

# Transition to Adulthood in IDD

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ECHO IDD Wraparound  
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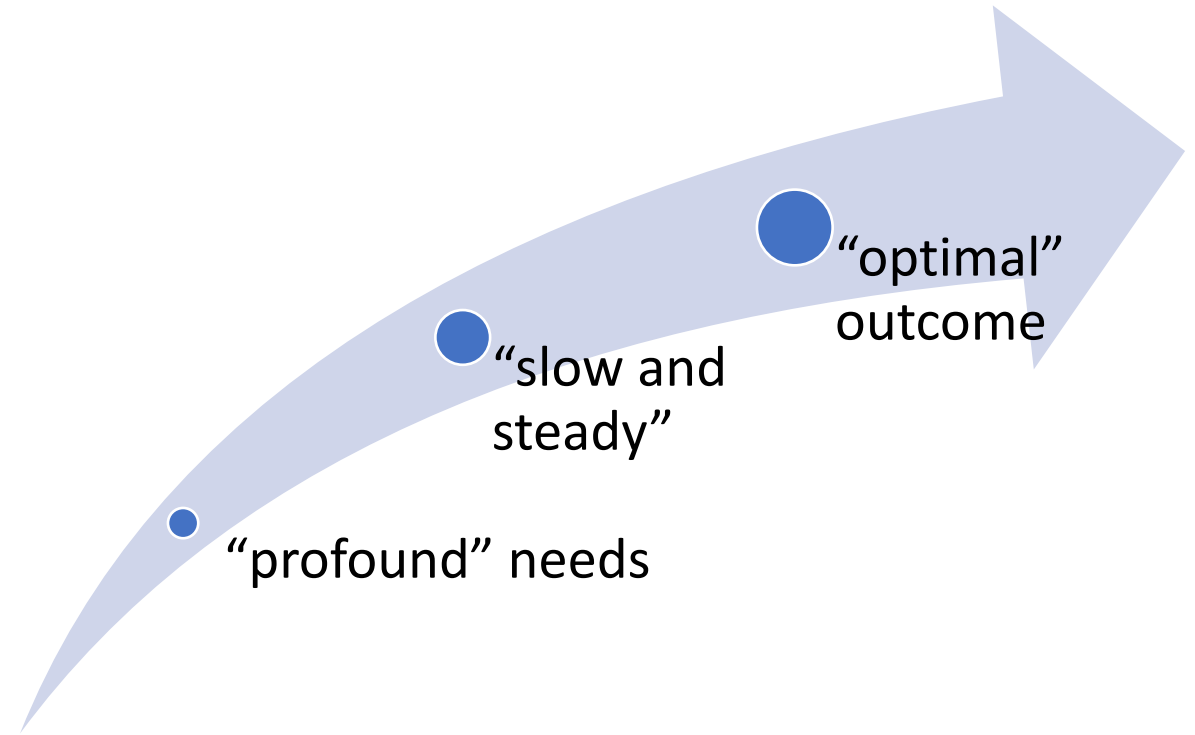


# Objectives

- Review outcome trajectories into adulthood and factors influencing outcome for individuals with ASD/IDD
- Understand the importance of successful transition to adulthood and identify barriers to successful transition for individuals with ASD/IDD
- Review factors related to success in adulthood including community participation/employment and co-occurring mental and physical health
- Become familiar with resources to assist in successful transition to adulthood

