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

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October 10, 2022

A short introduction...

2009 – 2013
(Undergrad)

2014 – 2017
(Clinic coordinator)

2009 – 2013
(Collaborative Family Study)

2017 – 2022
(PhD Student)

2022 – ?
(Postdoctoral Fellow)
Agenda

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

A note on terminology...

ASD = autism spectrum disorder
ID = intellectual disability
TD = typically developing
DD = developmental disabilities
Transition to Adulthood

Youth with Disabilities: Falling Off the Transition “Service Cliff”
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; Wandry & Pleet, 2003; Whitney-Thomas & Hanley-Maxwell, 1996

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

(Blacher & Baker, 2007)
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

Participants (N=109)

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

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

**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).

<table>
<thead>
<tr>
<th>Challenges/ worries</th>
<th>Goals</th>
<th>Attitudes</th>
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<tbody>
<tr>
<td><strong>What has been hardest for you about this period in your child’s life?</strong></td>
<td><strong>When you think about your young adult’s future, maybe 5 years from now, what are your goals for your young adult?</strong></td>
<td><strong>What emotions come up for you when you think about your child’s future?</strong></td>
</tr>
<tr>
<td><strong>What do you worry about most for your child?</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Young Adult Transition Outcome Composite (TOC)

<table>
<thead>
<tr>
<th>TOC Domain</th>
<th>Score Descriptors</th>
</tr>
</thead>
</table>
| 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)

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?
Mothers' Goals: Commonalities across Diagnostic Groups

Professional: TD 70%, ASD 87%, ID 56%
Independence: TD 49%, ASD 57%, ID 59%
Social: TD 55%, ASD 52%, ID 56%

Professional Goals: Differences by Diagnostic Group

Meaningful career: TD 49%, ASD 52%, ID 16%
Finding employment: TD 9%, ASD 22%, ID 38%
Professional Goals: Representative Quotes

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
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

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

Social Goals: Differences by Diagnostic Group

- TD
- ASD
- ID

Qualitative themes:
- Family/Kids
- Friendships
- Relationships

% of parents in each group:
- TD: 21% Family/Kids, 0% Friendships, 34% Relationships
- ASD: 9% Family/Kids, 17% Friendships, 26% Relationships
- ID: 9% Family/Kids, 11% Friendships, 25% Relationships
Social Goals: Representative Quotes

**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

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

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

***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)
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?

Mothers’ Challenges and Worries: Commonalities across Diagnostic Groups
Common concerns across diagnostic groups
Independence: Making Life Choices

“The terrible twos, no such thing. Tantrumming 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

Common concerns across diagnostic groups
Independence: Financial Stability/Career

“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
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

"The anxiety, depression, nursing school, all that, and I'm like, 'Oh dear goodness make it stop.'"
– Mother of a TD young adult

"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

"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

Continuum of dependence: Differences by diagnostic group

<table>
<thead>
<tr>
<th>Qualitative themes</th>
<th>TD</th>
<th>ASD</th>
<th>ID</th>
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<tr>
<td>Continuum of dependence</td>
<td>59%</td>
<td>57%</td>
<td>67%</td>
</tr>
<tr>
<td>Continued dependence on caregiver</td>
<td>0%</td>
<td>8%</td>
<td>0%</td>
</tr>
<tr>
<td>Struggle with the balance</td>
<td>29%</td>
<td>56%</td>
<td>36%</td>
</tr>
<tr>
<td>Watching young adult struggle</td>
<td>71%</td>
<td>0%</td>
<td>14%</td>
</tr>
</tbody>
</table>

% of patients in each group
Continuum of dependence

Representative quotes

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 fail 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

Mothers’ Challenges and Worries: Differences by Diagnostic Group

<table>
<thead>
<tr>
<th>Qualitative Themes</th>
<th>TD</th>
<th>ASD</th>
<th>ID</th>
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<tbody>
<tr>
<td>Parent Mental Health</td>
<td>9%</td>
<td>39%</td>
<td>42%</td>
</tr>
<tr>
<td>Victimization</td>
<td>4%</td>
<td>39%</td>
<td>26%</td>
</tr>
<tr>
<td>Social Support</td>
<td>11%</td>
<td>44%</td>
<td>27%</td>
</tr>
<tr>
<td>Caregiver Aging</td>
<td>2%</td>
<td>30%</td>
<td>49%</td>
</tr>
<tr>
<td>Navigating Services</td>
<td>2%</td>
<td>9%</td>
<td>46%</td>
</tr>
<tr>
<td>Transition Loss</td>
<td>4%</td>
<td>17%</td>
<td>3%</td>
</tr>
</tbody>
</table>
Differences in social concerns by diagnostic group

“...That someone will take advantage of her.”
– Mother of a young adult with ID

“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

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

“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

“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

Victimization
Social Support

Parent Mental Health
Caregiver Aging
Navigating Services
Theme unique to parents of TD youth: Transition loss

“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

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?
**Mothers’ Attitudes**

“Pretty much wishful thinking. She’s very content to live off of unemployment. These couple of classes are not doing anything.”
– Mother of a TD young adult

