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Faith Duensing

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**Health Care Transition Experiences of Youth with Intellectual Disabilities in a  
Post-Secondary Inclusive Program**

Faith Duensing

College of Education and Health Professions

University of Arkansas

December, 2022

## **Introduction**

Between the ages of 18-21 years old, youth and young adults make the transition from pediatric to adult health care. While it may be an easy and seamless transition for some, that is not always the case, especially for youth and young adults with disabilities.

The American Academy of Pediatrics highlights the steps of transition starting at age 12 and continuing through the age of 18+ years old. These steps include discussing office transitions policy with the youth and parents, initiating a jointly developed transition plan with the youth and parents, reviewing and updating the plan over the years, preparing for adult care, and then finally implementing the adult model of care (Cooley & Sagerman, 2011). These steps are a helpful start in the planning process for health care transitions (HCT) which may need modifications and considerations for individuals with disabilities.

Individuals with disabilities experience several distinct health disparities compared to their peers without disabilities. They have “less access to health care, have more depression and anxiety, engage more often in risky health behaviors such as smoking, and are less physically active,” (CDC, 2019). These health disparities leave youth and young adults with disabilities at a disadvantage even before beginning the HCT. Additionally, low-income and racial minority youth on the autism spectrum were found to be less likely to receive health care transition services than their higher income, White peers (Eilenberg et al., 2019). According to data collected by the CDC during the COVID-19 pandemic, it was found that individuals with disabilities were more likely to report difficulty getting vaccinated, (CDC, n.d.) faced a greater risk of poor health outcomes, reduced access to routine services and care, experienced adverse social outcomes, and individuals with intellectual and developmental disabilities were six times more likely to die from COVID (NIHCM, 2021).

A big gap we came across when looking into the current literature on the HCT of young adults with disabilities is the lack of perspective from the young adults themselves. As said by Kaehne in a systematic review on HCT research, “the absence of young people in the study design and implementation process but also the widespread absence of their voices in the studies themselves as participants is disappointing” (Kaehne et al., 2019, p.1). There have been several studies conducted that investigate the perspective of parents, doctors, and other health care/educational professionals and stakeholders (Franklin et al., 2019; Kaehne et al., 2019; Malapela et al., 2020) but few have interviewed or investigated the perspective of the young adults going through the transition.

### **Specific Aims of the Project**

In young adults ages 18-21 who are making the HCT from pediatric to adult care, what have their experiences been, what types of facilitating resources have been available to them, and what barriers and information gaps did they experience during their transition? The goal of this project was to learn more about the HCT experiences of young adults with disabilities and their families to learn and develop ways that health care providers, post-secondary programs, Universities, and parents can help better prepare young adults for this transition in the future.

### **Literature Review**

The databases of CINAHL Complete, Academic Search Complete, Health Source: Nursing/Academic Edition, MEDLINE, MEDLINE Complete, Social Work Abstracts, and Teacher Reference Center were searched using EBSCOhost to find articles that were relevant to our PICOT question and research. The databases were searched together using the search terms “health care transition” AND “cognitive disability or cognitive impairment or disability or disabilities or disabled or impairment or impaired or intellectual disability.” The search returned

349 results. 205 articles published before 2018 were excluded to only include recent articles published within the last 5 years. This left 144 articles which were then further narrowed down to only include those with the full text. The remaining 20 articles were sorted through for relevancy. There were limited articles that focused solely on individuals with intellectual and developmental disabilities. The majority of the HCT literature focused on individuals with chronic health needs or physical medical conditions like cystic fibrosis or spina bifida

While youth are turning 18 and beginning to go through their HCT, they are also transitioning from secondary education into post-secondary programs, the work force, social and community programs, and/or independent living. Each of these transitions has its own implications and factors necessary for success. For our research, we focused on the health care transition specifically. The goal of a successful HCT process “includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood,” (Cooley & Sagerman, 2011, p.1).

