

Navigating the Road from Adolescence to Adulthood for Youth with and without Developmental Disabilities: Parent Perspectives

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A short introduction...



2009 – 2013
(Undergrad)

Collaborative
Family Study

2014 – 2017
(Clinic coordinator)



2017 – 2022
(PhD Student)



2022 – ?
(Postdoctoral Fellow)

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Agenda

- Background on transition to adulthood
- Methods for this study
- Results
- Implications
- Resources/helpful tips

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A note on terminology...

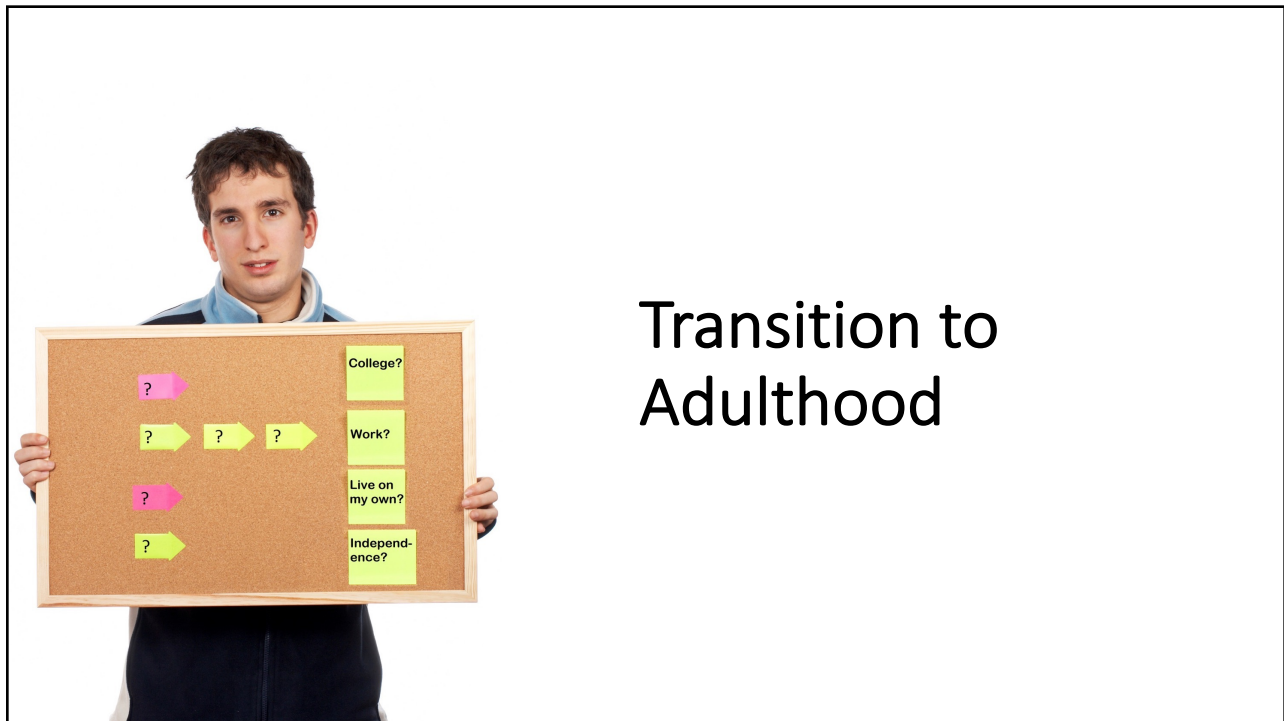
ASD = autism spectrum disorder

ID = intellectual disability

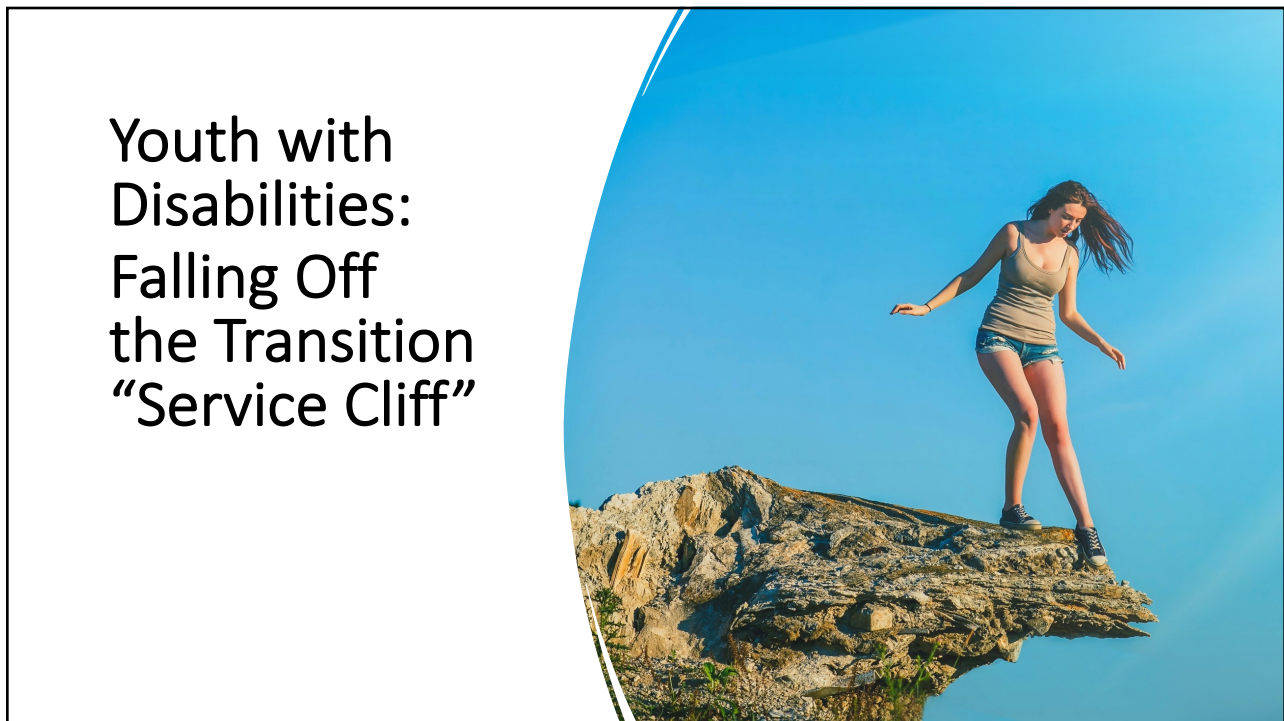
TD = typically developing

DD = developmental disabilities

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Parent Role during Transition for Youth with Disabilities

- Parents as **collaborators, decision makers, role models, trainers, mentors, and systems-change agents**
- A time of **worry, stress, fear, change, and uncertainty**
- **Concerns** include:
 - Identifying where their young adults are going to **live**
 - Helping young adults secure **employment**
 - Finding **social** activities
 - Finding available agency **assistance**
- The **limited resources** in the adult service system add to the stress!



