparing students with ASD for life after high school

Rec. #5: CSDE monitor requirement for parents to receive transition-related materials, and should revise “Building a Bridge” to be more useful to parents

Finding: Need for better distribution of publications helpful to transitional services



Finding: Parents and students need greater awareness of transitional services-only option, transition materials, Student Success Plans, and benefits of realistic, specific goals

- The most frequent reason parents gave for their sons/daughters not remaining in high school to receive transitional services-only was they did not know the option was available
- Evidence that receipt of transitional services-only, and realistic and specific transition goals are beneficial to both students and parents
- Many parents had never heard of or received materials related to transition, and also may not be aware of the requirement for a Student Success Plan

Rec. #6: CSDE develop and distribute Parents Bill of Rights to include:

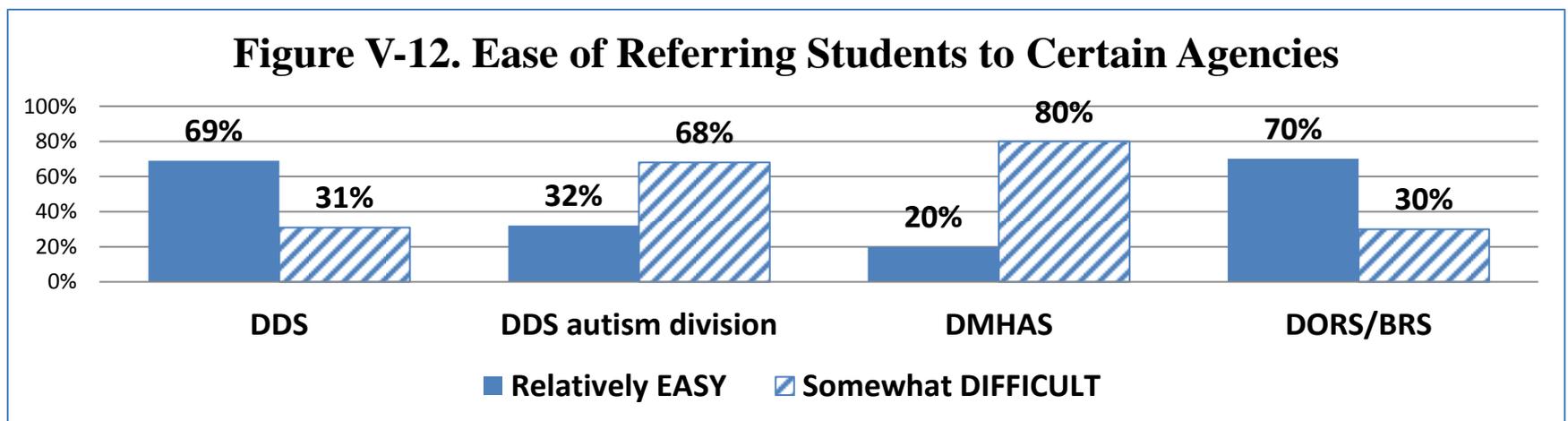
- Parents have right to ask for consideration of transitional services-only (18-21 program)**
- Parents are entitled to receive certain transition-related materials (e.g., “Building a Bridge”)**
- Their son or daughter is required to have a Student Success Plan**
- Their son or daughter needs realistic and specific IEP post-school goals**

Rec. #7: ASDAC find ways to improve interaction between agencies and transition coordinators, and between agencies and parents

Findings: Transition coordinators report that DDS Division of Autism Spectrum Services and DMHAS are:

- somewhat inaccessible and difficult to make referrals to
- less likely to attend PPT meetings if invited or make outreach efforts to students and families

Transition coordinators want greater access/consistency about available services



Rec. #8: CSDE consider feasibility of recommending law similar to the Massachusetts “Turning22Law”

Finding: One state requires high schools to identify the appropriate adult state agency that will be needed by students with disabilities once they exit high school