To investigate the perceived role of nurses in the HCT, Malapela et al. (2020), interviewed 18 nurses and three main themes emerged: to be a support system, to be an advocate, and health promotion. They found that “Nurses in the study highlighted the lack of awareness about the transition process as a barrier to proper transition” and they expressed a need for promoting HCT resources and community support services for youth and families (p.3).

Franklin et al. (2019), conducted interviews with parents of the youth and young adults with disabilities and discovered three major themes. The first was “inefficient and siloed systems” (p.3). Parents expressed a lack of support in the HCT, reported that they didn’t receive referrals to adult primary care providers (PCPs), and felt that they were left to search for care on their own. Some even reported that the lack of a provider during the transition period kept their

child from being able to participate in activities since there was no way to get a physical form completed and signed. The next major theme was “left out here floundering in adulthood” (p.5). This theme surfaced from the repeated experience of having to wait (Medicare waiting lists, support groups waiting lists, accessibility waiver waitlists) and the social isolation that it caused. One parent reported “The waiting list [for the I/DD waiver] now is expected, projected to be about a 10-year-wait (M, #2, 26 yo)” (Franklin et al., 2019, p.5). The last common theme to come out of this research was “hope despite uncertainty” (p.5). Parents displayed feelings of relief and reported feeling reassurance that even though their situations were new, difficult, and uncertain, that having parent peer support was beneficial (Franklin et al., 2019).

## **Methodology**

### **Participants**

Participants for this study were recruited by reaching out to the director of a post-secondary inclusive program at a University. The specific program is designed for “individuals age 18-24 with mild cognitive disabilities who do not demonstrate significant behavioral or emotional problems...(the program’s) students must have been served in special education in public schools and have an IEP (Individualized Educational Program) or have had similar programming in alternative settings. Students should display functional literacy and math skills as well as demonstrate satisfactory academic progress within their modified course work.” The director forwarded our email to students and mentors in the program and interviews were scheduled with interested participants. My honor’s advisor and I met with the group of students and mentors to tell them about the study and answer their questions. Consent forms were passed out at this point. Requirements for the student participants: to be a college aged student with disabilities in a post-secondary program or a college-aged peer mentor chosen by the post-

secondary inclusive program to support college aged students with disabilities. We also reached out to the parents of the participants with disabilities by email to invite them to participate. We conducted our research with 11 college aged students with disabilities, 6 of their parents, and 6 of their peer mentors. We applied for and received IRB approval to protect the rights and welfare of our participants. Subjects were kept anonymous by the use of code names in our research.

	University Youth with Disabilities	Family Members	Peer Coaches
<b>Gender</b>			
Female	5 (45.5%)	6 (100%)	6 (100%)
Male	6 (54.5%)	0	0
Other	0	0	0
<b>Race</b>			
White	10 (90.9%)	6 (100%)	5 (83.3%)
Black/African American	1 (9.1%)	0	0
Asian	0	0	1 (16.7%)
<b>Age</b>			
18-21	7 (63.6%)	0	4 (66.7%)
22-25	4 (36.4%)	0	2 (33.3%)
26-35	0	0	0
36-45	0	1 (16.7%)	0
46-55	0	3 (50%)	0
56-65	0	2 (33.3%)	0

Table 1. Participant Demographic Data

## Materials

The only physical materials we used were \$20 Walmart gift cards to thank participants for their time, a demographic survey done on Google Forms, and *Got Transition* surveys. We got permission from *Got Transition* via email to use their surveys in our research.

We conducted and recorded the qualitative, semi structured interviews, some over zoom and some in person, and had them transcribed to text to be analyzed using NVIVO software. I conducted the interviews with the peer mentors and parents and my honor's advisor conducted the participant interviews for the students with disabilities.

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

## Self-Care Skills Assessment for Young Adults

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name	Legal name	Date of birth	Today's date
----------------	------------	---------------	--------------

**SELF-CARE IMPORTANCE & CONFIDENCE**
Please circle the number that *best* describes how you feel now.

How important is it to you to manage your own health care?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10  
not | very

How confident do you feel about your ability to move to manage your health care?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10  
not | very

MY HEALTH & HEALTH CARE	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to ask questions when I do not understand what my doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I have full privacy in my health care at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I have to sign a form if I want others at my visit and to allow them to see my medical records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know at least one other person who will support me with my health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to make and cancel my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a summary of my medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get a referral if I need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I need to do to keep my health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**MY MEDICINES**
If you do not take any medicines, please skip this section.

