



DREXEL UNIVERSITY

A.J. Drexel

Autism Institute

Links Between Secondary Services and Adult Services

Penn State Autism Conference 2017

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<http://www.drexel.edu/AutismInstitute>

Agenda

- ◆ Thank you for inviting me to your conference
- ◆ About me
- ◆ Contributors
- ◆ Defining the Problem
- ◆ Transition
- ◆ Unmet needs and dissatisfaction with services
- ◆ Links
 - Waivers
 - College
 - College life programs
 - Project Search
 - OVR
- ◆ Questions

About me

- ◆ School Psychologist
- ◆ BCBA-D
- ◆ 20 + years working on behalf of children, adolescents and adults
- ◆ Worked in-district before going teaching at university
- ◆ Faculty
- ◆ Research
- ◆ Clinical work – model building

Contributors

- ♦ Paul Shattuck, Ph.D.
 - AJ Drexel Autism Institute
 - *Life Course Outcomes Program Area Leader*
- ♦ Anne Roux, Ph.D.
 - AJ Drexel Autism Institute
 - Senior Research Associate
- ♦ Jessica Rast, MPH
 - AJ Drexel Autism Institute
 - Research Associate
- ♦ Amy Edwards, Ed.D.
 - AJ Drexel Autism Institute
 - Research Associate
- ♦ PA ASERT collaborative

Defining the Problem

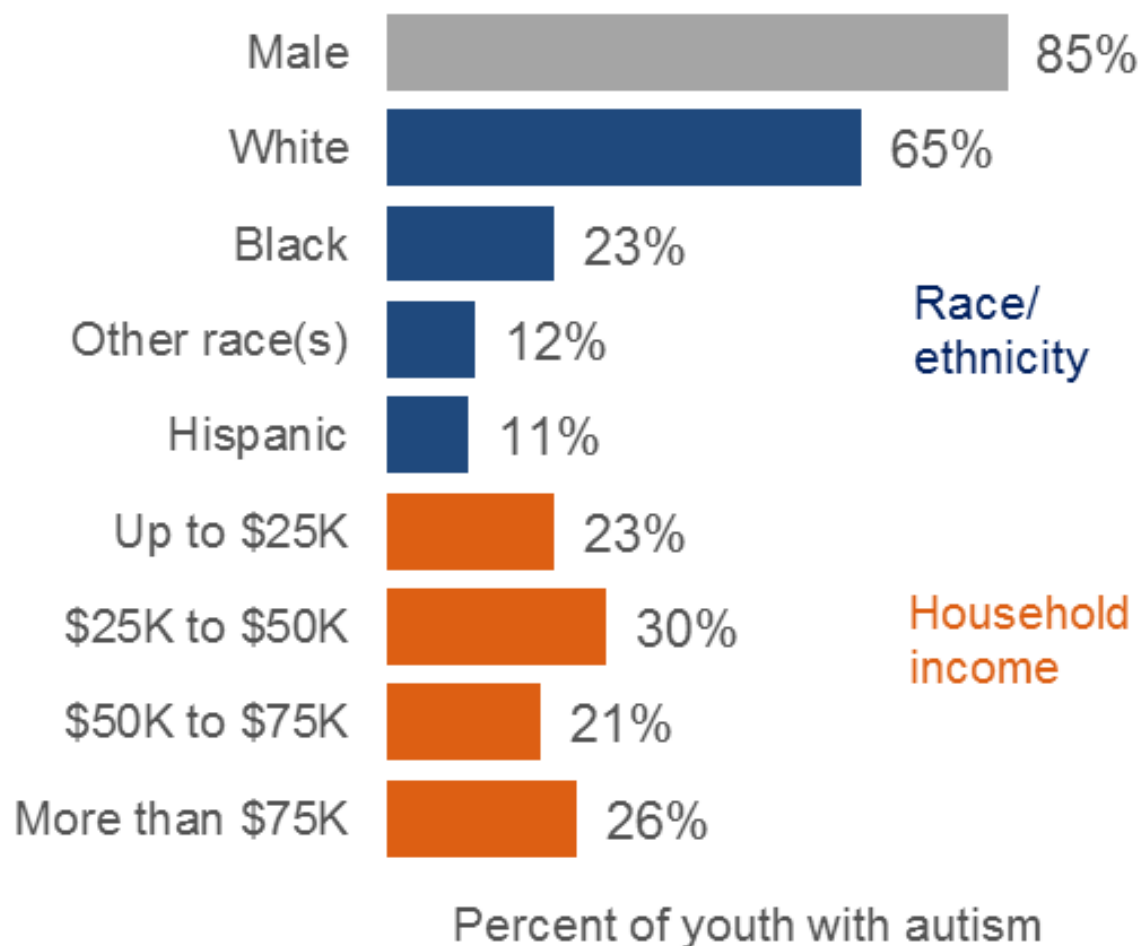
**National Longitudinal Transition Study-2
(NLTS2)**

PA Autism Needs Assessment data



Characteristics at age 17

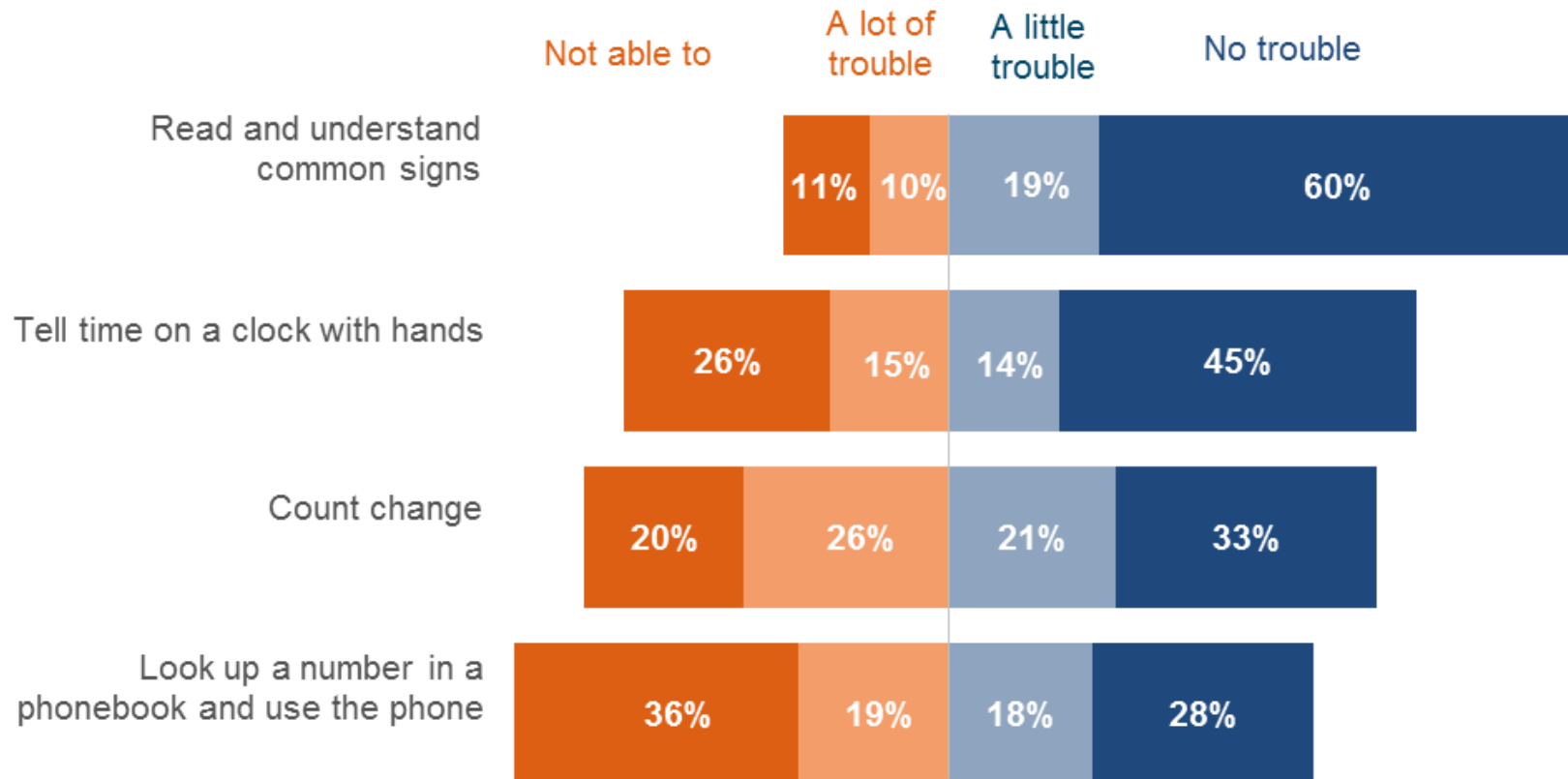
Most youth with autism in the NLTS2 were male, white, and from a wide range of household incomes.