Bianco et al., 2009; Boehm, Carter, & Taylor, 2015; Cooney, 2002; Kraemer & Blacher, 2001; Wandy & Fleet, 2003; Whitney-Thomas & Hanley-Maxwell, 1996

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❖ For parents of youth with disabilities, optimism buffers the impact of challenging youth behaviors on parenting stress and wellbeing

(Blacher & Baker, 2007)

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Objectives for this research

Describe parents' challenges during the transition period and parents' goals for their young adults across diagnostic groups

Identify predictors of successful young adult transition outcomes

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The Collaborative Family Study

Participants (N=109)



	Typically Developing (n=53)	Autism Spectrum Disorder (n=23)	Intellectual Disability (n=33)	F
Full Scale IQ	110.7 (12.1)	106.8 (14.5)	61.5 (12.4)	169.7***
Adaptive behavior	97.6 (8.6)	77.7 (8.3)	70.1 (9.5)	114.6***
Youth sex (% male)	43.9	87.0	61.8	7.0**
Mother age	54.6 (6.0)	52.1 (9.3)	55.1 (6.5)	1.4
Mother ethnicity (% Caucasian)	75.5	68.2	67.7	2.9

Note. *** $p < .001$; ** $p < .01$. ID group includes participants with co-occurring ASD+ID and participants with borderline ID (IQ between 70-84).

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Measures

Semi-Structured Parent Interview

- A 30-60 minute interview examining parents' challenges and worries during the transition, their goals for their young adults, and their attitudes towards the future

Young Adult Outcome Measure

- **Transition Outcome Composite (TOC):** an overall measure of young adult transition based on 3 key outcomes: 1) participation in professional activities, 2) participation in social activities, and 3) independence

Parent Wellbeing Measures (completed at youth age 13/15 and follow-up)

- **Symptom Checklist (SCL):** measure of parent mental health
- **Family Impact Questionnaire (FIQ):** examines the child's impact on the family; also an indicator of parenting stress
- **Life Orientation Test (LOT):** measures dispositional optimism, or generalized positive (or negative) expectancies about the future

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Qualitative analyses

- ❖ Two separate thematic coding systems were developed to understand parents' challenges/worries and parents' goals.
- ❖ Parents' attitudes towards the future were coded on a 1-4 scale (higher scores indicate more positive attitudes).

Challenges/ worries

- *What has been hardest for you about this period in your child's life?*
- *What do you worry about most for your child?*

Goals

When you think about your young adult's future, maybe 5 years from now, what are your goals for your young adult?

Attitudes

What emotions come up for you when you think about your child's future?

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Young Adult Transition Outcome Composite (TOC)

TOC Domain	Score Descriptors
Professional	0 = full-time employment or enrollment in a 4-year university 1 = community college enrollment or other part-time post-secondary education enrollment, or part-time paid employment 2 = a supported or sheltered employment or education program 3 = day center, or no employment or educational enrollment
Social	0 = many friends (5+ friends) and high self-rated social satisfaction 1 = some friends (1-5 friends) and high satisfaction, or any number of friends with moderate satisfaction 2 = any number of friends with low satisfaction 3 = no friends, or one friend with low satisfaction
Independence	0 = living independently with or without roommates 1 = in semi-sheltered accommodation (e.g., group home, dormitory) or still at home, with high degree of self-rated autonomy 2 = living with parents, with some autonomy 3 = living with parents with limited autonomy or in an institution or residential facility

Note. Ratings for each of the 3 domains are summed to create the Overall TOC (0-9 scale)

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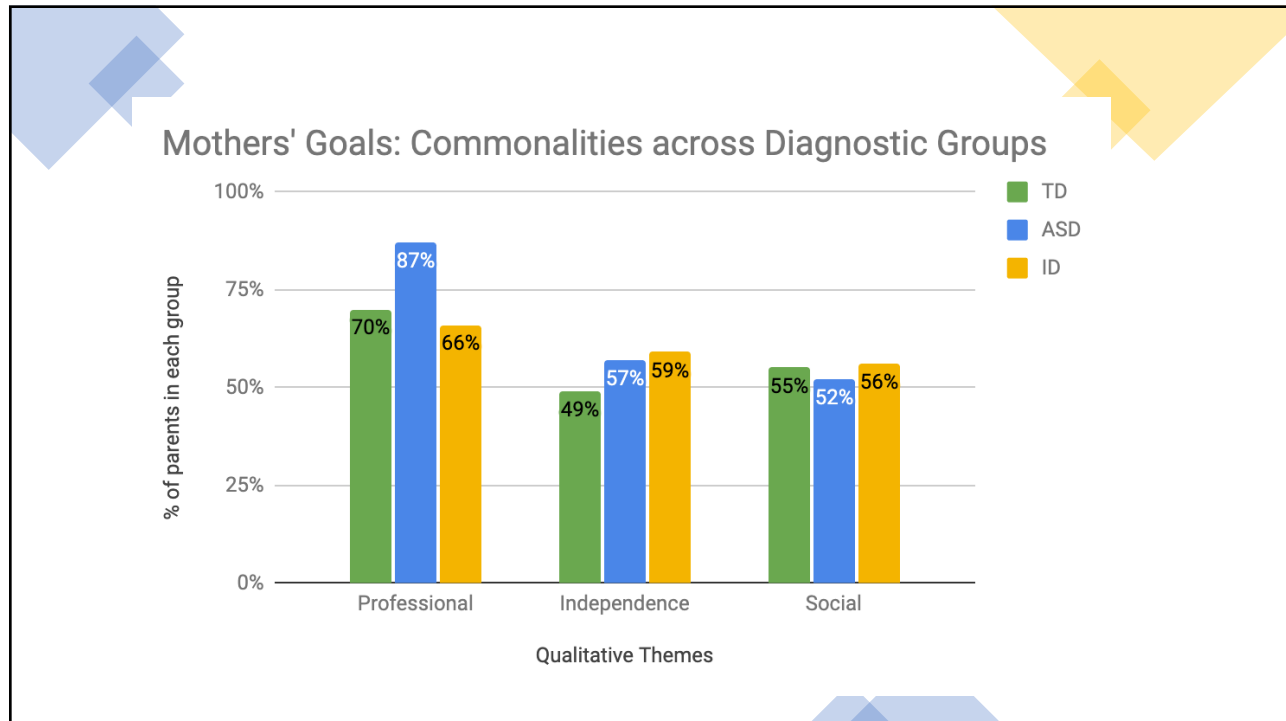
Research Question #1

What transition goals do parents have for their young adults?

