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Health Care Transition for Adolescent and Young Adults with Intellectual Disability: Views from the Parents☆

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ABSTRACT

Purpose: This study explored the health care transition (HCT) experiences of parents of adolescents and young adults (AYAs) with intellectual disability (ID), 18–33 years of age, including barriers and facilitators to the AYA's transition to adulthood within and between the medical, educational, community, and vocational systems.
Design and methods: A qualitative descriptive design with semi-structured individual interviews with 16 parent participants was used. Purposive sampling of parents was utilized with variation on race/ethnicity and AYA age, stage in transition, and condition. This study was conducted through a major medical center in the southeast United States. Content analysis was utilized.
Results: Three overarching themes represented the factors and essence of supporting AYAs with ID transition to adulthood. Inefficient and siloed systems illuminated barriers families are commonly experiencing within and between the medical, educational, community, and vocational systems. 'Left out here floundering' in adulthood, described the continued inadequacy of resources within each of these systems and parent's having to find available resources themselves. Hope despite uncertainty, included the perceived costs and benefits of their AYA's disability and the value of parent peer support in providing key knowledge of resources, strategies, and perspectives.
Conclusions: Our findings illuminate the need for improved infrastructure to provide effective HCT and partnerships to help integrate HCT support within other life course systems. Results support the rationale for non-categorical HCT-focused approach.
Practice implications: A parent peer coach-facilitated intervention offers promise for bridging the gap between systems and meeting family needs.

Despite increasing recognition of the critical nature of health care transition processes for youth with special health care needs (White et al., 2018), adolescents and young adults (AYAs) with intellectual disability (ID) remain among the least likely to receive transition services (Acharya, Meza, & Msall, 2017; Blomquist, 2007; Newman et al., 2011; Woodward, Swigonski, & Ciccarelli, 2012; Young-Southward, Philo, & Cooper, 2017). The overarching goals of health care transition (HCT) are to support AYAs in reaching their optimal level of health and achieving their fullest potential (Got Transition, n.d.; Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Progress has been made in HCT services (American Academy of Pediatrics, 2002; Betz, 2017; Blum et al., 1993; Brown et al., 2016; Cooley et al., 2011; White et al., 2018; Federal Partners in Transition Workgroup, 2015), but there has been little improvement for AYAs with ID (Bindels-de Heus, van Staa, van Vliet, Ewals, & Hilberink, 2013; Cooley et al., 2011; Federal Partners in Transition Workgroup, 2015; Woodward et al., 2012). This is particularly concerning given that AYAs with ID, often with co-occurring medical and psychiatric conditions, experience health disparities and inequities (Krahn & Fox, 2014) and face life-long challenges with learning, decision-making, language, mobility, self-care, and independent living (Boyle et al., 2011).

Parents are key partners throughout the HCT trajectory as they work to achieve and maintain health, safety, and well-being for their AYA with ID, and commonly face long-term caregiving responsibilities (Steinway, Gable, Jan, & MINT, 2017). Parent caregivers experience less support as their child exits high school and pediatric-based supports, and enters adult-based community and medical services (McKenzie, Ouellette-Kuntz, Blinkhorn, & Demore, 2017; Patton, Ware, McPherson, Emerson, & Lennox, 2018). Parents report feelings

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of loss, abandonment (Davies, Rennick, & Majnemer, 2011), uncertainty, and lack of necessary preparation by pediatric health care providers during this transitional period (Davies et al., 2011; Schultz, 2013; Young et al., 2009). Parent caregivers of AYAs with ID experience significant caregiver burden, emotional demands (Blacher, Kraemer, & Howell, 2010; Cadman et al., 2012; Cheak-Zamora, Teti, & First, 2015; Gerhardt & Lainer, 2011; McKenzie et al., 2017; Spiers, 2015), and stress (McKenzie et al., 2017; Patton et al., 2018) during this transition. Parents of AYAs with ID have important expertise in recognizing their child's needs, knowing their child's baseline functioning, and recognizing their potential; therefore, they are instrumental partners in care (Davies et al., 2011; Kingsnorth, Gall, Beayni, & Rigby, 2011; Pickler, Kellar-Guenther, & Goldson, 2012). To improve HCT support for AYAs with ID and their parents across the transition to adulthood, a deeper contextual understanding of the barriers and facilitators among medical, educational, community, and vocational systems is needed.

Background and significance

The global prevalence of ID is 1% (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Within the United States (US), an estimated 6.5 million individuals have ID, making it the most common type of developmental disability (American Academy of Pediatrics, 2015). Many individuals with ID in the US who would have previously died during childhood, are now living into adulthood primarily due to advances in healthcare, medicine and nutrition (Coppus, 2013). According to the U. S. Census Bureau, in 2010 approximately 1.2 million non-institutionalized adults had ID (Brault, 2012). The extended life expectancy of the pediatric ID population and the shift in focus to community-based services makes understanding the HCT and other transition related experiences of AYAs with ID and their parents critical. This is necessary for improving partnerships with parents and identifying strategies to improve this HCT process for the ID population.

Inconsistent differences between mothers and fathers of children with developmental disabilities have been identified in relation to their health (Davis & Carter, 2008; Marquis, Hayes, & McGrail, 2019), parental roles (Glidden & Natcher, 2009; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011), perceptions and attitudes (Simmerman, Blacher, & Baker, 2001), and markers of chronic stress (Foody, James, & Leader, 2015). Mothers have been shown to have poorer mental health (Davis & Carter, 2008; Emerson & Llewellyn, 2008; Foody et al., 2015) and lower levels of well-being (Olsson & Hwang, 2008) than fathers. Fathers were also found to have higher stress (Rivard, Terroux, Parent-Boursier, & Mercier, 2014) and more negative indicators of physiological health (increased heart rate variability and higher blood pressure) than mothers (Foody et al., 2015). Few studies have compared health, stress, or parenting among fathers and mothers of children with ID within the AYA developmental period (Marquis et al., 2019; Patton et al., 2018).

