

Transition Planning and Support for Young Adults with Developmental Disabilities: Parent and Young Adult Perspectives

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Outline

- Background
- Study Objectives
- Methods
- Results
- Takeaways
- Implications

Developmental Disabilities (DD)

Autism Spectrum Disorder (ASD)

- In the U.S. **1 in 36** children are diagnosed
- Deficits in **social communication** and interactions and **restricted and repetitive** patterns of behavior

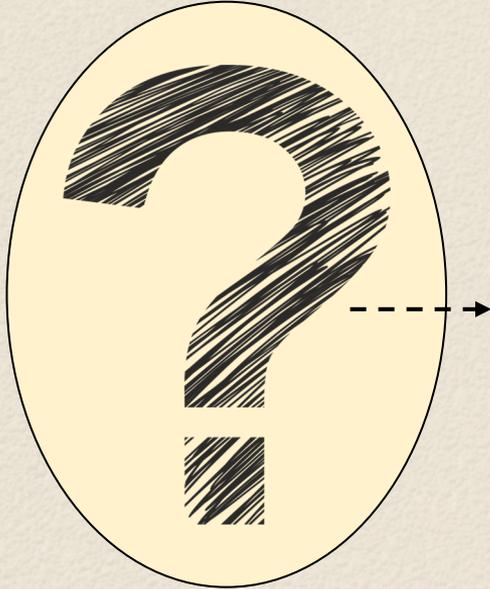
Intellectual Disabilities (ID)

- Prevalence across the world is **1%**
- Deficits in **intellectual and adaptive functioning**

ASD + ID

- 18.04% of children with ASD meet for ID
- 28% of children with ID meet criteria for ASD