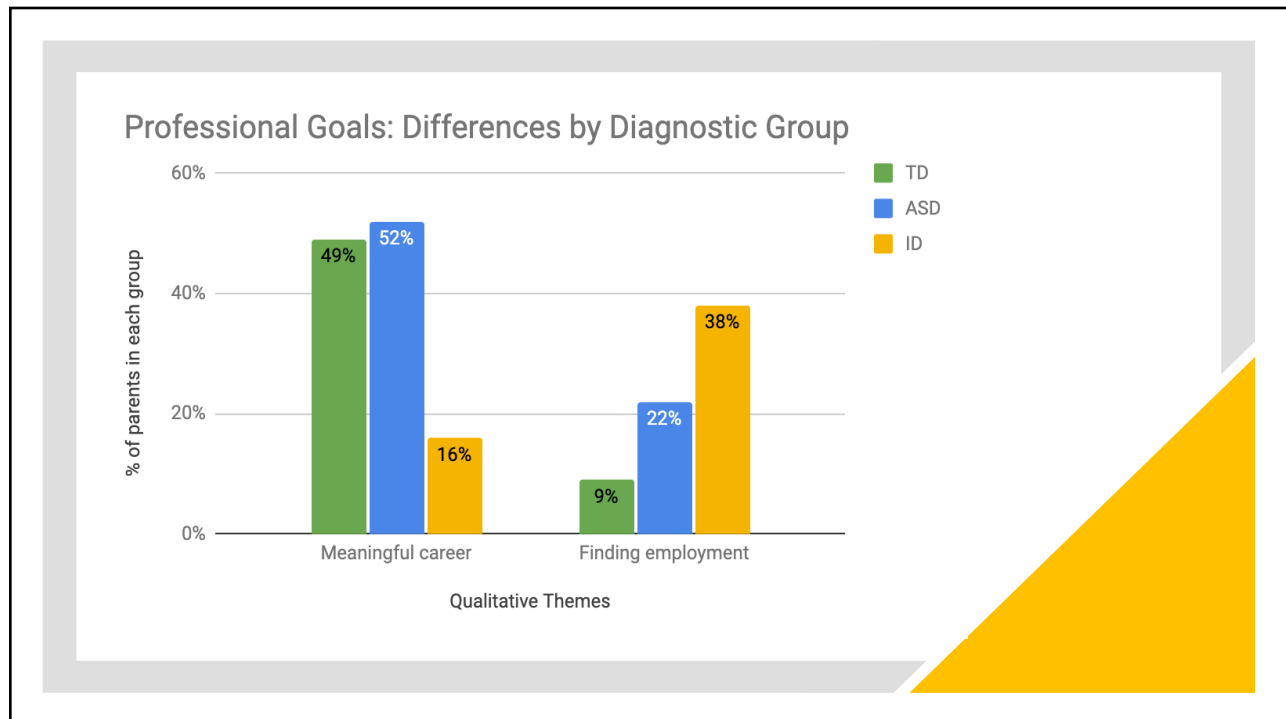
- Do they differ among parents of youth with ASD, ID, and TD?
- Do parent goals align with young adult transition outcomes?



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Professional Goals: Representative Quotes

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Meaningful Career

“My goal for him is that he will finish [school] and be a physical therapist... and be in a successful career somewhere where he wants to be.”

– Mother of a TD young adult

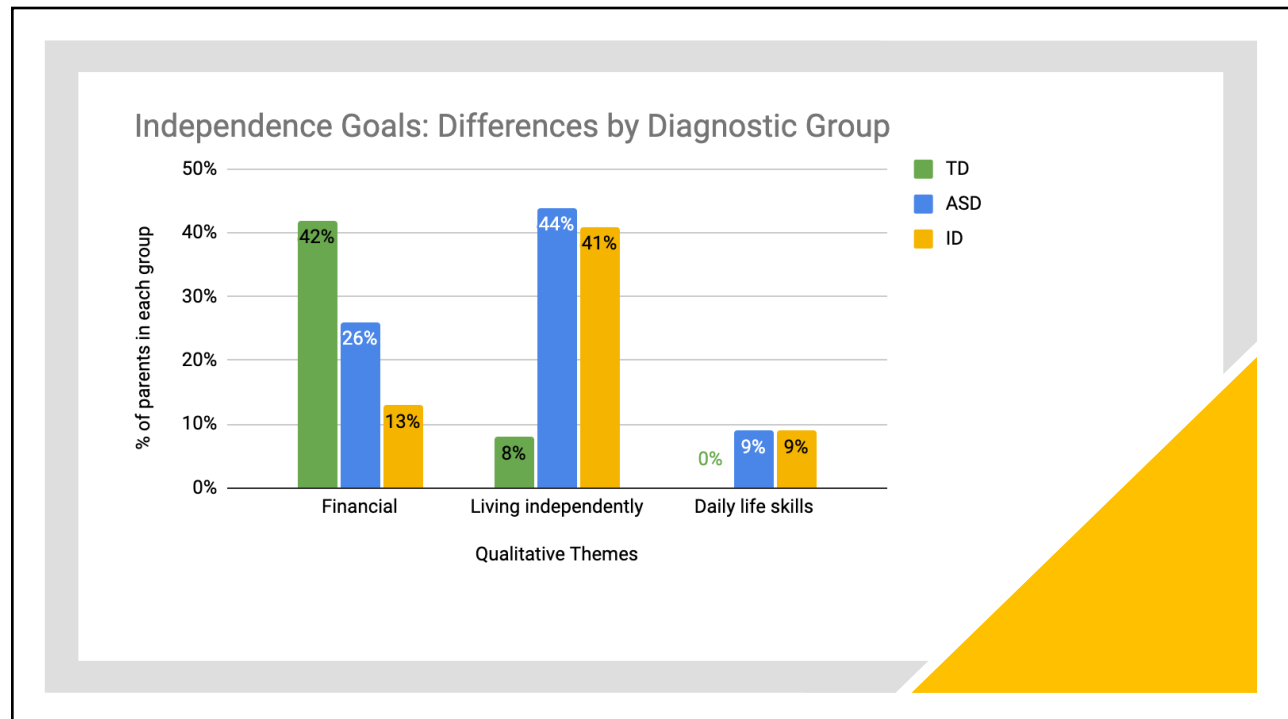


Finding a Job

“In a perfect world... that he’s got a job that seems to be relatively stable.”