There remains a paucity of literature examining key transitions for AYAs with ID, and most studies focus on one type of developmental disability (e.g. ASD (Cheak-Zamora, Teti, Maurer-Batjer, & Koegler, 2017)) or a severity of ID (e.g. profound ID (Gauthier-Boudreault, Gallagher, & Couture, 2017)) rather than including families with diverse levels of ID and identifying commonalities. The purpose of this study was to explore the HCT experiences of parents of AYAs, 18–33 years of age residing in the community. We were particularly interested in the barriers and facilitators to the AYA's transition to adulthood within and between the medical, educational, community, and vocational systems. The research questions guiding this study were 1) What are the HCT experiences of AYAs with ID from the perspective of the parents? 2) How did their health care providers assist them in preparing for and navigating transitions outside of the medical system? and 3) What barriers and facilitators to support the transition of their AYA were present within and between the medical, educational, community, and vocational systems?

Design and methods

Study design

A qualitative descriptive (Sandelowski, 2000) design was utilized to explore parents' experiences with an AYA who had transitioned into adulthood. This naturalistic design, which is less interpretative than other qualitative approaches such as phenomenology or grounded theory, is appropriate for research on describing the who, what, and where of experiences and gaining insights on a poorly understood phenomenon (Kim, Sefcik, & Bradway, 2017; Sandelowski, 2000). This design allowed us to produce an in-depth description of parents' experiences with AYA transition, and a comprehensive list of barriers and facilitators to transition (Sandelowski, 2000). We studied a purposive sample of 16 parents who varied on race/ethnicity and AYA age, stage in transition, and condition. This sample size allowed us to meet informational redundancy (Sandelowski, 2008). We approached 22 parents for this study and 16 participated (72%).

Participants

The study was conducted at a major southeastern US medical center. Participants were recruited through (a) referral from their health care provider or (b) self-referral based upon flyers posted in the community (e.g. city recreational areas) or shared through email listservs of community organizations (e.g. city recreational, Autism Society, Special Olympics). Parent inclusion criteria were a) parent and/or legal guardian of AYA, between 18 and 33 years of age with diagnosis of ID; b) ability to read, speak, and understand English; and c) ability to provide consent. We studied parents of AYAs from the age range of 18 to 33 years to more closely match contemporary definitions of this developmental period (Aubin et al., 2011; Lang, David, & Giese-Davis, 2015), but more importantly because we were interested in studying parents' experiences with barriers and facilitators to HCT. Parental perspectives may be influenced by the distance in time from the actual transition, or by the length of time an AYA needed to transition. Additionally, due to the frequent mismatch between chronological age and developmental age in AYAs with ID, who may remain in high school until their 22nd birthday, this larger age range is particularly important.

AYA and parent characteristics are summarized in Tables 1 and 2. The parent sample ($N = 16$) included 12 mothers (one adoptive) and four fathers. One parent for each AYA was interviewed except for two AYAs for whom interviews with both a mother and father were conducted at the parents' request. Of the 14 AYAs represented in this study, seven were between 18 and 25 years of age and seven were from 26 to 33 years.

Table 1
Characteristics of parents participating in interviews ($N = 16$).

	n	%
Sex		
Female	12	75
Male	4	25
Race		
Non-Hispanic White	12	75
Non-Hispanic Black	4	25
Marital status[a]		
Single	2	13
Married	13	81
Highest education completed[b]		
High school	–	–
College	12	75
Employed		
No	8	50
Yes	8	50

[a] Missing data on one parent.
[b] Missing data on four parents.

Table 2
Characteristics of adolescent/young adult children ($N = 14$).

	n	%
Sex		
Female	6	43
Male	8	57
Race		
Non-Hispanic White	3	21
Non-Hispanic Black	10	71
Asian	1	7
Age		
18–25 years	7	50
26–33 years	7	50
Developmental disability[a]		
Intellectual disability	14	100
Moderate severity	3	21
Severity not reported	11	79
Autism	4	29
Down syndrome	3	21
Epilepsy	2	14
Cerebral palsy	3	21
Traumatic brain injury	1	7
Other genetic condition	1	7
Currently employed (part-time or more)		
18–25 years old	3	21
26–33 years old	2	14

[a] Developmental disability diagnoses were based on parental report.

Data collection instruments and procedures

A semi-structured interview guide prompted participants to describe their experiences in the following content areas—child's medical history and HCT experiences, self- and family- management practices, school experiences, community and social connections, vocational experiences, family support and adaptation, AYA's personality, and long-term planning. These questions were chosen to allow parents to tell the full story of their transition experience. See Appendix A. After obtaining institutional review board approval (Pro00074983), informed consent was obtained from each parent and assent was obtained from the AYA.

Individual interviews were conducted in a private office space within the medical center or via phone. The interviews were conducted between November 2016 and December 2017. All interviews were conducted by the first and second author, both of whom were trained in individual interviewing methodology. Interviews lasted an average of 1 h 27 min (range: 51–136 min). No compensation was provided to parents. A verbatim transcript of each interview was created, and accuracy was verified with the audio file.

Data analysis

Transcripts were analyzed utilizing a content analysis technique described by Sandelowski (2000). Informational redundancy (Sandelowski, 2008) was confirmed as no new themes were identified (Saunders et al., 2018). Digital transcripts were viewed and organized utilizing a text-based analysis software program (ATLAS.ti 8). All transcripts were read completely to immerse the coders in the story (Tesch, 1990). Next, transcripts were coded by the first author (MSF) using a combination of in vivo and open coding searching for content representative of key concepts (Hsieh & Shannon, 2005; Tesch, 1990). A codebook was developed and refined. A second coder (SLD) with substantial coding expertise reviewed 20% of coding to verify the coding and codebook. Categories for this study were derived inductively from the data and not from prior research or existing theoretical frameworks (Hsieh & Shannon, 2005). A definition was developed and exemplars were identified for each code, category, and subcategory (Hsieh & Shannon, 2005). This team constantly assessed and promoted trustworthiness and rigor through a systematic coding process, utilizing two coders, and developing and maintaining an audit trail of the coding and category decisions made throughout this analysis. See Fig. 1 for further details on this data analysis approach and an example illustrating this process.