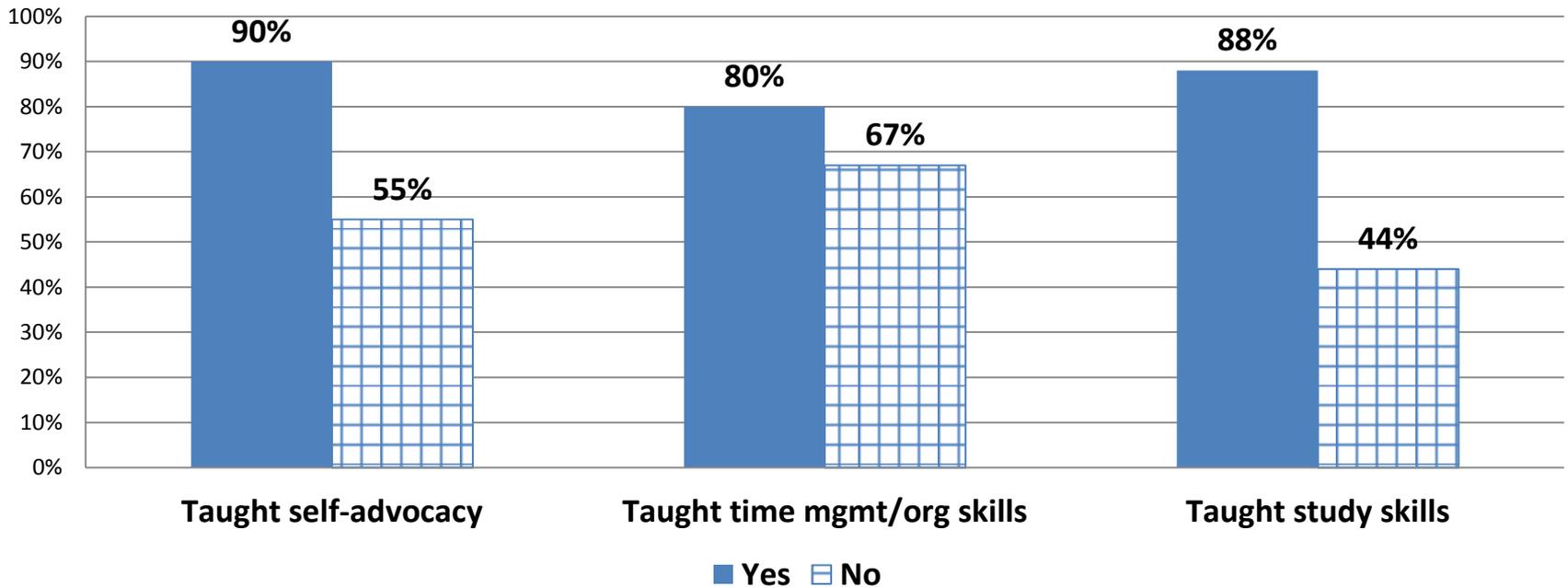
- Called the Turning22Law
- Requires high school students with disabilities to participate in a two-year planning and referral process prior to exiting high school
- Plan requires identification of adult state agency that can best meet the needs of the exiting student
- Helps agencies anticipate demand and develop needed funding requests

Transitional Services Related to Post-Secondary Education for Students with ASD

Rec. #9: CSDE train transition coordinators to develop IEP goals related to self-advocacy, time management/organization, and study skills

Finding: Need adequate preparation for college during high school

Figure VI.4. College Student Skills Taught in High School and Satisfaction with Life



Rec. #10: For college-bound, IEP or SSP should consider goals decreasing reliance on supports

Finding: To prepare students for college, the high school experience needs to more closely mirror the college experience

- Supports may have been put in place during high school
- Although some accommodations available in college, not as comprehensive or intense
- The need to taper off supports must be a belief shared by all parties involved

Rec. #11: CSDE publicize advantages of college immersion

Finding: Another strategy for helping high school students anticipate the college experience, and be better prepared is an immersion experience

- An immersion experience offers a taste of college life in a supportive environment
- Examples include:
 - “boot camps” the summer before freshman year
 - summer bridge programs

Rec. #12: Board of Regents (BOR) consider replicating Step Forward programs at other CT community colleges

Finding: Gateway Community College serves students with ASD through two programs

- Step Forward I for high school students (\$21,000 per year)
 - Interpersonal communication skills, career exploration, and work readiness
 - Reduce reliance on high school accommodations
- Step Forward II for post-high school (\$21,000 per year)
 - Work experience
 - May attend college classes
 - > 90% complete programs; 2/3 successfully complete college classes

Rec. #13: BOR consider replicating Disability Resource Center model to other CSUs

Finding: SCSU serves students with ASD through the Disability Resource Center

- Program available free of charge to all students who self-identify
- Provides “wraparound” services:
 - Weekly one-on-one meetings for ½ hours with staff person
 - Assistance with course selection
 - Special math sections
 - Foreign language substitutions
- >90% remain at SCSU through calendar year

Rec. #14: UConn consider replicating Beyond Access program at other UConn campuses

Finding: UConn serves students with ASD through the Beyond Access program

- Serves students with ASD (20%) and other disabilities
- Track I: Students meet with strategy instructor 3 hrs/week (\$3,400 per semester)
- Track II: Students meet with strategy instructor 1 hr/week (\$1,700 per semester)
- Work on time management, study skills, stress management, etc.
- 36 of 38 program participants with ASD graduated from UConn since 2008 (95%)

Transitional Services Related to Post-High School Employment and Vocational Services

Rec. #15: The ASD Advisory Council (ASDAC) identify ways to increase use of vocational programs

Finding: Need for greater accessibility/availability of vocational programs for individuals with ASD

- Both parents and transition coordinators surveyed by PRI reported challenges accessing vocational programs
 - 60% of transition coordinators agreed that “Vocational programs are difficult to get into”
 - 80% of parents of children with ASD aged 15-25 agreed with the statement

Rec. #16: Department of Rehabilitation Services (DORS) clarify eligibility for Bureau of Rehabilitation Services (BRS) through info campaign