Transition out of High School



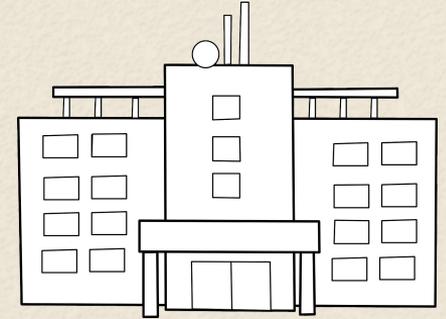
Low employment

Low graduation rates

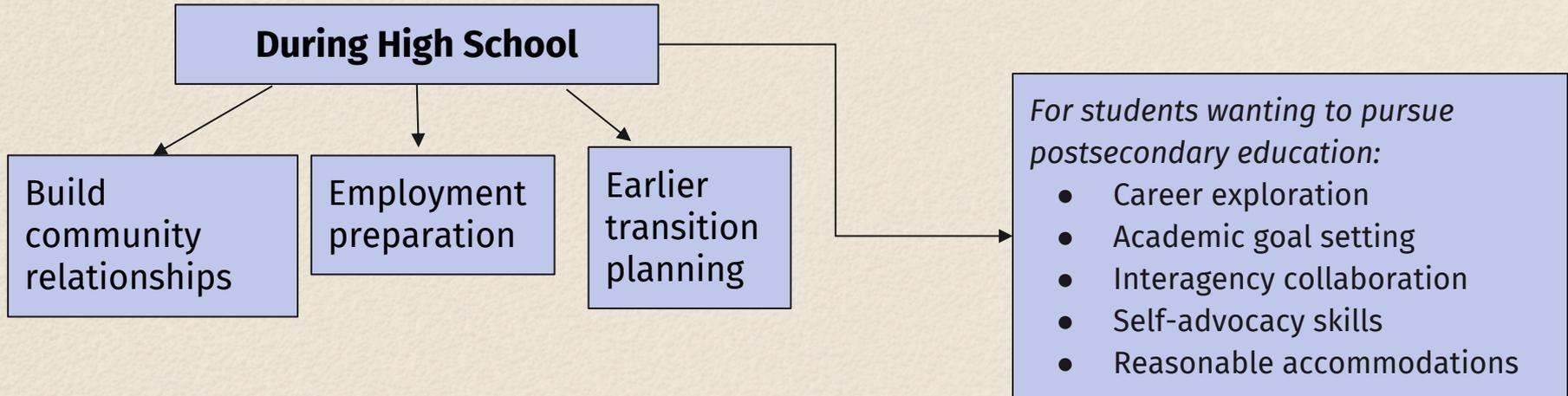
Challenges and Barriers



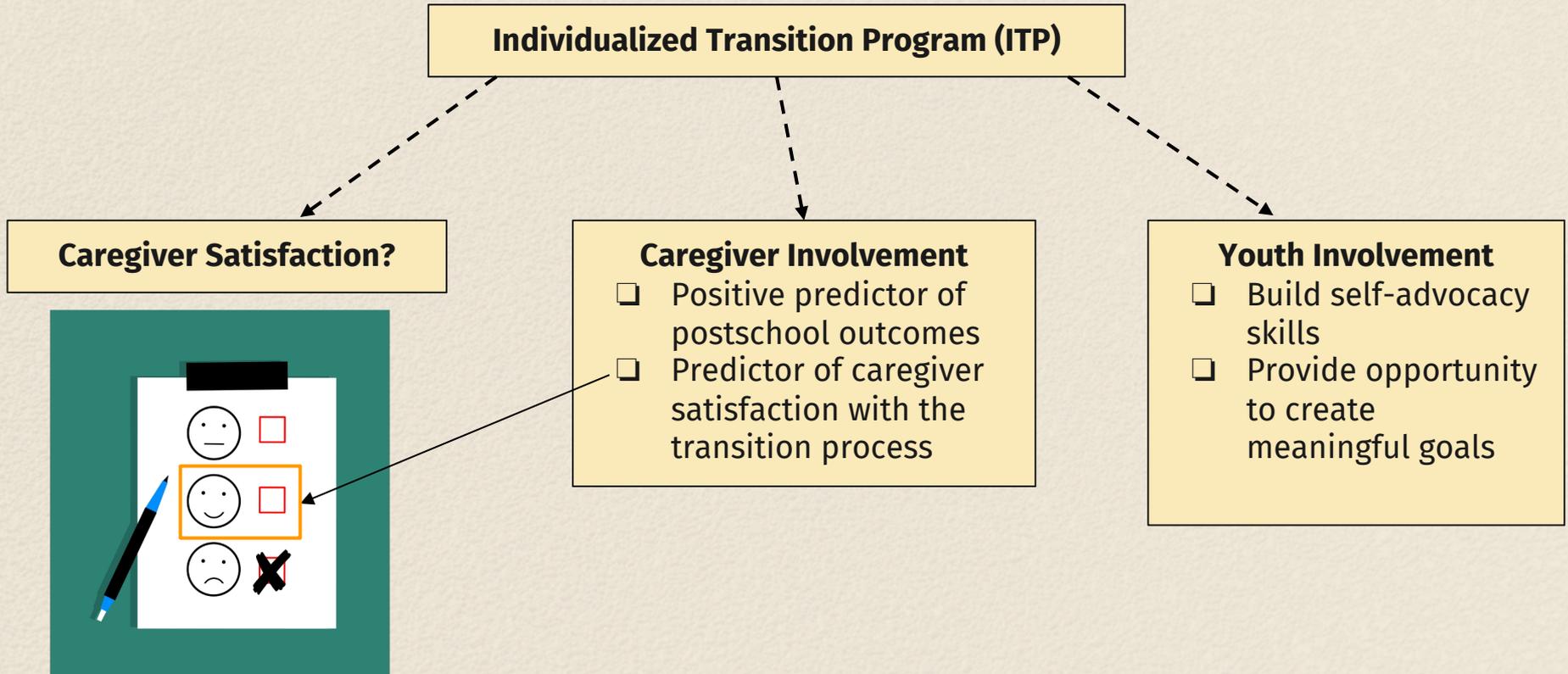
Service Systems



Existing Services, Resources, and Recommendations



Individualized Transition Program (ITP)



Study Objectives

1. Explore what supports (i.e., resources and services) were available and supports needed to youth with and without DD before exiting high school.
2. Identify whether caregivers were satisfied and involved with their youth's Individualized Transition Program (ITP) and if their youth were involved.