I know my own medicines.

I know when I need to take my medicines without someone telling me.

I know how to refill my medicines if and when I need to.

**WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?**

1
Transitioning to an Adult Approach to Health Care Without Changing Clinicians
Six Core Elements of Health Care Transition™ 3.0

The Six Core Elements of Health Care Transition® are the copyright of Got Transition®. This version of the Six Core Elements has been modified and is used with permission.

got transition.

Figure 1. Image of Got Transition Survey



## **Procedure/Data Collection**

Before beginning the interview, all participants were given a summary of the research, told that their participation in the study was completely voluntary and that their identity would be kept anonymous throughout our research, and they were asked for permission to record the interview for future analysis. Student participants with disabilities completed their interviews in person. Additionally, they completed their demographic survey and *Got Transition* survey on paper while the questions were read out loud to them. Parent and Peer Mentor participants were emailed the *Got Transition* survey as a clickable document and the demographic survey as a Google Form to complete and send back. Once the two surveys were completed, a zoom meeting was scheduled to conduct their interview. During the student interviews, they were asked questions about their University experience, their general transition to the University, their general HCT, their understanding of the HCT, their personal experience of their HCT, their healthcare needs, their personal responsibility for healthcare, their self-determination of their healthcare, and their future goals and needs. Parent participants were all asked questions that inquired about the same topics in regard to their child's health and transition experience from their point of view. In addition to these questions assessing the participants experiences going through the HCT, we also had a unique opportunity to inquire about our participant's experiences through the COVID-19 pandemic since our research was designed pre-COVID and data was collected after University courses returned to campus.

## **Data Analysis**

A team of two researchers, my honor's advisor and a doctoral student, completed the analysis of transcribed interview data while I analyzed the survey and demographic data.

For the interview data the two researchers first read two transcripts together to identify codes that were identified in the data (e.g., “leaving mom”), as well as codes that were sought specifically from the data (e.g., “barriers to health care”, “decision making”). An initial code book of codes and definitions were developed. Researchers then individually coded the transcripts of interviews with college students with disabilities and discussed additional codes added. Consensus discussions led to clearer definitions, merging and elimination of codes. Transcripts were recoded with the revised codebook. The same process was conducted with mentor and parent interviews. After the third round of consensus discussions, researchers began the process of identifying patterns across the data and exploring themes. Multiple themes were determined: students with disabilities and mentors had common experiences related to HCT, convenience was an important component in health experiences, and families and students had varied approaches to decision making and self-determination in those decisions based on specific health needs, family dynamics, and expectations for ability to make decisions.

For the demographic and survey data, the results were tallied, and percentages were calculated and added to a table by category.

## **Results**

After analyzing the data collected from our participant interviews, we discovered several recurring themes. First, was that all University students had complicated experiences transitioning into adult health care. The timeline and process of transition was not clear, and several students reported ending up transitioning to the same adult PCP as their parents or siblings due to convenience or familiarity.

“I got a new doc. I just got a new doctor. And my mom’s doctor is actually my... my doctor”

-Student.

The next theme was that there was very little noted support in and before high school for adult engagement in health care. When asked how their high schools, families, and Universities helped prepare them to live a healthy life, most talked about learning to eat healthy or the benefits of getting their steps in.

“They taught us about not eating Chick-fil-A every day.” -Student

A theme common to all University students was a gap in the knowledge necessary to be full consumers of health care systems. This was shown through a reported lack of use of the available University health services and the results of the *Got Transition* survey. Most notably, post-secondary inclusive students were unsure and wanted to learn how to get a summary of their medical information, where to seek care when their doctor’s office is closed, and how to get a referral. Lastly, we heard about how COVID-19 related anxieties were felt by all participants in both a health and general context. Our participant interviews were conducted in the fall of 2021, so we were able to hear about the lasting effects and impressions that the pandemic had on individuals.

