Leaving the Nest: Transition Challenges for Youth with ASD and Other DD's

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# Disclosures

• No conflicts of interest to disclose

# What is Transition Care?

• 4 components (Lotstein et al., 2010)

- Changing from pediatric to adult providers
- Changing insurance
- Self-care skills
- Education/employment

# Core Measure for MCHB since 1989

- Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;
- Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
- Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- Children are screened early and continuously for special health care needs
- Community-based services for children and youth with special health care needs are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

### **Poor Transition Outcomes**

### Health is diminished:

- Youth often unable to name their health condition, relevant medical history, prescriptions, insurance source
- Adherence to care is lower and medical complications are increased

### Quality is compromised:

- Discontinuity of care and lack of usual source of care are common
- Medical errors reported

### Costs are increased:

- Increased ER, hospital use, and duplicative tests result
- Increased long-term costs from consequences of lapsed care

## Need for Transition Improvement

- Transition affects an estimated 18 million "emerging young adults" ages 18-21, about ¼ of whom have chronic conditions; many more millions if those ages 12-26 counted.
- Young adults (ages 18-25) are less healthy than adolescents (ages 12-17) or adults (ages 26-35); they often are not connected to primary care; and they have the highest use of ER among those younger than age 75.
- Majority of youth are ill-prepared for this change.
- Surveys of health care providers consistently show they lack a systematic way to prepare youth, families, and young adults for transition from pediatric to adult health.

## Health Care Transition Definition

 "The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems" *Pediatrics* 2002

### Goals of Health Care Transition

Youth should have a planned process of gaining self management skills and independence that includes smooth transition of medical Information and integration into adult care

Position Paper of the Society of Adolescent Medicine 2003

Consensus Statement AAP, AAFP, ACP-ASIM, Pediatrics 2002

## National Context for Transition

- ACA: Transition an essential health home service, insurance expansions for young adults
- NCQA medical home standards on transition (plan of care, self-care support, transfer of medical records)
- Healthy People 2020 (discussion of transition planning with health care provider)
- CMS/CMMI focus on transition from hospital to home and meaningful use core measure on summary of care record
- IOM/NRC Report (2014): Investing in the Well-Being of Young Adults-Transition one of three top recommendations
- ACP: High Value Care Coordination

# AAP/AAFP/ACP Clinical Report on Health Care Transition

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets <u>all</u> youth, beginning at age 12
- Algorithmic structure with
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists

- Age 12 Youth and family aware of transition policy
- Age 14 Health care transition planning initiated
- Age 16 Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
- Age 18 Transition to adult approach to care
- Age 18-22 Transfer of care to adult medical home and specialists with transfer package

### Six Core Elements of Transition

- **1. Transition Policy**
- 2. Transition Tracking and Monitoring
- 3. Transition Readiness
- 4. Transition Planning
- 5. Transfer of Care
- 6. Transfer Completion



### Website: www.gottransition.org



How can I assess my progress in implementing the Six Core Elements?

### Transition in ASD

- Majority of adults with ASD unable to work, live independently or have personal relationships (Howlin, 2004; Sperry & Mesibov, 2005)
- 70-80% of children with ASD will demonstrate marked social impairment in adolescence and adulthood (Billstedt et al., 2005; Fombonne, 2003)

# Epidemiology of ASD

- Overwhelming majority of individuals with a pervasive developmental disorder have milder forms of ASD.
- Number of children suffering from "Asperger Syndrome" is double the number of children suffering from classic autism (VanBergeijk and Shtayermman, 2005).
- Most of the academic literature has focused upon the more severe forms of ASDs.
- Comparatively little attention has been paid to children and young adults who possess milder forms of the disorder.

## Life Course of ASD

- Paucity of research in this area
- Only 4% of studies are "lifespan studies" in autism (IACC, 2012)
- Limited data suggest most common co-morbidity is mood disorder (anxiety or depression) (Klin & Volkmar, 1996)
- Unclear what happens to sleep disorders and GI problems from childhood



### Poor High School Outcomes

- Rates of graduation for students with ASD are low:
  - 38% graduate with high school diploma
  - 18% received a certificate
  - 6% aged out
  - 6% dropped out
- Average assessment scores on Woodcock-Johnson for students with ASD were three standard deviations below the mean than those for non-disabled peers
- On Scales of Independent Behavior, only 16% of students with ASD scored at or above the man, and 65% scored more than six standard deviations below the mean