Results

The findings of this study were organized into three overarching themes: *Inefficient and siloed systems*, '*Left out here floundering*' *in adulthood*, *and Hope despite uncertainty*. These themes capture how parents have experienced these systems function and interact as well as the associated barriers and facilitators they have experienced during their AYAs transition into adulthood. See Table 3 for additional details. Each quote is referenced with the parental role (M for mother, F for father), AYA's participant number, and AYA's age at time of interview in order to provide additional context (e.g. M, #1, 26 yo).

Inefficient and siloed systems

The parents described that the medical, education, and community systems functioned as separate silos with minimal, if any, cross-system collaboration. They provided examples of missed opportunities in which the AYA and the parents would have benefited from collaboration between the health care providers and educational systems. One mother shared,

> "I think, in sixth grade, that would have been helpful. Because they just didn't understand him. And they didn't believe us. So, if the doctor would have – if we would have engaged – and that was probably our fault maybe we should have pressed it? If we'd engaged the doctor with the school, maybe they [the school] would have believed what they [the doctor] were telling them."
>
> [(F, #4, 29 yo)]

Parents also highlighted the disconnect between the school and the community and noted collaboration would have helped significantly with transition to adulthood.

Parents described how the lack of supports and the challenges of siloed systems impacted the AYAs and their own health and well-being. For example, one mother described the impact of under-resourced and separate systems, all ending their support when the AYA enters adulthood; "he did their camps in the summer… but [at] twenty-one, it all ends. And same with the schools…and the pediatrician too. So, it's like they turn twenty-one and you're on your own (M, #11, 24 yo)."

Parents provided examples of effective medical, educational, community, and vocational supports their AYA had experienced. Parents also recounted frustrating experiences with these systems. Findings from each system are described below.

Health care transition and difficulty saying goodbye

Parents described positive medical experiences including trusting relationships with medical providers and improvements in their AYA's health and functioning due to therapies. Frustrating medical experiences included health care clinicians (e.g. health care providers (e.g. medical doctors (MDs), nurse practitioners (NPs), physician assistants (PAs)), nurses, therapists) not listening to their concerns, difficulty locating providers skilled to meet their AYA's needs, medical errors, vague or absent communication, difficulty obtaining needed services, and health care providers' lack of collaboration with school and community resources.

When asked about their AYA's medical transition from pediatric to adult-based care, parents commonly described frustration, uncertainty, and/or shock. There were four patterns to the medical transition of AYAs: (1) abrupt age-related transition ($n = 4$), (2) transfer of care to an adult health care provider because of retiring pediatrician ($n = 5$), (3) continued care by at least one pediatric health care provider after

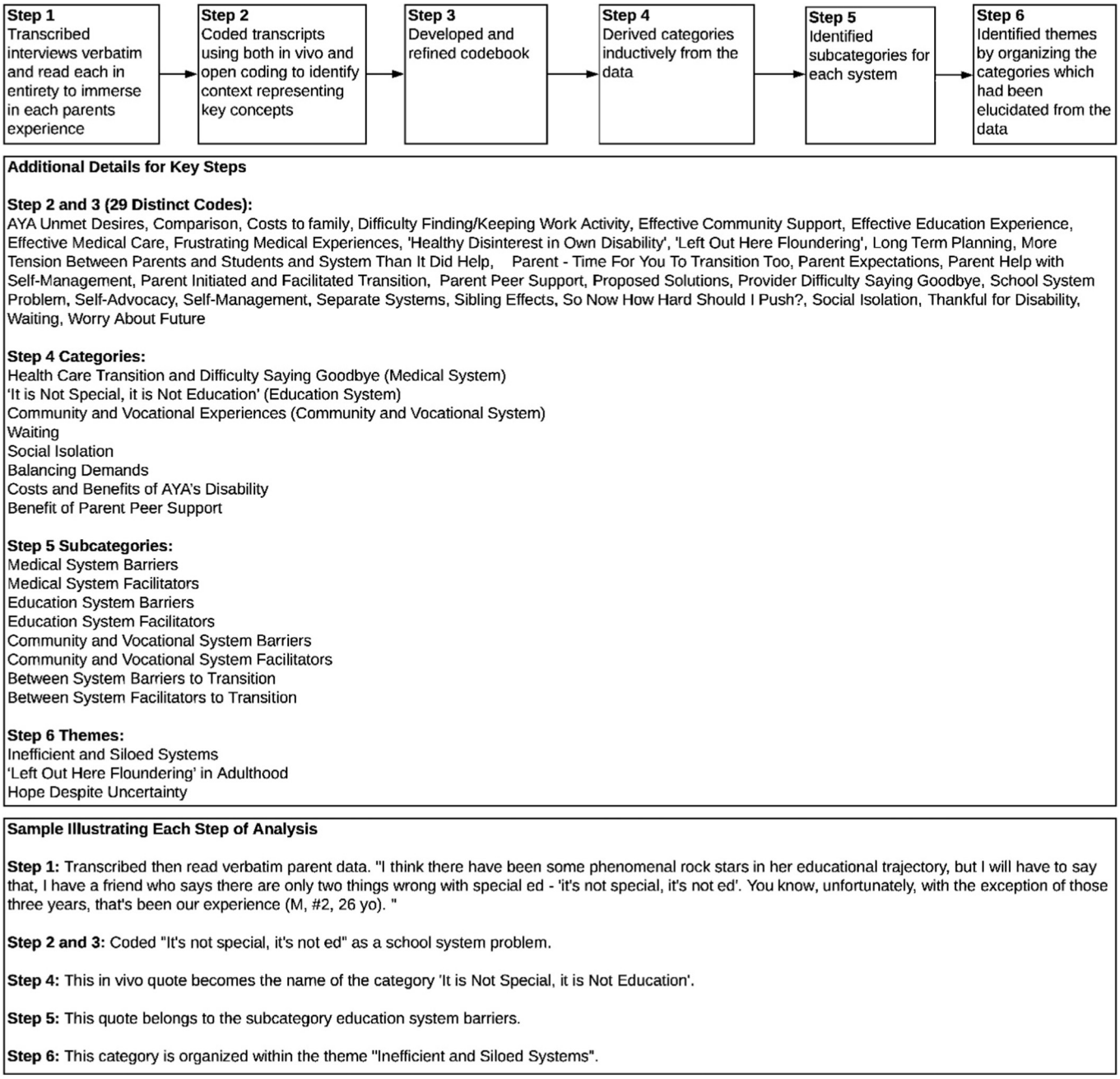

Fig. 1. Data analysis approach and sample.

