

Transition To Adulthood for People With Autism Webinar

— CONGRESSMAN —
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SERVING NEW JERSEY'S 3RD DISTRICT

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Transition to Adulthood

for people with Autism

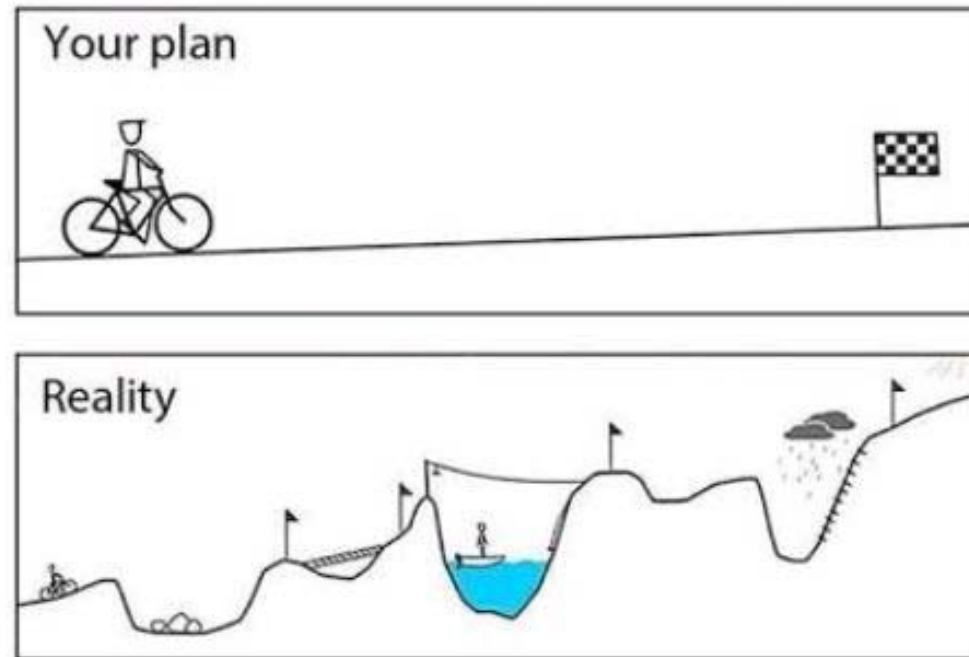


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Why is it important to plan?

- Research indicates that more than half of young adults with ASD are **not** successfully transitioning to adulthood in the first two years after high school. A successful transition would mean a person has a role to play in society, through employment or pursuing further education, for example.
- There is a real need for a wide variety of helpful resources that are available through a person's lifetime, but coordinating and managing it all is challenging.

Launching and Life Are Frequently Messy



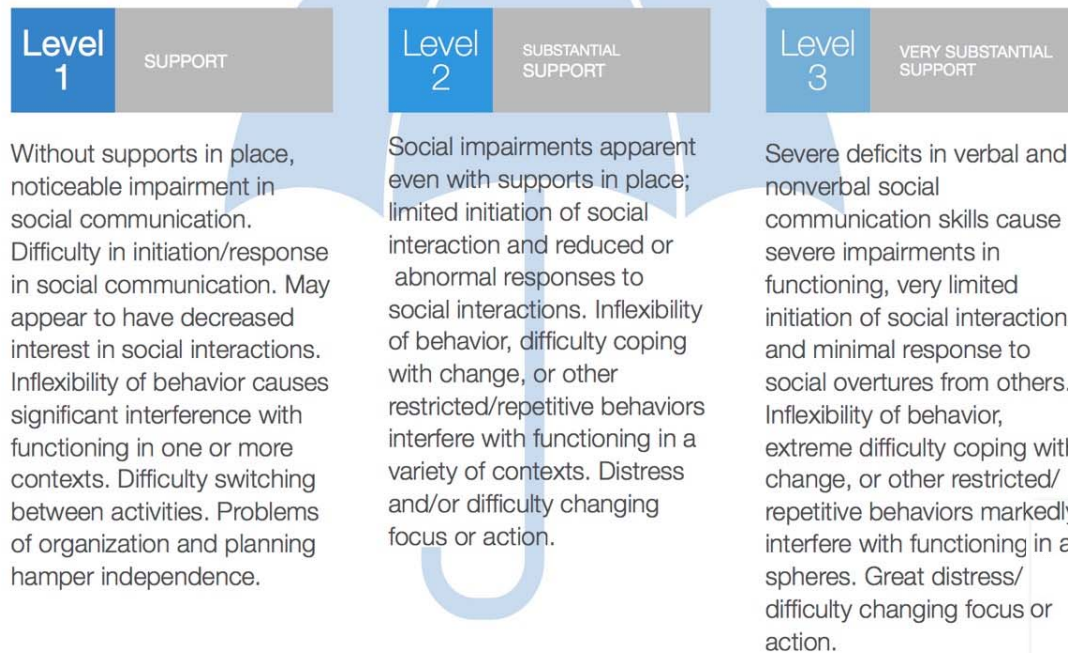
Important Considerations for Autistic Students



- Where do you receive services now?
 - IEP
 - Waiver
 - Health Insurance
 - Other
- Do those services end or change with age?
- If so, when?