– Mother of a young adult with ID

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Independence Goals: Representative Quotes

Financial

“I would hope that he is financially self-sufficient.”

– Mother of a TD young adult

Daily life skills

“I would like there to be more programs that help him learn how to be more functioning because 20 years from now, I’m probably not going to be around.”

– Mother of a young adult with ID



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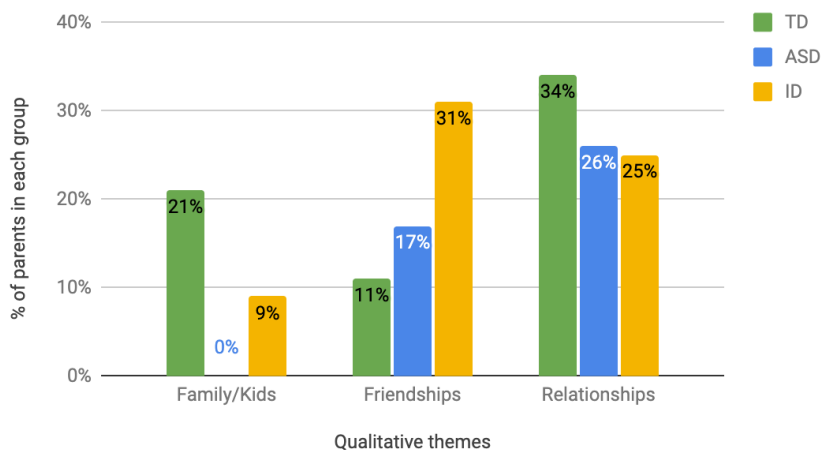
Living Independently

“I would like to see her in an independent living situation with roommates... I am not going to call it a group home because that term and that model is wrong... [but] an organized living situation with structured social activities... that to me would be the perfect setup. I sometimes think I'm going to have to be the one to create it.”

– Mother of a young adult with ID

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Social Goals: Differences by Diagnostic Group



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Social Goals: Representative Quotes



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Family/Kids

“I want the best for her, and I want her to be happy, and of course I want grandbabies.”

– Mother of a TD young adult

Relationship/Marriage

“I’d certainly like him to get interested in dating.”

– Mother of a young adult with ID

Friendship/Social Support

“I think his top three goals should be relationships. Forming them, making them, like how do I do that. Navigating those kinds of waters.”

– Mother of a young adult with ASD

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Mothers’ professional goals and youth diagnostic status predict young adult professional outcomes on the TOC

VARIABLE	b	SE	β	t	p
Constant	.51	.17		3.10	.003**
Meaningful Career	-.31	.20	-.14	-1.57	.120
Finding a Job	.57	.25	.21	2.32	.022*
DD Status	.84	.18	.39	4.58	.000***

*** $p < .001$, ** $p < .05$

Multiple linear regression, $F(3, 105) = 15.19$, $p < .001$, R^2 adjusted = .28.

Dependent variable: Professional TOC score (0-3 scale)

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Research Question #2

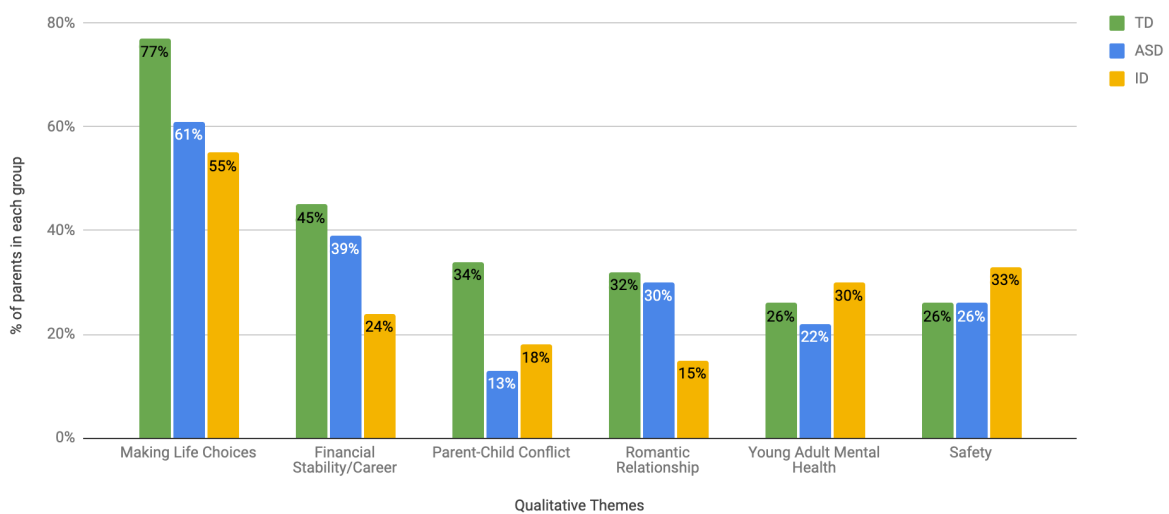
What challenges and worries do parents face during transition?

- Do challenges/worries differ among parents of youth with ASD, ID, and TD?



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Mothers' Challenges and Worries: Commonalities across Diagnostic Groups



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Common concerns across diagnostic groups

Independence: Making Life Choices



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“The terrible twos, no such thing. Tantruming threes, easy. Teenagers, EASY. It’s the 20-year-olds that are hard. For me, little kids, little problems, big kids, big problems... once they are launched the whole world’s open to them and hopefully you’ve taught them well and they make good choices... twenty-year olds the decisions they are making are big decisions, whether it be their major, who they date, if they are going to experiment with drinking or drugs. It’s bigger, more life changing or life impacting decisions. So, give me my six little kids any day and you can have my twenty-year-olds.”

– Mother of a TD young adult

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Common concerns across diagnostic groups

Independence: Financial Stability/Career



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“I worry that the transition into a career might be difficult because, well first it’s going to be difficult for him just to get that job. He is not going to interview well. He is not going to interview well at all. I think that he applied for and got an interview for Target and he wasn’t hired. Two interviews and he wasn’t hired. More than likely because he doesn’t interview very well.”

– Mother of a young adult with ID

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Common worries across diagnostic groups

"He basically is an adult [and] it was his responsibility to maintain those grades and those credit levels and keep that scholarship alive. Unfortunately, it was his responsibility, but it was our money. So, it was kind of difficult."

– Mother of a TD young adult

Parent-child conflict

"The anxiety, depression, nursing school, all that, and I'm like, 'Oh dear goodness make it stop.'"

– Mother of a TD young adult

Young adult mental health

"I worry a lot about the things she cannot understand like what's good and what's bad. I worry about the older people that are on social media and her not understanding what's right or wrong on social media."