Current Study

Collaborative Family Study (CFS)

- Longitudinal study
 - Neurotypical group
 - Autism spectrum disorder
 - Intellectual disability
- Timepoint age ~21/22
 - Transition to adulthood



Participants

Young Adult Information (full sample):

- WISC at age 13:
 - M = 94.5 (SD = 25.1; Range = 42-136)
- Adaptive skills (Vineland):
 - M = 86.6 (SD = 15.4; Range = 53-117)
- Race/Ethnicity (n, %)
 - White: 61 (63.5)

Caregiver Information:

- Race/Ethnicity (n,%)
 - White 81 (72.3)
- Income:
 - >\$95,001 = 55.4%
- Education (n,%):
 - BA and above = 34 (69.6)

Demographic Information	Young Adults (<i>n</i> =99)	Caregivers (<i>n</i> =116)
Gender (n, %)		
Male	59 (59.6)	11 (9.5)
Female	40 (40.4)	105 (90.5)
Age (M; SD; Range)	21.8 (1.26; 20-25)	54.9 (6.87; 36-80)
Diagnostic Category (n, %)		
Neurotypical (NT)	50 (50.5)	--
Developmental Disabilities (IDD)	49 (49.5)	--

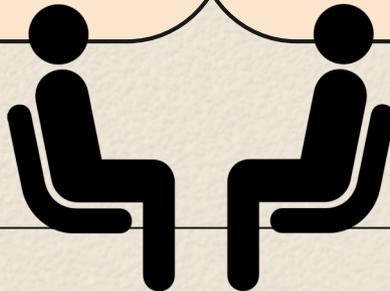
Semi-Structured Interviews

Caregiver Interview

1. Was there anything you, your child or perhaps the school did, that really helped in the transition?
2. Was there anything you wish you or your child had done?
3. Can you think of any ways the service systems (e.g., school, doctors) could have better supported the transition, or is there a specific type of service that you wish existed?

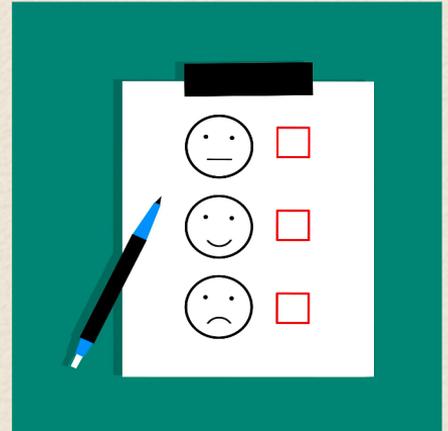
Young Adult Interview

1. What things did you do to prepare yourself for life after high school?
2. Is there anything that you wish you had done, or any type of class or service that you wish existed that would have been helpful?



ITP Questionnaire

- Caregivers completed this questionnaire to understand the experiences and involvement with their youth's ITP
- Young adult involvement and participation
 - Likert 1-7 (1 = never, 7=always)
- Caregiver involvement
 - Likert 1-7 (1=never involved, 7=always involved)
- Overall caregiver satisfaction
 - Scores could range from 5-35 (e.g., 5-11=very dissatisfied - 30-35=very satisfied)



Existing Supports

Social Support

Adaptive Skills

Employment/Career Preparation

Transition-Specific Preparation

**Lack of Support
(Caregiver only)**

Existing Supports

Adaptive Skills

“When looking at the future I knew [YA] was interested in going to [country name redacted], so I gave him the self-help skills you need to go. You have to bathe, you have to brush your teeth. It is very basic but if you can’t [do] things I can’t send you away, out of my clutches. So, he met all of these goals, whatever they were, we held him accountable and there were real ones. He got his license at 16. He always kept us posted on where he was. He has been responsible, but we have been actively parenting him. This is not just good luck.”

- Caregiver of a YA with DD

Employment/ Career Preparation

“[Having a job] helped me [to learn] how to make or how to raise (save) money and how to buy things and pay for them.”

-YA with DD

Social Support

“I would say that he had support in high school. [...] the principal was very supportive. The teachers were extremely supportive. He got a good amount of support in the transition from high school to college.”

- Caregiver of YA with DD

Transition-Specific Preparation

“I had a pretty solid support system. My parents were the ones that I wouldn't say were pushing me to go to college, but they would help me with that. So as far as college applications and all that stuff go, they were very helpful in taking me to go visit the colleges.”

-NT young adult

Supports Needed

Accessibility of
Services/Information
(Caregiver only)

Adaptive Skills

Career
Planning/Preparation

Involvement in
Transition Planning

Financial Education

Guidance on
Postsecondary
Education Planning

Q2: What services and resources do caregivers and youth wish existed during this time?

Supports Needed

Accessibility of Services/Information

“I guess in a perfect world, I would love to see some kind of organization, including a website, that puts out all the possibilities for people like our kids that are this age because I feel like the information that’s available to us is very piecemeal in that we find it out different ways and there are lots of things that we can miss. I also feel like we’re overwhelmed.”