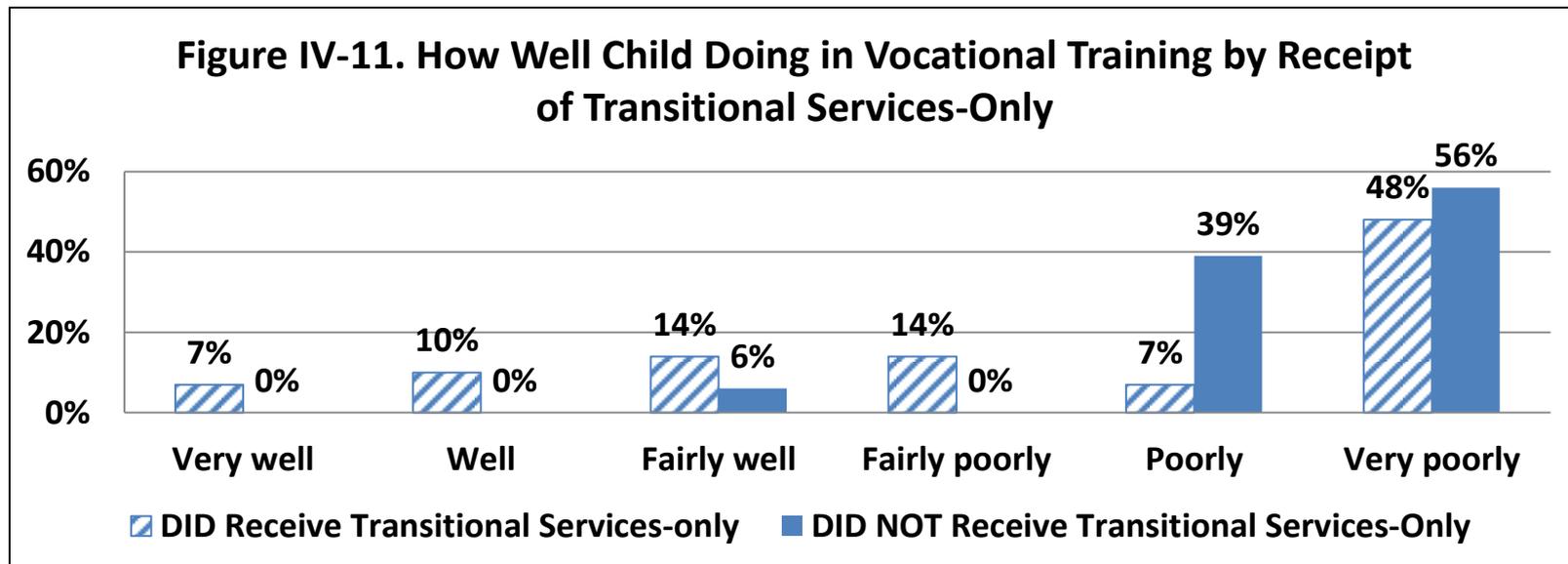
Finding: Need to clarify eligibility for Bureau of Rehabilitation Services (BRS)

- Who may receive assistance from BRS?
 - BRS may **only** assist individuals who can become competitively employed.
 - With the exception of the Employment Opportunities Program (EOP), BRS only provides **short-term** (time-limited) vocational rehabilitation (doesn't matter if on another agency's waiting list for services).
 - If need long-term supports, then source identified before BRS can provides initial short-term (time-limited) services
- Inconsistency of information from BRS personnel

Rec. #17: Local school districts provide transitional services for students interested in vocational training and competitive employment

Finding: Need to provide transitional services for students interested in vocational training and competitive employment

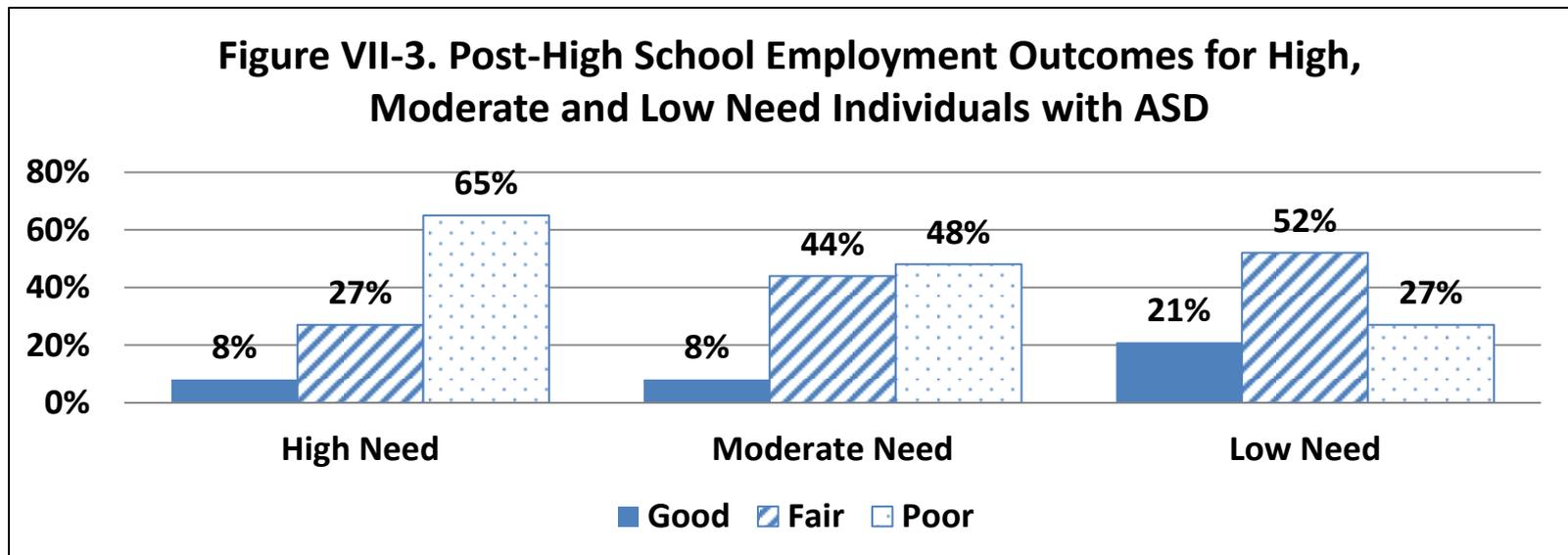
- Many students struggled in the area of vocational training
- But former students who had received transitional services-only did somewhat better in this area



