

# Health care transition recommendations for young people with intellectual and developmental disabilities and co-occurring mental health conditions: Stakeholder survey findings

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## ABSTRACT

**Background:** Limited knowledge exists as to the supports and services young people with IDD and co-occurring mental health conditions need to transition to adult-focused health care and adulthood.

**Methods:** The survey findings presented were part of a larger investigation that explored these service and supports needs obtained from 144 respondents. Data reported for this investigation were obtained from 144 respondents who answered the question, "What do you think would be most helpful to assist young people with IDD and mental health conditions with the transition from child to adult health care (not including mental health care)?"

Qualitative analysis based upon the social-ecological model was undertaken.

**Findings:** Based on the social-ecological model (SEM), health care transition needs were reported in four of the five SEM domains-Individual, Family, Provider, and Systems Level. The responses were most frequently categorized in the SEM domains in following descending order: Individual, Provider, System and Family.

**Conclusion:** Implications for research and practice suggest that multi-level approach is needed to address the range of service needs for young adults with IDD and co-occurring mental health conditions.

## 1. Introduction

Health care transition is an expanding field of practice and research that is gaining in relevancy and recognition of the importance to create service models that facilitate interconnection between pediatric and adult-focused systems of care. Public health and adolescent health leaders have advocated for the implementation of HCT service models beginning more than thirty years ago<sup>1-3</sup>. In 1993, a landmark position paper by the Society for Adolescent Medicine published the first definition of health care transition that continues to be the predominant referent: "...as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems."<sup>1</sup>, p.570.

Despite the advances in the field with the implementation of HCT programs in selected settings<sup>4-6</sup>, evidence-based HCT models of care are lacking. As well, what constitutes successful person-centered outcomes of care have yet to be determined<sup>7-11</sup>. Other challenges exist with unequal HCT service development affecting selected populations of youth and young adults with childhood acquired conditions. Noticeable

disparities with the provision of HCT services exist when reporting evidence pertaining to the populations of youth and young adults with intellectual and developmental disabilities (IDD) including those with co-occurring mental health conditions<sup>12-14</sup>.

Limited literature exists to inform development of HCT practice models for youth and young adults with IDD, despite the prevalence rate of 8.56 % in children aged 3-17 years<sup>15</sup> as compared to considerably lower prevalence rates for other childhood acquired chronic conditions, such as childhood cancer<sup>16</sup>, cystic fibrosis<sup>17</sup>, congenital heart disease<sup>18</sup>, type 1 diabetes<sup>19</sup> and sickle cell disease<sup>20</sup> that receive more attention in the literature. Secondary analysis of national surveys, namely, the National Survey of Children with Special Health Care Needs and National Child Health Survey for over a decade have revealed ongoing disparities with the provision of health care transition services for youth with developmental disabilities (up to 17 years of age)<sup>12-14,21-23</sup>.

As experts have warned, the HCT service challenges and barriers for youth and young adults with IDD can result in untoward health consequences due to delays in accessing care<sup>6,12-14</sup>. Adverse HCT outcomes are accentuated for youth and young adults with IDD and co-occurring

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mental health conditions as even greater challenges in accessing adult mental health services have been well documented due to limited availability of mental health providers with IDD expertise and treatment capacity, problems with insurance coverage and differing eligibility criteria for adult-focused mental health services as compared to child mental health<sup>24-32</sup>. These barriers to needed adult-focused mental health services can lead to a worsening of the mental health condition, disruption with social relationships and decline in overall quality of life and future planning<sup>26,28,32-34</sup>.

A more recent publication by this authoring team based upon this survey study reported barriers to accessing adult-focused mental health services for young people with IDD based upon socioecological model. Stakeholders representing a broad array of constituents (self-advocates, families, community-based and healthcare providers) offered diverse perspectives about barriers to mental health care. These barriers included societal discrimination, language and cultural barriers, diagnostic bias and labelling, problems with treatment approaches, lack of mental health providers and professional training and the need for family support and training<sup>35</sup>.

Limited knowledge is available as to what supports and services would be of assistance in supporting young people with IDD and co-occurring mental health conditions to transition to adult-focused health care and adulthood. This study, part of a larger investigation, was conducted to explore what types of assistance would be helpful for this population of young people to transition to adult-focused health care<sup>35</sup>.

## 2. Methods

### 2.1. Study sample

The survey sample for this study was recruited via the email distribution list of the University of Southern California (USC) University Center for Excellence in Developmental Disabilities (UCEDD), located in Southern California which contains approximately 3000 email addresses, which includes addresses of individuals throughout the state. The inclusion criteria for this

survey investigation was delimited to those who were 18 years and older with an IDD, an IDD self/disability advocate, family member of individual with IDD, or a community-based service provider or health care professional involved in the IDD system of care. Community-based service providers were associated with the IDD, educational and rehabilitation service systems. A diverse group of health care professionals was represented that included physicians, mental health practitioners (psychiatrists, psychologists), nurses, occupational and speech therapists. Initially, 283 completed surveys were received. Six surveys were excluded as the respondent was younger than 18 years of age resulting in 277 surveys available for analysis. Data reported for this investigation were obtained from 144 respondents who answered the open-ended question, "What do you think would be most helpful to assist young people with IDD and mental health conditions with the transition from child to adult health care (not including mental health care)?"

