

# Transition Survival 101: How and When to Create a Transition Plan

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Special Learning

Step by Step

"Under the Individuals with Disabilities Education Improvement Act of 2004, (IDEA 2004, PL 108-446), students diagnosed with autism who have turned 22 or graduated from high school with a regular diploma no longer have a legal right to appropriate transition services, such as life skills training, transportation, vocational training, and individual and family counseling"



Wehman, P., Smith, M.D., Schall, C. (2009). Autism and the transition to adulthood – success beyond the classroom. Baltimore, Maryland: Paul H. Brookes Publishing Co.



## **Today's Objectives**

Upon completion of *Transition Survival 101: How and when to create a transition plan*, participants will be able to:

- 1. Identify potential barriers individuals may face as they become adults;
- 2. Identify resources that may assist adolescents and adults with successful transition;
- 3. Understand what data and information is needed to create an effective transition plan.





## **Autism Spectrum Disorder**

#### > Autism

- Qualitative impairment in social interaction
- Qualitative impairment in communication
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities

#### > Asperger's

- Qualitative impairment in social interaction
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities



# Autism Spectrum Disorder in Adolescence

- Adolescence is a risk period for emergencies of serious mental disorders
  - Profound psychological, physiological and social change during adolescence
  - Rates of mental health problems increase during adolescence
- Sometimes difficulty teasing out





## Autism Spectrum Disorder in Adolescence

- Overall improvement of autism symptoms and internalized behavior improve most during the period of time the individual participates in school placements and rates of improvement slow significantly following exit from these placements
  - Individuals with comorbid intellectual disability initially present with lesser degree of improvement prior to transition from high school;
  - Individuals without intellectual disability presented with greater degree of improvement prior to exiting high school, but ongoing gains slowed to rate similar to the rate observed in those with comorbid diagnoses.
  - Domains of repetitive behavior, social reciprocity, and verbal communication improved slowed significantly;
     domain of non-verbal communication worsened
  - Domain of externalized maladaptive behavior and asocial behavior generally did not change in level; internalized maladaptive behavior slowed significantly.



Taylor, J.L., Seltzer, M.M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disabilities*, 40(12), 1431-1446.



## **Always a Transition**

- We all grow up...
  - Infant to toddler
  - Toddler to kindergarten
  - Kindergarten to elementary
  - Elementary to middle school
  - Middle school to high school
  - High school to adulthood
  - Adulthood to aging





#### **Identified Problems During Transition**

- Evidence shows that problems occur during transition in diverse settings across several countries
  - A study in the US in 1997 showed that there is a gradual decline in inpatient, outpatient and residential services from the ages of 16-17, compared to 18-19 years old
  - A survey in the US, covering 41 states, found the ¼ of child mental health services and
     ½ of adult services offered no transitional support
  - Another study indicated that the reason for lack of continuity of care was due to separate policies for access of care (specific to adults and children from the state level) and lack of shared planning
  - Other countries has separate services for those diagnosed with a mental health disorder and developmental disabilities



#### **Transition Problems in Mental Health Care**

- In physical health, there are emerging models of practice to improve the transition process and outcomes – there is nothing comparable to mental health care
  - A poor transition leads to disruption in continuity of care and lose of services leads to poor outcomes
  - Those with neurodevelopmental disorders (like autism) are at greater risk of "falling through the cracks" during this time of transition





#### **Barriers**

- Barriers to optimal transition:
  - Changes in established, long term therapeutic relationships
  - Differences in adult and children models of care
  - Young people's level of maturity and understanding
  - Differing perceptions of the adult care system
  - Adult resistance to transfer
  - Family stressors
  - Inadequate education and training for adult care providers on adolescent disorders
  - Lack of organizational support
  - Effects of poor transition
  - Most disruptive outcome is that young people with ongoing needs disengage from services during the transition process



## Effects of poor transition

Most disruptive outcome is that young people with ongoing needs disengage from services during the transition process





### Autism Treatments & Services During School

- Education
- Special needs services such as speech, OT, PT, APE, tutoring
- Formal social skills groups and training
- Counseling
- Positive behavior supports and behavior support plans
- Community training
- Job placement, training and coaching
- > Self-contained placements, and individual inclusion opportunities
- Access to peer models, structured peer mediated interventions
- Individualized education and service plans
- Bus service





## Autism Treatments & Services Beyond School

- Approximately 56% of children aged (6-17 years old) with ASD, take a variety of medications ranging from:
  - Stimulants
  - Anti-anxiety or mood-stabilizers
  - Antidepressants
  - Sleep medications
  - Antipsychotic medications
  - Anti-seizure meds to help decrease challenging behaviors
- Case Management
- Home respite support services
- Mental health services
- Medical evaluation and services
- Ongoing assessment and evaluation