AYA turning 21 years old (n = 5), and (4) smoother transition due to parent-initiated transition planning ($n = 7$).

One example of poor coordination with HCT, shared by most parents, was ineffective preparation and communication by pediatric health care providers regarding AYA's transfer to adult health care providers. Parents described how pediatric health care providers demonstrated difficulty saying goodbye. Parents who experienced abrupt age-related transition (18, 20, or 21 years of age) were informed without preparation or recommendation by the pediatric health care provider. One mom described "We went to see [the doctor] literally on her 18th birthday, and he said 'I can't see you anymore…. You will have to switch to adult (M, #7, 18 yo).'" She described it as "abrupt" and that she and her AYA were "blindsided". Another parent recalled the day she and her then-18-year-old AYA were told they could no longer be seen in the pediatric office: "they cut the ties, and it was traumatic… it was 18 and you're done (M, #4, 29 yo)". Five AYAs' transfers to adult health care providers were precipitated by their pediatrician retiring. Parents rarely described providers or practices engaging in HCT education activities, therefore the majority of these AYAs lacked the preparation for successful transition to adult-based care.

Parents attributed pediatric providers' reluctance to promote transition to an adult health care provider to a) inadequate system support, b) concern about adult providers' ability to provide the necessary care, and c) the pediatric-based providers' attachment to the individual AYA. As one mother explained,

> "her adult care needs take priority now… so I think that we will eventually get there, and – but I feel like, you know, it was slow. It was not always met with the kind of support that I'd hoped for. And some of that, again, is inadequate system support, but some of it also was an investment as an individual to this particular child."
> [(M, 2, # 26 yo)]

Table 3
Themes, categories, and supporting quotations for parental experiences helping their adolescent/young adult children with intellectual disabilities navigate into adulthood.

Theme	Categories	Supporting Quotes
Inefficient and siloed systems	Health care transition and difficulty saying goodbye	"He said, 'you know, I really don't keep children after they're eighteen' and I said that's fine, and he didn't refer me to anybody (M, #13, 24 yo)."
	'It is not special, it is not education'	"When it comes to education and the other part, no, he has been left behind (M, #10, 27 yo)."
	Community and vocational experiences	"The sad thing is because he wanted to do Special Olympics and we couldn't get his Special Olympics (physical) form signed because he didn't have anybody [health care provider] to do it (M, #11, 24 yo)."
'Left out here floundering' in adulthood	Waiting	"The waiting list [for the I/DD waiver] now is expected, projected to be about a 10-year-wait (M, #2, 26 yo)."
	Social isolation	"She so needs to have a group, you know? She really does. It's so important. It would make her feel so much better. She might be able to come off some of these medications for depression and stuff if she had a group, you know (M, #5, 26 yo)?"
	Balancing demands	"Even with all the best-laid plans, we are still in that place, going, we haven't made all those good transitions happen…it's just not a very robust support system (M, #2, 26 yo)."
Hope despite uncertainty	Costs and benefits of AYA's disability	"Having a family member like her alters all of our plans (M, #12, 19 yo)."
	Benefit of parent peer support	"I was constantly meeting with other families…I was a support to them, but it was also nice to have somebody who understood [me] to talk to (M, #13, 24 yo)."

This parent encouraged the pediatric specialist to allow them to transition to an adult-based care clinic, but the provider refused: "I kept going, 'we'll go to the other clinic!' And he was going, 'Nope, nope, nope. I want to see her here.' … [I] felt it was really important for her no longer to be seen as a pediatric patient (M, #2, 26 yo)." Parents explained how, after so many years with their pediatric health care provider, they and their child had become more like friends than patients. Parents described how they felt their pediatric team lacked trust that the adult health care providers would continue to provide person-centered care which contributed to their reluctance to recommend transition to an adult health care provider. Of the AYAs ≥21 years old at the time of interview ($n = 10$), five continued to receive care from a pediatric health care provider (primary or specialist) beyond their 21st birthday.

Seven AYAs experienced smoother transitions because of parent-initiated health care planning. Their parents described initiating HCT conversations with their AYA's pediatric health care provider ($n = 2$) or transferring their AYA during childhood or early adolescence to a family medicine or Med-Peds provider ($n = 5$). Parents expressed desire to know this provider is "always going to be in his life (F, #3, 19 yo)" and can provide care to the entire family. Additional facilitators commonly identified as supporting the transition of their AYA within the medical system included health care providers knowledgeable about the AYA's disability and having additional personal experience caring for others with a disability.

'It is not special, it is not education'

Parents used strong language to describe their predominantly negative experiences with the educational system. One mother began with "basically it sucked (M, #1, 26 yo)", another described it as "a nightmare (M, #2, 26 yo)". This mother later continued, "I think there have been some phenomenal rock stars in her educational trajectory, but I will have to say that, I have a friend who says there are only two things wrong with special ed – 'it's not special, it's not ed' (M, #2, 26 yo)". Parents expressed that they felt the special education focus in high school shifts to vocation losing important emphasis on academics. As one mother explained "in the 9th grade they stop academics (M, #8, 33)" and further explains.

> "I'm not an advocate for them just preparing them for a job once they get to the 9th grade…. Put them in a job in high school and have them start doing the job training. I had no problem with that. But don't stop the academics."
>
> [(M, #8, 33 yo)]

While most parents identified teachers and principals who had been champions for their child, parents also recounted negative experiences often, such as the school system not providing the help their AYA needed, lack of understanding about their AYA's needs, and frustration with the Individualized Education Plan (IEP) processes. One father explained "You know, they do the bare minimum, what is required by law, but there is nothing else. All these kids need more than bare minimum (F, #12, 19 yo)." Many parents emphasized the constraints educators face in the current system (e.g. time, limited financial resources, teacher to student ratio, class composition, etc.). Parents identified ways the IEP experience caused tension and trouble, and at times questioned its worth. When asked if she found the IEP useful, one parent responded

> "No. I mean, you go in and meet, and they say they're going to this and that and this and that. It sounds wonderful. But the reality is they really are just trying to get through the day. You know? I think IEPs probably cause more tension between parents and students and the system than it did help."
>
> [(M, #1, 26 yo)]

Another parent, noting the IEP's usefulness and its challenges, shared

> "I thought it was [helpful]! Because I knew how to use it. You know? For a lot of families, they come in and they get a piece of paper and they're asked to sign their name. A ten-minute IEP meeting, you know? And five IEP meetings in an afternoon. That's absurd. … I wasn't going to go away until I was satisfied."
>
> [(M, #2, 26 yo)]

Even parents with self-identified expertise (e.g. public-school teacher, administrator, developmental specialist, or professional disability advocate) described the educational system as difficult and frustrating to navigate despite their knowledge. One parent described their educational experience with their AYA as "hard. And you know, I am a teacher, and so I saw it from both sides, from the teacher aspect and from the parent aspect (M, #4, 29 yo)".