Source: National Longitudinal Transition Study-2

Characteristics at age 17

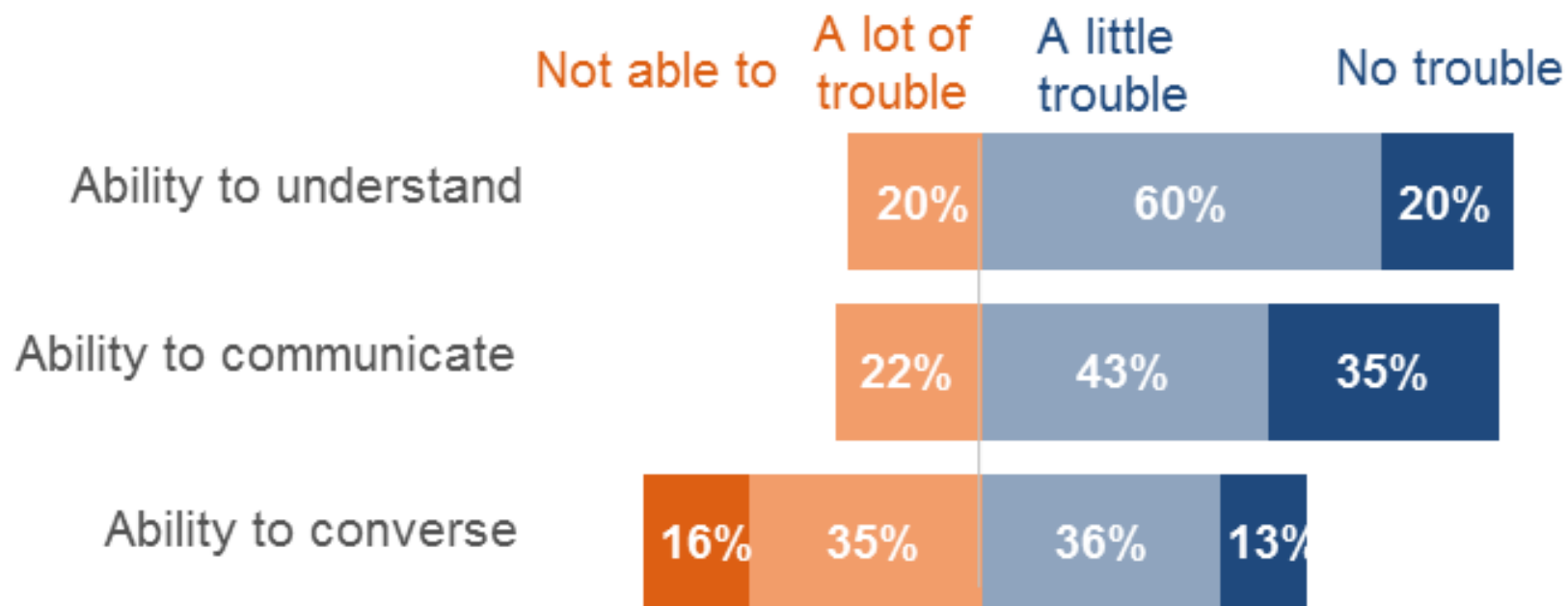
Many could understand common signs and tell time. Half or fewer could count change and use the phone with little or no trouble.



Source: National Longitudinal Transition Study-2

Characteristics at age 17

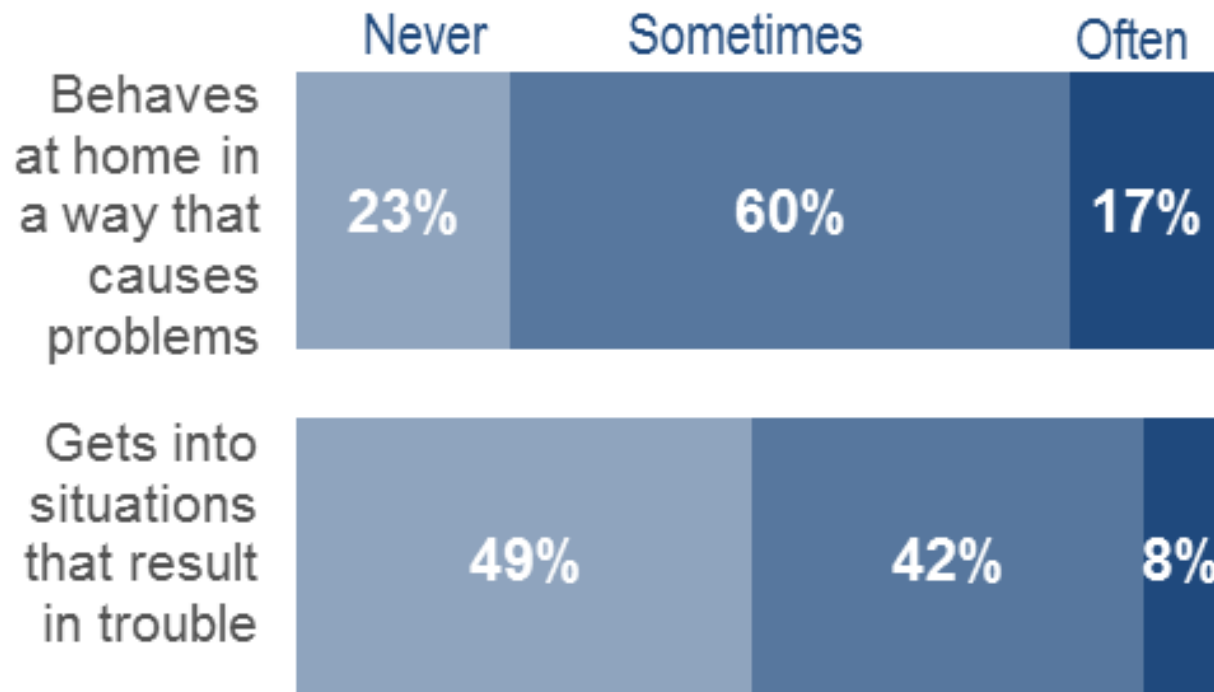
Ability to understand and communicate exceeded youth's ability to converse.



Source: National Longitudinal Transition Study-2

Characteristics at age 17

Many adolescents had behavioral challenges at home...



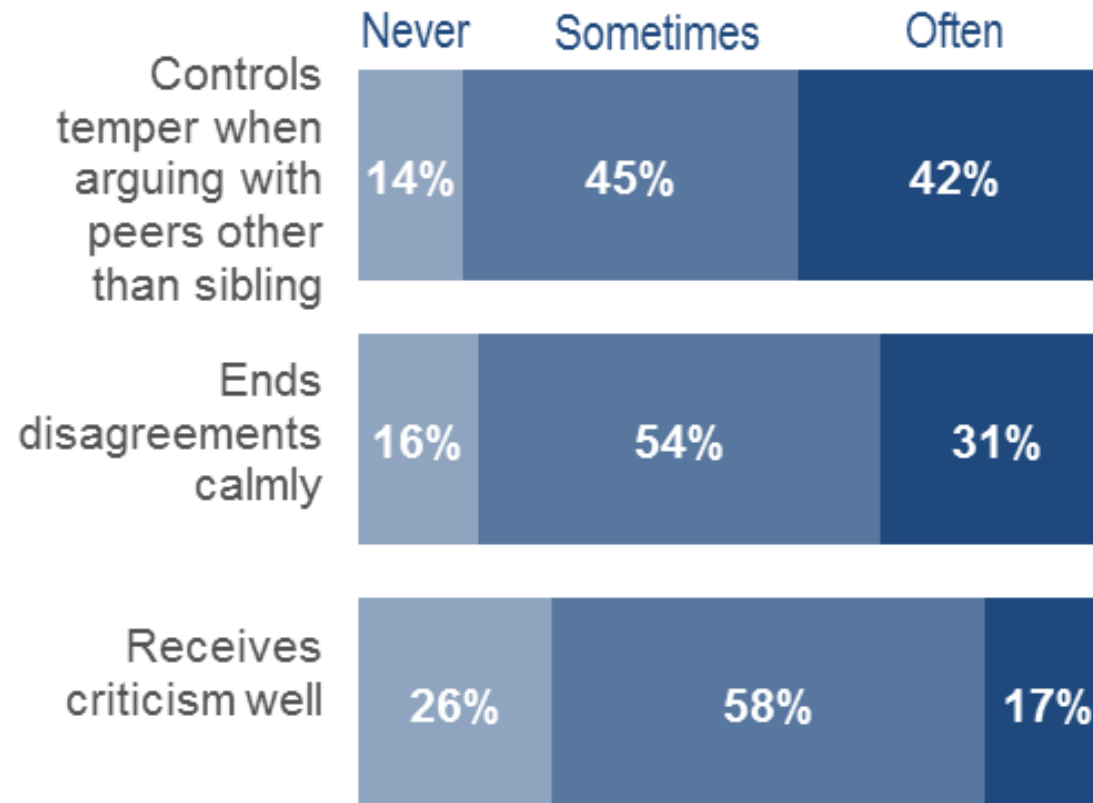
Source: National Longitudinal Transition Study-2