### 2.2. Survey instrument

A HIPPA compliant REDCap and anonymous survey<sup>36,37</sup>, entitled *Survey on Transition Needs of Youth and Young Adults with Intellectual and Developmental Disabilities* was distributed via the USC UCEDD email list between February and March, 2022. This survey consisted of 99 closed and open-ended items to elicit input from diverse group of stakeholders about their perceptions of the transition to adult health care experience of youth and young adults with IDD and those with IDD and co-occurring mental health conditions and whether HCT experiences differed between these two groups. Items generated for this survey were based upon literature evidence and the HCT and IDD experience and expertise of the research team<sup>38-43</sup>. Participant input was sought as to their

perceptions of the barriers to adult-focused health care and types of support needed to facilitate the transfer of care to adult-focused providers for young people with IDD and those with IDD and co-occurring mental health conditions. Previous reports generated from this survey study have been published on stakeholders' perspectives on the barriers to adult health care for youth and young adults with IDD and those with IDD and co-occurring mental health conditions<sup>35</sup>. This study received IRB approval and was granted exempt status.

### 2.3. Qualitative analysis

Two members of the research team (C.M., C.B.) separately coded responses generated from the research question to explore stakeholders' perceptions of assistance needed by young people with IDD and mental health conditions with the transition from child to adult health care. The social-ecological model (SEM)<sup>44,45</sup> was used as the organizing framework to code data according to the major themes of individual, family, provider, system and societal levels of HCT assistance and its corresponding subthemes for each of the major themes. This thematic framework was used in a previous analysis on the barriers to care for youth with IDD and co-occurring mental health conditions and adapted for use in this analysis. The adaptation for coding responses included combining subthemes, adding new subthemes and deleting others not relevant. Coded responses were compared and grouped according to the themes and subthemes and in instances wherein there were differences, discussion ensued until agreement was reached<sup>46,47</sup>. The themes and subthemes generated from the respondents are presented in Table 2 and reported in the results section.

## 3. Results

### 3.1. Demographics

Of the 144 respondents, the largest group of stakeholders were disabilities advocates (68; 47.2 %) followed by community-based service providers (45, 31.3 %) and health care providers (30, 20.8 %). When asked the type of activities these respondents were involved in, empowerment and advocacy (99, 68.8 %) followed by service referrals (78, 54.2 %) were the two most common responses. All other activities identified were reported by less than fifty percent by participants. More than fifty percent of respondents indicated they worked with children 6 years and older through adulthood. This group of respondents provided services to a diverse population of individuals with IDD and co-occurring mental health conditions ranging from more than seventy percent who serve Hispanic (110, 76.4 %) and white (110, 76.4 %) individuals and to a large percentage who serve African Americans (97, 67.4 %) and Asian (89, 62 %) individuals. Smaller percentages were reported for other ethnic groups as presented in Table 1. Prominent among the diagnostic categories of individuals served were autistic people (136, 94.4 %) and those with IDD (120, 83.3 %). Other IDD diagnostic categories associated with individuals served were greater than sixty-five percent.

Demographics were compiled for a subgroup of health care providers (N = 30) of this sample to compare and contrast findings as to possible differences in profile characteristics gathered. The rank ordering of activities performed in the providers' roles were similar to the entire sample. The rank ordering of age groups served were fairly similar with the exception that a smaller percentage reported providing services

to young people ages 19-21 years (9.30 %), a pivotal age for transition to adult health care. The rank ordering of ethnic and the diagnostic categories of individuals with IDD served were similar to the entire sample.

### 3.2. Qualitative analysis

The majority of respondents who answered the question "What do

**Table 1**  
Sample demographic data.

N = 144	n	%
Disabilities advocate (self-advocate, family advocate, professional advocate, etc.)	68	47.2 %
Stakeholder in community-based organization/resource (Regional Center, education, vocational rehab, etc.)	45	31.3 %
Provider (psychologist, psychiatrist, DBP, general pediatrician, nurse, social worker, etc.)	30	20.8 %
Not Answered	1	0.07 %
In your role, what type of activities are you involved in?	N = 144*	
Empowerment and advocacy	99	68.8 %
Service referrals	78	54.2 %
Patient education	60	41.7 %
Case management	59	41 %
Other (please describe below)	59	41 %
Psychosocial support	34	23.6 %
Direct mental health care	21	14.6 %
Direct health care (other than mental health care)	20	13.9 %
Diagnostic Testing	9	6.2 %
Do you primarily serve populations in California?		
Yes	131	91 %
No	11	7.6 %
Not Answered	2	1.4 %
Age Group Work with*		
5 years or less	70	48.6 %
6–10 years)	77	53.5 %
11–15 years	93	64.6 %
16–18 years	95	66 %
19–21 years	103	71.2 %
22–26 years	91	63.2 %
27 years or older	79	54.9 %
Race of Populations Served *		
Hispanic	110	76.4 %
White	110	76.4 %
African American	97	67.4 %
Asian	89	62 %
Native Hawaiian or other Pacific Islander	52	36.1 %
American Indian or Alaska Native	44	31 %
Other	35	24.3 %
What population do you serve		
Autism	136	94.4 %
Intellectual Disability	120	83.3 %
Cerebral Palsy	96	66.7 %
Down Syndrome	96	66.7 %
Epilepsy	95	66 %
Other	59	41 %
Yes or some have co-occurring condition	145	100 %
Providers		
N = 30	n	%
In your role, what type of activities are you involved in?		
Empowerment and advocacy	18	60 %
Patient education	17	57 %
Service referrals	13	43.3 %
Direct mental health care	12	40 %
Psychosocial support	12	40 %
Case management	11	37 %
Other	8	26.7 %
Diagnostic Testing	5	17 %
Direct health care (other than mental health care))	5	17 %
Age Group Work with		
5 years or less	15	50 %
6–10 years)	18	60 %
11–15 years	20	66.7 %
16–18 years	22	73.3 %
19–21 years	9	30 %
22–26 years	15	50 %
27 years or older	18	60 %
Race		
Hispanic	27	90 %
White	23	77 %
Asian	22	73.3 %
African American	22	73.3 %
Native Hawaiian or other Pacific Islander	12	40 %
American Indian or Alaska Native	7	23.3 %

**Table 1 (continued)**

N = 144	n	%
Other	6	20 %
What population do you serve		
Autism	29	97 %
Intellectual Disability	28	93.3 %
Down Syndrome	24	80 %
Cerebral Palsy	21	70 %
Epilepsy	21	70 %
Other	7	23.3 %
Yes or some have co-occurring condition	30	100 %

you think would be most helpful to assist young people with IDD and mental health conditions with the transition from child to adult health care (not including mental health care)?” offered single suggestions, some offered more than one but the suggestions generally followed singular themes. Analysis of data generated aligned with the SEM levels as discussed below and presented in Table 2 and Fig. 1.