Rec. #18: DORS promote advantages of at least part-time employment

Finding: Need to promote advantages of working part-time vs. not at all

- Individuals with ASD more likely to be employed part time than full-time
- In national study of young adults with disabilities, young adults with ASD averaged the lowest number of hours worked (24 hours per week)
- Regardless of the number of hours worked, high school exiters responding to who were competitively employed expressed greater satisfaction with life.



Rec. #19: DORS take lead on developing an info campaign on impact of employment on benefits

Finding: Need to understand impact of employment on benefits

- Parents confused about how employment would impact federal and benefits such as social security and Medicaid
- This confusion causes parents to discourage employment for their sons and daughters
- Need to provide training in this area including “work incentives”

Rec. #20: CSDE work with transition coordinators to address advantages and logistics of youth employment with parents

Finding: Need for parents/families to play a role in supporting students in their employment efforts

- Pilot to promote increased employment for graduating students with disabilities found:
 - Families were unprepared for child’s employment schedule
- A BRS pilot with some school districts found disconnect for parents about life after high school
 - Families unprepared to support sons/daughters in their jobs, especially transportation to and from work
- Parents need to understand the importance of employment in the transition to adulthood

Rec. #21: CSDE and BRS promote summer employment while students with ASD are still in high school

Finding: Need to encourage summer employment while in high school

- One of the best predictors of future employment is high school summer job
- National Collaborative on Workforce and Disability for Youth recommends summer jobs
 - Gain valuable work experience
 - Prepares student for work when older

**Rec. #22: Department of Developmental Services (DDS)
consider establishing full-time employment position**

Finding: Despite increasing emphasis on employment for all DDS clients, there is currently no position dedicated to the promotion of employment

- DDS placing increasing emphasis on employment
- An evaluation DDS by a national employment network recommended DDS consider creating a full time position focused on employment

Rec. #23: DORS take lead in developing shared definition of “competitive employment”

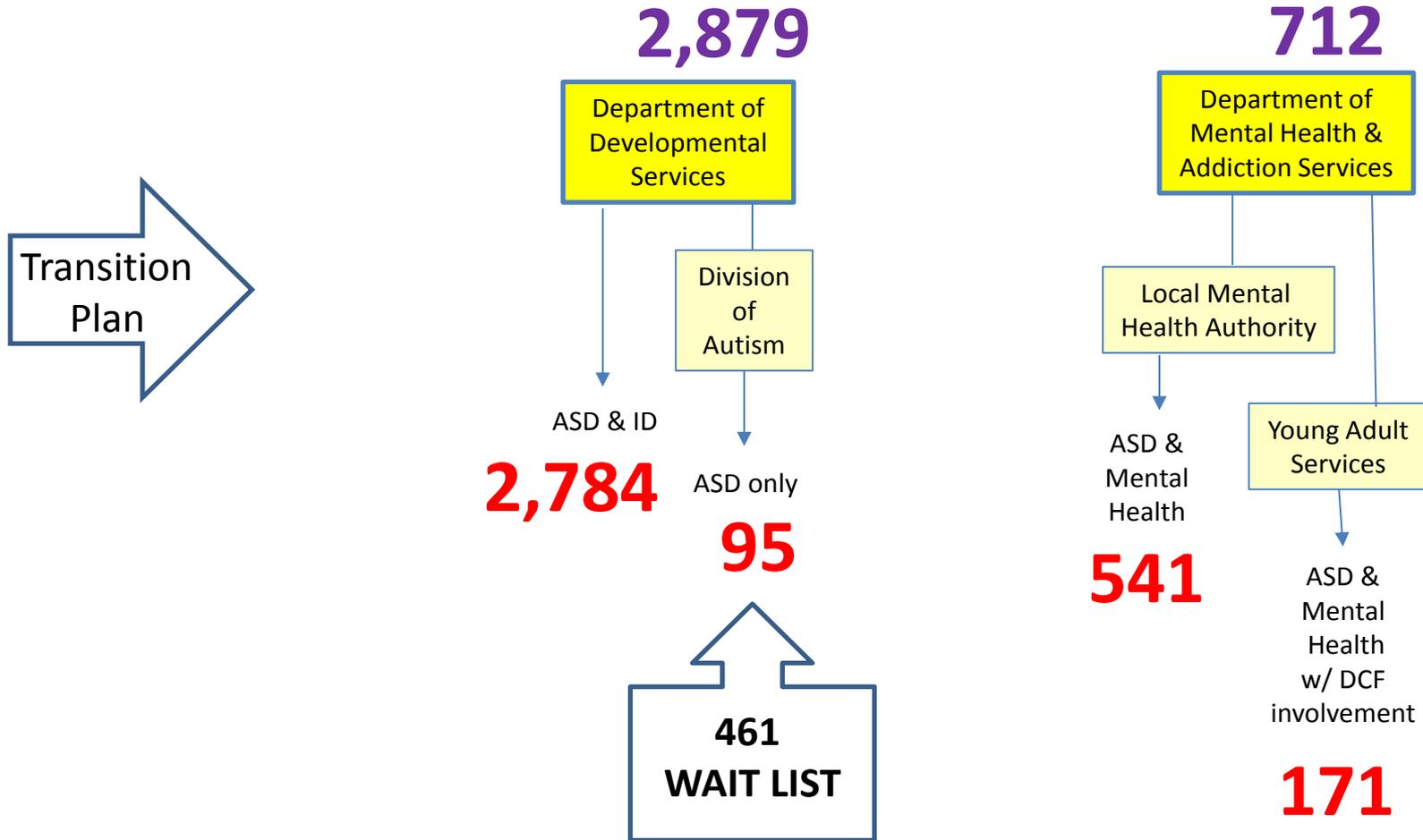
Finding: Need to understand what is meant by “competitive employment”