Because of their difficulty obtaining adequate support within the public education system, seven AYAs were removed from public education by their parents to receive their education through homeschooling, charter school, or private school. One father described placing his AYA in a different school system for high school due to a teacher not understanding his son's needs, explaining "we've now got him in a different school, different environment, different surrounding, and [he] is a total different child (F, #3, 19 yo)." Parents expressed concern about the higher teacher to student ratios in public schools and how a couple of students with significant symptoms distract teachers and staff from being able to focus on the educational needs of other students. Another parent who also removed her child from public school explained

> "you know, and quite frankly we're very lucky, because we were able to put her into a private school… the public school systems, they tried. I mean, but, it's just so easy, especially for someone like her, to fall through the cracks. Because she was very sweet, very quiet. You know, she never demanded any attention."
>
> [(M, #9, 29)]

Additional facilitators supporting the educational and transition experiences of their AYA included teachers with extensive special needs expertise that have worked with the AYA over time and IEP meetings advocacy support through disability rights organizations.

Community and vocational experiences

Parents described community opportunities (e.g. chorus, sports, camps) as helpful for their child's health and for their family's socialization. Some community groups were specific to youth with special needs, while others were non-specific. Parents highlighted the limited number of community opportunities and age restrictions that led to their AYA aging-out without similar activities to replace them. Additional facilitators commonly identified as supporting the transition of their AYA within the community and vocational systems, and across other systems, included knowledgeable case managers, community guides with community organizations (e.g. The Arc), and home- and community-based waiver services that provide the AYA with support to work on goals across settings. One parent explained the valuable information she received from her case manager; "she told us 'you gotta sign up for this, you gotta get on the waiting list so that'…she knew what programs to hook him up with and a lot of parents don't know anything" (M, #14, 24 yo).

Long waitlists for home- and community-based services were also commonly identified. Parents described waiting months for responses regarding potential vocational services and waiting years (e.g. 7, 10) to access waiver funding to cover important community-based rehabilitative support and care for their AYA. A mother explained

> "I hope at some point we'll get appropriate supports in place…. There really are not good supports to help people master job skills and stay invested and stay involved, unless you've got a waiver, or you've got other resources you can tap into."
>
> [(M, #2, 26 yo)]

Post-secondary education options were noted to be helpful for gaining vocational skills but expensive when not included in covered services. Each parent expressed desire for their AYA to have a job; however, the minority of AYAs ($n = 5$) were currently employed. One mom explained "if there is no resources in the community…then all the…plans in the world aren't going to help…a lot of these rural counties don't have anything (M, #13, 24 yo)."

'Left out here floundering' in adulthood

Parents described their AYA's change to an adult routine after high school as a letdown for their AYA and themselves. Parents identified ways they felt they and their AYA were floundering due to lack of supports and opportunities. Three categories of experiences were identified as contributing to this experience of 'floundering' in adulthood. These categories are "waiting", "social isolation" and "balancing demands". See Table 3 for additional details.

Waiting

While parents provided examples of waiting for services and supports for their AYA at earlier stages, this experience was more prominent once their AYA with ID had exited school. For example, waiting on insurance cards with a new adult health care provider's name to access medical services, or waiting for months for responses from professionals such as case coordinators. Parents described the importance of frequently following up to ensure progress was being made. Another mother explained that her AYA "is a high school graduate. She got a diploma, which was pretty cool… [she] is graduated to nowhere! So [she] hangs out at the house …. She's been on the waiting list for 8 years (M, #2, 26 yo)". This mom described the 10-year waitlist, initially projected as a 5-year waitlist, for the waiver to receive adult services. Another mother described how their AYA waited 9 years for a waiver. Another father described.

> "I don't think anybody was developing a plan for him for afterwards…I mean we searched – we had been searching since he got out of high school. And so, he's been out of high school for ten years, and we just found [community support] two years ago."
>
> [(M, #2, 26 yo)]

Due to lack of opportunities and waiting lists for those that are available, parents, part jokingly, but clearly frustrated, spoke of their young adult being on "sabbatical", "extended vacation", "in a gap year", or "retired".

Social isolation

Parents commonly described their AYA with ID as experiencing social isolation and identified three key contributors: reduced friend networks, limited community inclusion opportunities, and lack of jobs/daytime structure. Parents described problems that came from losing friends they had in school. All parents described the AYA's and their own desire for their AYA to have more friends. One father shared

> "as you and I typically developing people get older our world gets bigger, um, and for these people with developmental delays, as they get older, their world gets smaller… the rest of the world just kind of leaves them behind, because they can't keep pace with what we're doing…her friend circle has truly gotten smaller."
>
> [(F, #12, 19 yo)]

Most parents described a lack of community inclusion. One mother explained "there's nothing for her that is missing in her life other than a more open, accessible, receptive community". Her mother continued; "the gap is that we don't have a community that welcomes all of us (M, #2, 26 yo)."

The final, consistently identified contributor to social isolation was difficulty finding and keeping work. One mother stated, "we all are kind of left out here floundering (M, #1, 26 yo)" describing the lack of resources providing job skill support. Another parent described: "there was a huge void after high school (F, #4, 29 yo)."