### 3.2.1. Individual level

The Individual Level Theme Refers to the interventions that were offered by respondents that would assist young people to transition their pediatric care to adult- focused health care. This theme is focused on individual-focused interventions that are designed to facilitate their transition to adult-focused health care. The Individual Theme is composed of the following eight subthemes that will be described below: *need for peer support, need for person-center approach, need for provider support, self-advocacy/independence, supported decision-making/legal issues around guardianship, need for advocate or non-family support, need for individual training, communication strategies* (Table 2).

**3.2.1.1. Need for peer support.** Respondents indicated the need for providing peer supports. Responses indicated that peer supports would be of unique assistance to facilitate achievement of the benchmarks of adulthood. Illustrative of this perspective, one of the respondents stated: “*Support groups or organization, peer interactions resources, more choices of activities to participate and lots more independent or group housing.*” (stakeholder of community-based organization [SCBO], #225). Another respondent suggested that “*more success stories, more social support with people like them...*” (Disability advocate [DA], #7) would be of assistance to young people with IDD and co-occurring MH conditions.

**3.2.1.2. Need for person-center approach.** Respondents suggested that intervention strategies should be based upon the young person’s needs, and to view holistically each individual’s strengths as well as challenges. That is, one of the participants shared the following statement to illustrate, “*This amounts to treating them as people, not only cases*” (DA, #173).

**3.2.1.3. Need for Provider Support.** One of the respondents recognized the importance of having the young person and family provided services that fostered transition to adult-focused healthcare providers that were based on a team approach. This perspective is evidenced by the following statement: “*...stress the idea of the importance of a wraparound team*” (DA #70).

**3.2.1.4. Self-advocacy/independence.** Several respondents identified promoting self- advocacy would be helpful to young people as they transitioned to adult-focused health care. One respondent recommended that, “*...empowering young people to take a more active role in their care*” (Provider [P], #115). Another respondent recommended that “*...education on rights of adults with disabilities (a person may never have known disability rights or options for accommodations before now)*” (DA #96). A few respondents suggested that facilitating independence for young people with IDD with co-occurring mental health conditions would be helpful to them as they transition to adult-focused care. One of the

**Table 2**  
Caption.

3.2.1	<b>Individual Level</b>	
3.2.1.1.	Need for Peer Support	More success stories, more social supports with people like them (DA #7) More resources and referrals to places that can also help with the transition, peer support etc. (SCBO #58). Peer support (DA #184). A mentor, i.e., 1:1 support (doesn't always have to be the same person, but consistency/small pool of people is important) (DA #184). Use of peers in discussion/trainings (SCBO #225). Support groups or organizations, peer interactions resources, more choices of activities to participate and lots more independent or group housing. Use of advance technology tools to assist better quality of daily life's process and obstacles. (SCBO #225). On going support, peer (DA #268).
3.2.1.2	Need for Person-Center Approach	A person centered approach that allows for continuity of care would be best. CalAIM's general approach to whole person health makes sense for those outside of Medi-Cal too, especially during transition times (SCBO #167). Person-Centered practices. This amounts to treating them as people, not only cases (DA #173). Real world circumstances, options and potential consequences communicated in a non-judgmental and person centered way (P #250). Access to treatment modalities that support the youth with IDD and MHC to articulate their needs and engage in treatment (SCBO #208).
3.2.1.3.	Need for Provider Support	Again, To be able to have a connected care team of specialists (i.e. Neurologist, Endocrinologist, Allergist, Dentist, Primary Care (DA #83). Stress the idea of the importance of a wraparound team. (DA #70). Having a consistent staff with youth before and after transition to adult hood (SCBO #85).
3.2.1.4.	Self- Advocacy/Independence	Self advocacy and rights (DA #19). Empowering young people to take a more active role in their care. Supported decision making with a assistance in facilitation (SCBO #73). Holding services independently of children services (adults may feel unwelcome or like imposter if using services targeted toward children) (DA# 96). Empowering young people to take an active role (P #115). Preparing them for the independence from all the support (SCBO #90). Begin making decisions and carrying responsibilities in their teen years (DA #117).
3.2.1.5.	Supported decision- making, legal issues around guardianship	We need something short of conservatorship that would provide ongoing support. (DA #13). Identifying trusted individual to help follow up on care or conservatorship (P #15). Empowering young people to take a more active role in their care. Supported decision making with a