– Mother of a young adult with ID

Safety

"I would say love. Will he find a companion that will accept him and support him and love him? I think that's probably my biggest fear or biggest worry."

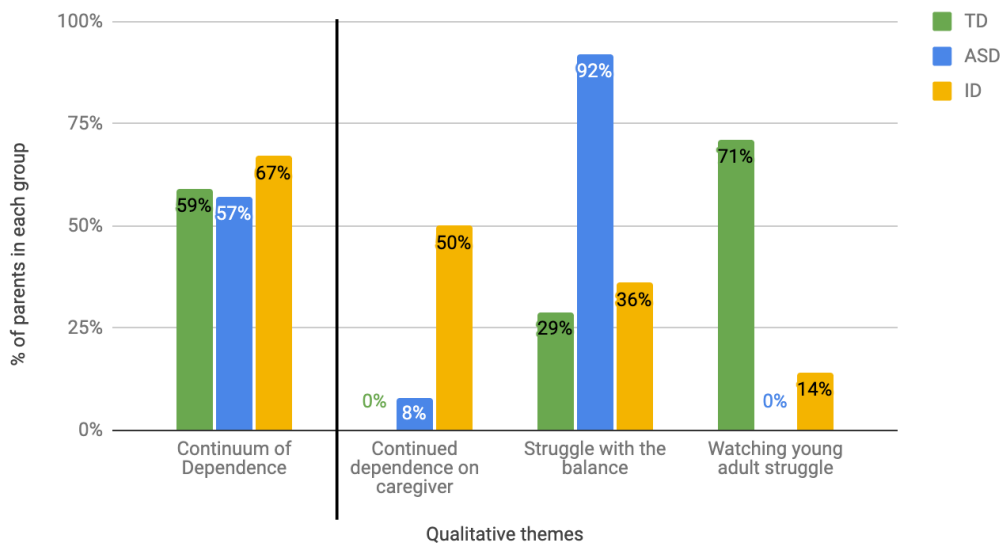
– Mother of a young adult with ASD

Romantic relationships



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Continuum of dependence: Differences by diagnostic group



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Continuum of dependence

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Representative quotes

Independence

Continued dependence on caregiver

“The hardest part for me... so a child needs its mother, right? But at some point, they start not [to]... I never had that... that’s hard for the parent because you’re done... you’re ready to not have to be there every moment... I think it’s biological because it is so hard to be there for his every need.”

– Mother of a young adult with ID

Struggle with the balance

“I feel like my job is being as supportive as I can while still trying to set appropriate boundaries for somebody living at home... and continue to figure out the balance of when to parent and when to let him fall and make mistakes. It’s very very tricky.”

– Mother of a young adult with ASD

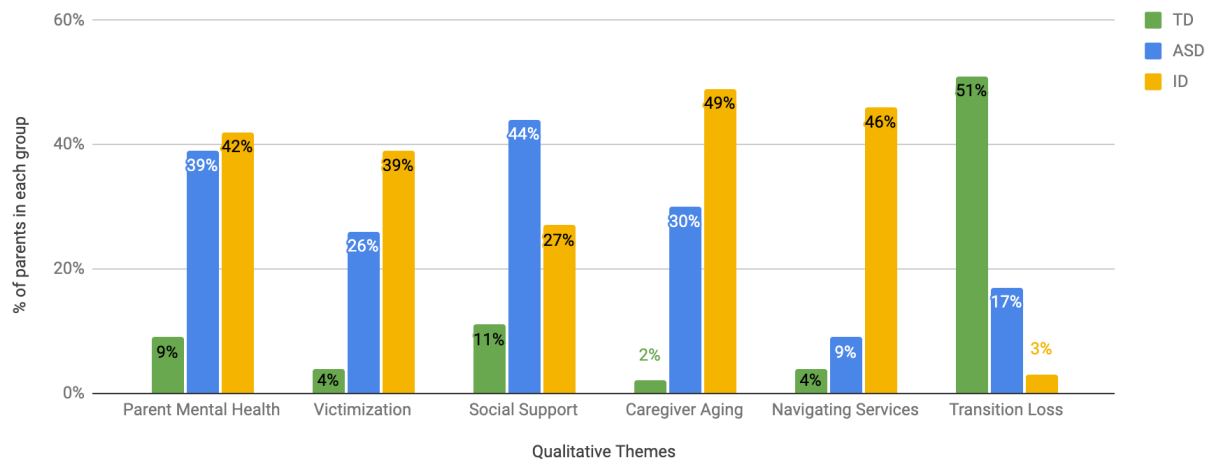
Watching young adult struggle

“I just get to watch her make mistakes and see her fail, and see her make bad choices, and I can encourage her, but I can’t ground her in, I can’t make her do anything, you know. I have to just watch and see what happens and so that’s really hard.”

– Mother of a TD young adult

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Mothers' Challenges and Worries: Differences by Diagnostic Group



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Differences in social concerns by diagnostic group

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“...That someone will take advantage of her.”

– Mother of a young adult with ID

Victimization



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“Watching him cry because he’s lonely... I see all his typical friends and my friends who have kids his age that are typical and oh my god, they’re in Peru, they’re in Paris, they’re in school for a year in Scotland. They’re doing all kinds of grown people activities. My son, again, home alone, so lonely, doesn’t know what to do. He’s looking at MeetUp for different groups.”

– Mother of a young adult with ASD

Social Support

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Themes unique to parents of youth with disabilities



“The hardest part is being tired. Like, I want to be able to support him to be successful... And I’m exhausted. It’s like sometimes I have to drag myself out of bed cause I’m so tired and I’m like, ‘How much longer can I hang on?’”

– Mother of a young adult with ASD

Parent Mental Health



“It scares the crap out of us. What’s going to happen to him? He has no siblings... He’s going to have nobody. Who’s going to take care of us when we’re old?”

– Mother of a young adult with ASD

Caregiver Aging



“[She] is using three agencies and her brother is using another three, so for me that is six agencies to manage. Sometimes I feel like... what is the alternative? I wish they could all just go away or, better yet, maybe I can hire someone to coordinate all of these services.”

– Mother of a young adult with ID

Navigating Services

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Theme unique to parents of TD youth: Transition loss



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“Just missing him. I miss him... it’s just different because he’s not here; he’s not in my house. So that is a different way of communicating and different way of loving than you’re used to as a mom because you are used to him being physically right here. So that’s the hardest part, they’re not here.”