One Size Does Not Fit All

Autism Spectrum Disorder in the DSM



■ Level 1 (IQ > 85)
■ Level 2 (IQ 71-85)

Welcome to the Transition Roadmap to Housing and Residential Supports!

In the roadmap you'll find:

- Goals and action steps to help guide your transition to living on your own in independent housing
- Links to extra resources for more information
- Words in blue. These are terms that you may hear often when learning about your choices for housing. If you click on a blue word, you'll see its definition. There's also a complete glossary of all the terms at the end of the Roadmap.

Welcome to the Transition Roadmap to Postsecondary Education!

In the roadmap you'll find:

- Goals and action steps to help guide your transition to education after high school
- Links to extra resources for more information
- Words in blue. These are terms that you may hear often when learning about employment. If you click on a blue word, you'll see its definition. There's also a complete glossary of all the terms at the end of the Roadmap.

Welcome to the Transition Roadmap to Meaningful Employment!

In the roadmap you'll find:

- Goals and action steps to help guide your transition to working as an adult
- Links to extra resources for more information
- Words to Know. These are terms that you may hear often when learning about employment. If you click on one of these words, you'll see its definition. There's also a complete glossary of all the terms at the end of the Roadmap.

Crystal A. Harms, M.Ed., BCBA,

Autism Speaks Volunteer Advocacy Ambassador for New Jersey

Transition Planning through the IEP Process

Mary Jean Knerniger, M.Ed., BCBA, Principal, Transitions at BCSSSD

Kathie McMahon, M.Ed., BCBA, Transitions at BCSSSD

Crystal A. Harms, M.Ed., BCBA, Autism Speaks Volunteer Advocacy Ambassador for New Jersey

When should Transition Planning begin?

- As a part of the special education, IEP process, the law requires that transition planning occur starting when the student turns 14 years-old.
- That does not mean that a family should wait until age 14 to start this process.
- Person Centered Planning can begin as early as in elementary school.

Who should be considered as a member of the IEP Transition Planning Team?

- The student and their family ... parents know their child best
- Immediate teaching staff
- Therapists (PT, OT, SLP, BCBA, etc.)
- Future placements (employer, provider of volunteer opportunities)
- Agencies providing home services
- Department of Developmental Disabilities Representative
 - Families cannot sign up for services until age 21.
- Department of Vocational Rehabilitation Representative
 - Students may apply to become a DVRS client at age 14 and receive Pre-Employment Transition Services.

When should my child graduate?

- Students who have earned the required 120 credits may receive their diploma, but once this happens, the student may no longer receive transition services.
- The family should also consider whether the student is prepared for further education, employment, and/or independent living.
- If the student leaves the educational program after age 18, they may not return.
- A student who earns there 120 credits may choose to continue to receive transition services and receive their diploma upon exiting at age 21.

Should my child continue an academic program or focus on functional skills and CBI?

- The New Jersey Department of Education requires that every student follow the academic curriculum, albeit with modifications and accommodations, as necessary.
- BUT Community based instruction is also required. Functional goals and community-based instruction must also be occurring.
- Do not wait until High School or even Middle School ... begin CBI in the elementary grades
- Understand the difference between a field trip and CBI.

An Example: BCSSSD 4 Levels of Transition Programming

- College-bound
- Fully supported employment
- Community based training and volunteer opportunities providing community participation
- Day programs that provide sensory stimulation and environment enrichment

Jennifer Arey, LSW

Social Worker, Rowan SOM RISN Center

Medical Transition

Jennifer Arey, LSW Social Worker, Rowan Integrated Special Needs (RISN) Center



Why transition?