#### Studies Show...

- One-half of school-aged children with ASD were 5 years old or older when they were first diagnosed
- More than half of individuals with autism are considered non-verbal
- ➤ 2011 survey results of a 10-year study of more than 11,000 youths enrolled in special education show after high school:
  - 39.1% receive no services
  - 9.1% receive Speech compared to 74.6% during school
  - 41.9% receive Case Management compared to 63.6% during school
- Family income and education are associated with access to services almost 6 times higher odds will not receive services if low income





## Studies Show (cont'd)

- ➤ Most young adults live with their parents up to 79%
- Race and ethnicity is also a variable in access to services
- ➤ Higher functioning individuals suffer a sharp decrease in or no access to services
- Many adolescents with autism score low on:
  - Independent living and self-care skills
  - Functional cognitive skills
  - Social skills
  - Communication
- The first few years following school as a new adult are the most crucial predictors to future success





- Overall remaining high level of need
- Change
  - Increase in challenging behaviors?
  - Supports needed to prevent
  - Decrease in environmental structure and control
- Communication challenges and language impairment
- Social interaction, skills and relationship difficulties
- Need for ongoing, daily supervision and support
- High rates of comorbid health and mental health problems (e.g. epilepsy, anxiety, depression)





- High and ongoing need for case management and care coordination
  - Multiple health care providers
  - Multiple services needed
  - Management of funding resources
  - Education of available services
  - Aid in accessing services
  - Loss of service continuity
- Transportation
- Loss of entitlements
- Funding and services access decrease





- Lack of knowledge about what services are available
- > Services are often provided by multiple agencies and funding sources; no central agency for this population and age making navigation more difficult
- Lack of community placement options
  - Living and residential
  - Employment
  - University and colleges increasing currently
- Behavioral challenges prevent inclusion in the community
- Few programs teach safety and abuse prevention





- Lack of planning for and/or resources to successful fading/decrease in family support
- Need for long term plan when caregivers age
- > Increased crisis and stabilization needs; few places to receive this level of care
- Physical height and weight and its relation to safety, treatment options, and placements
- Limited day activity and support options
- Quality of life questions
- Grief, coping, and family system needs





# **Challenges:**What Studies Tell Us

- Results suggest that adult services do not provide adequate opportunities for adults with ASD who do not have intellectual disabilities
  - Family income was unrelated to initial severity of maladaptive behavior observed or improvements observed when individuals were in school;
  - Families with higher levels of income were able to better facilitate a more successful transition to adulthood, and
  - In securing services that better meet the individual's level of need

Taylor, J.L., Seltzer, M.M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disabilities*, 40(12), 1431-1446.





### **Adolescent to Adulthood**

- General considerations in transition planning from adolescent to adulthood:
  - Post-secondary education
  - Employment
  - Independence
  - Living arrangements
  - Relationships
  - Community recreation and leisure
  - Financial supports





#### **The Transition Plan Overview**

- Core Beliefs
- > Who
- > What
- When
- Where
- > Why
- Ongoing review





#### **Core Beliefs**

- Person first
- Competence
  - Self-confidence
  - Self-esteem
- Preference
- > Independence
- > Interdependence
- Planned
- Organized
- Focus on "what people with autism can do"





#### The Transition Plan: Who

- Who: The Transition Team
  - Family/Caregiver
  - Individual
  - IEP Team
    - special ed teacher, intervention specialist, paraprofessional, principle, counselor, speech pathologist, occupational therapist, physical therapist, behavior analyst, transition facilitator
  - Psychologist
  - Psychiatrist
  - Behavior Analyst
  - Local support service coordinators
  - Vocational specialist
  - Counselor, Social Worker
  - Residential and community-based coordinator





### **The Transition Plan: What**

- What: Comprehensive individual assessment and planning document
  - Assessment
  - Treatment and educational goals
  - Service needs and establishment plan
  - Timeline projection and benchmarks that create a "Path" and checkpoints for review of progress
  - Checklist of responsibilities by person, and as a team
  - Follow-up reviews





## The Transition Plan: When, Where and Why

- When
  - Literature states as early as 12 but no later than 16 years old
  - IDEA 1997 requires planning process to begin by age 14
- Where
- > Why
  - It is critical the team identifies the supports needed to ensure the highest potential for success in later life
  - There are a significant number of challenges one may face as part of the transition
  - There is typically a great deal of time needed to complete and implement all components of the transition plan