-Caregiver of a young adult with DD

Employment and Career Preparation

“I think better career advising would be really nice. I don't know how much career advice I really got...better career advice and especially in the sense that college is not necessarily a necessity for a comfortable life.”

-NT young adult

Adaptive Skills

“A class that prepares you to go on your own. The real responsibilities of adulthood. That would have been very helpful for being on your own like paying for things on your own, living on your own, managing time. I think those for me would have been helpful to develop more back in high school to prepare myself for college and what I wanted to do.”

-NT young adult

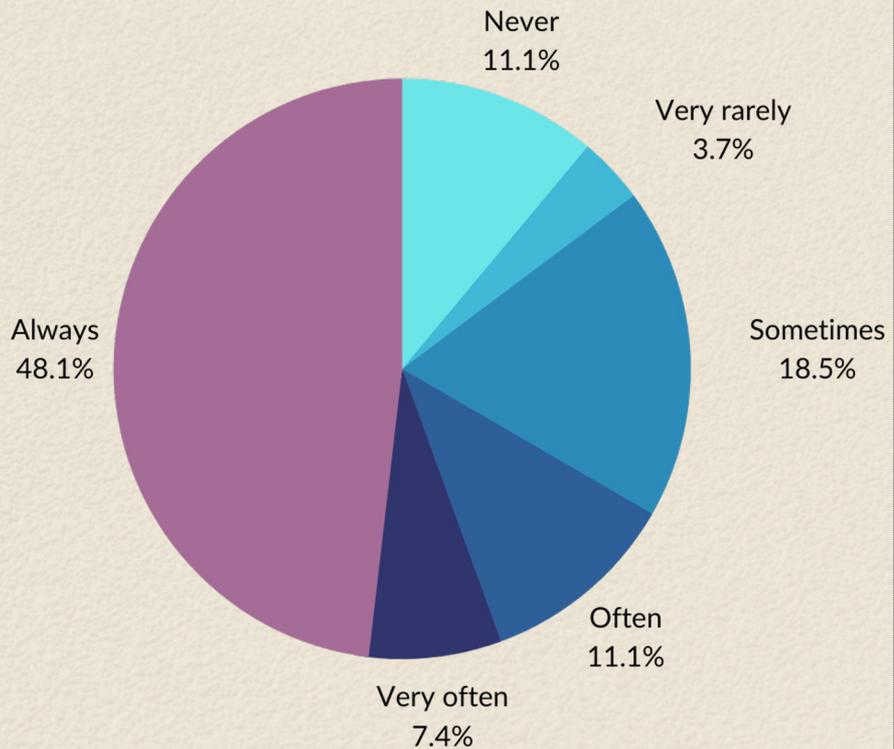
Involvement in Transition Planning

“I probably wish that I had a clearer idea of what I wanted to do with my future because now instead of filmmaking I'm going for a psychology major. And I guess it's always been a worry of mine because I hear a lot of stories of people taking years to find out what they want to do in college, and I don't want to spend so much money taking so many classes. And then [you hear] all the horror stories about student loans so that doesn't help.”