**Table 2 (continued)**

		assistance in facilitation (SCBO #73). Empowerment, person-centered and whole-person philosophies. Education AGAINST conservatorship and in favor of supported decision making (DA #73).
3.2.1.6.	Need for advocate or non-family support	Youth without family support (eg foster youth) need a stable advocate who stays with them during and after the transition to ensure their needs are met. (SCBO #43). More advocates (DA #123). A mentor that will follow up with them, jobs & financial support and entertainment for youth (DA #129). Special Needs persons need support from well- educated mentors/caregivers. (DA #220). A mentor, i.e., 1:1 support (doesn't always have to be the same person, but consistency/small pool of people is important) (DA #221). Support groups or organizations, peer interactions resources, more choices of activities to participate and lots more independent or group housing. Use of advance technology tools to assist better quality ofdaily life's process and obstacles (DA #230).
3.2.1.7.	Need for individual training	Education on rights of adults with disabilities (a person may never have known disability rights or options for accommodations before now (DA #96). Have a way to provide audio or written information that the patients can understand. And for them to be able to gain access to it for their Living skills instructors or family members to interpret and explain. (P #125). Information, educational options at their level, group learning (P #136). More education for young people and their families as well as follow up (P #160). Educating individuals/caregiver about services/advocacy/financial needs/medical services/legal services/decision making (DA #190). Real world circumstances, options and potential consequences communicated in a non-judgmental and person-centered way (P #250). Educating and providing resources that support individuals with IDD and mental health conditions (SCBO #266). How to access critical support, and where can they go for mental health support (SCBO #80).
3.2.1.8.	Communication strategies	Better communication with caregivers (DA #6). AAC devices (DA #126). Better Communication (DA #146).
3.2.3.	<b>Family Level</b>	
3.3.2.1.	Need for Family Support and Training	Respite for families (DA #16). Support to their families and the client with accessible integrated resources (PA #23). Greater support and education for parents (P #24). Update info provided to families (P #66). Support and education to families (SCBO #100). Preparing the parents to be allies of their children (SCBO #147). Parent

(continued on next page)

Table 2 (continued)

		education and regional center active support (DA #148). Provide counseling to parents and families (SCBO #239). More education for young people and their families as well as follow up (P #160). Education individuals/caregiver about services/advocacy/financial needs/medical services/legal services/decision making (DA #190). Training for parents on how to assist their children into adulthood such as conservatorship and adultliving (DA #282).
3.2.4.	<b>Provider Level</b>	
3.2.4.1.	Need for case management, systems navigation, coordination of services, follow-up	Education and assistance with systems navigation (SCBO #20). A long term case manager to assist with the transition (SCBO #21). Earlier contact with Regional Center, coordination of services (P #24). Case manager (DA #57). Better Coordination, Collaboration and Continuity of Care; Teaching Self Advocacy (SCBO #61). Periodic check in (DA #92). Regular check-ins; personalized/specific accommodations (reduces costs & waste and increases effectiveness of accommodation) (SA #96). Increased support in finding providers, setting appointments, same as above (P #103). Help in finding providers that really understand the person with I/DD (SCBO #105). Coordinated transfer to adult services (P #118). Case management, coordinating care (SCBO #151). More education for young people and their families as well as follow up (P #160). Someone needs to check on the families even if the family doesn't call back or follow up. Families get overwhelmed and forget to follow up, so then the system forgets about these kids/people (P #160). A more coordinated approach between systems of care. Its too hard for the family and person with a disability to manage sometimes. (DA #166). Consistent stable cm services who is dedicated to this need (P #174). Connecting them with appropriate care/support; Provide families training and support to support their adult children. (DA #215). Having a liaison from the pediatric facility help with the transition (DA #233). Specialized case management with targeted expertise to meet complex needs. (SCBO #253). Periodic check in (DA #92).
3.2.4.2	Need for professional training	More education to providers on how to successfully support individuals with IDD. Education that someone with IDD can also have a separate mental health need (P #77). An in depth educational requirement of both IDD & mental health conditions across the board for ALL staff, top staff to bottom staff. (SCBO #237). Education on Mental Health and IDD, if you have IDD/MH does not mean you cannot

Table 2 (continued)

3.2.4.3.	Need for warm handoff	be independent or have goals. (SCBO #247). Warm handoff, not having to repeat same concern to every single person hand off too (SCBO #41). In my experience individuals with IDD and mental health conditions have larger teams – which can mean more changes and transitions for them. These changes and transitions could be better handled with some overlap (allowing both/all providers to bill for services during the warm hand off) and or extending child services past 22 to be flexible to 25 IF they wanted (SCBO #52). A transition meeting with both providers (DA #86). A transition meeting between the pediatric team with the new medical provider team (P #112). Really education teachers, parents and students earlier about the role of preparing for adult services, and begin the "warm hand off" at least in the final public school year so the transition is not like hitting brick wall! (P #213).
3.2.4.4.	Needs, problems with transition planning, timelines	Transition planning much sooner; placements made specifically with this population in mind; agencies not pointing the finger at each other as being responsible for this population, but ALL of them taking responsibility for them (DA #12). More preparation early on in the process, prior to age 18 so lengthy legal issues can be started. More assistance with job assistance and participation in adult programs so young adult can participate without being kicked out due to behaviors or mentalhealth crises (DA #88). Support and education to families, info provided early in process (DA #100). Summary that comes with the pt (P #185). Simplified medical information. (SCBO #196). Medicare and or CalOptima coverage to select medical centers or doctors-dentists for health care (DA #204). Give pediatric care services a list and plan for adult services (P #229). Greater involvement by the school districts who have access to these teens in IEP meetings (SCBO #256). Provide multiple appointments to familiarize the pt. with the changes and why (P #228). I wish I knew. Ghosting by previous providers certainly doesn't help! (DA #200). More mental health providers willing to see patients with IDD (P #81). A family doctor who provides continuity of care. and psychiatrists who understand that medical conditions often cause psych symptoms (DA #132). Availability of psychiatrists who could see IDD population. (DA #259). Having service providers that specialize with people with IDD (P #111). Same as young people with IDD without mental health conditions except including
3.2.4.5.	Lack of mental health providers or staff	

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Table 2 (continued)