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Characteristics at age 17

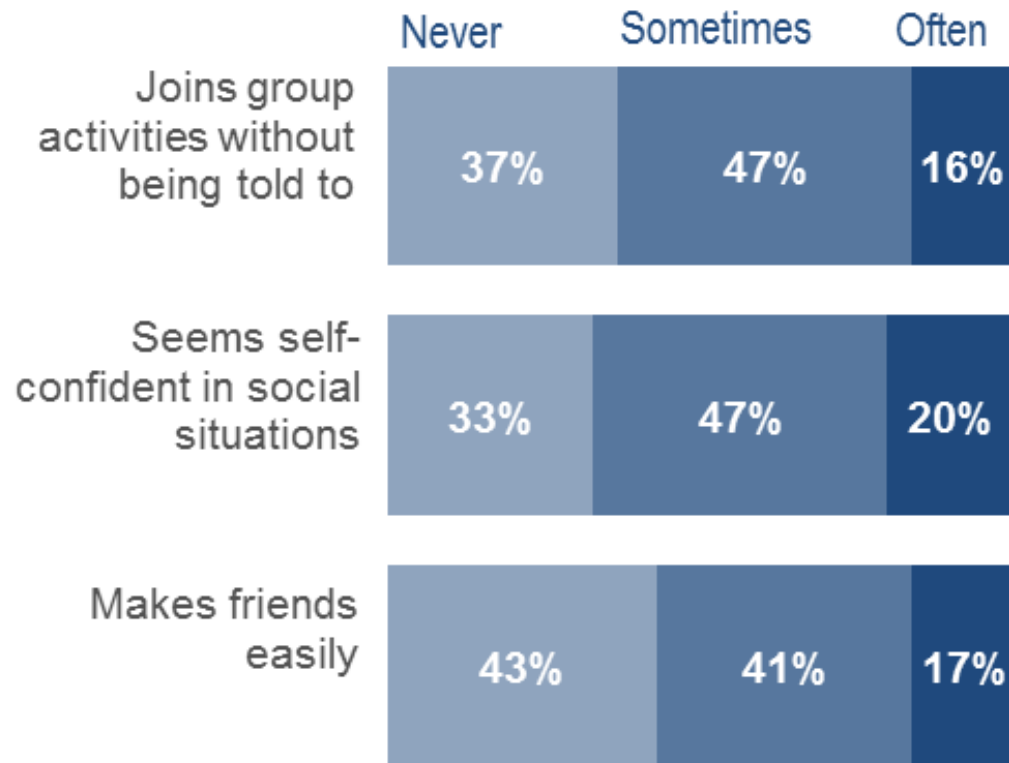
...but many were able to exert self-control at least sometimes during disagreements and arguments.



Source: National Longitudinal Transition Study-2

Characteristics at age 17

Over one-third of youth never joined group activities, felt self-confident socially or made friends easily.



Source: National Longitudinal Transition Study-2

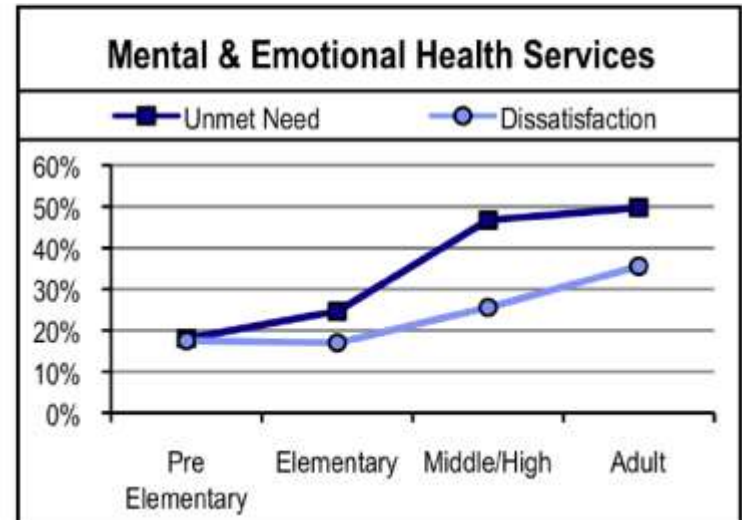
PA Needs Assessment

Mental & Emotional Health Services

Individuals with autism from every age group report that their needs for mental and emotional health services are not being met and that they are dissatisfied with many of the services they receive.

Mental & Emotional Health Services include:

- ◆ Counseling for Anxiety
- ◆ Mental Health Counseling
- ◆ Support Groups
- ◆ Relationship Counseling
- ◆ Drug & Alcohol Counseling



Unmet Need for Services

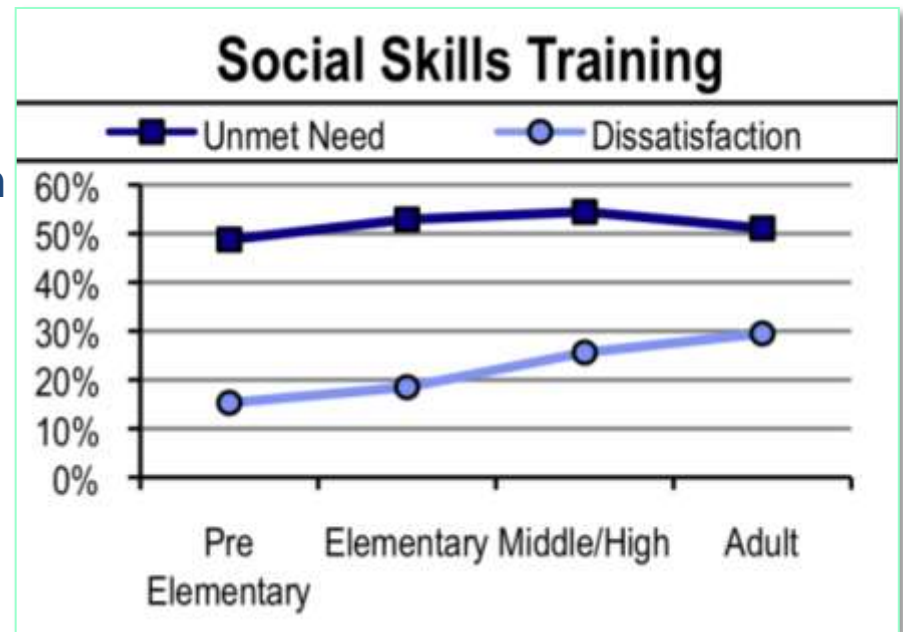
- ◆ Unmet need for mental health services substantially increases with age, because of both increasing need as individuals age and a lack of available services for adolescents and adults with autism.
- ◆ Almost half of all individuals in the middle/high school group and almost 3 in 5 adults have unmet mental health needs.



