

Transition to Adulthood

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ECHO IDD Wraparound
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Disclosures

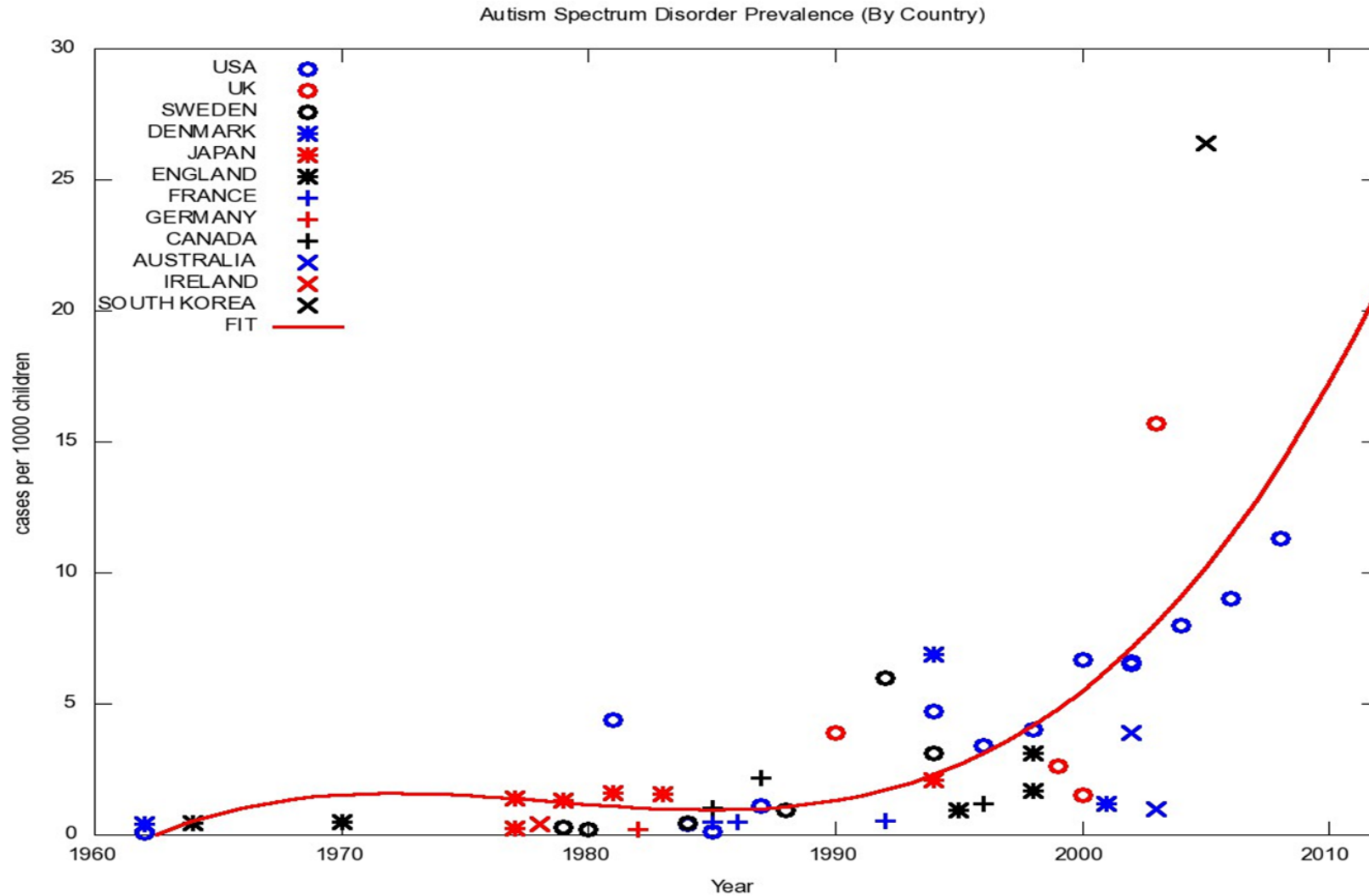
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Objectives