# Poor Post-Secondary Employment Outcomes

- Employment rates for individuals with ASD, regardless of intellectual disability, range from 4-12% (Taylor & Seltzer, 2011)
- Individuals with ASD who have completed college report significant challenges with underemployment or chronic unemployment (Attwood, 2007; Barnhill, 2007; Hendricks & Wehman, 2009; Henninger & Taylor, 2012; Hurlbutt & Chalmers, 2004; Schall, Targett & Wehman, 2013)
- Individuals with ASD have lower rates of participation in vocational or technical education, employment, and postsecondary education in 2- or 4-year programs than their peers with speech and language impairments, learning disabilities, or intellectual disabilities for as long as 7 years after high school (Shattuck et al., 2012)

# **Employment Experiences**

- People with ASD are more likely to lose their employment for behavioral and social interaction reasons rather than their inability to perform work tasks (Dew & Alan, 2007; Hurlbutt & Chalmers, 2004; Unger, 1999).
- Higher levels of social inclusion and acceptance were correlated with longer job retention (Belcher and Smith, 1994)
- Individuals with ASD initially required a very high-intensity level of support on job and social skills; however, most achieved a reasonable level of independence within a year of intervention.

# Possible Transition Strategies for ASD—Postsecondary Employment

- Transition-focused curriculum in high school
- Paid work experience while in school
- Training in self-care/independent living
- Career awareness
- Occupational courses
- Community experiences

# Components of Successful Transition-to-Work Programs

- identification of the most appropriate work settings and placements
- provision of effective on-the-job supports
- provision of long-term support services for the employer and the employee with ASD
- analysis of costs for support
- Recognition of the positive effects of employment on individuals with ASD

# Poor Secondary Education Outcomes

- Individuals with ASD enroll in and complete postsecondary education and training programs at rates far below that of students with other disabilities (Newman, 2005).
- Services for students with ASD in postsecondary education are insufficient and uncoordinated (White, Ollendick & Bray, 2011)
- Students who attended "regular" high schools, performed at an above-average academic level or participated in their transition plans were more likely to participate in postsecondary education (Chiang et al., 2012)

# Possible Transition Strategies for ASD–Postsecondary Education

- 1. Instructing students with ASD in natural environments from Grades K through 12.
- 2. Using Person-Centered Planning models in transition planning.
- 3. Developing local, regional, and/or state-level cross-agency coordinating teams.
- 4. Incorporating universal design principles in developing postsecondary courses and materials.
- 5. Providing peer mentoring for students with ASD.
- 6. Providing educational coaching.
- 7. Providing concurrent engagement in employment.
- 8. Enhancing social pragmatics and communication skills.
- 9. Enhancing self-determination and self-advocacy skills.

# Project SEARCH

- Project SEARCH model (e.g., intensive business-based internships, collaboration, and complete embedment in the final year of high school; Datson, Riehle, & Rutkowski, 2012) with ASD-specific interventions:
  - regular behavioral consultation with a behavior analyst
  - consistent structure to unstructured internship rotations
  - behavioral definition of workplace social skills, idioms, and work expectations
  - use of visual supports
  - use of self-monitoring reinforcement programs
  - intensive social skills instruction through role play and behavioral practice
  - intensive instruction and monitoring of student success.

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### Student Support Services/ Disabled Student Programs & Services

**Meet the Staff** 

#### **Coordinator, Student Support Services:**

<u>Jeffery Ross jross@taftcollege.edu</u> has been with Taft College since 1976. He got his B.S. degree in Social Services from California State University, Pomona. He received his M.A. degree in Special Education from California State University of Bakersfield. Jeff is a Learning Disabilities Specialist and a certified High Tech Specialist.

Jeff designed and established the Transition to Independent Living (TIL) program, which has brought Taft College national recognition for its highly successful, one of a kind residency program for developmentally disabled adults.

#### Coordinator's Assistant/Student Support Services:

<u>Kathy Evarts kevarts@taftcollege.edu</u> has been with Taft College since 1988. Her job is to assist and track special day classes, maintain academic and vocational records, aid disabled students with registration and forms related to coursework. She assists with independent living skills training, basic skills instruction and the transition process of our developmentally disabled students. She also acts as a liaison between the Student Support Services Coordinator, the students and their families, and other related agencies.

Kathy was born in Bakersfield, CA. and attended local schools, including Taft College. She played a major role in the conception and implementation of the Transition to Independent Living program (TIL). She was awarded the EOPS/CARE *Most Supportive Staff Member* for 1999/2000.