Several barriers were noted to the AYA keeping jobs once employed. Parents described their child's need for additional understanding and support and their employers' understanding of this. One issue was that their AYAs' "normal" appearance can be a great thing but can also work against them. One family explained "many people, even in his job right now, I'm sure that they think he should be able to do more than what he does, because he looks and appears very normal (F, #4, 29 yo)." Parents noted that jobs in food service and retail, which are more commonly available, can be difficult to manage for an AYA with ID that has "temptations" with food or difficulty working with and understanding money. Of the currently employed AYAs, the parents' described their work as contributing to improved confidence, new skills, and improved social connection.

Balancing demands

Parents described uncertainty regarding how hard they should push to find work and community opportunities while balancing their own needs and those of the other parent and siblings. One mom explained,

> "I just wish there was more available for her…I question should I be more aggressive about looking for things and starting things and all. But then I also have a part of me that says, well I need to be happy, too… So, there's – it's a guilt."
>
> [(M, #1, 26 yo)]

Parents described working hard to balance promoting their AYA's independence and self-management and ensuring they can succeed when their parents are no longer able to provide support. It is noteworthy that these parents were actively working to improve their own AYA's adulthood experience and support other AYAs with ID. Examples of parent-led efforts included education and collaboration efforts between police and the disability community, contributing to the development and expansion of inclusive community living environments, advocating

politically for improved adult-based services, and developing other community engagement activities.

Hope despite uncertainty

Parents described troubling uncertainty about their AYA's condition, their transition to adulthood, and their adult AYA's future. While all of the AYA's represented in this study had diagnosis of ID (initially confirmed through various means including health care provider recommending the family for study inclusion or parent report via phone with parents who contacted the study team through flyers), when parents were asked about their AYA's diagnosis during the interview, none initially identified their AYA as having an ID diagnosis. Later in the interview some referred to their AYA's developmental delay or IDD [intellectual and developmental disability]. Among parents that confirmed an ID diagnosis, uncertainty of the AYA's ID severity was common. Despite describing significant costs and challenges with their child's disability, parents displayed hopefulness, which appeared to be facilitated by parent peer support. The two categories derived from the data composing the hope despite uncertainty theme were 1) costs and benefits of AYA's disability and 2) benefit of parent peer support. See Table 3 for additional details.

Costs and benefits of AYA's disability

Parents identified costs experienced as a result of their AYA's disability including financial burden, inability to travel, loss of job opportunities because of need to ensure economic stability and insurance, marriage difficulty, having a different life and retirement than they had planned, and effects on siblings. Financial concerns, though identified, seemed to receive less emphasis than other family-related costs; impact on siblings was the most commonly reported concern. One mother explained the cost of disability to the family, stating "You know, having another sibling has an impact, let's be real. Um, but with special needs it has a profound impact (M, #2, 26 yo)."

As parents described concern about the impact of a sibling with ID on their other children, they also described ways in which they hoped or believed their other children were stronger due to having a sibling with special needs. One parent explained:

> "many families have been broken up by [disability]. There's a lot of stress and strife that happens within families when there's a child with a disability… I feel that we have all been – and including her – have been pretty resilient…we've learned a lot along the way… and are probably even more [close]."
>
> [(M, #7, 18 yo)]

After sharing these costs, they all consistently clarified that having an AYA with special needs outweighed; was worth it, made them better, and made their life richer as a result.

Benefit of parent peer support

Peer support from other parents of children with ID was an important source of hope, motivation, and connection to resources. Both formal and informal supports from other parents were described as important towards gaining perspective about life with a child that has a disability and learning about new resources and solutions. Parents also described gaining motivation and inspiration by witnessing and engaging in programs and support networks developed and sustained by other parents.

Learning about the experiences of other parents provided perspective. For example, by comparing to other families navigating more difficult issues parents reframed their own AYA and family's challenges; examples of this were provided across the AYA's life course. As difficult as their experiences were, they each knew AYAs and parents that had more difficulty navigating life in the context of an ID, which appeared to contribute to their optimism. One parent described "She certainly gets to do and participate in a lot of things that other kids don't."

Parents described opportunities their AYA engaged in, developed by parents of children with disabilities to address the need for adult opportunities for this population, including a theater program incorporating drama and speech/language improvements and various individual and team-based adult recreational activities. Parents articulated the valuable resource provided by other parents during this transitional time. One mother explained "I get so excited when I come over here and my friend tells me, 'Hey, do you know about this? Do you know about this? Do you know about this? Do you know about this?' (M, #6, 20 yo)" Each of these components of parent peer support were identified as facilitators to their hopefulness despite their uncertain future.

Discussion

This study explored the HCT experiences of parents of AYAs with ID, including barriers and facilitators to the AYA's transition to adulthood within and between the medical, educational, community, and vocational systems. By studying parents of AYAs 18–33 years, a broader age than is commonly utilized in HCT studies, we were able to identify concerning gaps in HCT services and other supports within and across systems for the ID population. Based on estimates that medical care explains only 10–20% of a populations modifiable contributors to healthy outcomes (Hood, Gennuso, Swain, & Catlin, 2016; Magnan, 2017), it is critical to seek ways systems can collaborate to optimize health for the ID population.

Our first theme, *Inefficient and siloed systems*, illuminated barriers families are commonly experiencing within and between the medical, educational, community, and vocational systems. Within the medical system, we found that the parents commonly described their AYAs with ID HCT experiences with frustration, uncertainty, and/or shock. Most parents described ineffective preparation for transition to adult-based care. The parents commonly described that if they were provided referral to an adult health care provider, their pediatric health care provider abruptly transferred them to an adult-based care team with limited to no preparation and communication. Parents attributed abrupt transfers and health care providers reluctance to transition AYAs to adult- based health care providers to inadequate system support, concern about the adult providers' ability to provide the care, and the pediatric-based providers own attachment to the AYA. Parents' report of pediatric providers reluctance to promote transition to adult providers are consistent with previous studies among AYAs with other childhood-onset chronic conditions. Physicians have agreed there is a lack of available and adequate system supports (Okumura et al., 2010; Peter, Forke, Ginsburg, & Schwarz, 2009), insufficient numbers of adult health care providers willing to provide care (Okumura et al., 2010; Peter et al., 2009), lack of training and competency to provide needed care (Okumura et al., 2010; Oskoui & Wolfson, 2012; Peter et al., 2009), and reluctance to "let go" (Bell et al., 2008; Peter et al., 2009) due to the close bond with families and 'mistrust' of adult providers (Bell et al., 2008). This study has provided new knowledge on the HCT experiences of AYAs with ID. Having a pediatric health care provider coordinating referral to an adult or family health care provider who understands their child's needs and skilled to care for their AYAs and entire family helped them navigate the medical transition to adulthood better, but the minority of participating parents experienced this.