PA Needs Assessment

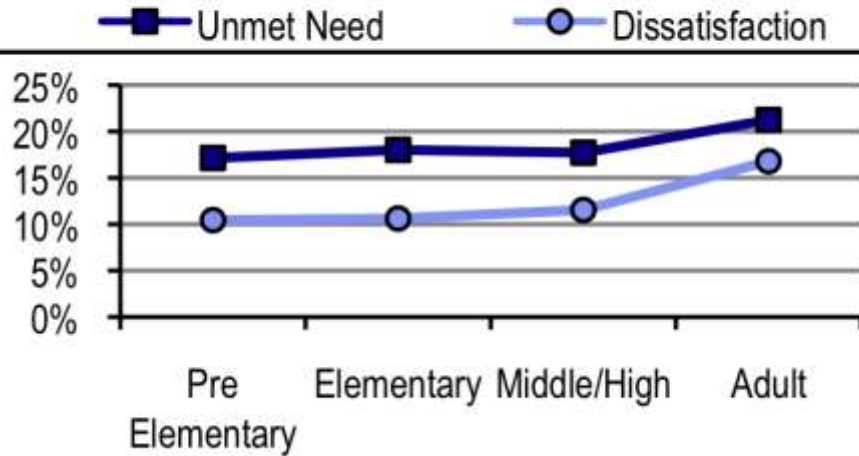
Unmet Need for Services

- ♦ Mental and Emotional Health
- ♦ Social Skills Training
- ♦ Functional Therapy and Physical Health
- ♦ Sexual Health Education
- ♦ Behavior Support Services
- ♦ Summer Services

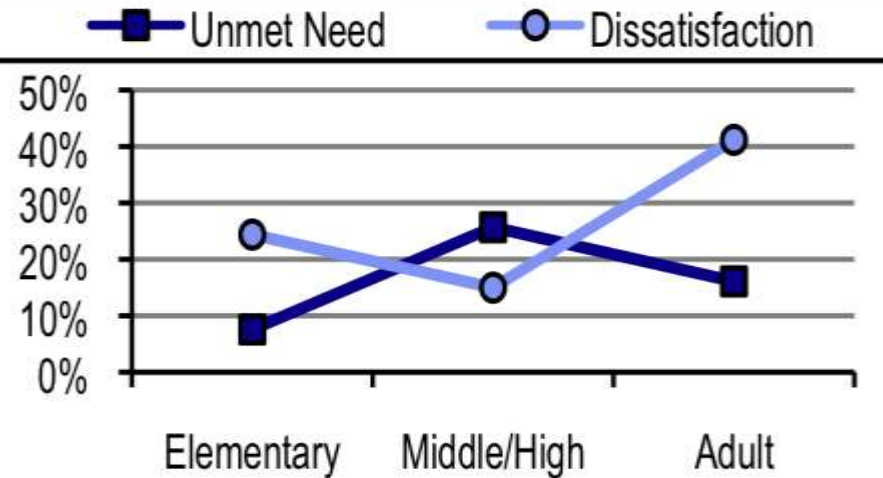


PA Needs Assessment

Physical Health Services



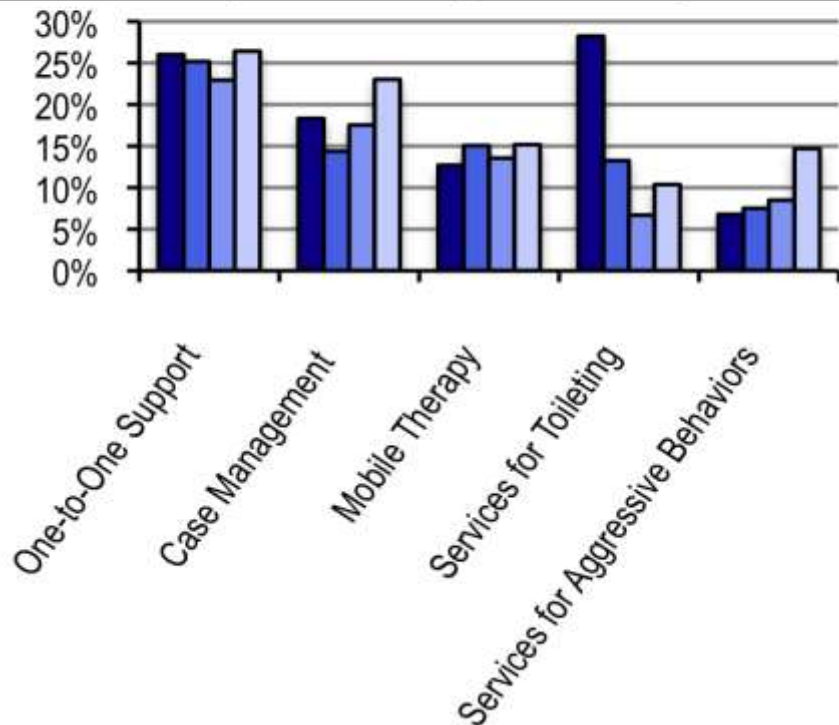
Sexual Health Education



PA Needs Assessment

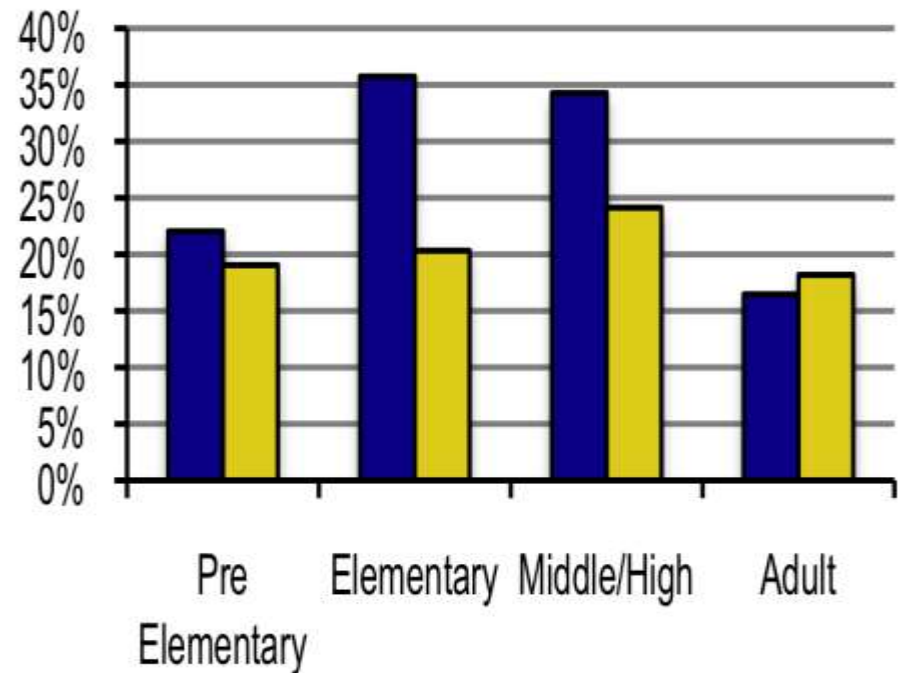
Unmet Need for Behavior Support Services