- “My child’s pediatrician knows them best and is happy to see them as an adult.”
- “The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine have stated that, “[a]fter the age of majority, all youth deserve to be treated as adults and to experience an adult model of care,” even when they require decision-making support or are under legal guardianship” (ASAN, 2013)
- Approach to patient care differs from pediatrics to adult
- Patient needs change
 - Reproductive & women’s health
- Not transitioning reduces access to services for children and adolescents (CHOP, 2017)

Barriers

- Locating/lack of new provider(s) who understand your child's unique needs
- Sedation
- Insurance
 - Transition to Medicaid
- Lack of training and/or resources
 - Adolescents with autism are least likely to receive guidance on transition to adult healthcare from their doctor – about 9% (Leeb, 2020)
 - 15% with behavioral conditions (eg ADHD)
 - 20% with emotional conditions (eg anxiety, depression)
 - 13% with learning disability
 - 10% with intellectual disability/developmental delay
 - Many doctors offices lack support staff needed to assist with successful transition and lack time to review complex medical histories (CHOP, 2017)

Age to start transition process

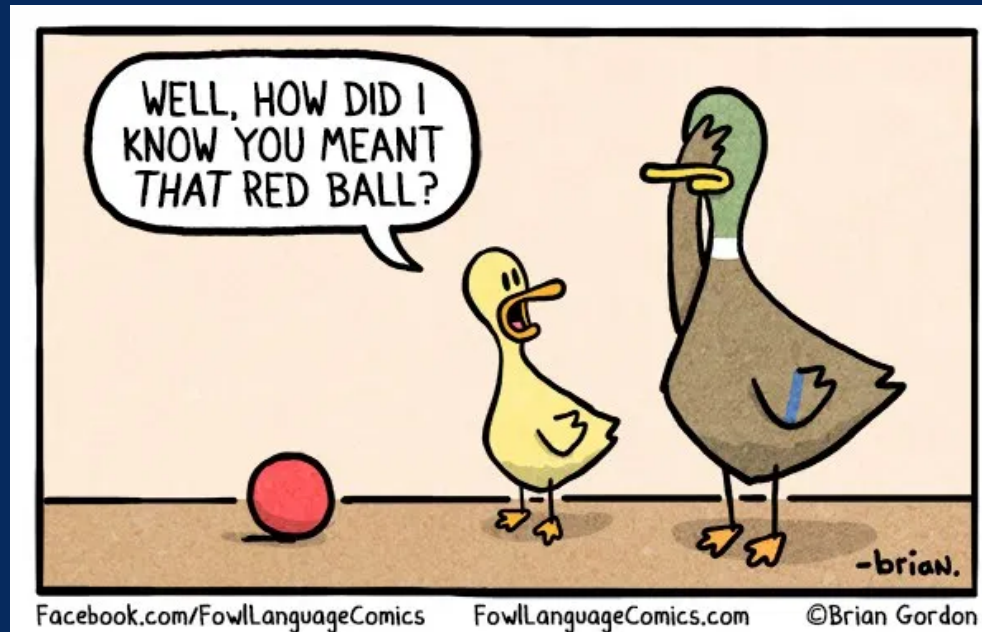
- Age 12
 - Begin transition as per the American Academy of Pediatrics (AAP, 2018)
 - Identify potential barriers and solutions
- Ages 14-16
 - Some dentists require transition at age 15
 - Begin considering potential doctors and preparing a transition summary
- Ages 16-18
 - Consider Power of Attorney and Supported Decision Making or Guardianship
 - Visit/meet potential new doctors if possible
- At age 18
 - Apply for SSI
 - If deemed eligible, automatically enrolled in Medicaid
 - Maintain enrollment in parent insurance policy as long as possible
 - HIPAA release forms allow doctors to speak to parents as needed without the need for guardianship
 - Apply for guardianship if needed
- By age 21
 - Complete transition to new doctor

What doctor(s) does your child need?

- Primary Care Provider (PCP; only if seeing a pediatrician)
 - Family Medicine
 - Internal Medicine
- Psychiatry
 - Some PCPs may be willing to prescribe your child's behavioral health medications depending upon your child's level of need and their practice policy
 - Experience with developmental disabilities is a MUST as medications can have different interactions with this population than typically seen with the general public
- Dentist
- As your child reaches adulthood, their developmental disability will often stabilize, reducing or even eliminating the need for certain doctor's services:
 - Developmental pediatrician
 - Neuropsychologist
 - Neurology - Only if they have a neurological condition/concern beyond autism (eg migraines, epilepsy)

Fostering independence & self-determination

- Inability is not the same as lack of opportunity
- Sometimes, it's just easier as parents to do it ourselves!



