Table 1. Key Excerpts on the experience of disability for CHD patients from dyadic interviews with families

Social and Identity Shifts	"I guess it's a little bit scary to think about how it would like alter [my heart], alter me. Because I'm kind of fine with how I am now. So, if they would have to put me on the beta blockers, I'd kind of be a little bit scared to see what would happen. Because I'm already tired as it is…." [late teen patient, moderate cardiac disease, out of state suburb] "….I'm a high schooler…and I was born a disabled person....I was also born with hearing loss, and I have a record of surgeries." [early teen patient, moderate cardiac disease, urban] *[When asked what made it harder to transition]* "I don't know, just like the stressfulness of it. Like just being a bigger school, with different people….being in the high school environment and with people that are going from eighth grade." [early teen patient, great complexity, urban] "And so we're just thankful, because in hindsight, you just can't expect other people to be able to pick up on [disability] and really be able to laser focus in that carefully. So we're really thankful that we were able to do that. People home educate for all sorts of different reasons. But [child] needed [it], and we did a lot of exploration, but he needed an Orton-Gillingham style approach. And then, yeah, so it was all about reading, all about spelling, and that really worked…." [late teen patient, great complexity, urban] "So just working through those details, and going from school to school, you know, sometimes you had that director of student services who would fight you tooth and nail over services" [parent to a young adult patient, moderate complexity, urban out of state]
Narrowing support as they age	"I can always come with you to your appointment. Even when you're 40, I'll come with you." [pre-teen patient, great complexity, suburban] "What we absorb as our own responsibility because social, educational, economic and medical structures fall well short. Others, not impacted by these things do not prioritize them. Not when they vote, or what they advocate for… Caring for a loved one is an honor and a visceral, tangible, embodied, even ritual way to get to love someone. Without a doubt. The literal act of love is constant. That is a grounding thing. It only becomes challenging and even burdensome when we are left by friends, family, systems. We do it, own it, feel it completely on our own. Isolation compounds the physical and emotional work." [mother to a medically complex young adult, simple cardiac defect, urban] "It's going to put more responsibility on me, and I don't really want more responsibility. But I'm going to have to deal with those responsibilities to keep me healthy and safe. So, I mean, I'm a little concerned about that because I've always kind of had everything taken care of for me. So now soon, I'm not going to have that. So I need to be informed about what I have to do more, so I kind of know what to do. Yeah, so, I mean, a little bit unsure how that's going to go, but hopefully, it will be fine." [late teen, moderate complexity, out of state urban] "How we got here is complicated. [My child with CHD] was in this situation, and its complex. But not impossible. Then [their] sister got sick. And my attention, as a mother, went there. And I couldn't focus solely on [the child with CHD]. And then we found our new normal. And my husband, well. I already explained how he got [sick]. And then he was gone. And everything changed again. And the focus had to change too." [Dyadic interview, describing the cause of a young adult patient's trajectory] "It doesn't get easier when your kid has procedure umpteen-hundred. The anxiety compounded by the night's tornado warning and lack of sleep only added to the adventure. And she still managed the fear and explanations like a rock star. [They] woke from anesthesia as her usual delightful self. We also needed to begin our breakfast routine at 4:30 am to finish in time to give 8 hours before the procedure. And thanks to help and supports from a few friends, it all went pretty smoothly." [Dyadic interview, mother and patient, parent speaks about their role toward a young adult with congenital heart disease and genetic syndrome]
Disability health paradox	"Yeah, I heard about supported decision making. From a social worker. But should we go through all of the work and time involved when, at the end of the day, some doctor is going to tell us that he isn't capable? And that when we transition to the adult side, and he needs something, we need to get guardianship" [Mother to a young adult with medical complexity, simple cardiac defect, urban] [When asked about their transition to the adult clinic] "Well, we didn't have a choice." [Parent to a young adult, great cardiac complexity, rural]

	[Interviewer]: “And then what about when your medicine is running out, do you need help figuring out when it’s running out?” Patient: “Yes.” Interviewer: “Yeah. Or you feel like you could do that on your own?” Patient: “No, my mama.” Mother: “Well, you’re pretty good about letting me know. Like think about when you fill your pillbox up, you say, I only have three left or something like that.” [*Dyadic interview, describing how they support a young adult with their medication*] “ You cant expect them to really be able to laser focus in that carefully. So we’re really thankful that we were able to do that. People home educate for all sorts of different reasons. But [child] needed [it], and we did a lot of exploration, but he needed an Orton-Gillingham style approach. And then, yeah, so it was all about reading, all about spelling, and that really worked….” [late teen patient, great complexity, urban] “So just working through those details, and going from school to school, you know, sometimes you had that director of student services who would fight you tooth and nail over services” [parent to a young adult patient, moderate complexity, urban out of state] “Yeah. I think, you know, the biggest thing is that a lot of providers aren’t necessarily like educated on it. Like the bigger ones are, I would say like, you know, the clinics and the doctors’ offices. And, you know, the bank was fine with it. But the bank was kind of just like, oh, okay, if you say so, that we need to add this to [your child’s] file, like we’ll add it to the file kind of a thing. But, yeah, so it’s just work. [Mother to a late adolescent on choosing supported decision-making as a legal alternative to guardianship]