3.2.4.6.	Need for medical providers specifically knowledgeable in IDD mental health	the mental health practitioner in the transition process (DA #240). Drs to understand co-morbidity of anxiety & autism & epilepsy ... and dangers of medicating for anxiety (DA #145). Looking comprehensively for physical causes of MH conditions. Open minded And supportive professionals (DA #272). More and better medical and mental health resources (SCBO #260). We need more resources prepared to work with dually-diagnosed individuals (SCBO #267). Relational therapy rather than poorly trained ABA therapists. Also we need safe places for routine health care such as dentist or blood draw where you have workers who understand that you might need a lot of time to sit in the chair and be ready etc. (DA #258).
3.2.4.7.	Need for bilingual, culturally proficient providers	Cultural proficiency amongst professionals (DA #214).
<b>3.2.5. Systems Level</b>		
3.2.5.1.	Problem with regional center system	Regional case load reductions (DA #100).
3.2.5.2.	Service systems challenges	Tracking of wait times for referrals to the actual start of providing services would identify service failures (SCBO #167).
3.2.5.3.	Being bounced between agencies	Have both sectors communicate and work with each other bridge the gap of service not passing from one hand to the other. Work Cohesively (SCBO #175).
3.2.5.4.	Difficulties finding healthcare and mental health providers	Identifying adult providers (NI #210). Locating psychologists (DA #211).
3.2.5.5.	Need for care coordinator or navigator	Coordination between agencies and resource availability (DA #64). Coordinated transfer to adult services. (DA #118). A more coordinated approach between systems of care. Its too hard for the family and person with a disability to manage sometimes (DA #166). Assigned care coordinator that does weekly check- ins (P #251). The care coordinators (P #252). Specialized case management with targeted expertise to meet complex needs (SCBO #253).
3.2.5.6	Need for crisis intervention	Informed crisis training. (SCBO #38). Same as all IDD youth, however, I think that families have a greater fear of their dually diagnosed child not following their care plan and having worse outcomes (hospitalization or jail as an example) (SCBO #106).
3.2.5.7.	Problems with access to care	Close health services, health care too far away (DA #135). Figure out how to defer mandated transitions in health care for this population until brain development has stabilized in the late 20 s. Imposing health care transition on this population at all given its complex needs should be re-examined (SCBO #167). Legal/consent-based barriers to care (P #199).
3.2.5.8.	Problems with DD service system	Providers vendored with Regional Centers need more staff who proactive with their clients. Same

Table 2 (continued)

3.2.5.9	Need for Improved Mental Health system	goes for the direct service providers (DA #273). Regional center service coordinators have huge caseloads and are not equipped to supervise complex medical conditions, including mandated transitions in healthcare providers. This work is delegated to similarly ill-equipped families (SCBO #167). More informed advocates and better trained/monitored regional centers and their counsel. Those with MH are seen as dangers to IDD settings (DA #265). A mental health system that better supports those with MH needs; educational materials describing the transition process and resources (DA #51). Early Screening of mental health conditions (SCBO #63). Set up user friendly mental health system for easy access (P #66).
3.2.5.10	Financial	A program offering incentives to MH providers that receive on-going education and training on how to best serve the IDD/MH population (SCBO #113).
3.2.5.11.	Housing	Housing options (DA #11). Also we need housing that is akin to Regional Center housing but that is age appropriate – currently Regional Center housing sees young adults placed not with peers but with mature adults (DA #13). More expansive residential opportunities and care, informed crisis training, informed treatment, cross agency case management. START Services expanding in California is a positive step forward (SCBO #38). Supportive housing (DA #142). Housing (DA #182). Support groups or organizations, peer interactions resources, more choices of activities to participate and lots more independent or group housing. Use of advance technology tools to assist better quality of daily life’s process and obstacles (DA #96).
3.2.5.12.	Need for employment resources, training	Again, a plan where Department of Rehabilitation actually supports without a fight!!! (DA #14). Making connections between school life skills (non- diploma) high school programs and community employers to identify participants and appropriate opportunities for employment/ volunteer/learning in transition to adulthood (DA #95). Appropriate job training (DA #163).
3.2.5.13.	Community-based resources and supports	Availability of quality community and home-based supports (DA #17).

respondents suggested, “Begin making decision and carrying responsibilities in their teen years” (DA, #117).

3.2.1.5. *Supported decision-making, legal issues around guardianship.* Issues pertaining to supported decision-making and guardianship were raised by respondents, which is an issue unique to this population of young people. This perspective was exemplified by the following statements: “We need something short of conservatorship that would provide



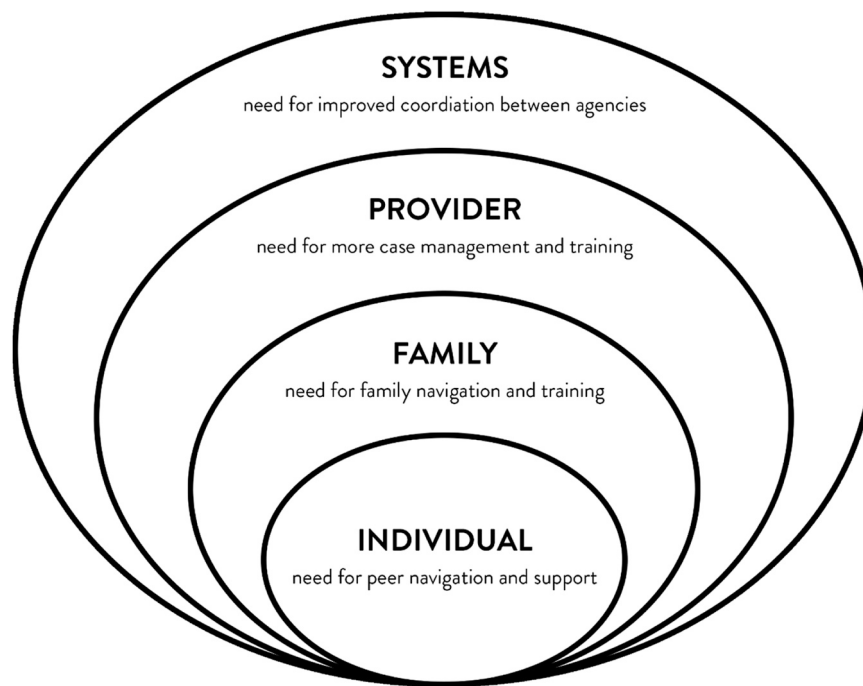


Fig. 1. Barriers to transition using the social ecological model.