– Mother of a TD young adult

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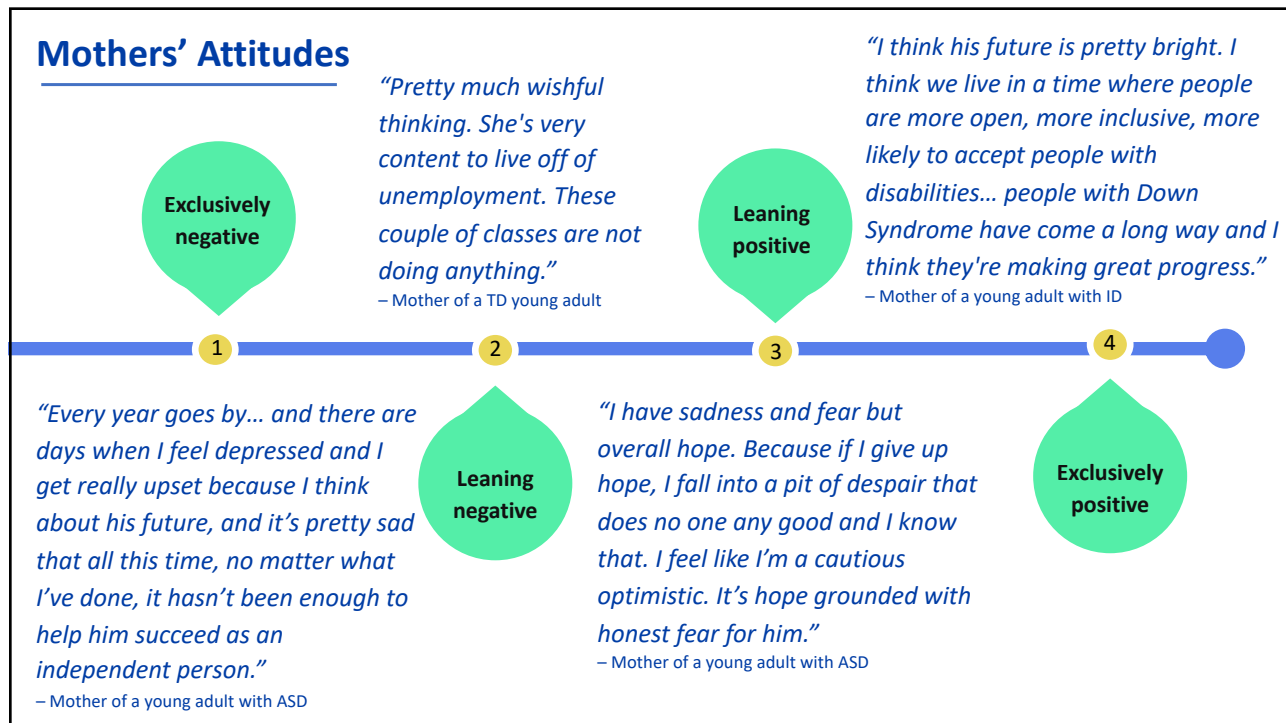
Research Question #3

What is the role of parental wellbeing in adolescence?

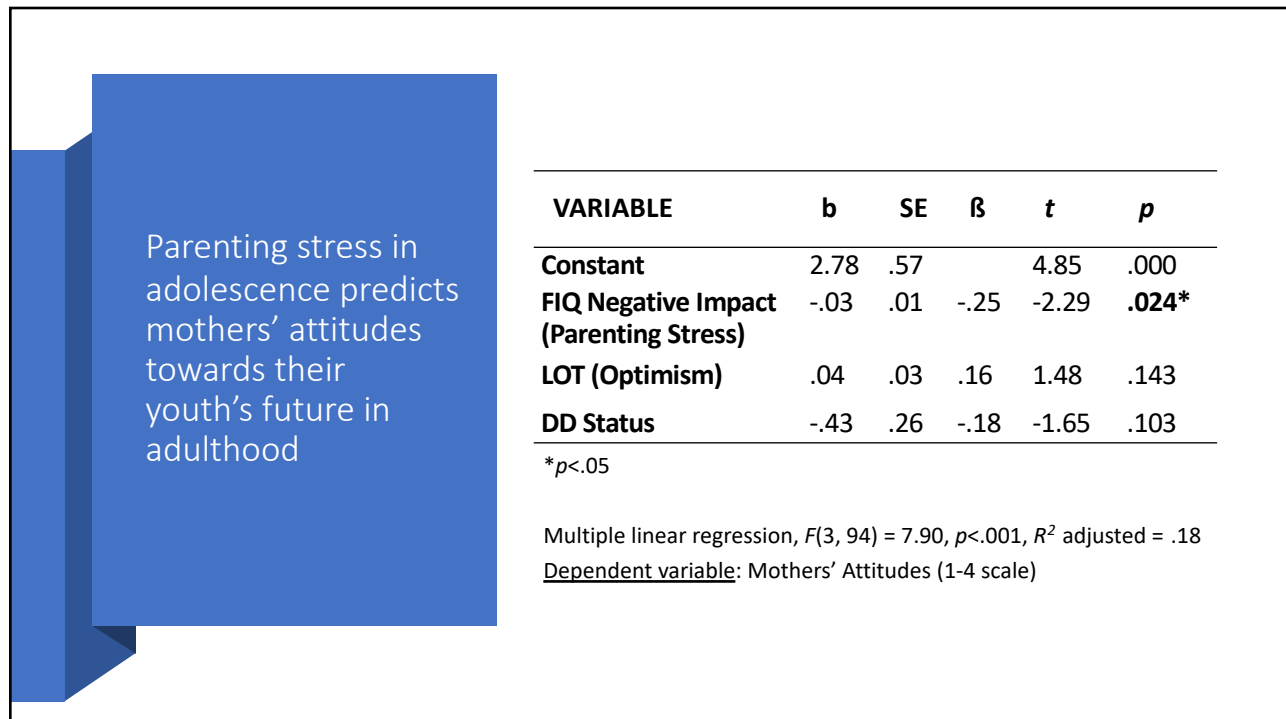
- Does parent wellbeing in adolescence impact parent attitudes towards their child’s future in young adulthood?
- Does parent wellbeing impact young adult transition outcomes?



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Maternal optimism in adolescence and youth diagnostic status predict young adult outcomes on the TOC

VARIABLE	b	SE	β	t	p
Constant	3.95	1.16		3.41	.001
SCL (Mental Health Symptoms)	-.004	.02	-.03	-.28	.783
FIQ Negative Impact	.03	.03	.13	1.01	.314
FIQ Positive Impact	-.03	.04	-.08	-.87	.385
LOT (Optimism)	-.10	.04	-.19	-2.34	.022*
DD Status	2.65	.43	.55	6.23	.000***

*** $p < .001$, * $p < .05$

Multiple linear regression, $F(5, 88) = 20.60$, $p < .001$, R^2 adjusted = .51

Dependent variable: Overall TOC Score (0-9 scale)

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Implications

Transition to adulthood can be difficult for all, but mothers of youth with disabilities experience additional challenges, including concerns around their own mental health and wellbeing.