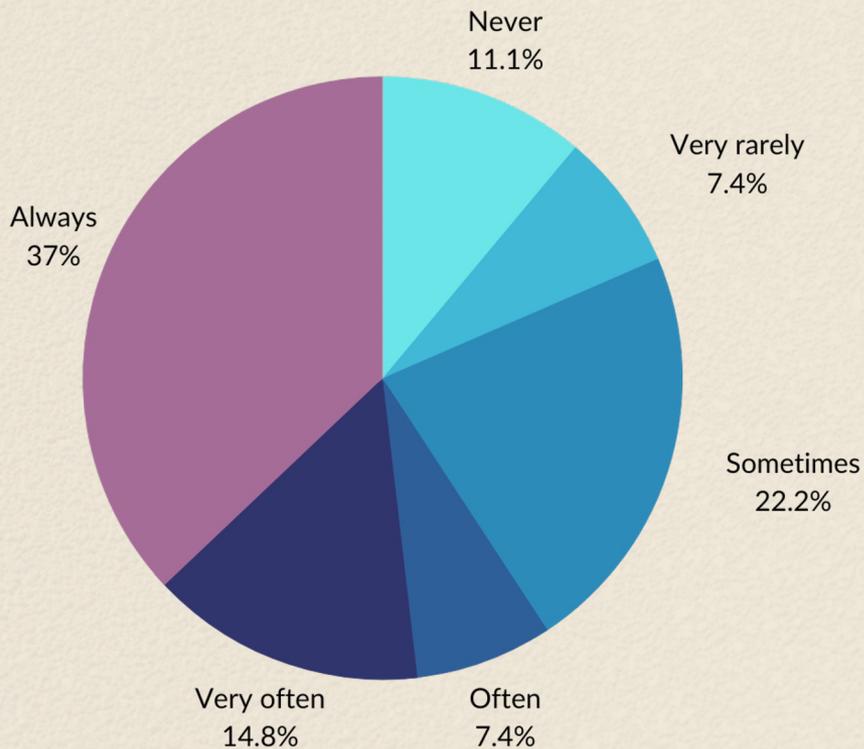
-Young adult with DD

Individualized Transition Program (ITP) (N=27)