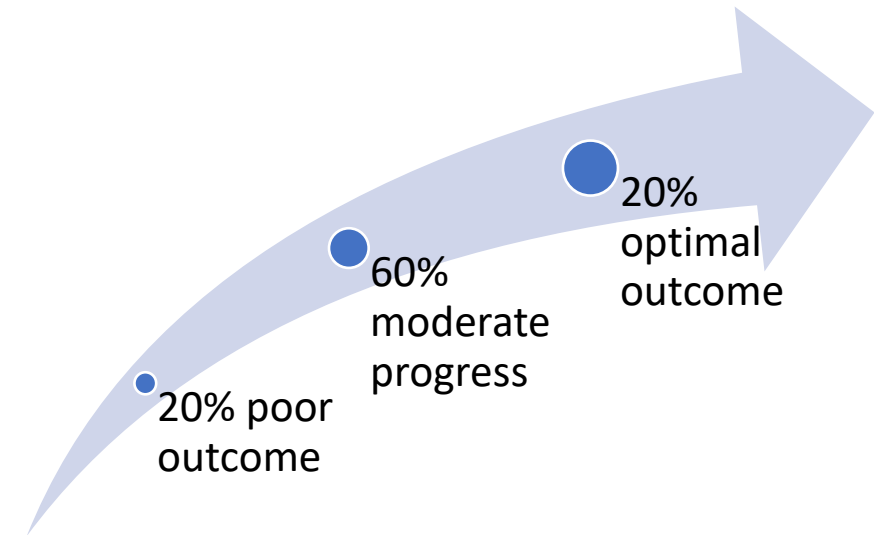
- Review outcome trajectories into adulthood and factors influencing outcome for autistic individuals.
- Understand the importance of successful transition to adulthood and identify barriers to successful transition for individuals with IDD.
- Review highlights of vocation and community participation related to impact of successful transition to adulthood.
- Familiarize with some resources to assist in successful transition to adulthood.

Autism Spectrum Disorder Prevalence (by Country)



Outcome Trajectories in ASD

- optimal outcome (Helt, 2008)
- Roughly 60% make progress but continue to require some types of support 3-25%
- Approximately 20% remain severely impacted requiring 24/7 support (Seltzer, 2004)