Parents provided limited examples of ways their AYA's health care providers assisted them in preparing for and navigating transitions outside of the medical system. Parents did identify health care providers as interested in their AYA's development and activities beyond their medical appointments as demonstrated by inquiring about their activities outside the clinical walls (e.g. school and community activities). However, heath care providers and health care teams were not recognized as a substantial source of information on adult-based resources, connectors to such resources, or preparation for transition to adulthood beyond the medical system. Parents identified ways they believe their AYA would have benefited from collaboration between the health care,

education, and community system. However, because of this lack of preparation and collaboration their AYA missed out on valuable opportunities that could have improved their transition.

Barriers and facilitators to support the transition of the AYA to adulthood within and between the medical, education, community, and vocational systems were further explored. Primary barriers consistently described by parents within and between each system were inadequate resources within each system, having to find resources themselves, and believing there is a better way for them to learn of resources available through each system in a timely, efficient manner with improved coordination of systems. Parents did not describe any appreciable collaboration between the education or medical system. However, previous studies have found that schools are a central provider and coordinator of mental health services for adolescents (Burns et al., 1995; Farmer, Burns, Phillips, Angold, & Costello, 2003) including those with autism spectrum disorder (Narendorf, Shattuck, & Sterzing, 2011). While it is possible that schools provided mental health services earlier in the AYAs lives, it is notable that, within this study, parents did not identify the school as a source of mental or physical health services. A primary facilitator parents identified as supporting their transition within and across these systems was parent peer support.

The core components of the second theme '*Left out here floundering*' *in adulthood* were continued inadequacy of resources within each of these systems and parents having to find available resources themselves. Parents described waiting for services and supports, the social isolation their AYA with ID experiences due to reduced friend networks, limited community inclusion opportunities, and lack of daytime structured activities (e.g. work). Parents also detailed the difficulty of balancing demands to help their AYA find work and community opportunities while balancing their own needs and the needs of others (e.g. siblings). Parents expressed desire for improved collaboration across systems and belief that this would address gaps their AYA has experienced. However, the results suggest that developing and improving specific supports within each of the systems may be just as important as collaboration between services. One example is the 10-year-wait list for adult based care waivers. While collaboration within systems, could potentially improve the likelihood the AYA will be evaluated early for eligibility for adult based services and be placed on the waitlist, ultimately the 10-year-wait list for adult based care waivers will only be addressed by providing more of these waivers to address these unmet needs.

Our findings illuminate the need for improved infrastructure to provide effective HCT and partnerships to help integrate HCT support within other life course systems (e.g. educational, vocational, community) (White et al., 2018). Service models and interventions focused on HCT and collaboration between systems are required to address the needs of AYAs with ID and their parents. The limited HCT support the participants of this study received was commonly limited to health care providers themselves, despite providers' awareness of their difficulty addressing the psychosocial needs of young adults (Peter et al., 2009) and lack of resources and time to coordinate care (Steinway et al., 2017). Clinics specializing in transition care and equipped to provide comprehensive transition services have been effectively utilized to meet the needs of AYAs with childhood-onset chronic conditions (Cadogan, Waldrop, Maslow, & Chung, 2018; Steinway et al., 2017; Woodward et al., 2012). More specifically, transition support clinics utilizing a comprehensive noncategorical approach, providing non-disease specific services, can tailor care to the needs of the individual AYA (Woodward et al., 2012). This noncategorical approach is valuable as transition experiences and difficulties are common across populations (Nguyen, Stewart, & Gorter, 2018; Stewart et al., 2014). The similarity of transition difficulties experienced by parents in this study despite diverse causes of ID and heterogeneity in ID severity reinforced the value of a non-categorical approach.

Study findings represented by our final theme, *Hope despite uncertainty*, included the perceived costs and benefits of their AYA's disability and demonstrated the value of parent peer support in providing key knowledge of resources, strategies, and perspectives. Parent-to-parent peer support was an important source of hope, motivation, and connection to resources during this transition period. This illuminates the potential of a parent peer coach-facilitated HCT intervention for this population. Parent partnerships are one way to address the recent clinical recommendation for integrated HCT support within other life course systems (White et al., 2018). Parent-to-parent peer mentorship and parents as transition experts have shown positive impacts for parents of youth with ID and other disabilities (Freeman et al., 2015; Kingsnorth et al., 2011; Nguyen et al., 2018) as they have the critical element of the shared experience (Nguyen et al., 2018) that health care providers commonly lack. Including parent peer coaches as a member of this care delivery team is particularly promising within the context of value-based care models.

There are limitations of this study that should be noted. Parents were not directly asked what types of changes in specific services they believe would be helpful to address the barriers they experienced. Therefore, this limited our ability to identify specific interventions families believe would be beneficial to improving their experience and recognize relative value to families. Additionally, with this sample size and study design we are not able to determine the impact of demographic factors or severity of ID on families' experiences which are likely to influence barriers experienced by different families. The generalizability of this study may be limited by the use of a single medical center in a single state. However, parents from a geographical radius of up to 150 miles away were recruited. Additionally, the sample was mainly mothers who were college educated. Despite these limitations, this study contributes greater understanding of the transition experiences for AYAs with ID and their parents.

Implications for practice and research

In order to provide comprehensive, quality HCT support for AYAs with ID and their parents, it is crucial to recognize the simultaneous transitions these families are undergoing and implement strategies within clinical practice to address these needs. Partnerships with AYAs with ID and their parents, that foster collaboration among life course systems are necessary to facilitate successful transitions to adulthood. Despite the broad range in severity of ID and comorbidities (e.g. autism, Down syndrome), the parents in this study described common unmet HCT needs that could be targeted with similar interventions. This supports the rationale for non-categorical HCT-focused interventions to improve care and promote the health and well-being of AYAs with ID and their families. A parent peer support intervention is a promising approach for bridging the gap between systems and addressing family needs for knowledge, hope, and resource connection during this transition period.