- Person's history
  - Development and growth
  - Specialized placements and/or hospitalizations
  - Services previously received and their outcome
  - Learning history, style and acquisition rate
  - Family history
- General strengths and challenges
- Life goals and preferences
  - Individual
  - Parent/Guardian
- Psychological and diagnostic profile
- Physical and medical health history





- Medication management history and current status
- Current and planned living arrangements
- Resources available
  - Financial
  - Natural environment supports
  - Family supports
  - Social service supports
  - Education supports until 22
  - Adult specific supports upon 18 years of age







- Current adaptive skills baseline
  - Communication
  - Independent living and self-care
  - Job skills
  - Integration and inclusion abilities
  - Post-secondary education readiness skills
  - Self-regulation and monitoring skills
  - Relationship and social skills
  - Safety
  - Problem-solving
  - Recreation, leisure skills
  - Community skills
  - Money management
  - Mobility
  - Self Assessment, Self Reinforcement





- Motivation & Interests Assessment
  - Likes
  - Dislikes
  - Current access/limits to likes;
     response expectations
  - Specific preferences
  - Possible likes to explore
  - Communicate likes and dislikes
  - Natural environment supports

- Social Skills Assessment
  - Conversation
  - Perception and theory of mind
  - Soft skills
  - Abstract social thinking
  - Non-verbal communication
  - Social Rules





- Cognitive and Academic Abilities > Challenging behavior assessment
  - Reading
  - Writing
  - Math
  - Computer skills
  - Reasoning and Logic
  - Problem-solving skills
  - Functional application of skill sets

- Summary of indirect assessment measures
- FBA, if applicable
- Comorbid conditions
- Current and/or needed behavior support plan(s)





- Vocational skills
  - Job interests
  - Specific components of job
  - Executive functions
  - Social skills
  - Self-regulation and management
  - Work habits

- Post-secondary education skills
  - Mobility
  - Executive functions and selfmanagement
  - Social skills and relationships
  - Classroom readiness and management
  - Communication and topographies
  - Academic baseline and interests





#### Additional Assessment Of Strengths & Challenges – Assessment Components 7

- Adaptive/Adaptive
  - Communication & Verbal Skills
  - Receptive Language/Comprehension
  - Visual-spatial Skills
  - Reasoning
  - Written Expression
  - Organizing Ideas
  - Connecting Ideas
- Behavioral/Emotional Challenges
  - Attention and Concentration
  - Impulse Control
  - Frustration Control
  - Acceptance of Authority
  - Anxiety Issues
  - Depression Issues

- Sensory Challenges
  - Noise
  - Light
  - Smells
  - Taste
  - Touch
- Motor Challenges
  - Fine Motor Limitations
  - Gross Motor Limitations
- Social Challenges
  - What do I do too much of?
  - What do I do too little of?





- Current treatments and services at transition plan initiation
  - Progress summary from current treatments
  - Challenges remaining
- Updated treatment and education goals and objectives
- Services and treatments needed to continue
- New services and/or treatments needed to establish
- Inclusion opportunities
- Assessment of local services:
  - Availability
  - Access
  - Cost
  - Financial support





- Outside service organizations:
  - Current outside organizations providing services
  - Outside organizations that will continue providing services as part of the transition plan
  - All organizations involved as part of the adult service plan following transition
  - Outside organizations identified to establish service
- Referrals and/or additional assessments needed
- Transition timeline
- Transition team responsibility checklist





### Laws to Know

- ➤ EPSDT
  - Early Periodic Screening Diagnosis and Treatment
  - All children with a disability must be provided medically necessary treatment and services
- > IDEA
  - Individuals with Disabilities Education Act (1975)
- > IDEIA
  - Individuals with Disabilities Education Improvement Act (2004)
- > FAPE
  - Free and Appropriate Public Education
- > WIA
  - The Workforce Investment Act (1998)
  - One stop career centers





#### Resources to Know

- Social Security Benefits
- Rehabilitation programs and services
- Department of Developmental Disabilities
- Department of Health and Human Services
- Medicaid Waivers
- Medicare
- Medicaid Card services
- Local community, county and state services
- Adult day support, day habilitation programs
- Community employment organizations
- Benefits Specialists





### **Resources to Know**

- Benefits Specialists
- Job Coaches
- Job Assessment services
- > Transportation services
- Residential facilities
- Crisis and stabilization facilities
- Group home living options





### **Additional Resources**

- Vineland Adaptive Behavior Scales, Second Edition (Vineland-II)
  - A measure of adaptive behavior from birth to adulthood
  - http://psychcorp.pearsonassessments.com/HAIWEB/Cultures/enus/Productdetail.htm?Pid=Vineland-II
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