Factors Impacting Outcome

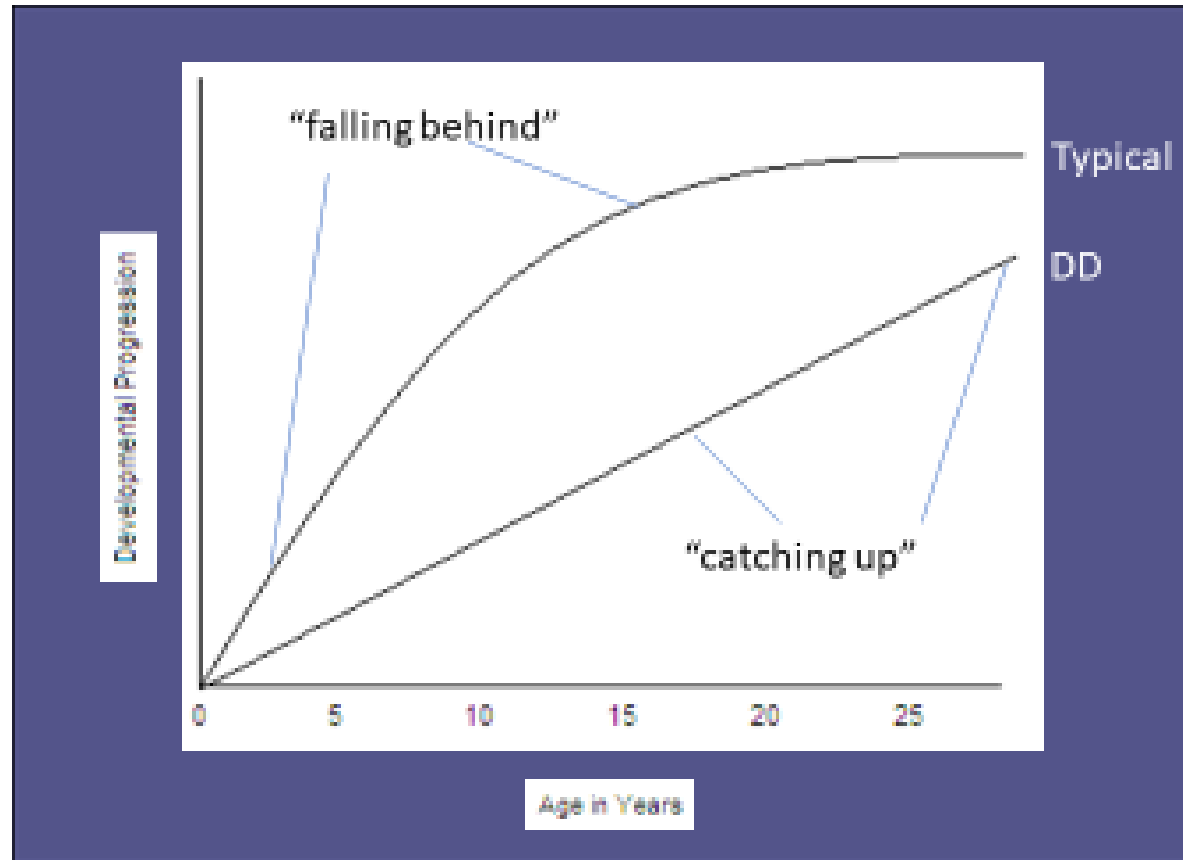
- Intrinsic

- Cognitive ability (IQ, IQ subscore splintering, executive functioning)
- Severity of core autistic deficits – communication, social, restricted interests (motivation)
- Medical health (epilepsy, sleep disorders, GI, “syndromic”)
- Mental health (depression, anxiety, etc.)
- Specific disruptive behaviors (hygiene, aggression, etc.)
- Functional ability