# Outcome Trajectories in ASD

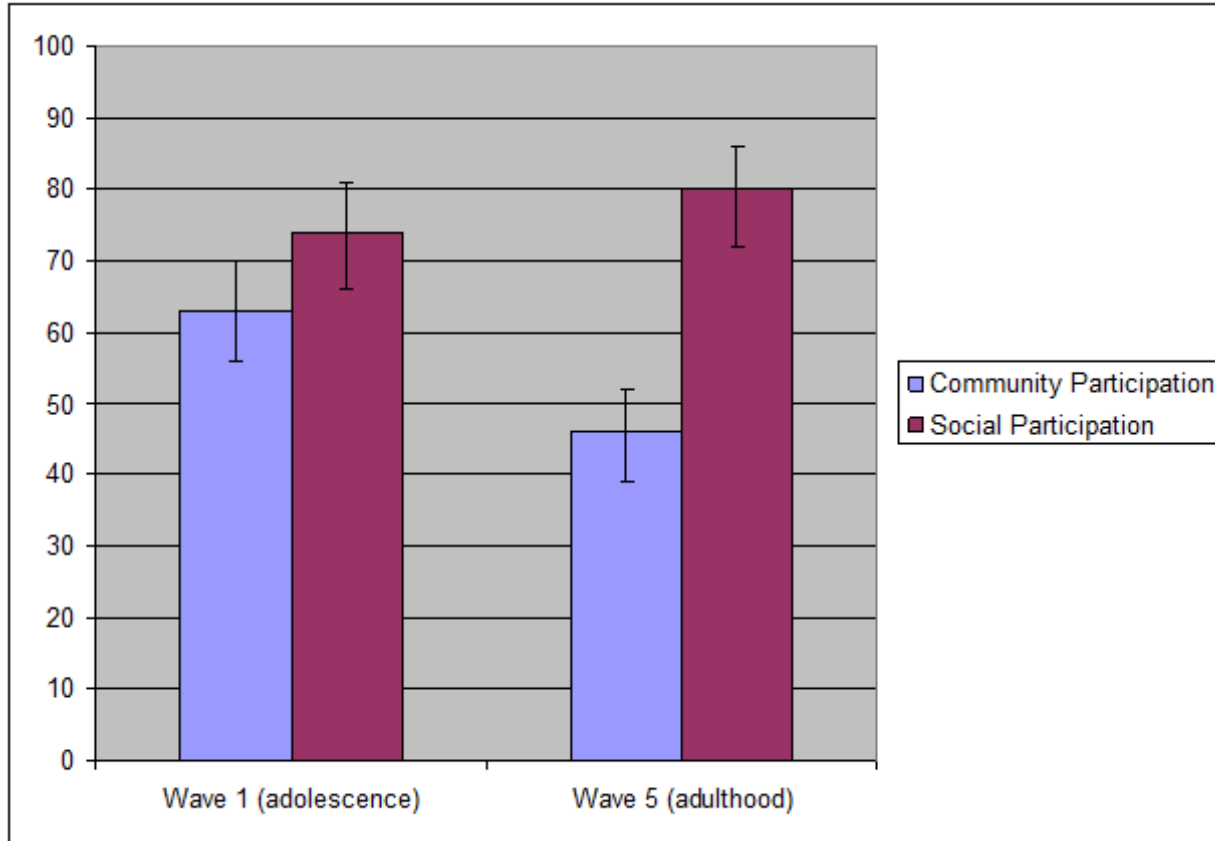
- “optimal outcome” (Helt, 2008)
  - “Masking” vs developmental progress and learning?
  - 10-20%?
- Most make progress but continue to require some types of support
- Approximately 10-30% remain profoundly impacted requiring 24/7 support (Seltzer, 2004)



# Factors Impacting Outcome

- Cognitive and adaptive skills
- Core autistic features
- **Mental and physical health**
- Presence of challenging behaviors
- Socioeconomic status
- Access to services
- **Presence of a “case manager”**

# Successful Transition – Who is the “Case Manager”



- National Longitudinal Transition Study (NLTS-2)
  - **Household income and “case manager” at wave 1 influenced **community participation as an adult** (defined as ANY participation outside of school in prior 12 months)**
  - “**case manager**” at wave 1 influenced **social participation as an adult** (defined as ANY get together, social event, or phone call to friend in prior 12 months)

Community Participation - “has youth participated in community activities in the last 12 months”