“At first, it was really hard. I had to go on antidepressants because my whole world had changed.” - Mentor

“We were going to do Special Olympics track and field. I was like weeks away from claiming, like winning some more medals, but COVID just cheated me out of it.” - Student

	Post Secondary Inclusive Students (%)			Peer (%)		
	No	I want to learn	Yes	No	I want to learn	Yes
I know how to get a summary of my medical information.	18.2	54.5	27.3	0	0	100
I know how to get a referral	36.4	36.4	27.3	16.7	0	83.3
I know where to get care when my doctor's office is closed	0	54.5	45.5	0	0	100
I know how to ask questions when I don't understand	18.2	27.3	54.5	0	0	100
I know my family medical history	36.4	27.3	36.4	0	16.7	83.3
I know when to take my medicine without someone reminding me	9.1	27.3	63.4	0	0	100

Table 2. *Got Transition* survey data

## Conclusion

Overall, our research highlighted the need for additional resources and improved multi-disciplinary cooperation in order to facilitate a more seamless health care transition for young adults with disabilities.

Specific implications for health care providers that were discovered during our research include the need for a more explicit discussion on the specific role of Pediatric and Adult PCPs. During our interviews, students had difficulty explaining the differences in providers beyond the age ranges of patients that they treat. A clear discussion with the Pediatrician about their model of care and the way it shifts as they transition into adulthood could help explain to young adults why the HCT happens when it does and what the goals of transition are. Students also expressed that they had little to no warning of when the HCT was to occur so clearer communication between providers and families during this time would help young adults and their parents prepare for this transition better both emotionally and logistically. Lastly, students discussed a lack of direction for where to secure health care after leaving their pediatric PCP. In addition to a referral to an adult PCP in their hometown, it would be helpful for students attending post-

secondary programs or Universities away from home to have a discussion about where to seek care while they're away. Students reported mostly waiting to schedule routine care visits with their providers from home and going to urgent cares and clinics around town for needs that arouse while at school. It could be helpful to have a referral from their home-based provider for where to seek care for their specific health needs in case something would come up.

### **Limitations to our Research**

While our conclusions are valuable insight into the transition experiences of students at one University, future research can be built off our study to explore the influence that geographic location and community has on the HCT experience.

Due to our interviews being conducting in the midst of the pandemic, a noted limitation to our research is that the reported experiences and use of University resources may be specific to that time. They may not be reflective of the way students generally seek health care during typical times.

### **Implications for further research**

While conducting this study we came across more topics that need to be further explored in order to get the full picture of HCT experiences of youth and young adults with disabilities. The first major question is how to initiate better communication between pediatric and adult PCPs. We've seen again and again that this gap in communication has a negative impact on HCT experiences so it's important to explore ways to bridge this gap and study the impact it has for families. The next avenue for future research involves exploring the results of implementation of transition programs and resources like *Got Transition* in the high school, University, and post-secondary inclusive program context. The *Got Transition* survey and other similar resources can help families get a baseline of what skills they needed to work on and where their health

knowledge gaps are so that they can ask more direct questions when talking to their providers and advocate for themselves where possible. In addition to supplemental resources, it is important to explore the impact that more comprehensive education and preparation for the HCT from the Pediatrician would have on youth and parent experiences. The last main area of future research we identified was a need for more in-depth comparison of the HCT experiences of parents and their youth adults. A lot could be learned from the insight into their differences in understanding of health and the HCT. It would be valuable to see where their health understanding aligns so that parents and providers would know where their young adult's strengths lie and be able to and promote their independence, personal responsibility, and self-determination.

In conclusion, health care transitions are a complex process, and everyone deserves to have adequate assistance and resources to make that transition seamless. It is important to continue investigating the perspectives of young adults with disabilities so health care providers, parents, teachers, and other disciplines can support them in the best way.

## Resources

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