Skill building

- Skills to practice:
 - Signing in at the doctor's office
 - Offering at check-in non-driver's ID and insurance cards
 - Scheduling an appointment
 - Calling the doctor's office with a question
 - Making a list of questions for the doctor ahead of appointment
 - Knowing medication list
 - Knowing major allergies (e.g. penicillin, nuts)
 - Refilling prescriptions
 - Practicing calling emergency contacts and role play 911
 - Taking public transportation to the appointment
- Before any new doctor's appointment, ask to come tour the office, meet the staff, and see the exam room to ease anxiety

Resources

- National Center for Health Care Transition (Got Transition)
 - <https://www.gottransition.org/>
- Transition to Adulthood: A Health Care Guide for Youth and Families
 - <https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>
- NIMH Transition Aged Youth Webinar Series - Making Health Care Transition Work for Youth with Autism: Youth and Parent Perspectives and National Resources
 - <https://iacc.hhs.gov/meetings/autism-events/national-autism-coordinator/transition-aged-youth/health-care/>
- Charting the LifeCourse – has person centered planning tools including healthcare
 - <https://www.lifecoursetools.com/>

References

- CHOP (2017), Transitioning to adult care: Supporting youth with special health care needs [Pdf file], https://policylab.chop.edu/sites/default/files/pdf/publications/Transitions_Of_Care.pdf
- White, Taylor (2020, September 25), Transition to adult healthcare is often challenging for autistic children, *Spectrum News*, <https://www.spectrumnews.org/news/transition-to-adult-healthcare-often-challenging-for-autistic-children/>
- Leeb, R.T., et al. (2020). Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders - United States, 2016-2017. *CDC Morbidity and mortality weekly report*, 69(34), 1156–1160. <https://doi.org/10.15585/mmwr.mm6934a2>

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NAVIGATION SUPPORT COORDINATION

Navigating the Seas of DDD
Serving Ocean & Monmouth County
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Gaining access to DDD

Apply for Medicaid Eligibility

- Apply for SSI (Supplemental Security Income) at age 18
 - SSI Approval=Automatic Medicaid Eligibility
 - If SSI-ineligible, apply for New Jersey Medicaid
- For Medicaid eligibility information, go to [Medicaid Eligibility and DDD \(click\)](#)

Apply for DDD Eligibility/Intake Application

- At age 18 or older you can complete DDD Intake Application
 - DDD services not accessed until age 21
- To download the DDD Eligibility Application, go to [Where to Apply for Services \(click\)](#)

Complete the NJ Comprehensive Assessment Tool (NJCAT)

- Mandatory assessment tool that evaluates support needs in three main areas: (1)self-care, (2)behavioral, (3) medical
- Establishes an individual's tier
 - Tier determines the individualized budget



Support Coordination

- **Mandatory service for individuals registered with DDD & using fee-for-service**
 - used to gain access to needed service providers, state plan services, as well as community resources.
- **Individual/family can choose a Support Coordination Agency**
 - If a family doesn't choose a Support Coordination Agency DDD will auto assign you one
- **Intake meeting occurs with the individual receiving support coordination services and their supporters to get to know one another**
 - Reviews the NJCAT & individualized tier/budget
 - Gathers information to create the NJISP & PCPT
 - Discusses potential DDD service providers and community resources one may be eligible for
 - From this meeting the PCPT & NJISP is created
- **Conducts mandatory monthly, quarterly, annual contacts to ensure progress**
 - Available as needed and not limited to monthly, quarterly, & annual contacts.



Additional Resources

The Arc of New Jersey, Planning for Adult Life: [Archived Webinars \(click\)](#)

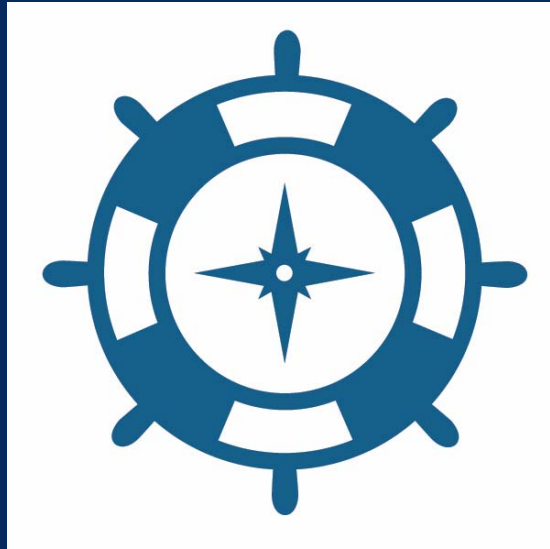
The Boggs Center on Developmental Disabilities guide on [Selecting a Support Coordination Agency \(click\)](#)

A Timeline for Students Exiting School & Turning 21 from DDD [Graduates Aging Out of the School System \(click\)](#)

DDD Webinar on [Completing the DDD Assessment for Service Eligibility: NJCAT \(click\)](#)

Supports Program and Community Care Program Policies & Procedures: [A Quick Guide for Families \(click\)](#)





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