ongoing support” (DA #13). Another respondent shared that “Identifying trusted individual to help follow-up on care or conservatorship” (Provider #15) would be helpful to a young person transitioning to adult-focused health care.

**3.2.1.6. Need for advocate or non-family support.** Respondents shared input on supports needed for youth who may not have family support such as those who are in foster care. Support identified included mentors, legal counsel, support groups and advocates. As one respondent noted, “Youth without family support (e.g. foster youth) need a stable advocate who stays with them during and after the transition to ensure their needs are met” (SCBO, #43).

**3.2.1.7. Need for individual training.** Several stakeholders identified that youth and their families should be provided education on a variety of topics to assist them with the transition to adult-focused health care and adulthood. A stakeholder noted, “Educating individuals/caregiver about services/advocacy/financial needs/medical services/legal services/decision making” (DA #190) during this transition period would be helpful.

**3.2.1.8. Communication strategies.** A few respondents identified that improved means of communication was needed not only between providers and caregivers and the need for “AAC devices” (DA #126).

### 3.2.2. Family Level

The Family Level Theme is composed of intervention strategies suggested by respondents that would be helpful to families during the transition process to adult health care providers and other sources of assistance. Respondents identified sources of assistance that enable parents to navigate this process for not only themselves but also for their children. One subtheme was subsumed within this theme: *need for family support and training* as depicted in Table 2.

**3.2.2.1. Need for Family Support and Training.** The majority of recommendations for Family Level Theme were categorized in the subtheme, *Need for Family Support and Training*. The eleven recommendations for family support and training were for respite, counseling, coordination of

services and education. As one respondent stated, “update info provided to families; set up user friendly mental health system for easy access” (P#66). Another respondent suggested that, “Someone needs to check on the families even if the fam doesn’t call back or follow up. families get overwhelmed and forget to follow up, so then the system forgets about these kids/people” (Provider #160).

### 3.2.3. Provider Level

The Provider Level Theme reflected respondents’ perspectives about the role of providers involved with the provision of health care transition services. The stakeholders’ provided input on providers’ training needs, their roles and responsibilities associated with HCT planning, service and workforce capacity, and seven subthemes were generated from the data pertaining to the Provider Level Theme. These seven subthemes were *need for case management, systems navigation, coordination of care, follow-up; need for professional training; need for warm handoff; needs, problems with transition planning, timelines; lack of mental health providers or staff; need for medical providers specifically knowledgeable in IDD mental health; need for bilingual, culturally proficient providers.* (Table 2).

**3.2.3.1. Management, systems navigation, coordination of care.** Respondents identified the importance of integrating service elements into HCT planning such as service coordination, navigation, case management and education. One respondent suggested, “Greater support and education for parents, earlier contact with regional center, coordination of services.”

**3.2.3.2. Need for professional training.** Respondents shared perspectives that health care providers involved with HCT needed additional training to adequately support young people and their families during this process. One respondent commented for the need for “in depth educational requirement of both IDD & mental health conditions across the board for ALL staff, top staff to bottom staff” (SCBO #237).

**3.2.3.3. Need for warm handoff.** Several stakeholders shared concerns about the need for a “warm handoff” between pediatric and adult-focused health care providers. Respondents shared thoughts about the

warm handoff such as “warm handoff, not having to repeat same concern to every singled person” (SCBO #41), “transitions could be better handled with some overlap (allowing both/all providers to bill for services during the warm handoff)” (SCBO #52), and “...begin the ‘warm hand off’ at least in the final public school year so the transition is not like hitting a brick wall” (P 213).

**3.2.3.4. Needs, problems with transition planning, timelines.** Several stakeholders offered input on improvements needed with the HCT process, especially with this population. Of particular note, a stakeholder recognized distinctions to be addressed with HCT preparation: “More preparation early on in the process, prior to age 18 so lengthy legal issues can be started. More assistance with job assistance and participation in adult programs so young adult can participate without being kicked out due to behaviors or mental health crises” (DA #100).

**3.2.3.5. Lack of mental health providers or staff.** Several respondents identified the importance of having mental health professionals/staff available to provide need mental health services. These sentiments were echoed by the following statements: “More mental health providers willing to see patients with IDD” (P #81), and “Availability of psychiatrists who could see IDD population” (DA #251).

**3.2.3.6. Need for medical providers specifically knowledgeable in IDD mental health.** A respondent noted that medical providers needed to have a better understanding of IDD and the co-morbidity of mental health conditions. This perspective was exemplified with the statement, “Drs. to understand co-morbidity of anxiety & autism & epilepsy...and dangers of medicating for anxiety” (DA #145). This statement offered by a respondent indicates the service need for young people with IDD and co-occurring mental health condition: “...having service providers that specialize with people with IDD” (P #111).

**3.2.3.7. Need for bilingual, culturally proficient providers.** The issue of cultural proficient providers was raised as an intervention need. The respondent referred to the importance of “...cultural proficiency amongst professionals” (DA #214).