- Different state agencies define “competitive employment” in different ways.
- Depending on the definition of “competitive employment”, the number of employed individuals can vary significantly.
 - E.g., either 13% or 41% of high school exiters are competitively employment depending on definition used
- 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.

Post-High School Independent Living

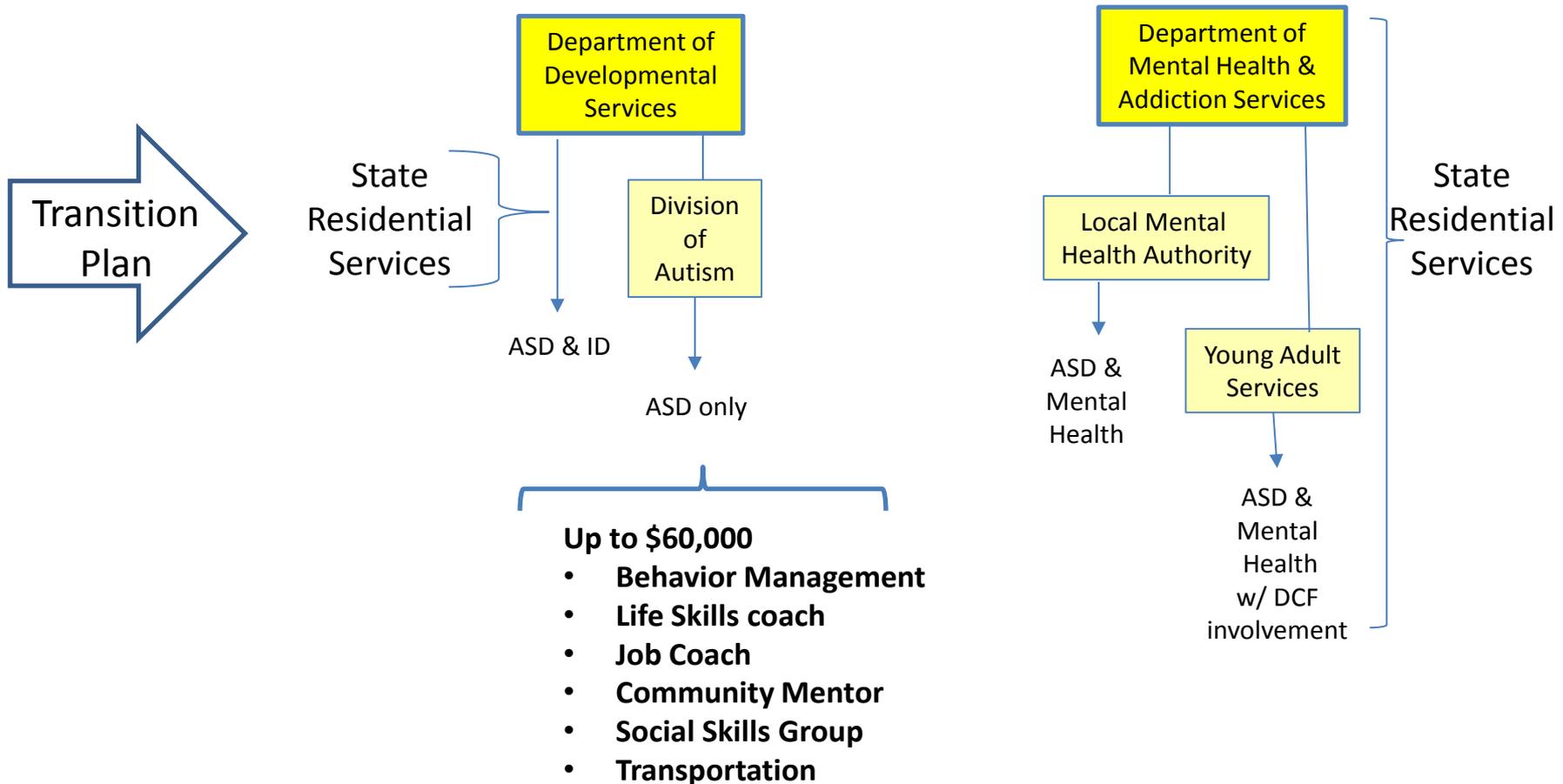
Major State Agency Involvement for ASD Population

ELIGIBILITY BASED ADULT SERVICES



Major State Agency Involvement for ASD Population

ELIGIBILITY BASED ADULT SERVICES



Challenges and Barriers

- Wait lists exist for all residential services offered by state agencies.
- Limited state residential supports are available for 'ASD only'.
- Broad range of spectrum needs may require new and different residential models to be considered.
- Families need information and guidance on traditional and alternative options.