■ Pre Elementary ■ Elementary ■ Middle/High ■ Adult



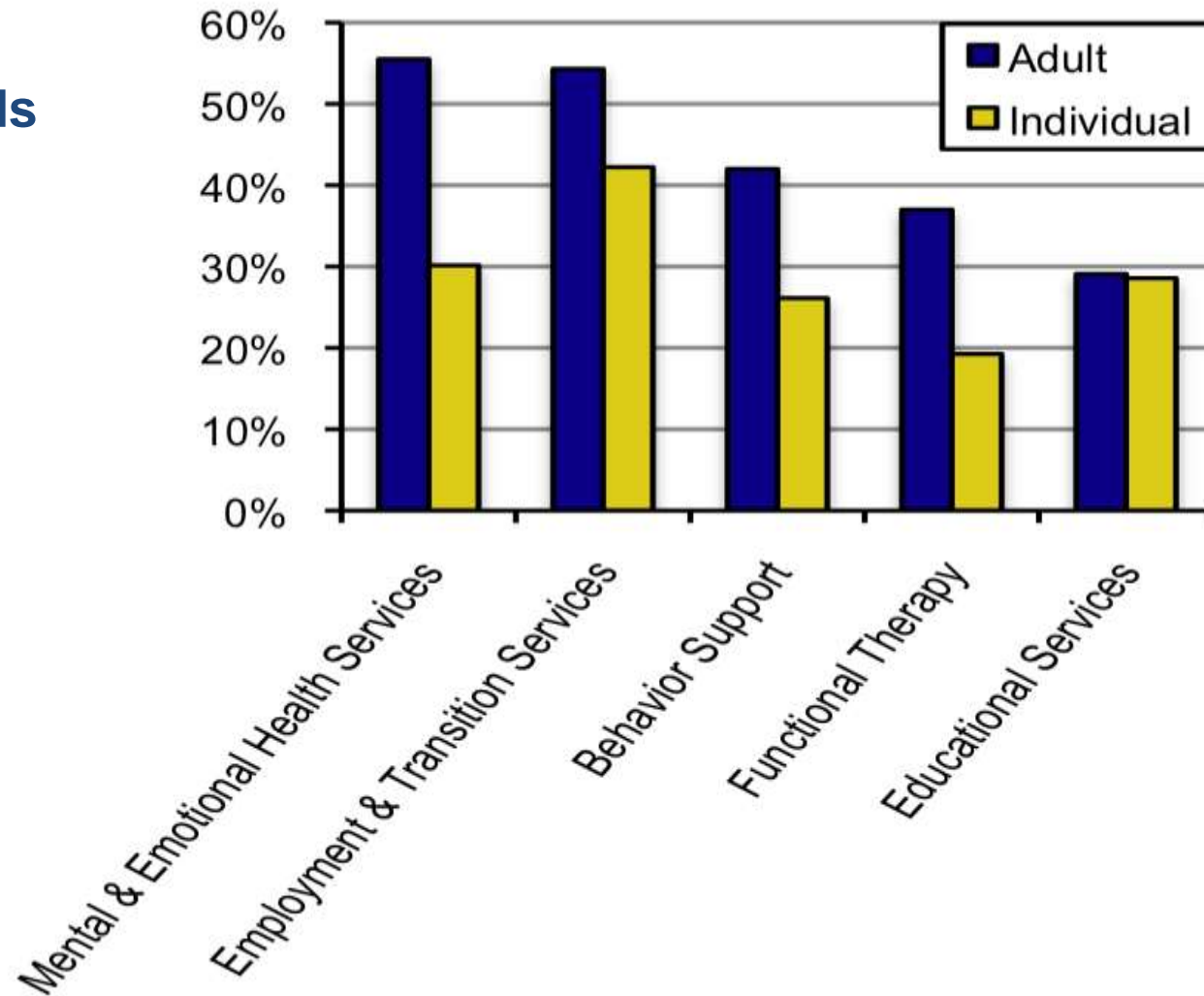
Summer Services

■ Unmet Need ■ Dissatisfaction

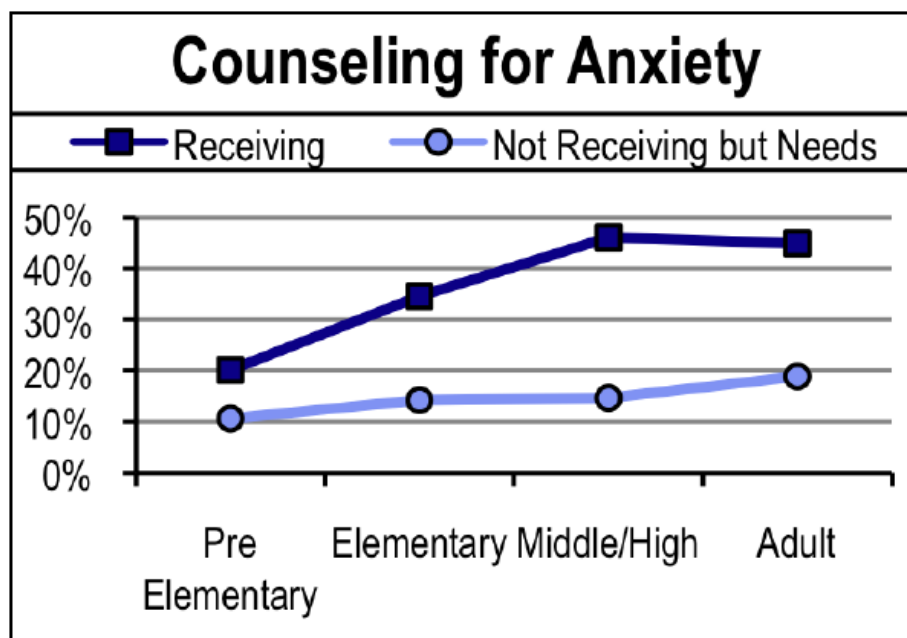


PA Needs Assessment

Unmet Needs for Adults



PA Needs Assessment Cont.



Counseling for Anxiety

- ◆ 45% of adults with autism receive services to address anxiety.
- ◆ An additional 20% of adults with autism report needing this service.

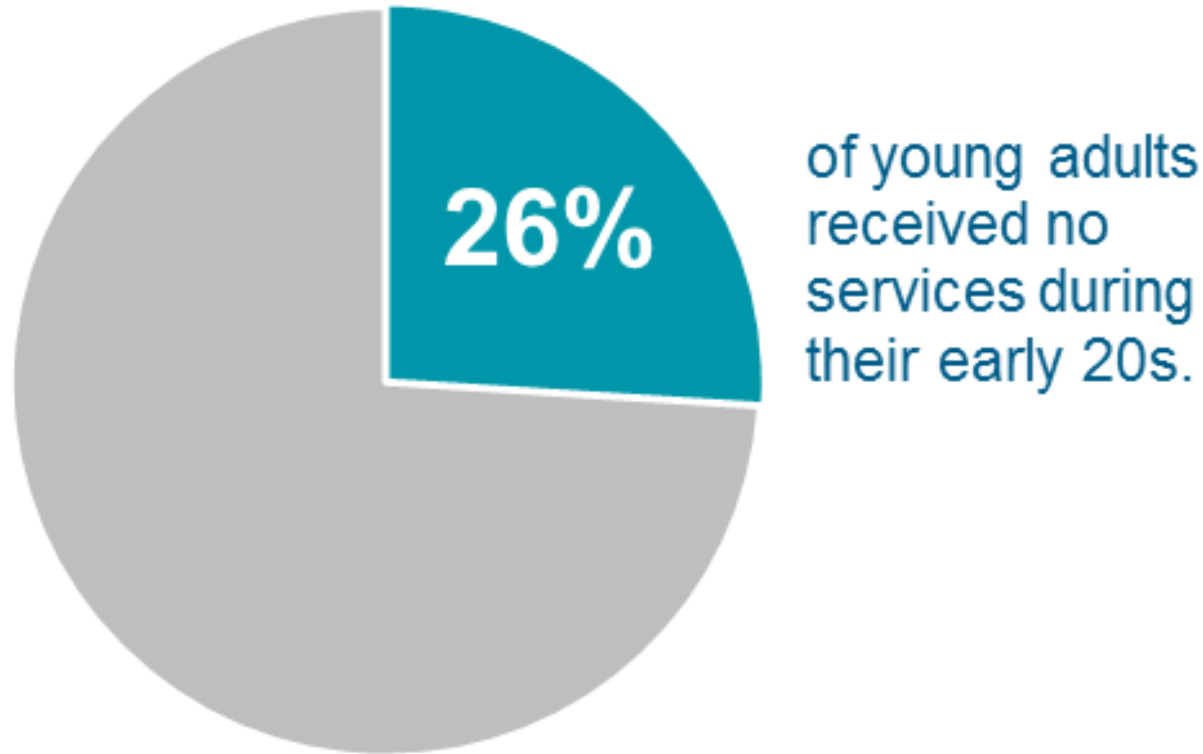
Unwanted police interaction

- ◆ Approximately 10% of adult cases reported police interaction
 - Illicit drug use
 - Sexual misconduct
 - Not following social norms, and police commands

*Clinical Evidence from case consultation (2013-2015)

The Services Cliff

Autism does not end when children reach adulthood. Most will need some type of services or supports.



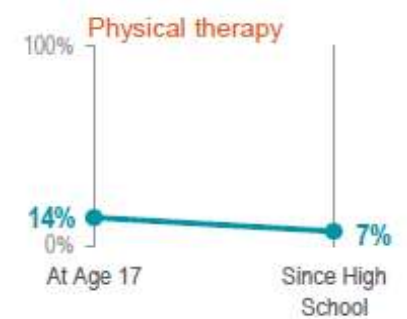
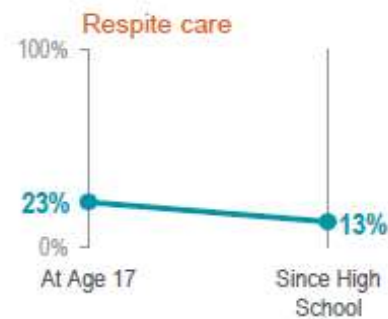
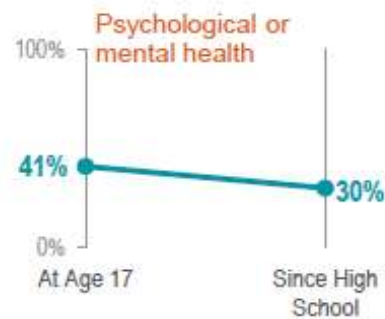
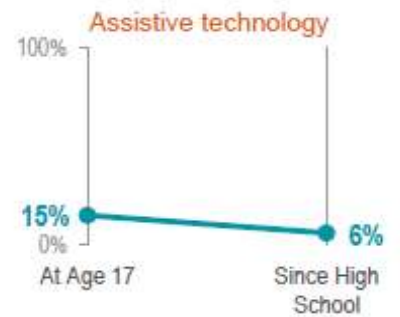
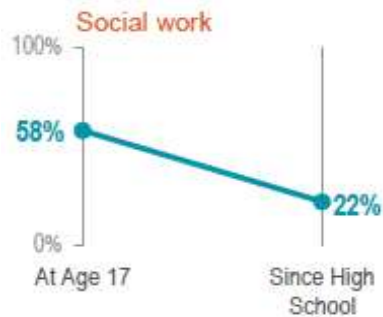
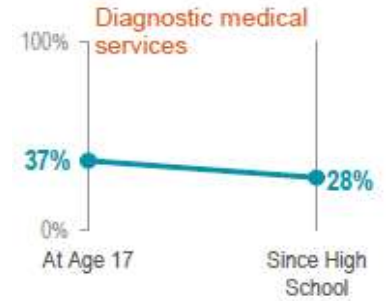
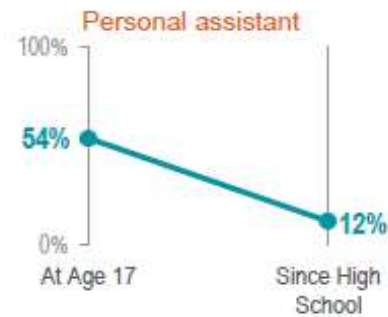
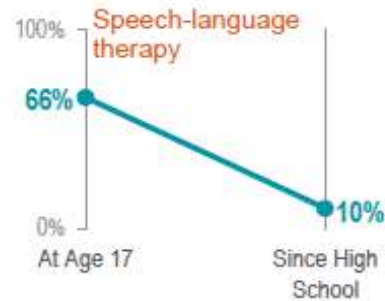
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The Services Cliff