“I think his future is pretty bright. I think we live in a time where people are more open, more inclusive, more likely to accept people with disabilities... people with Down Syndrome have come a long way and I think they’re making great progress.”
– Mother of a young adult with ID

“Every year goes by... and there are days when I feel depressed and I get really upset because I think about his future, and it’s pretty sad that all this time, no matter what I’ve done, it hasn’t been enough to help him succeed as an independent person.”
– Mother of a young adult with ASD

“I have sadness and fear but overall hope. Because if I give up hope, I fall into a pit of despair that does no one any good and I know that. I feel like I’m a cautious optimistic. It’s hope grounded with honest fear for him.”
– Mother of a young adult with ASD

**Parenting stress in adolescence predicts mothers’ attitudes towards their youth’s future in adulthood**

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<tr>
<th>VARIABLE</th>
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<td>.57</td>
<td>4.85</td>
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<tr>
<td>FIQ Negative Impact</td>
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<td>.01</td>
<td>-.25</td>
<td>-2.29</td>
<td>.024*</td>
</tr>
<tr>
<td>(Parenting Stress)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOT (Optimism)</td>
<td>.04</td>
<td>.03</td>
<td>.16</td>
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<td>.143</td>
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<td>-.18</td>
<td>-1.65</td>
<td>.103</td>
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</table>

*p<.05

Multiple linear regression, \( F(3, 94) = 7.90, p<.001, R^2 \) adjusted = .18

Dependent variable: Mothers’ Attitudes (1-4 scale)
Maternal optimism in adolescence and youth diagnostic status predict young adult outcomes on the TOC

<table>
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<tr>
<th>VARIABLE</th>
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<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
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<td>1.16</td>
<td>3.41</td>
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<tr>
<td>SCL (Mental Health Symptoms)</td>
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<td>.02</td>
<td>-.03</td>
<td>-.28</td>
<td>.783</td>
</tr>
<tr>
<td>FIQ Negative Impact</td>
<td>.03</td>
<td>.03</td>
<td>.13</td>
<td>1.01</td>
<td>.314</td>
</tr>
<tr>
<td>FIQ Positive Impact</td>
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<td>.04</td>
<td>-.08</td>
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<td>.385</td>
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<tr>
<td>LOT (Optimism)</td>
<td>-.10</td>
<td>.04</td>
<td>-.19</td>
<td>-2.34</td>
<td>.022*</td>
</tr>
<tr>
<td>DD Status</td>
<td>2.65</td>
<td>.43</td>
<td>.55</td>
<td>6.23</td>
<td>.000***</td>
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</tbody>
</table>

***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)

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.
Resources and tips for employment and post-secondary education
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

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
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

Integrate Autism Employment Advisors

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

Autism goes to college:
Understanding the experiences & needs of university students with autism

https://www.autismgoestocollege.org

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”

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.
**Resources and tips for building social skills and social engagement**

**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
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.

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.
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

UCLA PEERS® for Dating

- 16-week dating skills program for young adults with ASD
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.
Regional Center Adult Services

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 trainings, 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

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 in LA and Ventura Counties
Many parents in LA and Ventura Counties have questions and challenges relating to raising children with special needs. Parenting in LA and Ventura Counties is a weekly radio program that provides parents with information on common issues faced by families. Call 424-353-1414 for more information.

Parenting Network
Provides free weekly workshops in Los Angeles County for parents with children ages 3-18 who are developmentally delayed. Workshops are conducted by Child Developmental Specialties, a nonprofit agency that provides support and resources for families of children with special needs. Call (323) 527-2700 for more information.

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Many parents in LA and Ventura Counties have questions and challenges relating to raising children with special needs. Parenting in LA and Ventura Counties is a weekly radio program that provides parents with information on common issues faced by families. Call 424-353-1414 for more information.

Parenting Network
Provides free weekly workshops in Los Angeles County for parents with children ages 3-18 who are developmentally delayed. Workshops are conducted by Child Developmental Specialties, a nonprofit agency that provides support and resources for families of children with special needs. Call (323) 527-2700 for more information.

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.

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 may refer to a service provider in Los Angeles County that procures lifts, hospital beds, commodes, and other medical equipment.

Parenting Network
Provides free weekly workshops in Los Angeles County for parents with children ages 3-18 who are developmentally delayed. Workshops are conducted by Child Developmental Specialties, a nonprofit agency that provides support and resources for families of children with special needs. Call (323) 527-2700 for more information.

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.

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

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
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.

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

Source: [https://selfhelp.courts.ca.gov/options-help-someone-impairment-or-disability](https://selfhelp.courts.ca.gov/options-help-someone-impairment-or-disability)
Thank you!

Eunice Kennedy Shriver National Institute of Child Health and Human Development, Grant number: 34879-1459 (PIs: Bruce Baker, Jan Blacher, Keith Crnic)

All the staff, graduate students, and undergraduate research assistants who have been involved with this ongoing study

The young adults and their parents, who have generously given their time and insight over the last 20 years

Q & A