Higher parent expectations can enhance youth transition outcomes. Thus, the importance of having high expectations should be emphasized in parent training programs.

As optimism and parenting stress in adolescence impact both youth transition outcomes and mothers' attitudes towards their youth's future, harnessing positivity and addressing parenting stress early on is critical.

These findings can inform the design and delivery of more effective supports for parents during their youth's transition into adulthood, including guiding parents in navigating the adult service system and providing psychoeducational workshops and resources.

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Resources and tips
for employment and
post-secondary
education

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4 Tips for Finding Employment/Identifying Career Goals

1. Discuss career interests with your young adult
2. Develop a career action plan based on young adult's 10-year goal
3. Identify helpful contacts for professional networking
4. Conduct informational interviews with contacts in the field of interest
 - a. Practice informational interviews with your young adult prior to conducting them



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3 Self-Advocacy Tips for Employment and Postsecondary Education

1. Support your young adult in identifying their strengths and challenges, and turning their challenge into a strength
2. Discuss what types of accommodations and supports your young adult will need to succeed in college or the workplace
 - a. Practice requesting accommodations with your young adult
3. Identify current and/or future mentors in college and/or the workplace



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UCLA PEERS® for Careers

- 20-week program for undergraduate and graduate students with ASD who are interested in acquiring job-related, social, and practical skills for a successful transition from educational to employment settings
- Teaches students necessary skills for obtaining and maintaining a job and provides an internship experience to practice learned skills



NOW ENROLLING FOR PEERS® FOR CAREERS!

UCLA College to Career

ARE YOU LOOKING FOR A JOB OR INTERNSHIP? DO YOU STRUGGLE WITH SOCIAL COMMUNICATION?

FREE SOCIAL SKILLS GROUP FOR COLLEGE STUDENTS WITH ASD

This research study includes a 20-week program teaching employment-related skills, followed by a 10-week internship!

Participants must be currently or previously enrolled in junior college, community college or 4 year university.

- Building a resume
- Interviewing skills
- Finding a good career fit
- Navigating the work environment
- Stress management and executive function
- Conflict resolution

CONTACT:
(310) 267-3377
PEERSCLINIC@UCLA.EDU
WWW.SEMEL.UCLA.EDU/PEERS

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Integrate Autism Employment Advisors

- Offers employment resources for candidates on the autism spectrum and helps organizations identify, recruit, and retain professionals with autism.



See success at work

Skilled autistic professionals reaching their potential; a workforce delivering non-traditional solutions; candidates and clients recognizing the value of an inclusive environment—that's success at work.

FOR EMPLOYERS

FOR CANDIDATES

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Mentra



- A neurodivergent-friendly talent platform that matches neurodiverse individuals with employers that value their strengths through humanistic artificial intelligence and community-driven design.

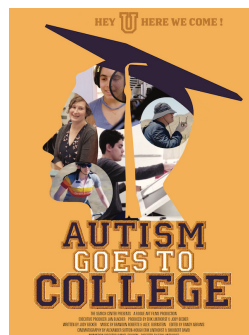
**Bring your
neurodiversity
to work**

Use our accessible web app to match with employers who value your strengths.

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Autism goes to college:

Understanding the experiences & needs of university students with autism



<https://www.autismgoestocollege.org>

Bolourian, Y., Zeedyk, S. M., & Blacher, J. (2018). Autism and the university experience: Narratives from students with neurodevelopmental disorders. *Journal of Autism and Developmental Disorders*, 48(10), 3330-3343.

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National Resources

U.S. Department of Education

<https://www2.ed.gov/about/offices/list/ocr/transition.html>

- Guide: *“Students with disabilities preparing for postsecondary education: Know your rights and responsibilities”*



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National Resources

Autistic Self-Advocacy Network (ASAN): “Navigating College: A Handbook on Self Advocacy”

<http://autisticadvocacy.org/>

www.navigatingcollege.org

- A guide published for autistic students written by autistic adults
- Provides first-person insights from current and past college students on the autism spectrum on various aspects of the higher education experience including disclosure, classroom accommodations, dorm life, and sexuality.



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Tip: Find a Source of Friends with Common Interests

- **Topics for discussion:**
 1. Which groups might your young adult fit in with based on their interests?
 2. Create a plan for joining social activities where your young adult might meet potential friends with common interests.
- **Meetup.com** provides in-person and online groups for adults
 - Groups are regional and based on common interests
 - Activities are primarily recreational
 - Examples of meetups:
 - Movie meetups
 - Gaming meetups
 - Anime meetups
 - Sports fan meetups
 - Alumni groups
 - Hiking meetups
 - LARPing



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Los Angeles Neurodiversity (LAND)



- A social, support, and advocacy community for neurodivergent adults and/or self-advocates that organizes peer support groups, family events, and other beneficial events throughout LA County or online every month.

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The Help Group's Club LA

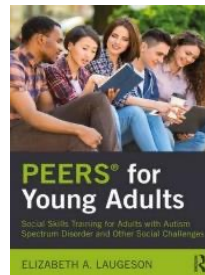
- Part of Advance LA, Club LA is a social community for young adults ages 18 to 29 who have diverse challenges
- Offers a variety of activities for participants, including movie nights, bowling, anime events, gaming tournaments, hiking or nature walks, beach days, museums, and other local LA events.



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UCLA PEERS® for Young Adults Social Skills Groups

- Finding and choosing good friends
- Conversational skills
- Starting and entering conversations
- Exiting conversations
- Electronic communication
- Appropriate use of humor
- Get-togethers
- Dating etiquette
- Handling arguments
- Changing a bad reputation
- Handling teasing and bullying



Young adults will learn about:

- Using social media and online platforms to develop and maintain friendships
- Conversational skills
- Entering & exiting conversations
- Appropriate use of humor
- Electronic communication
- Dating skills
- Organizing get-togethers
- Handling stress and related building handling disagreements
- Handling dating pressure

PEERS® Social Skills Group for Young Adults

• PEERS® for Young Adults is an evidence-based social skills intervention for motivated adults who are interested in making and keeping friends and/or developing romantic relationships.

• Young adults and social coaches (including parents or other caregivers) attend 16 weekly telehealth sessions over Zoom for 60 minutes each week.

• Young adults are taught social skills through didactic lessons and role play demonstrations, and practice these skills during online socialization activities.