Rec.#24: DDS consider establishing a housing coordinator position for the autism division. Within available resources, assist ASD wait list families to develop an individual housing plan.

Finding: Limited state residential supports are available for ‘ASD only’ population.

- ASD waiver doesn’t allow for much residential support.
- Existing state options limited to those w/ co-occurring condition (ID or MH).
- State housing options have long wait lists or only available under crisis situations.
- Without state options, must remain in family home or self-pay for private providers, sometimes at expensive rates.

Rec.#25: Establish a one-stop housing resource for individuals with ASD

Finding: Families need information and guidance on traditional and alternative residential options.

- Families often surprised at long waiting lists (sometimes 5 or more years).
- Residential models and options may seem similar and can be confusing.
- Families seeking own housing solutions may be unfamiliar on how to proceed or not jeopardize benefits.

Rec.#26: Establish ASDAC subcommittee on housing to produce a report on the present and future ASD residential needs, best practice guidelines, and plan of action proposals.

Finding: Without options, the demand for residential services will likely reach crisis level.

The group should:

- Examine the array of housing options that work for spectrum
- Survey wait list families to anticipate demand
- Collaborate w/ housing officials and developers to explore public/private partnerships
- Review whether:
 - Existing models for ID work for ‘ASD only’
 - Existing regulatory structure discourages or restricts options
 - More flexibility is possible or needed to facilitate use of waivers

Supports for Independent Living

State Supported Services

- Medicaid
 - State Plan outlines coverage
- Medicaid Waivers
 - optional, five-year approval, capped
 - DDS has 5 waivers; one specific for individuals w/ ASD aged three and older
- State appropriations for programs & services

Recent Development

- New Medicaid State Plan Amendment
- CMS allowing coverage for ASD services previously not funded under Medicaid
- Will help many of the individuals on wait list who are Medicaid eligible
- Does not apply to Children's Health Insurance Program (HUSKY B)

Challenges and Barriers

- Limitation of resources to expand ASD waiver
- Requires long-term supports
- ‘One size fits all’ approach doesn’t work for ASD spectrum
- Lack of transportation and life skills
- Significant financial burden for families
- Families need navigational & coordination support

Rec.#27: DSS w/ DDS should examine feasibility of providing children served in the HUSKY B program with the same coverage being considered under the Medicaid State Plan amendment.

Finding: Proposed changes in new Medicaid State Plan Amendment do not apply to Husky B.

- New Medicaid State Plan Amendment will expand ASD coverage for medically necessary services under Early and Periodic Screening, Diagnostic and Treatment (EPSDT) up to age 21.
- EPSDT does not apply to Husky B leaving this group of youth out of expanded ASD coverage.
- Expanded coverage allows for a range of services not previously funded.

Rec.#28 : Division survey of the individuals and families on ASD wait list to compile information on immediate and upcoming needs and their levels of existing resources and support.

Finding: Dramatic increase in ASD wait list suggests there is significant demand not being met.

- Limited information captured on ASD wait list families.
- Division does not monitor what particular services are being sought.
- Survey results can be used for planning and perhaps prioritizing assistance.

Rec.#29: ASDAC should consider establishing subcommittees on transportation and life skills.

Finding: Lack of transportation and long-term supports negatively impacts ability to live independently for many individuals w/ ASD.

- Transportation one of frequently mentioned challenges by families, providers, and professionals.
- Depending on location, availability of public transportation can vary.
- Difficulties w/ executive functioning (e.g., problem-solving, managing new situations) is a challenge in obtaining skills to live independently or with lower levels of supervision.

Rec.#30: Create an interim family grant program for the 'ASD only' population similar to one established for individuals with intellectual disabilities to help offset disability- related expenses.

Finding: Financial burden is significant for families caring for relative w/ASD.

- Beyond medical costs, many families require non-medical services with high out-of-pocket spending.
- Family grant program already exists for individuals with ID.
- Temporary grants can be lifeline for many families.