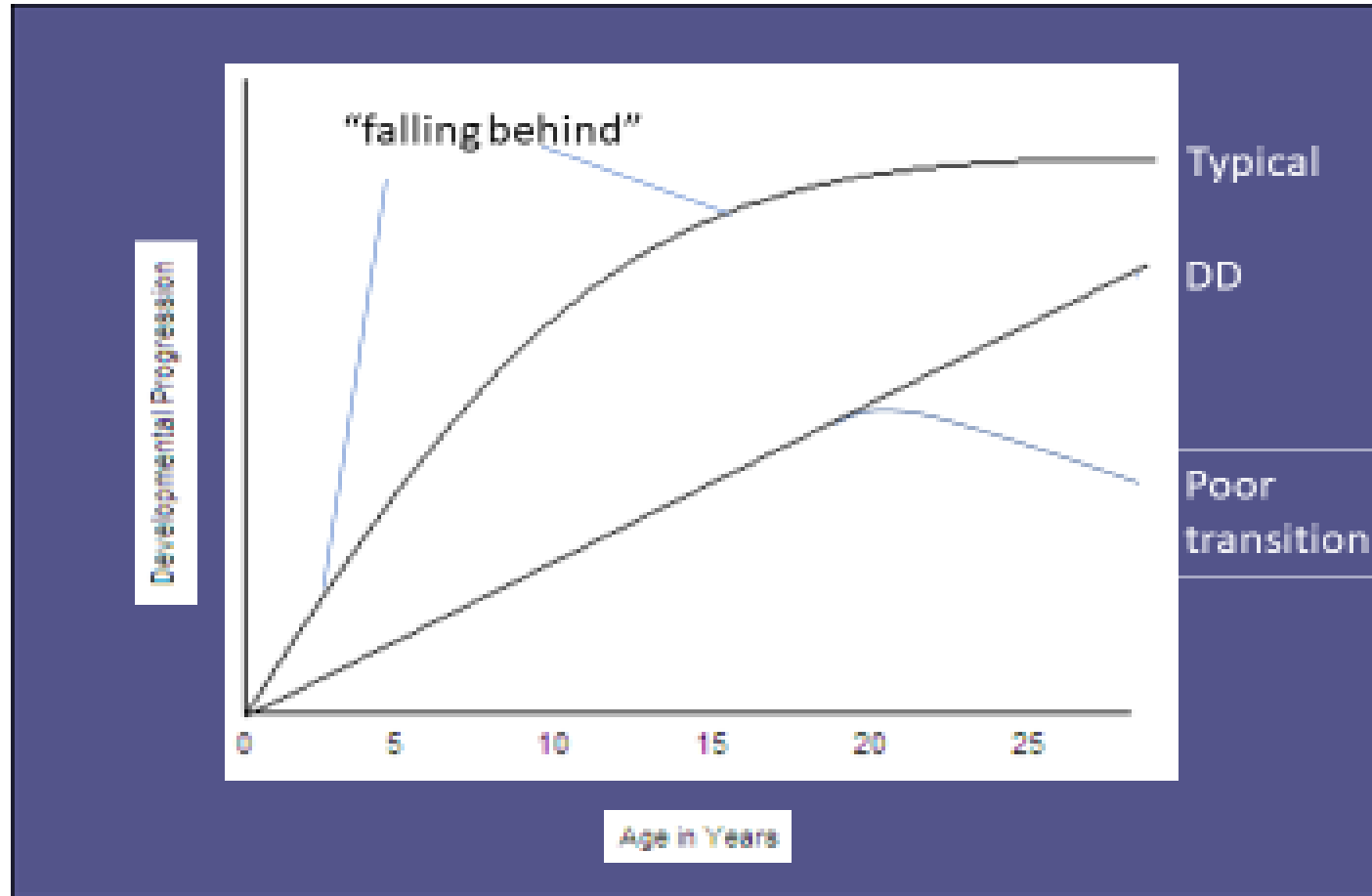
- Extrinsic

- Socioeconomic
- Access to services/early intervention
- “Case management”