YA Involvement

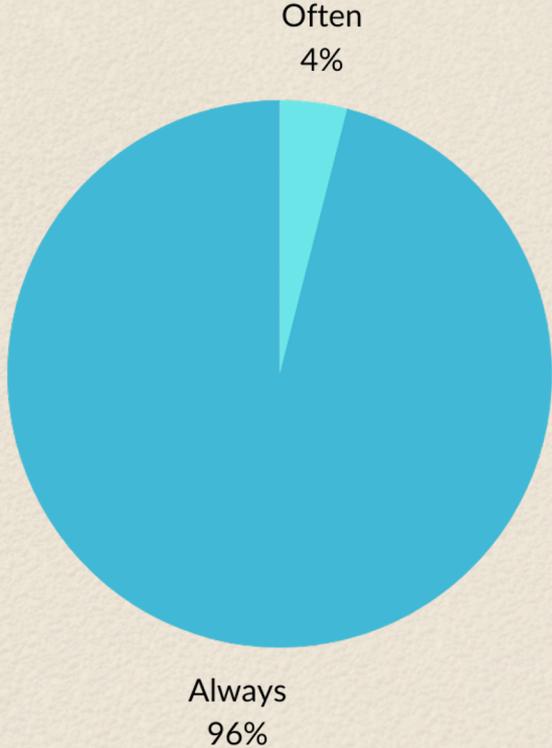


YA Participation

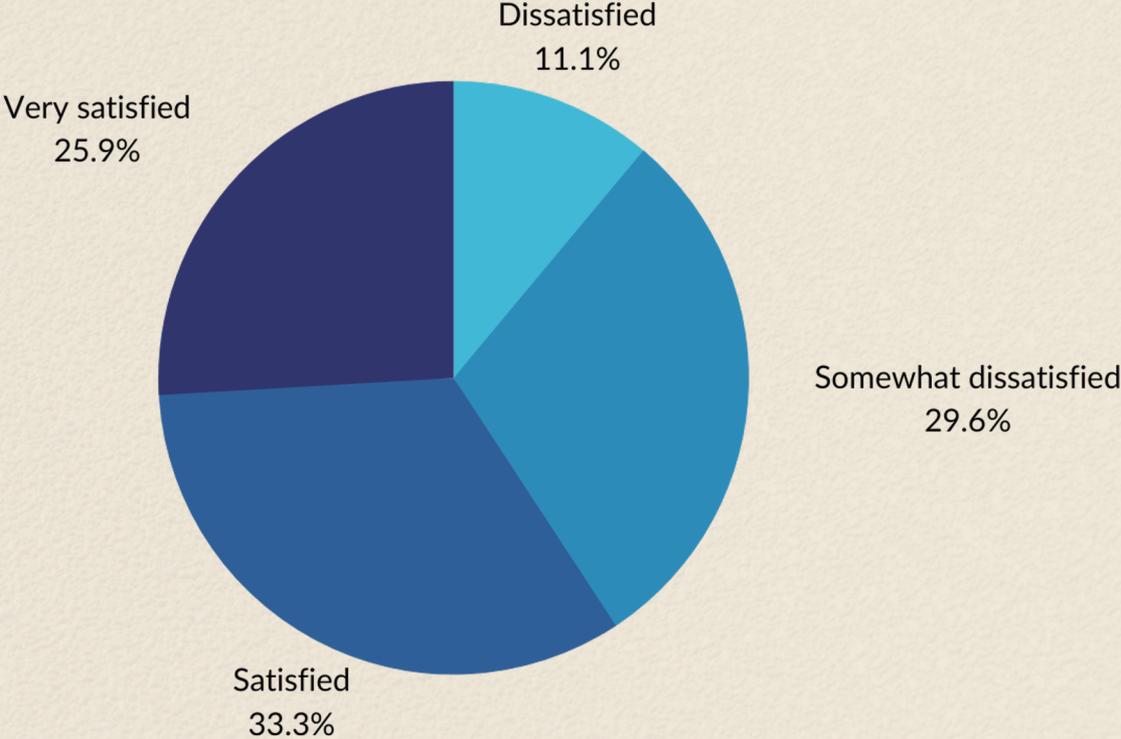


Q3: How involved were young adults with their ITP?

Caregiver Involvement



Overall Caregiver Satisfaction



Q4-5: How involved were caregivers with their youth's ITP? How satisfied were caregivers with the ITP?

Existing Supports – Key Takeaways

- Social Support
 - Positively impacts maternal well-being
 - Helpful in navigating the service system
 - Higher quality of life for adults with ASD
- Transition-Specific Preparation
 - Options include applying to postsecondary education, requesting appropriate accommodations for postsecondary education, and locating transition-specific programs for young adults with IDD consistent with recommendations



Supports Needed – Key Takeaways

Existing and Needed Supports

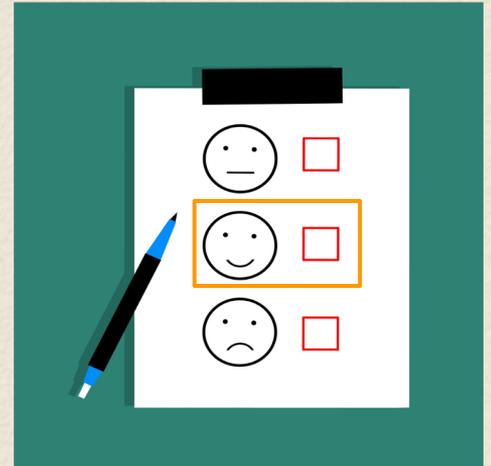
- Adaptive Skills
 - Enrolling in home economics courses, after-school classes, or courses provided by regional centers
 - Predictor of postsecondary outcomes for young adults
- Career Planning and Employment
 - Enrolling in internships, searching for shadowing experiences, and participating in part-time employment can help build these early employment and career exploration experiences Sense of independence, financial benefits, and social interactions

Supports Needed

- Accessibility of services and information
 - Increases caregiver strain
- Caregiver and Young Adult Involvement
 - Some young adults want more independence without their caregivers stepping in
 - Young adults can build self-advocacy skills and create meaningful future goals aligned with their interests

ITP Takeaways

- Over 96% of caregivers reported involvement in their young adult's ITP process
 - Positive predictor of in-school and post-school outcomes
- 59% of caregivers reported being satisfied/very satisfied with their young adult's ITP
 - Dissatisfaction could be related to the goal setting and ITP delays
- Over half of this study's young adults were involved and participating in their ITP
 - Youth with ASD and ID attend IEP meetings significantly less than youth with other disabilities
 - Self-advocacy skills



Implications

- Efforts in special education should be made to strengthen and increase supports and services intended to produce successful transitions into adulthood.
 - Service systems should prioritize collaborative efforts with researchers to develop more effective career and higher education preparation.
 - There needs to be a greater push for ITP involvement by young adults themselves, as these transition plans are integral for their future well-being.
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Resources

- ITP 101 <https://undivided.io/resources/individual-transition-plan-itp-101-476>
- UCLA PEERS for YA:
<https://www.semel.ucla.edu/peers/young-adults>
- UCLA PEERS for Careers:
<https://www.semel.ucla.edu/peers/peers%C2%AE-careers>
- Self-Determination Program (SDP) – Regional Centers:
<https://www.dds.ca.gov/initiatives/sdp/>
- Autism Speaks – Autism and the Transition to Adulthood Tool Kit: <https://www.autismspeaks.org/tool-kit/transition-tool-kit>



Acknowledgments

- Dr. Jan Blacher and Dr. Bruce Baker
- Dr. Megan Galligan, Dr. Elina Veystman, and Dr. Christine Moody
- The CFS families
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (Grant number: 34879-1459; PIs: Bruce L. Baker, Jan Blacher, Keith Crnic)

Thank you!
Any questions?

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