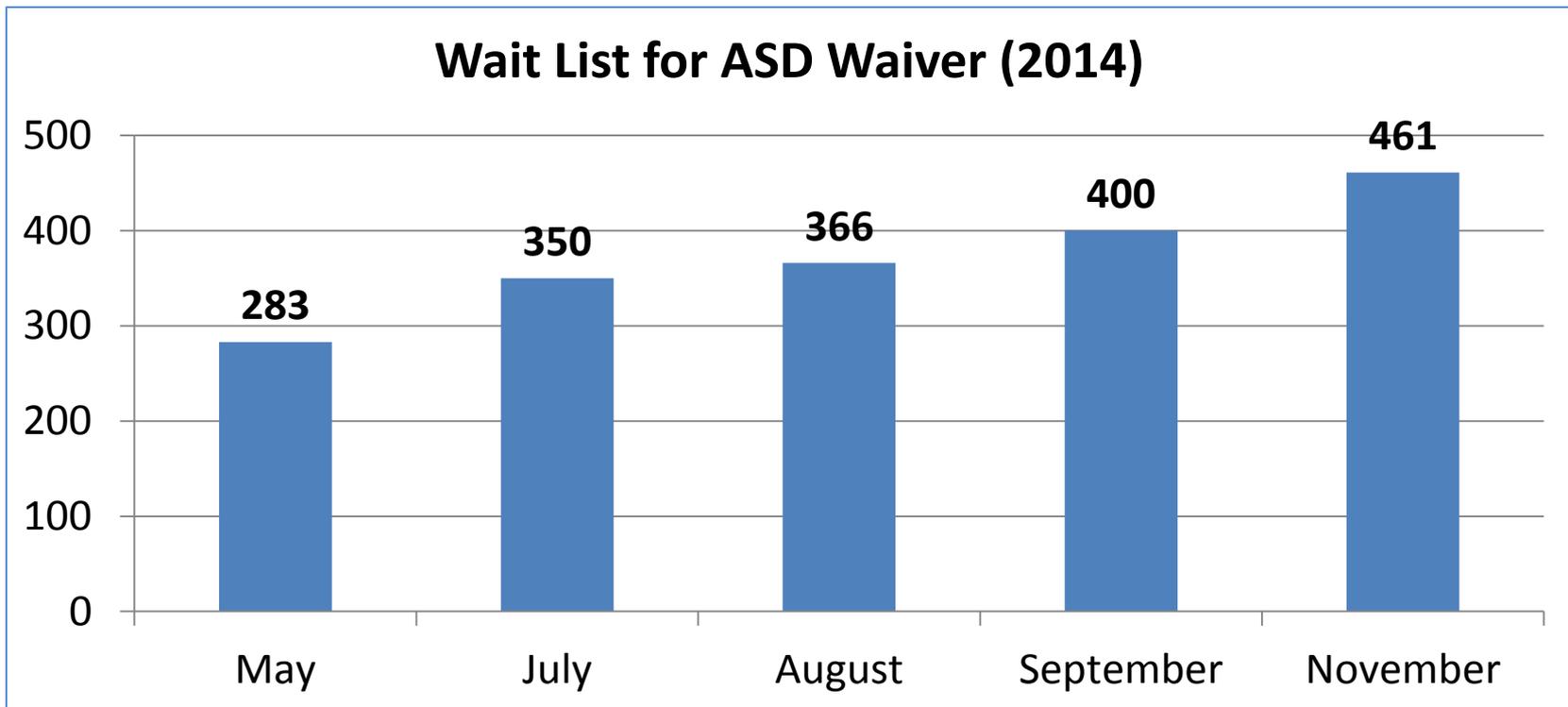
Rec.#31: Consider passing Achieving a Better Life Experience (ABLE) act modeled after the federal legislation.

Finding: Another way to financially assist families is through creation of tax-free accounts for disability-related expenses.

- Allows families to save for expenses without jeopardizing government benefits.
- Withdrawals allowed for qualified disability expenses.
- Bi-partisan legislation being considered by federal government and expected to pass.
- Massachusetts just passed own version.

Rec.#32: Within available appropriations, consider hiring additional ASD resource specialists.

Finding: Volume of wait list makes it untenable for two staff to manage requests, home visits, and perform outreach events.



Rec.#33: Division should have access to education and transition advisors, upon request & w/in availability, for 'ASD only' population to provide guidance or referral to other supports.

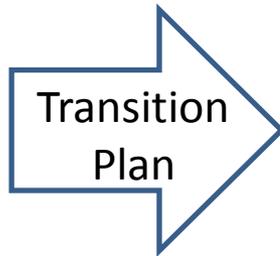
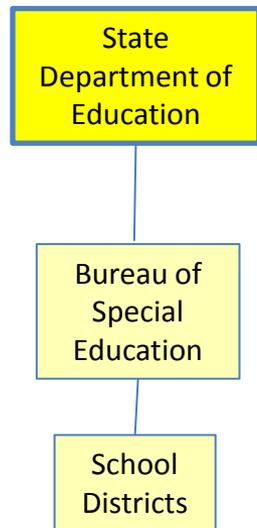
Finding: Division would benefit from resources available in DDS regions for clients w/ ID.

- DDS regions have resource teams that includes education and transition advisors for clients w/ ID.
- New Medicaid Amendment will provide and improve care coordination for medically necessary services but focus is not education or transition.
- This would assist wait list families to connect to other state and/or community-based supports for education and transition.