Social Participation – “get togethers, invitations, or phone calls in the last 12 months”

*Myers, 2015*

# Barriers to Optimal QoL in Adulthood

- Workforce shortage
  - Physicians serving adults with ASD, only 20% received training during residency (Bruder, 2012)
  - Parents view PCPs as unable to assist vast majority of autism-related problems (Carbone, 2013)
  - Job coaches, counselors, in-home service providers, etc.
- Resource shortage
  - Housing, employment/community supports, transportation
- Physical and mental health
- Parents/caregiver supports
  - Alignment of future planning; Financial barriers
  - Promoting independence and self-advocacy

# What is Optimal QoL for Adults with ASD/IDD?

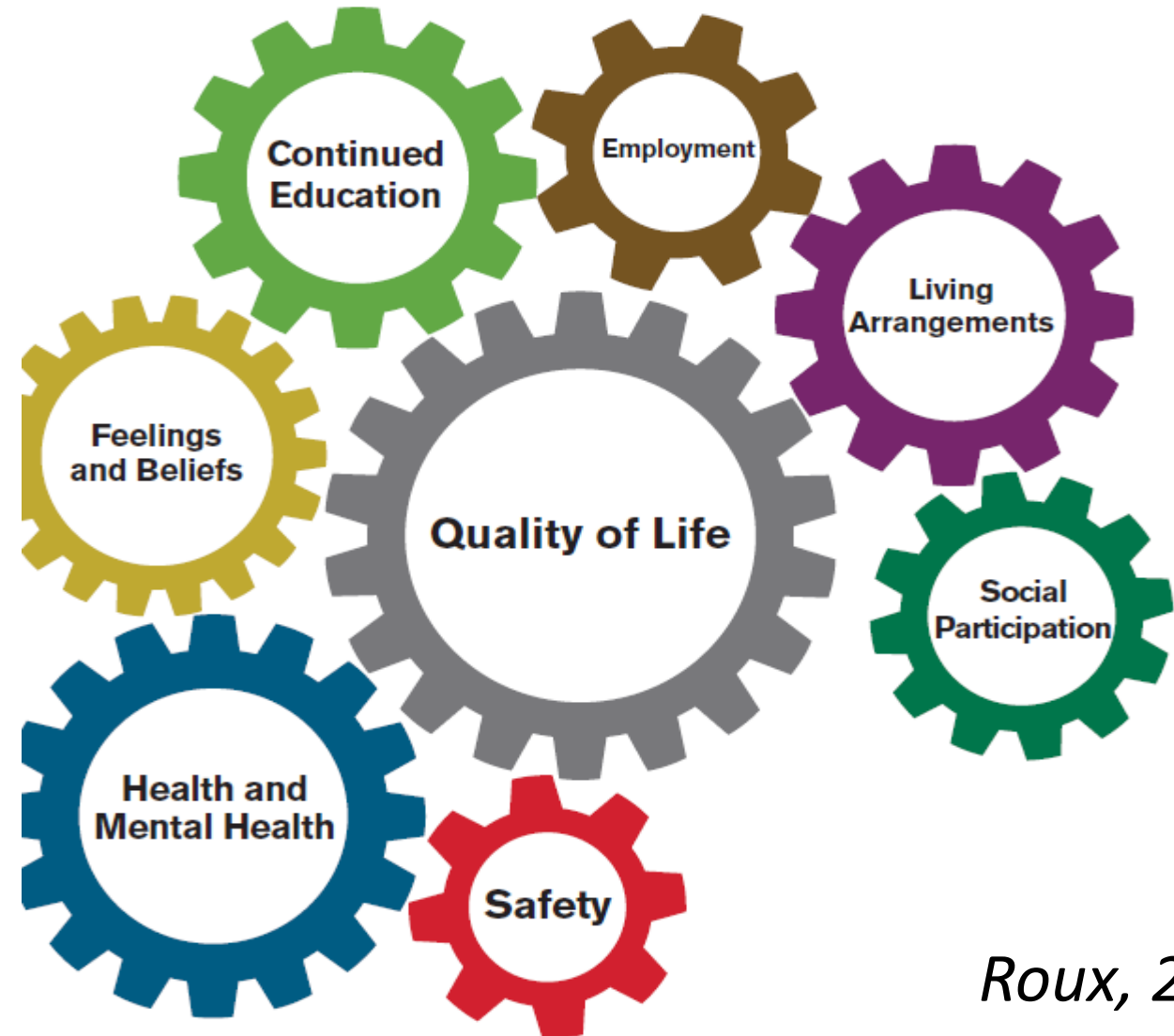
- Parent/caregiver perspective (First Steps classes, 2016)
  - Community access
  - Health and wellness
  - Making friends
  - Education and employment
- Self-advocate perspective (Howlin, 2023)
  - Develop a positive self-identity
  - Improve understanding of ASD/IDD in the community
  - Access to mental health and physical health services
  - Access to the community
  - Recognize impact of trauma, social isolation, and stigma
  - Sensory environment modifications
  - Focus on strengths