Services consistently decreased following high school.



Percent who received service at age 17 compared to percent who ever received service after high school.

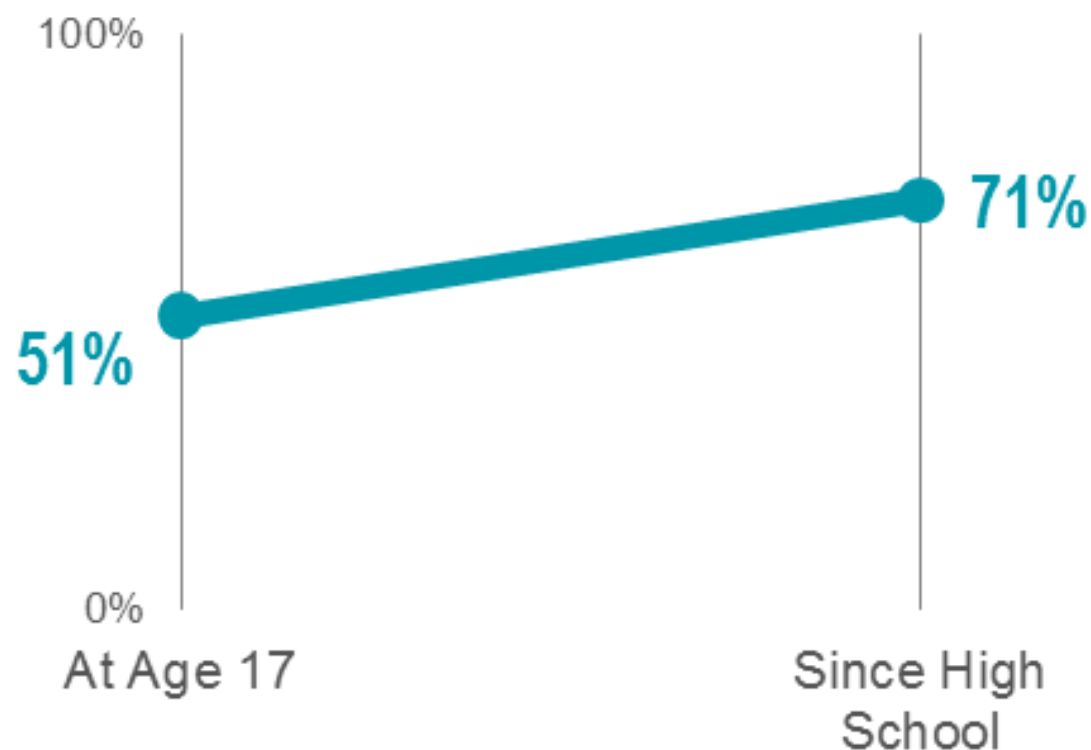
Source: National Longitudinal Transition Study-2



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The Services Cliff

The percentage of families who reported some or great effort to access services increased following high school.



Percent families of young adults with autism

Source: National Longitudinal Transition Study-2



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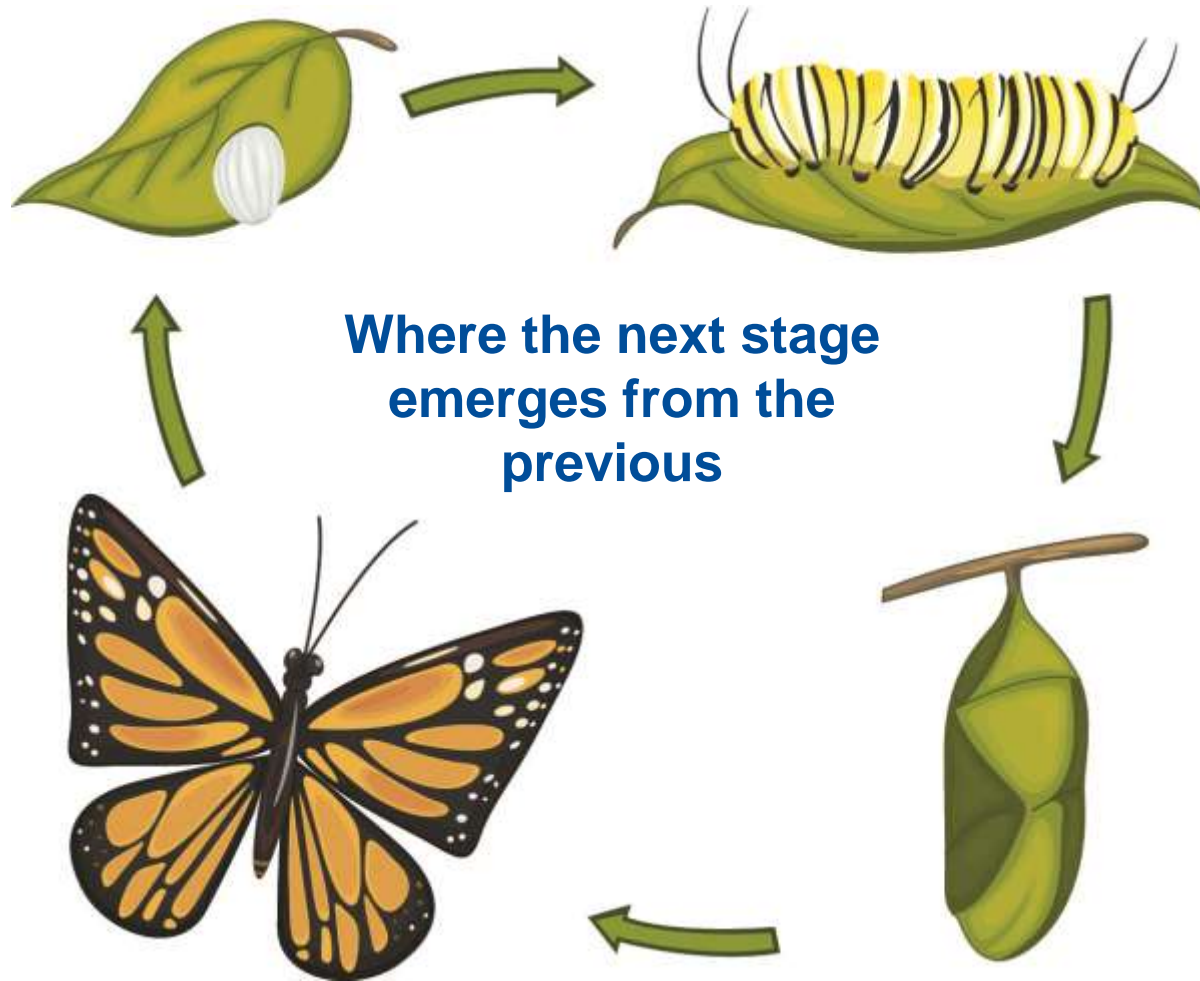


b : a movement, development, or evolution from one form, stage, or style to another