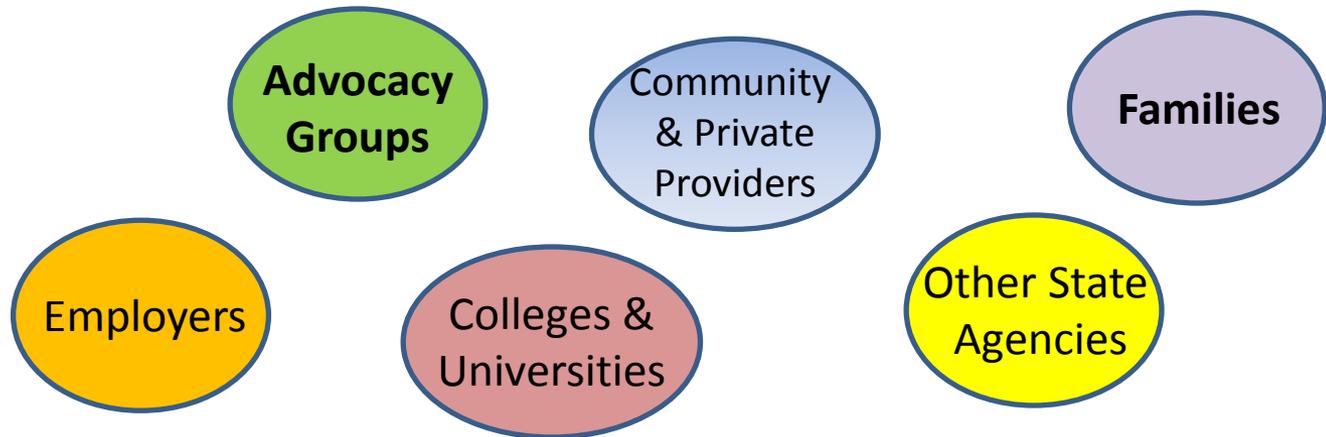
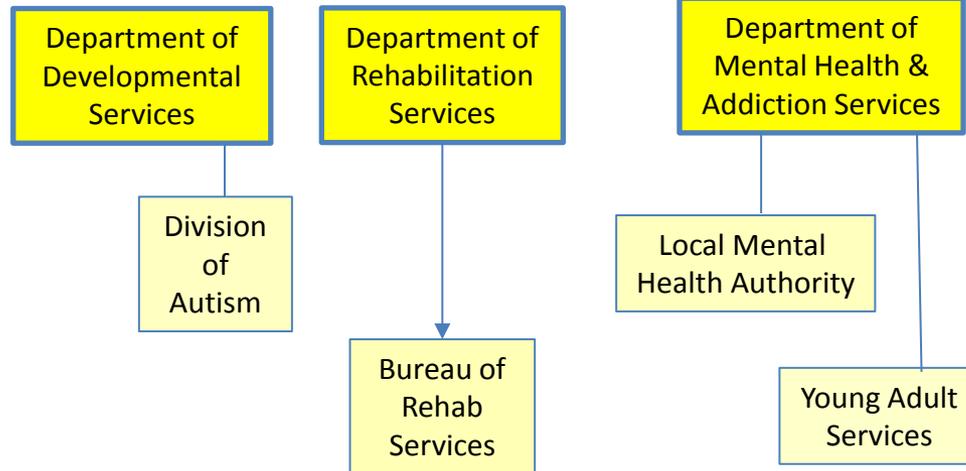
System Infrastructure

Major State Agency Involvement for ASD Population

ENTITLEMENT



ELIGIBILITY BASED ADULT SERVICES



Challenges and Barriers

- There is fragmented system of care.
- State's lead agency on ASD is still evolving.
- No centralized entity, limited data collection, lack of outcome monitoring.
- System navigational tools need improvement.
- Shortage of qualified workforce in ASD field.
- Limited funding necessitates leverage of resources.

Rec.#34: As lead agency, establish and maintain an integrated confidential data system that facilitates shared agency information.

Finding: There is limited data collection and a lack of outcome monitoring.

- Data not readily collected, tracked, or analyzed for population w/ ASD.
- Outcome data needed from variety sources.
- Needed to improve quality and establish best practices.
- Workgroup convened to determine data to be collected and benchmarks for monitoring progress.

Rec.#34: As lead agency, serve as one-stop resource regarding statewide resources, services, waivers, and community supports for individuals with ASD.

Finding: System navigational tools must be improved and made readily available.

- System for ASD is complicated, disjointed, and confusing.
- Caregivers usually responsible for locating and coordinating services.
- Difficult for all but especially when going from entitlement system to eligibility-based system.

Rec.#34: As lead agency, keep exploring opportunities to further develop and strengthen the system infrastructure through coordination of state-level work on ASD.

Finding: There is proliferation of state teams, group projects, and interagency committees.

- Several ongoing workgroups and projects with own purpose and goals.
- Mutually beneficial for information and efforts are shared and perhaps streamlined.
- Transition Interagency Strategic Planning group led by DORS good start at unifying efforts.
- Examine interagency agreements to clarify roles.

Rec.#34: As lead agency, identify funding sources that are flexible, diversified, and sustainable to be used in variety of ways to meet the ASD population's unique, and evolving needs.

Finding: Limited access to scarce funding necessitates leverage of resources.

- Division already has responsibility to locate potential funding streams.
- Seek and coordinate funding across agencies.
- Perhaps outreach and leverage with array of key stakeholders (e.g., advocacy groups, employers, universities, private providers).

Rec.#34: As lead agency, promote outreach activities that bring together significant stakeholders and interested parties.

Finding: More partnerships and collaboration can be developed.

- More collaboration with all Connecticut public and private institutions of higher learning.
- More presence at regional interagency transition teams.
- More outreach to job developers and potential employers.

Rec.#34: As lead agency, continue to develop an ASD training infrastructure

Finding: Work is already underway on training and credentialing.

- Provides statewide mechanism for disseminating best practices and promotes professional development.
- Offers education and training to raise awareness to persons who may interact with individuals w/ ASD.

Rec.#34: As lead agency, prepare an annual progress report listing accomplishments and activities of the division and council.

Finding: There is no annual report with detailed service summary, activities, or accomplishments.

At minimum, report should include:

- Number of children & adults served by state agencies
- Number of children & adults on wait lists for waiver services
- Measurable outcome data
- Unmet service needs
- New initiatives and proposals under consideration

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