# The Connection Among Outcomes

Quality of life is interconnected with all aspects of health and community involvement.

- *Healthcare must think “outside their lane” in addition to mental and physical health.*



*Roux, 2015*

# Employment and Community Participation

- ASD Employment rates 4.1% - 11.8% regardless of ID (Taylor & Selzer, 2011)
  - Lower rates compared to other DDs (Shattuck, 2012)
- Decline in employment status over time
  - Under-employment
  - Mental and physical health
- Taylor study (2014) - Greater vocational independence relates to -
  - subsequent reduction in autism symptoms
  - Reduced maladaptive behaviors
  - Increase in ADLs
  - The reverse does *not* hold true – autism severity does **not** correlate with having a job

# Mental and Physical Health

- Increased risk of physical health conditions
  - Sleep, GI, obesity, and epilepsy most common
  - Increased risk of other organ involvement in “syndromic” cases
- Challenges in establishing “medical home” as an adult
  - Knowledgeable providers
  - Physical barriers to access
  - Reduced health screening and wellness
- Increased risk of mental health conditions
  - Anxiety, depression, ADHD most common co-occurring
  - Reduced access to therapists and evidence-based therapies
  - Increased suicide risk correlated with cognitive ability
  - Be aware of regression is function (may represent depression, PTSD/trauma, catatonia)

# Housing and Safety

- Safety concerns in supported and independent living
- Pros and cons to continued living with nuclear family
- Supported living housing options limited
  - Especially with challenging behaviors

# Preparing for a “New World” of Services (AKA, “Piecing Together a Meaningful Life”)

- Preparing for “the cliff” – lack of adult services
- Think “person-centered, strength-focused”
  - Supported employment (often only 1-2 days)
  - Post-secondary ed. opportunities
  - “day programs”
  - Parks and Rec
  - Travel and family
  - Religious services/community



# Transition Resources

- Access recorded brief recorded presentations at this site:  
<https://wainclude.org/echo/echo-idd-wraparound/presentations/>
- Got Transition (<https://www.gottransition.org/>)
  - Federally funded national resource center on health care transition
- AASPIRE Healthcare Toolkit (<https://autismandhealth.org/>)
  - Primary care resources for adults on the autism spectrum and their primary care providers
- Informing Families (<https://informingfamilies.org/ages/ages-14-21/>)
  - Resource provided by the Washington State Developmental Disabilities Council, in Partnership with the Developmental Disabilities Administration
- Next Steps (Seattle Children's Autism Center)
  - Educational curricula tailored to parents/caregivers of ASD teens transitioning to adulthood
    - Steps to Independence classes – for college-bound/independent living individuals
    - Lifelong Learning classes – for DDA eligible individuals
  - Referrals accepted from WISe teams and COEs

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# Questions

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**THANK YOU!**

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