Lastly, policy supporting increased resources within each system and improved communication and activation of the transition plan across medical and school systems is necessary. This could include ways to effectively connect health care members with educational teams while having reimbursement strategies for each system to support effectiveness and sustainability. Policy for connecting life course systems and effectively activating comprehensive transition planning, such as connecting health care teams within the IEP transition planning process, should be explored.

CRediT authorship contribution statement

Michelle S. Franklin: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft. **Logan N. Beyer:** Conceptualization, Methodology, Investigation, Writing - review & editing. **Samuel M. Brotkin:** Writing - review & editing, Project administration. **Gary R. Maslow:** Conceptualization, Methodology, Resources, Writing - review & editing, Project administration,

Supervision. **McLean D. Pollock:** Writing - review & editing, Project administration, Supervision. **Sharron L. Docherty:** Conceptualization, Validation, Formal analysis, Writing - review & editing, Supervision.

Appendix A. Interview guide

A.1. General information

Question 1: Tell me a little bit about [child's name]

Question 1a: Official diagnoses
Question 1b: Age at time of interview
Question 1c: Gender

A.2. Medical information

Question 2: Who constitutes your child's medical care team?

Question 2a: How often do you visit the doctor?
Question 2b: Does [child's name] currently see a pediatrician or an adult care provider?
Question 2c: Are there any specialists on your care team?
Question 2d: Do you receive any at home supports with care, like CAP-C?

Question 3: What is your relationship with these doctors like?

Question 3a: Who would you say is the most important figure in child's care? (Specialist or general)
Question 3b: Do you talk with doctors about life changes outside of medical needs?
Question 3c: Did you talk to your doctor about graduating from high school?
Question 3d: Do you talk to you doctor about the community groups your involved with?

Question 4: Have/did you ever talked to your pediatrician about the transition process into adult medical care?

Question 4a: When did you first start talking about transition?
Question 4b: Do you/did you feel ready to transition into adult care?

Question 5: (If in adult care) What was the experience like visiting an adult care provider for the first time?
Question 5: (If not in adult care) What do you think it will be like to visit an adult care provider?

Question 5a: What are your concerns?
Question 5b: What do you think will be beneficial about going to visit an adult provider?

Question 6: Who makes medical decisions for your child?

Question 6c: (If child makes decisions) What was the transition process like to prepare your child to make these decisions?
Question 6c: (If child does not make decisions) Do you think your child will be able to make these decisions in the future? Who will make these decisions long-term?

Question 7: Does your child have any on-going treatments (daily medications, therapy, etc.)?

Question 7a: Who fills the prescriptions/schedules appointments?
Question 7b: Who ensures the medications are taken at the proper time/amount or that appointments are attended?

Question 7c: (If child takes responsibility) What was the transition process like to prepare your child to take on this responsibility?
Question 7c: (If child does not take responsibility) Do you think your child will be able to assume greater responsibility for medication in the future? Who will be responsible long-term?

A.3. Education/vocation information

Question 8: What has the education process been like for your child?

Question 8a: Did your child receive the help he/she needed to maximize his/her potential in school?
Question 8b: Do you feel like the school system was helpful or a barrier?
Question 8c: What was the timing?

Question 9: Did [child's name] have an IEP at school, or any other official conversation about his/her education?

Question 9a: Was the IEP useful?
Question 9b: Did your child attend IEP meetings/meetings with school administrators?
Question 9c: What was the balance between parent and student advocacy?
Question 9d: Did you create a transition plan for after graduation from school? What did this plan include?

Question 10: Did the school system ever help connect you to community groups?
Question 11: Did the school system ever help connect you to medical care?
Question 12: (If graduated) What did [child name] do after graduation/leaving high school?

Question 12a: Which category: college, community college, job, day program, at home?
Question 12b: What do you see as [child's] ultimate track?

Question 12: (if still in school) What are [child name]'s plans for after graduation?

Question 12a: Which category: college, community college, job, day program, at home?
Question 12b: What do you see as [child's] ultimate track?

A.4. Community involvement

Question 13: What did/does [child] do for fun in high school?

Question 13a: Was/Is he/she a part of any teams, clubs, or groups?
Question 13b: Were/Are any of these groups' diagnosis-specific?

Question 14: (If graduated) What does [child] do for fun now?

Question 14a: Is he/she a part of any teams, clubs, or groups?
Question 14b: Are any of these groups' diagnosis-specific?

Question 15: (If graduated) Did [child] ever age-out of a group you used to enjoy? Did he/she find a new group to do similar things with?
Question 15: (If not graduated) Are you worried that [child] will age-out of activities he/she used to enjoy? Do you think it will be possible for him/her to find a new group to do similar things with?
Question 16: Did any of these groups encourage your child to go to the doctor or make post-graduation plans?

A.5. Social supports

Question 17: What is [child name]'s group of friends like?

Question 17a: Many friends or few?

Question 17b: Peer or differently aged friends?

Question 17c: Typical friends or friends with I/DD?

Question 18: Does your child feel accepted? What has been the impact of inclusion/exclusion?

Question 19: How has your family adapted to [child's] diagnosis?

Question 19a: Parental role? Responsibility distribution?

Question 19b: Impact on siblings?

Question 19c: Altered any decisions or plans?

Question 20: Does your extended family (grandparents, aunts, uncles, cousins) know about the diagnosis? How have they been involved?

Question 21: Has anyone in your family helped connect your child with medical resources? Educational resources? Community supports?

Question 22: Have you received any formal or informal supports from other parents going through similar experiences?

Question 23: What is your child's living situation? (Past, present, and future)

A.6. Emotions and personality

Question 24: How would you describe [child name]'s personality?

Question 25: How do you think your child feels about his/her diagnosis?

Question 26: Do you think your child is happy with how this transition process is going/has gone?

Question 27: (As a parent) how do you feel about this transition process?

Question 28: What would you do to make the transition process easy? What changes would you like to see? What would have made the world a better place for you son/daughter?

Question 29: Rank systems (medical, educational, and community).

Question 30: Is there anything else you want to tell me about that we haven't gotten to discuss yet?

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