• Social coaches attend separate telehealth sessions simultaneously and are taught how to assist young adults in making and keeping friends and/or dating.

Telehealth groups available NOW!

To enroll, please contact
(310) 267-3377
peersclinic@ucla.edu

For more information, visit
www.semel.ucla.edu/peers

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UCLA PEERS® for Dating

- 16-week dating skills program for young adults with ASD

Now recruiting for Telehealth via Zoom!

FREE UCLA DATING Program for Adults with Autism

This UCLA research study examines the effectiveness of **PEERS® FOR DATING**, a 16-week social skills program to help adults with autism spectrum disorder learn skills to find and maintain romantic relationships.

TOPICS COVERED:

- Choosing appropriate people to date
- Starting conversations
- Maintaining conversations
- Entering and exiting conversations
- Electronic communication
- Creating Dating Profiles
- Online Dating
- Letting someone know you like them
- Asking someone on a date
- Handling rejection
- Going on Dates
- Dating do's and don'ts
- Handling dating pressure
- Physical contact and sexual activity
- Relationship boundaries
- Conflict resolution

(310) 267-3377
Peersclinic@ucla.edu
www.semel.ucla.edu/peers

UCLA PEERS® Clinic
www.semel.ucla.edu/peers

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Resources and tips for accessing adult services

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4 Tips for Navigating the Adult Service System

1. Each Regional Center has a page that lists the typical services provided to consumers of each age group.
 - a. Familiarize yourself with the services available for adults.
Example: <https://westsiderc.org/services/18-to-22-years/>
2. Do not be afraid to ask for and advocate for the services you think your child needs!
3. Explore ALL the options before going to court.
 - a. E.g., supported decision making, power of attorney
4. Start working on generic services for this age group (if you haven't already), such as IHSS, SSDI, and Medi-Cal.
 - a. It can take a while and you will want those resources in place for transition into adulthood and independent living.

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Regional Center Adult Services

Self-Advocacy Groups
Consumer Advisory Committee (CAC) hosts a number of self-advocacy groups located throughout WRC's service area. Visit www.westsiderc.org for dates and locations.

Parenting Skills and Support
For individuals receiving WRC services who are parents. Specialized Parenting Skills agencies offer trained staff to provide support and on-going training for new parents or parents-to-be with information on pregnancy, delivery and care for a baby.

Incontinence Supplies
Referrals can be made to assist individuals with securing supplies available through Medi-Cal, private insurance or through WRC funding when no other generic source is available.

Medical Equipment
Families can access medically necessary equipment through referrals to Medi-Cal, Medicare, private insurance, or other generic sources. WRC, as payer of last resort, may also provide funding for equipment needs as determined through consultation with WRC specialists.

Written Translations and Interpretations
WRC offers written translation services for Individual Program Plans (IPPs) when the family's primary language is not English. Interpretation services for IPP or service planning/review meetings are also available.

*Please note that current legislation and regulation may require families to access their private insurance or managed care plan within Medi-Cal to obtain funding for these services. Your service coordinator will inform you about this process and will provide support as needed to obtain these insurance/managed care benefits.

Additional Referral and Resource Agencies

211 Services
Provides help with food, housing, employment, health care, counseling and more. Visit www.211.org or just dial 2-1-1.

Legal Advocacy through Office of Clients' Rights Advocacy (OCRA)
May provide individuals supported by regional centers with free legal information, advice, and representation. A Clients' Rights Advocate (CRA) is designated to each regional center to help with legal problems, conduct training, and investigate denials of rights. Call (310) 846-4949 and leave a detailed message for assistance.

State Council on Developmental Disabilities (SCDD)
This independent state agency provides advocacy and other assistance to ensure that appropriate laws, regulations and policies pertaining to the rights of individuals with developmental disabilities are observed and protected. SCDD regional offices provide services to individuals and their families including, but not limited to, advocacy assistance, training, monitoring and public information. Call (866) 802-0514 or email council@scdd.ca.gov.

Westside Council for Independent Living (WCIL)
Provides information, supports, and opportunities for adults to enhance their independence. Call 310-851-9245 or visit www.wcil.org.

Referrals to community agencies, events and other generic resources are also available through a service coordinator and the Westside Family Resource and Empowerment Center.





**SERVICES
AND SUPPORTS
AGES 18 TO 22**

 **WESTSIDE
REGIONAL CENTER**

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California Courts Self-Help Guide: Conservatorship

<https://selfhelp.courts.ca.gov/options-help-someone-impairment-or-disability>

- This guide has information about:
 - Definitions you need to know to understand options and rights
 - Options to help someone with an impairment or disability
 - General and limited conservatorships
 - A step-by-step guide to limited conservatorships

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Conservatorship: Understanding ALL the options

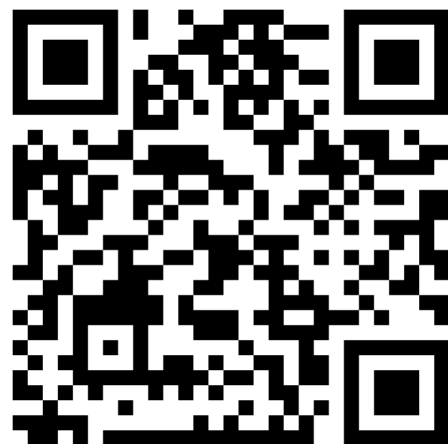
- A judge will only grant a conservatorship if no **less restrictive alternative** is appropriate.
- It is important to remember that **there may be other less restrictive options** for your young adult that should be considered first.

Option	Area of Assistance	Description
Supported Decision-Making	All	Person maintains decision-making power with the assistance of trusted individuals
Power of Attorney	Legal, financial	Person maintains decision-making power with the assistance of trusted individuals
Advanced Health Care Directive	Health (including mental health)	Plan memorializing person's health care desires and/or designating an alternate decision-maker
Representative Payee	Financial	Person or organization to handle individual's benefits, pay bills for them
Special Needs Trust or CalABLE account	Financial	Placement of funds into a specialized account that can be used to purchase qualified goods and services
Guardian ad litem	Legal	Person who takes over the role of a disabled or impaired individual in a court case
Limited conservatorship	Varies	A conservator makes decisions in specific areas where conservatee with a developmental disability is unable
General conservatorship	All	A conservator makes decisions generally, including medical, financial, etc., as outlined in the conservatorship papers

Source: <https://selfhelp.courts.ca.gov/options-help-someone-impairment-or-disability>

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Transition to
Adulthood for Youth
with Developmental
Disabilities and Autism
Spectrum Disorder:
A Resource Guide



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Q & A



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