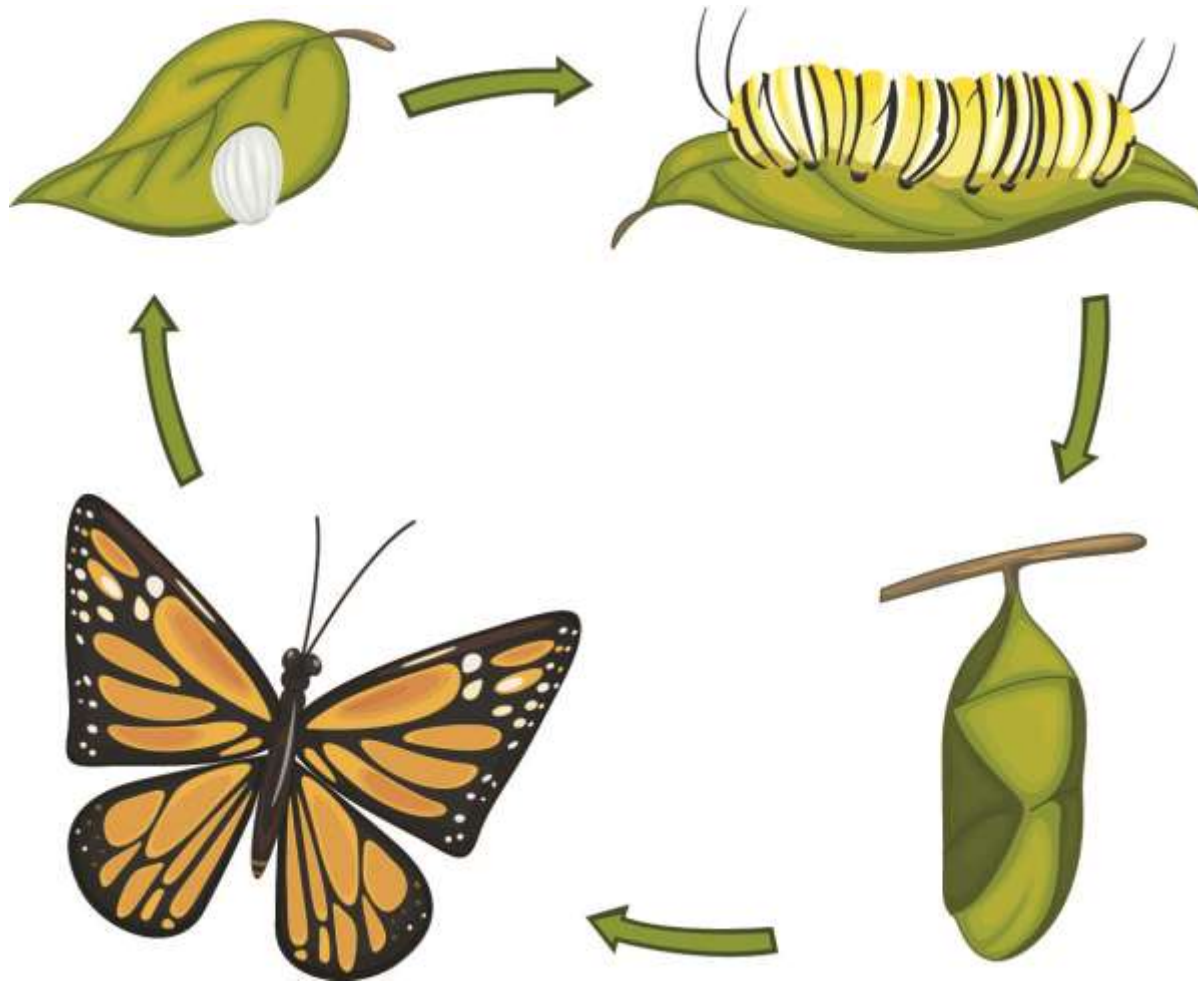
Stages of the lifespan



The word transition often conjures or evokes images of a chrysalis



A solitary process ...









Autism Parenting 08

by Lisa G Smith



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Running to the Store

by Lisa G Smith



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MAKE YOUR OWN AT PIXTON.COM

There is no ham in hamburgers.

by Lisa G Smith



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The Service Cliff review

- ◆ Services through IDEA end at age 21
- ◆ 26% adults receive no services
- ◆ 71% of parents/individuals indicate they are in need of services
- ◆ Unless your state has a waiver, and the waiver includes ASD w/out ID
- ◆ Or your state has an autism waiver
- ◆ And you can get enrolled in the waiver
- ◆ Lost services include – speech, OT, PT, Specialized instruction, behavior support, transition planning, respite care, mental health counseling, case management, social work, transportation support, and a personal care assistant
- ◆ What remains in Rx management – which often produces polypharmacy and a wide range of negative side effects and long-term outcomes

Links between secondary and adult services

- ◆ HS Transition plan (another day)
- ◆ College
- ◆ Job support provider agencies and OVR
- ◆ SSI
- ◆ College experiences
- ◆ College

College

Overview:

- ♦ What are the different types of college programs available and how do they differ in the type of supports that they offer.
- ♦ What are the questions that you should be asking and when should you start this process?
- ♦ What types of things should parents expect when starting on this journey.
- ♦ How can we best prepare our kids when they aren't getting what they need in school?

What are the different types of college programs available and how do they differ in the types of supports that they offer?

- ♦ **Four year college or university – private and public**
 - Can offer autism specific supports
 - Can have stable support
 - Support may come through Disabilities Services
 - May be free, or less expensive
 - May share supports across colleges, schools, departments, Institutes
 - Requires more self advocacy and independence among the students
 - Student may get “lost in the crowd”
 - Faculty may be disconnected from the supports program
 - Smaller, private universities/colleges may be very expensive



What are the different types of college programs available and how do they differ in the types of supports that they offer?

♦ Cooperative education

- Integration of classroom learning and hands on practical experience
- Academic credit
- Paid work experience
- Supported work experiences
- Try different career options



What are the different types of college programs available and how do they differ in the types of supports that they offer?

♦ Community college

- Geared towards diverse student learners
- Preparation for 4 year schools
- Smaller class sizes
- In the community
- Faculty may be more familiar with the ASD program/students
- Transportation may be easier
- Likely to have supports through disability services
- May not be ASD specific
- Likely to be free



What are the different types of college programs available and how do they differ in the types of supports that they offer?

- ♦ **Voc/Technical School – Culinary, digital/electronic, arts**
 - Programs are specific to individuals interest
 - Hands on experience
 - Highly specialized career
 - Small campus
 - Few faculty
 - Not up to speed yet
 - Few specific services
 - Will likely come at an additional cost
 - Internships and mentorships specific to your field of interest



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College Experience Programs

- ♦ **Life skills program**
 - Services and supports to help individual with ASD live and work independently
 - Integrates education, life skills, vocational, social/self-esteem, and leisure components.



What are the questions that you should be asking?

- ♦ **Before college: Is college the next step for me, or my child?**
 - Why college?
 - What's the career option?
 - What's the social benefit?
 - Will this help me be better at?
 - How is the high-school transition program preparing for college
 - What courses can I take in high school that will help me reach my employment goal?
 - Start preparing early – Junior year
- ♦ **Finding the right school**
 - What type of post-secondary program is the best fit for me?
 - What type of setting is best for me? (i.e. large vs. small student body, urban vs. rural settings)
 - Focus – academics, liberal arts??? technical
- ♦ **Financial Aid**
 - Qualify? Scholarship?
 - What additional expenses will I need to consider in addition to tuition? (i.e. assistive technology or any additional services)



What are the questions that you should be asking?

♦ Self advocacy

- What independent living skills are needed to be successful in a post-secondary setting? Cooking, cleaning, shopping
- What skills do I need to advocate for accommodations?
- With faculty, registrars office, advising, DS, Dorm/floor manager
- Motivation and skills need to ask for help when needed?
- Are there other students in the programs I am interested in that I can talk to about life on campus?

♦ Disclosures

- Am I comfortable discussing my diagnosis?
- Should partially or fully disclose?



What types of things should parents expect when starting this journey?

- ◆ There are differences between high school and post-secondary settings. It is important to prepare for these changes in advanced.

High school	Post-secondary Settings
IDEA: Section 504 of the Rehabilitation Act and Americans with Disabilities Act	Section 504 of the Rehabilitation Act
School district is responsible for identifying the disability and documenting progress	Students are responsible for providing documentation about their disability
Personal services are provided and are a right	Personal services are the students responsibility
Teacher functions as an advocate	Students are responsible for their own progress
Accommodations and alternations to the program can be made	Students identify there own needs. Minor accommodations can be made

What types of things should parents expect when starting this journey?