#### 3.2.4. Systems Level

The Systems Level Theme is composed of suggestions for services and challenges associated with service access and the services themselves. Thirteen subthemes were generated associated with the systems level. These subthemes *problem with regional center system, service systems challenges, being bounced between agencies, difficulties finding healthcare and mental health providers, need for care coordinator or navigator, need for crisis intervention, problems with access to care, problems with DD service system, need for improved mental health system, financial, housing, need for employment resources, community-based resources and supports.*

**3.2.4.1. Problem with regional center system.** A respondent noted that the need for transition services information being provided earlier and the need for care load reductions as evidenced by these comments, “Info provided early in process, regional case load reductions” (DA #100).

**3.2.4.2. Service systems challenges.** One respondent offered the following recommendation for identifying the source of service challenges: “Tracking of wait times for referrals to the actual start of providing services would identify service failures” (SCBO #167).

**3.2.4.3. Being bounced between agencies.** This respondent offered the suggestion to improving the transfer of care between pediatric and adult-focused service systems: “Have both sectors communicate and work with each other bridge the gap of service not passing from one hand to the other” (SCBO #175).

**3.2.4.4. Difficulties finding healthcare and mental health providers.** Two respondents noted in response to their suggestions for improving services would be to *locate adult-providers* (NI #210) and *psychologists* (DA #211).

**3.2.4.5. Need for care coordinator or navigator.** Many responses were obtained pertaining to the need for a service coordinator or navigator to assist young adults with IDD and their families through the transition process to adult-focused mental health care. This perspective illustrates this recommendation and service need, “A more coordinated approach between systems of care. Its too hard for the family and person with a disability to manage sometimes” (DA #166).

**3.2.4.6. Need for crisis intervention.** A few comments noted the need for services to address youth and family crisis needs. This statement exemplifies this view, “Same as all IDD youth, however, I think that families have a greater fear of their dually diagnosed child not following their care plan and having worse outcomes (hospitalization or jail as an example)” (SCBO #106).

**3.2.4.7. Problems with access to care.** Several responses were coded in this subtheme. One respondent identified that “health care too far away...” (DA #135) another suggested to “...defer mandated transitions in health care for this population until brain development has stabilized in the late 20 s” (SCBO #167).

**3.2.4.8. Problems with DD service system.** A number of respondents identified service problems that included, “...Regional Centers need more staff who proactive with staff” (DA #273), “Regional center service coordinators have huge caseloads and are not equipped to supervise complex medical conditions...” (SCBO #167).

**3.2.4.9. Need for improved mental health system.** Several respondents offered recommendations to improve the provision of mental health services. These suggestions included, “Early screening of mental health conditions” (SCBO #63) and “...user friendly mental health system for easy access” (P #66).

**3.2.4.10. Financial.** One respondent suggested that financial incentives to providers may be an option for service improvement. The idea was presented that, “A program offering incentives to MH providers that receive on-going education and training on how to best serve the IDD/MH population” (SCBO #113) might be helpful.

**3.2.4.11. Housing.** A number of participants identified the needs that young people have for housing, yet the needs were unmet. As one participant stated, “Also we need housing that is akin to Regional Center housing but that is age appropriate – currently Regional Center housing sees young adults placed not with peers but with mature adults” (DA #13).

**3.2.4.12. Need for employment resources, training.** Respondents identified long-term planning needs for job training and employment for this population of young people with IDD and co-occurring mental health conditions. A respondent noted that “appropriate job training” (DA #163) was needed.

**3.2.4.13. Community-based resources and supports.** A respondent noted that the need for supports extended to the community and home with this comment, “Availability of quality community and home-based supports” (DA #17).

## 4. Discussion

As these findings indicate, health care transition needs were reported in four of the five SEM domains-Individual, Family, Provider, and



Systems Level. The responses were most frequently categorized in the following Domains in following descending order: Individual, Provider, Systems and Family. Responses categorized in the Individual Level Theme, reflected the comprehensive suggestions for transition support that extend beyond the transfer of care from pediatric to adult-focused providers and other health-related needs as is typically reported in the literature<sup>43,48,49</sup>. There were many suggestions offered for a circle of support besides family support that included peers and non-family advocates. In the IDD community, efforts have been undertaken to bolster support needs beyond family support with peer support and advocates to foster more inclusion, participation and involvement in daily life and community living people<sup>50-53</sup>.

As well stakeholders, identified a range of accommodations that would be needed during this period of transition. These recommendations included legal assistance and guardianship for those with an intellectual disability, self-advocacy and empowerment training/support and assistive devices such as augmentative and alternative communication (AAC). Other input by respondents focused on future planning pertaining to benchmarks associated with adulthood such as independent living and employment. Long-term residential options, such as supportive housing, home-based supports were offered as young people with IDD and with co-occurring mental health conditions can have more limited options for living independently compared to the typical population. The needs for job training and placement and referrals to Department of Rehabilitation to foster employment opportunities were offered, again reflecting the acknowledgement that many of these young people will need additional employment supports and services compared to the typical population<sup>54-59</sup>. Needs for individualized training focused on rights, accommodations and community living skills needed using a variety of educational tools to facilitate learning have been identified in other studies as well<sup>58,60</sup>.

Interestingly, respondents focused on broad approach to transition. Several of the hallmarks associated with health care transition were not identified such as self-management of chronic condition needs; adult-focused specialty care needs, access to health insurance and sexuality and reproductive health education.

Health was more broadly conceptualized by stakeholders when generating suggestions for health care transition planning.

Relatively fewer suggestions were offered in the Family Level Theme and its subtheme. The suggestions offered for families aligned closely with the HCT literature on family needs; however, legal services needed such as conservatorship, reflected identification of needs specific to the IDD community<sup>59</sup>.