“catching up” in young adulthood



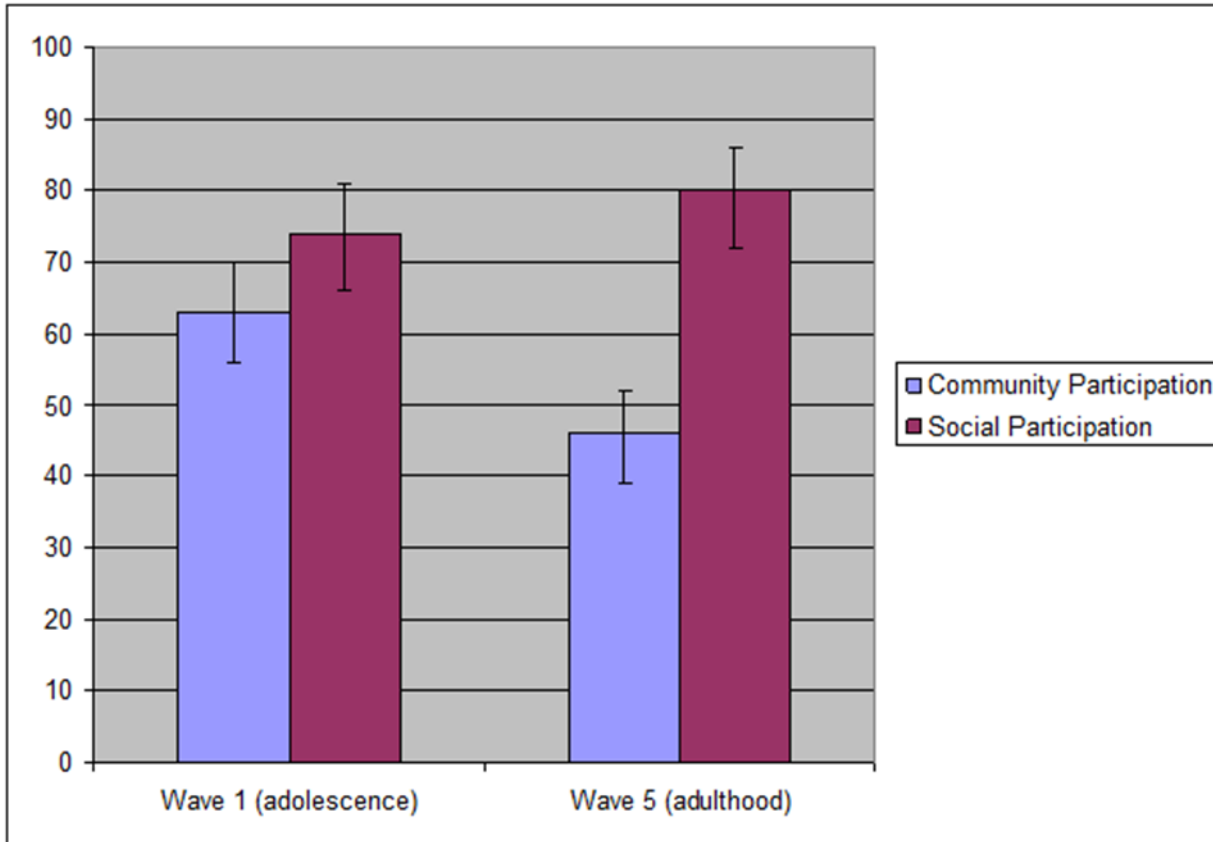
The “risk zone” of transition



Transition Planning

- Only 58% of youth with autism have a transition plan (Roux, 2015)
 - **Race disparity** – 60% transition planning for whites, only 46% for blacks.
 - As a result, over **one-third of adults in their 20's “disconnect”** and do not participate in school or get a job (compared to 8% for learning disabled, emotional disturbance, or speech/language impairment).

Successful Transition – Importance of “Case Management”



- 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 Success

- 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)
 - Lack of transition tools for pediatric providers
- Parents/caregiver “burnout”
 - anxiety about future planning
 - Financial barriers
- Who is the “case manager?”
 - Parent? Provider? School? The individual?

The Connection Among Outcomes

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



Roux, 2015

Hyperfocused on Preferred Interests – When is it a Good Thing?

- “special interest areas”
- Sciences, history & culture, animals, information and mechanical systems, belief systems, machines and technology
- Improves joint attention, social interaction, and anxiety
- 62% of adults feel focusing on preferred interests has helped not hindered success (majority of these individuals were high functioning and diagnosed as an adult)
- Only 10% felt their teachers were supportive of their preferred interests

Koenig, 2017

Advice from self-advocates – “*don’t just focus on the weaknesses*”



Employment

- 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
 - Unemployment and under-employment
- 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
 - **Conclusion - The job *is* the treatment!**

Community Participation



**Alyssa Burnett
Adult Life Center**



Transition Resources

- 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

Transition Resources – Next Steps Classes



Next Steps Improving Transition Outcomes through Parent/Family Education & Empowerment

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Objectives

- To assess the impact of Next Steps classes on family empowerment and readiness for transition to adulthood.

Background

- Within the next 15 years, an estimated 500,000 children in the United States with autism spectrum disorder (ASD) will enter adulthood.
- Limited research regarding transition tools designed to build caregiver skill and resiliency to help successful transition to adulthood
- We have developed and implemented three consecutive 90-minute classes entitled "Next Steps," focused on educating caregivers about transition related topics in small group settings. (See Figure 1. Curriculum Content).
- Next Steps classes have been successfully conducted over the past 5 years, serving over 200 families.