#### Learning Disabilities Specialist:

<u>Susan Vaughan</u> received her B.A. degree in Sociology, and her Master's degree in Vocational Rehabilitation Counseling from California State University, Fresno. She is a certified Vocational Evaluator as well as a certified Vocational Counselor. Susan is one of our instructors for the Learning Skills classes; in addition she conducts the assessments for learning disabilities.

#### Assessment Specialist:

We Offer Assistance For Students With, But Not Limited To The Following Disabilities:

Specific Learning Disabilities Developmental Delays Hard of Hearing/Deaf Vision Impairment/Blind Mobility Issues Temporary Disabilities Acquired Brain Impairment/Traumatic Brain Impairment Psychological Issues Other (Autism, ADD (H), Chronic Illness, etc.)



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The Program for the Education and Enrichment of Relational Skills

Laugeson, Founder and Director of the UCLA PEERS Clinic, and Dr.

States and the world. PEERS is a manualized, social skills training

Fred Frankel in 2005 and has expanded to locations across the United

spectrum disorders, but is also appropriate for teens and young adults

with ADHD, anxiety, depression, and other socioemotional problems.

(PEERS®) was originally developed at UCLA by Dr. Elizabeth

intervention for adolescents and young adults. It has a strong

evidence-base for use with teens and young adults with autism

#### PEERS

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FOREWORD BY JOHN ELDER ROBISON bestadling author of Lack Me in the Eyer My Life of the Apergeric

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### ELIZABETH A. LAUGESON, PSY.D.

The Science of MAKING FRIENDS Helping Socially Challenged Teens and Young Adults



## HCT-RN

- established in 2014 with funding from the Maternal and Child Health Bureau, partnership with UCLA, Drexel and Autism Speaks
- first collaborative research network aimed at addressing the health, family, and social needs of adolescent and young adults on the autism spectrum
- Network Design meeting in May 2015 in Washington, DC
- Program Manager: Tara Crapnell, OTD, OTR/L
- Contact us: autismtransition@mednet.ucla.edu
- www.AutismTransition.net







#### Health Care Transitions Research Network (HCT-RN) for Youth and Young Adults with Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is a neuro-developmental disorder, characterized by social communication deficits and restricted and repetitive behavior patterns that last a lifetime for most. Given the current prevalence estimates of ASD in the U.S. of 1 in 68 children, about 66,000 youth on the autism spectrum will turn 18 years old each year. Youth on the autism spectrum are especially vulnerable during the broad transition from adolescence to adulthood due to a myriad of factors, both intrinsic and environmental. The transition to adulthood is also a time of major service transitions loss of services upon exit from special education and attempts to access adult systems of care. Outcomes for adults with ASD are bleak with an estimated 50% of young adults on the autism spectrum completely disconnected from any employment or education opportunities during the first two years after high school.

The Health Care Transitions Research Network (HCT-RN) for Youth and Young adults with ASD aims to address this critical issue and to better understand the life course influences at the person, family, community, health system, and policy levels prior to, during, and following the transition to adulthood among individuals with ASD. The network is a forum for experts in the field to connect, collaborate, promote research, and develop innovative projects that will inform and translate into evidencebased practice and policy. Currently, our network is comprised of an interdisciplinary group of researchers, health care professionals, and individuals on the autism spectrum and their families who all aspire to improve and promote optimal transition into adulthood among this population.



# ACP Council on Subspecialty Societies

- 2015 created a Pediatric to Adult Transitions Workgroup
- 17 subspecialty societies have signed up to participate as well as AAFP, AOA, AAP and the National Partnership for Women and Families
- HCT-RN, SGIM and MPPDA leading effort to create clinical practice guidelines for successful transitions for ASD and other DD's

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Internal Medicine & Pediatrics			1245 16th St., Suite 125, Santa Monica, CA View Location 💡				
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### UCLA Medicine-Pediatrics



### Comprehensive Care Center

### Our Location:

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### Scheduled Appointments:

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Welcome to the new UCLA Med-Peds Comprehensive Care Center! We opened our doors on Monday, July 1, 2013 and has continued to grow and flourish. Our clinic is staffed by a wonderful group of Internal Medicine – Pediatric Physicians who are board certified in both Internal Medicine and Pediatrics. In addition to providing primary care for adults, we offer the full range of pediatric services for children, including



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# Thank you!

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  - 310-315-8900 for appointments
- Health Care Transitions Research Network for ASD
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