The Provider Level Theme and subthemes were similar to the issues that have been raised in HCT literature, namely the needs for adult-focused provider training to address the health care needs of young people with IDD and co-occurring mental health conditions<sup>60</sup>. Other health-related recommendations include the provision of service coordination and dedicated service coordinator, and warm handoff. A pervasive need reported by stakeholders was the need for more adult-focused medical and mental health providers and provider-focused training in IDD, which has been reported extensively in the literature<sup>14,24,25,60,61</sup>. Uniquely identified in this study was the need for bilingual, culturally proficient providers, which is reflected of the region wherein this survey was conducted.

The System Level Theme was composed of several subthemes that were focused on service needs such as staffing shortages associated with adult-focused

providers with IDD and MH expertise. These issues have been raised in other studies as well<sup>24-32</sup>. Unlike other states, California's IDD service system is an entitlement program for those who meet eligibility criteria that is different and less inclusive than the federal guidelines<sup>62</sup>. Despite the establishment of a long-standing entitlement program for the IDD population, access to mental health services was identified as a prominent need. As has been recommended in the HCT literature, service coordination was identified as service necessity to foster the transition to

adult- focused mental health professionals<sup>11,29,63-66</sup>.

Of note, in a prior publication<sup>35</sup> generated from this survey, we focused on barriers to transition to mental health care for young people with IDD and co-occurring MH conditions (as opposed to physical health care, which was the focus of the current manuscript). In the prior analysis, we identified an additional level, the Societal Level, in which we placed statements about discrimination such as "*(the DD service system) has a bias and propensity to deny cases using the excuse of primary diagnosis being mental health related vs. autism or IDD.*"<sup>32</sup>. We did not encounter similar statements pertaining to discrimination or refusal of care in the current analysis focused on health care (not mental health care). While we included questions about individuals with IDD and co-occurring MH conditions, responses tended to overlap greatly between those two groups. However, responses differed more significantly when discussing transition to the MH system versus the health care system in terms of physical health. This suggests different needs for intervention in each of these systems to better support young people with IDD with or without co-occurring MH conditions as they transition to adult MH care, health care, and adult serving systems. Of note, in this current analysis we found many more statements about need for case management and navigation support, while our prior analysis contained more statements about discrimination in the systems and individuals being bounced back and forth between the DD and MH systems. It could be that the frustration with major systems issues related to the MH system overshadowed some of the more practical suggestions about need for more case management and navigation in terms of MH care transition, that were instead highlighted in questions pertaining to health care transition.

These findings provide a robust description of service needs and recommendations for young adults with IDD and co-occurring mental health conditions. The service recommendations identified have application for development of HCT service models for this population. The recommendations offered by respondents provide a template for policy-related guidance for development and testing of evidence- based service models and informed best-practices training (Table 3).

## 5. Limitations

There are several limitations to acknowledge with this survey study. The findings were generated from a community of stakeholders in California, thus limited the generalizability of findings to other settings. The sample age of advocates was limited to those 18 years and older as an extended retrospective perspective of the HCT experience was desired. Furthermore, obtaining input from youth younger than 18 years would have required parent consent and youth assent, which would have been difficult to obtain. The self-advocacy stakeholders were not differentiated into subgroups of self-advocates, professional advocates and family members, which is a limiting factor in terms of fully understanding possible differences between subgroups. Not all survey respondents completed this item and it may have been due to completion fatigue as the survey contained many items.

## 6. Conclusion

There are a range of health care transition service needs for young adults with IDD and co-occurring mental health conditions. The qualitative analysis of these findings align with the elements of the Social-Ecological Model associated with Individual, Family, Provider and System Levels. A multi-level approach is needed to address the range of service needs for young adults with IDD and co-occurring mental health conditions. A broad array of service recommendations were offered that have been previously reported in the transition literature for young adults with IDD and co-occurring mental health conditions and provide direction for service development and implementation.

**Table 3**  
Practice and policy implications based on SEM.

Level	Sample Concerns	Potential Practice and Policy Implications
<b>Individual Level</b>	Need for more individualized support, including peer support; need for advocacy and mentorship, need for resources around supportive decision making	More opportunities for peer navigation
<b>Family Level</b>	Need for training and education about services, advocacy, financial needs, medical services, legal services, decision making, training for parents on how to assist their children into adulthood such as conservatorship and adult living	More opportunities for family training, starting early, as well as family navigation
<b>Provider Level</b>	Need for case management and navigation Need for professional training on how to better support individuals with IDD	As above, peer and family navigation and case management opportunities should be expanded. Health care professional training should include a focus on IDD at all levels (from pre-service training to continuing education)
<b>Systems Level</b>	Need for coordination between agencies and systems Need for crisis intervention training Need for expanded availability of health care and MH care services for individuals with IDD	Systems reform for better communication and seamless referrals Experts in IDD can partner with law enforcement for training Systems reform, including penalties for refusing care based on diagnosis, and/or incentives for providing quality care for individuals with IDD with our without co-occurring MH conditions

### ORCID authorship contribution statement

**Cecily L. Betz:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Conceptualization. **Sharon M. Hudson:** Writing – review & editing, Methodology, Conceptualization. **Alexis Deavenport-Saman:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Christine B. Mirzaian:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

### Ethics in publishing. The authors declare:

- The work described has not been published previously
- The article is not under consideration for publication elsewhere.
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- If accepted, the article will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder.

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Cecily Betz, the senior author of this article, is the editor in chief of Health Care Transitions. In keeping with ethical standards, she did not participate in the review or final decision of this paper, which were handled by another editor.

### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

### Data availability

The authors do not have permission to share data.

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