Methods

Data Collection-

- Course evaluations were collected from 13 families before and after the classes over 3 class cohorts
- Impact of classes measured utilizing 1) the Family Empowerment Scale, and 2) a survey questionnaire called Transition Daily Rewards and Worries Questionnaire (Glidden & Jobe, 2007)
- The Transitions Daily Rewards and Worries Questionnaire rates 28 statements on a 5-point Likert scale (e.g. "I am excited by the prospects for my child's future").

Next Steps – Class Series Structure

Class #1	Class #2	Class #3
<ul style="list-style-type: none"> Introduction Adult Outcomes Transition IEP Post-secondary Education Individual and Family / Sibling Supports 	<ul style="list-style-type: none"> Employment Housing/ Residential Community Participation Transportation Complementary Supports 	<ul style="list-style-type: none"> Legal Resources DDA, SSI, DVR, Medicaid, etc. Guardianship Finances Advocacy

Figure 1. Next Steps classes. Each 90-minute class attended typically by 5-7 parent/caregivers (available in-person or via video-teleconference).

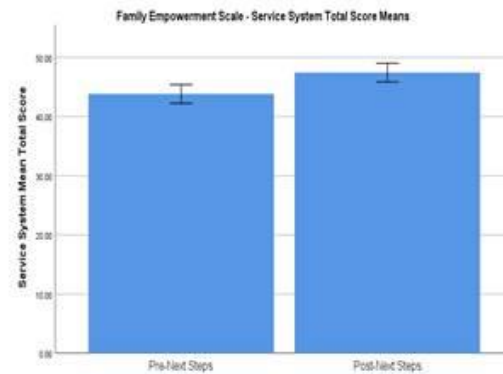


Figure 2. Family Empowerment Scale (see Results section).

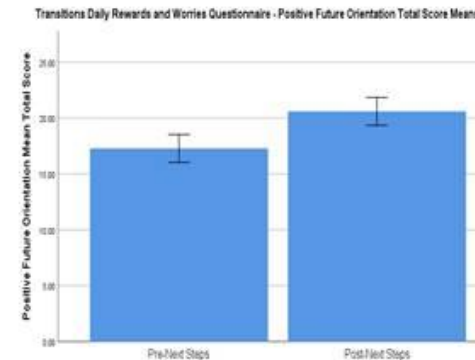


Figure 3. Transitions Daily Rewards and Worries Questionnaire (see Results section).

Results

Family Empowerment Scale

- Statistically significant increase in the mean scores of the Service System subscale - before Next Steps training (M = 44.38, SD = 6.23), and after training (M = 48.00, SD = 6.95). See Figure 2.
- Note: The Service System subscale is characterized as parental interactions with service systems to attain services needed by their child (Koren, Dechillo, and Friesen, 1992).
 - Question example - "My opinion is just as important as professionals' opinions in deciding what services my child needs."

Transition Daily Rewards and Worries Questionnaire

- Statistically significant increase in the mean scores of the Positive Future Orientation subscale - before Next Steps training (M = 18.00, SD = 5.61), and after training (M = 21.31, SD = 9.92). See Figure 3.
- Note: The Positive Future Orientation subscale is defined by general feelings of the parent surrounding their child's future (Burke, Fisher, & Hodapp, 2012).
 - Question example - "I am confident that my child will be okay even after I die."

Conclusions

- Administering transition-related curriculum in small group settings helps to empower families in accessing services, and feeling more positive about the future.
- Future directions include:
 - Improving our understanding of long-term impact of course participation.
 - Broadening delivery of the Next Steps to include non-English speaking families.
 - Including patients along with their caregivers in the Next Steps classes.

Follow up questions: please email andrea.valdez@seattlechildrens.org

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Questions

THANK YOU!

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