- ♦ Do not choose a program just because it has an autism support program
 - Choose a program that is the best fit for you
- ♦ College is new, and potentially difficult for many students
- ♦ There will be some failures – bad grades etc...
- ♦ Transition should be integrated into your IEP starting at 14 years old
 - most transition programs are not preparatory – start working with SD
- ♦ The college program may be ...unstable. Many of these programs are new be prepared for bumps
- ♦ The degree choice was a course sequence that does not suit student

Preparing for College while still in high school

- ◆ Attend IEP meetings and talk about transition and future goals
- ◆ Prepare for and take all standardized tests
- ◆ Research and visit post-secondary programs you may be interested in. Know what services are available for each.
- ◆ Prepare academic adjustment letters and self-advocate for adjustments (i.e. if more test time is needed)
- ◆ Practice independent living and social skills needed for college (i.e. waking up to an alarm or asking a professor for accommodations)

Challenges to Post-secondary education and employment

- ◆ The social/communicative deficits, and the restricted and repetitive bxs, along with the EF deficits, problem behavior and hyper and/or hypo sensitivities discussed above
- ◆ ... society is not ready or welcoming
- ◆ Individuals with ASD might need accommodations, and/or modifications to the post-secondary education or workplace settings
 - Accommodations are provided in college settings for those that disclose a disability
 - Modifications are much harder and perhaps unrealistic at university

School modifications and accommodations – challenges in adapting to the work place

- ◆ Accommodations –
 - will co-workers understand how to work with someone using
 - an augmentative communication device
 - a PECS binder, or ASL
 - how will co-workers respond to
 - a shorter work day
 - Large quiet office or private work space
 - Setting a specific temperature and light setting
- ◆ Modifications – how will co-workers respond to
 - Less work
 - Easier tasks
 - Flexible deadlines

Project SEARCH High School Transition

Project SEARCH is a one-year, school-to-work program for young people with autism and intellectual disabilities.

- Goal of competitive employment
- Total workplace immersion
- Internship rotations for career exploration and job skills acquisition
- Customized job-search assistance

Program Description

- ◆ One school year
- ◆ 8 interns with autism and intellectual disabilities
- ◆ Certified instructor and job coaches
- ◆ Immersed in host business culture
- ◆ Rotations through unpaid internships with continual feedback
- ◆ Outcome of employment in the community

Outcome of Employment

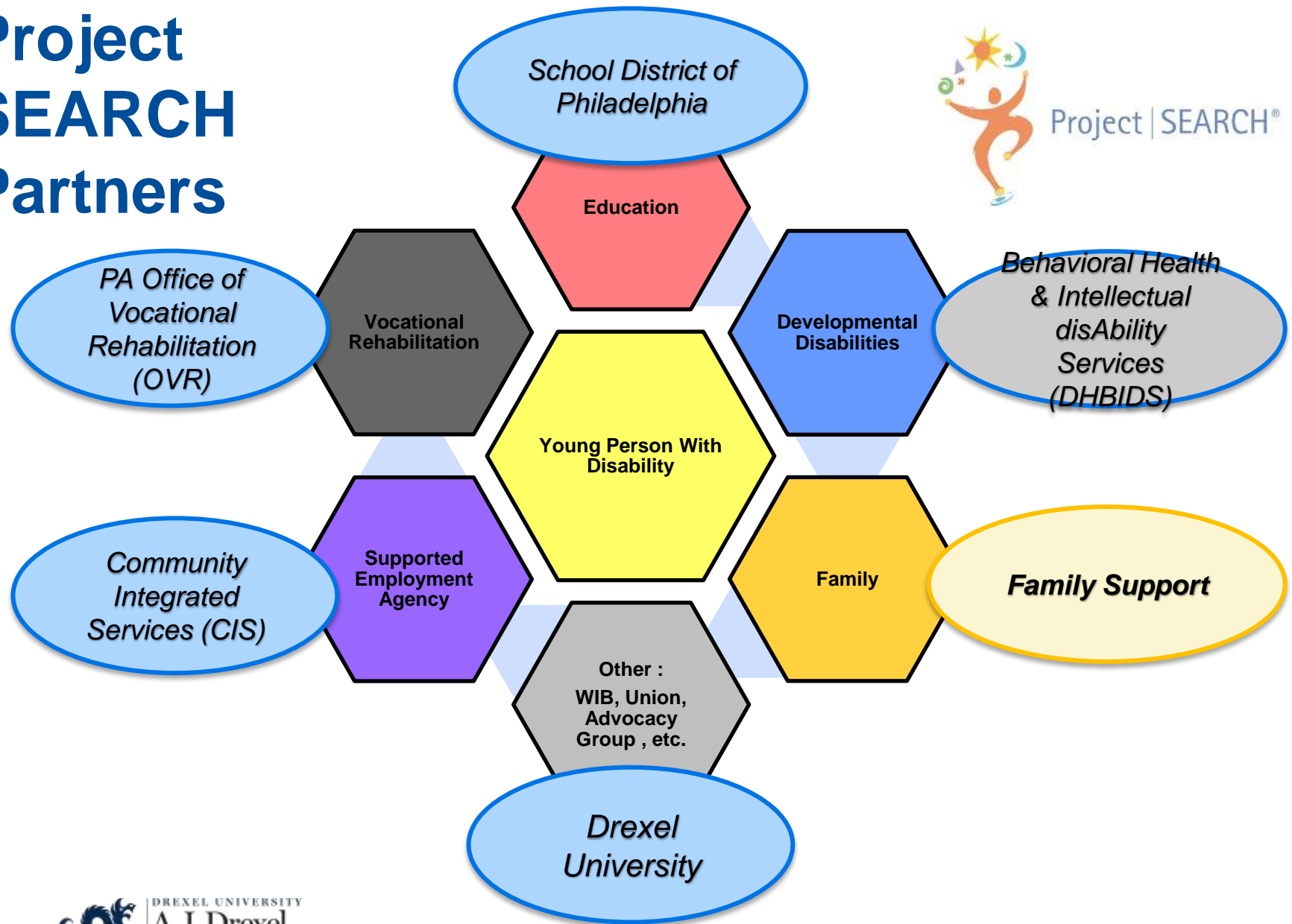
The Project SEARCH Definition of a Successful Outcome:

- Competitive employment in an integrated setting
- Year-round work
- 16 hours/week or more
- Minimum wage or higher

Program Description – Eligibility Criteria

- ◆ 18 – 21 years old
- ◆ Last year of school eligibility
- ◆ Eligible for services
- ◆ Appropriate hygiene skills
- ◆ Ability to take direction and change behavior
- ◆ Access public transportation
- ◆ Desire to Work!

Project SEARCH Partners





The Drexel Academic and Career Program (DAC)



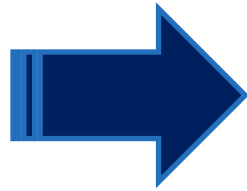
An Example of a Day in the life of a Project SEARCH intern

- 8:00 Employability Skills
- 9:15 Internship site
- 11:30 Lunch
- 12:15 Internship site
- 2:15 Review, Plan, Journaling
- 3:04 Depart





DAC is a two year, non-degree inclusive postsecondary experience for young adults with autism spectrum disorder.



The program's goal is for all students to obtain competitive integrated employment.



THE DREXEL DIFFERENCE

- The DAC is part of Transition Pathways| Life Course Outcomes Research Program at the Autism Institute
- Transition Pathways has partnerships with Phila School District, OVR, IDS, Community Integrated Services, and local businesses
- Support from renowned autism experts
- Leveraging Drexel resources: Co-op Program, Steinbright Career Development Center and focus on Civic Engagement
- Campuses in University & Center City, public transportation and the access to all the city offers

Applying for SSI – meeting or equaling the listing of impairments

- ◆ Matches closely to DSM – educational classification counts
 - Look at med and ed records for diagnosis/classification
- ◆ Step 1- Check earnings of individual at local SSI field office
 - Disability inhibits ability to work and make and income of \$1170/month – substantial gainful activity
- ◆ Step 2 – field office sends to state office called disability determination services – they decide
 - Expected to last 12 months or longer
 - Impairs ability to work
 - Be considered severe

Applying for SSI – cont...

The required level of severity for autistic disorders is met when the following requirements are satisfied. A doctor must have found the child has:

- deficits in reciprocal social interaction (found on any standardized autism assessment)
- deficits in communication and imagination, and
- a restricted repertoire of activities and interests (not needed for Asperger's syndrome).

And these deficiencies must cause serious limitations in at least two of the following:

- communicative/cognitive functioning
- social functioning
- personal functioning, and/or
- sustaining concentration, persistence, or pace.



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Questions



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