"Press On, Continue On": Rural Parents' Experiences of Transitions Within Early Intervention

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Abstract

Although all families experience a variety of transitions over time, families of children with exceptionalities tend to encounter more transitions during their children's earliest years. Transitions can be stressful and often include changes as part of early intervention or special education services. It is important to understand these transitions because the support families receive can influence child and family well-being. Therefore, we interviewed parents ($N = 28$) across a rural state about their experiences of transition over time. Using thematic analysis, three common themes emerged: (a) change is constant, (b) positive relationships support changing needs and priorities, and (c) parents need more support, information, or access to services or providers. Parents reported relationships and collaboration with providers to be important, yet insufficient, in supporting transitions. Rurality added some challenges to parents' experiences with transition. Recommendations include empowering families, providing more access and/or removing barriers to services, and building family efficacy through family-focused services.

Transitional periods are an important part of each family's experience since all families of young children experience change over time (Britto & Pérez-Escamilla, 2013; Bush & Price, 2020; McGoldrick et al., 2011). Yet, for families of children with exceptionalities, they may experience even more transitions throughout their child's earliest years (Hebbeler & Spiker, 2016; Rous & Hallam, 2012), such as those related to a variety of early intervention services for their children (e.g., Early Head Start; Maternal, Infant, and Early Childhood Home Visiting Program; Nurse–Family Partnership). Early intervention services may include those provided by Part C of the Individuals with Disabilities Education Act (IDEA, 2004), which supports children less than the age of 3 with an identified delay and/or disability. After the age of 3, some children with exceptionalities will transition out of Part C services and into Part B services of IDEA, commonly known as special education. Other meaningful transitions may also take place for these families and their children during this time period, such as changes in providers, beginning or ending additional services based on the needs of the child or family, and changes in day-to-day needs (Gothberg et al., 2017; Hebbeler & Spiker, 2016; Pang, 2010; Rous & Hallam, 2012).

The location in which families live, such as how urban or rural an area is, may also influence their experiences of Part C services and/or transitions over time (Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009; Murphy et al., 2013; Singh et al., 2019). The U.S. Census Bureau defines rurality as areas that have populations of 50,000 residents or less (Ratcliffe et al., 2016). Although young children in rural areas are more likely to be eligible for Part C services (Roberts et al., 2014) and receive special education services at a higher rate than children in urban areas (Grace et al., 2011), these children are frequently underrepresented in rural education research (Capizzano & Fiorillo, 2004; Grace et al., 2011; Thier et al., 2021). This is important given that parents in rural communities have identified barriers that include travel time or a lack of access to services, providers, or early intervention information (Cummings et al., 2017; Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009; Mann & Williams, 2011; Singh et al., 2019). The experiences that rural families face may exacerbate the stress

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and difficulties that are often associated with times of transition. Studies focused on the educational experiences of young children and their families in rural areas are rare, and more scholarship is needed (Thier et al., 2021). This study aims to fill this gap in the literature related to how families living in rural areas are supported by early intervention and the educational system during times of transition.

While a number of studies have focused specifically on families' experiences of transition into Part B services (Douglas et al., 2022; Malone & Gallagher, 2009; Podvey et al., 2013), few have focused more broadly on the multitude of transitions faced by families who have children with exceptionalities (Hebbeler & Spiker, 2016; Rous & Hallam, 2012) and even fewer have focused on transitions within early childhood for families living in rural areas (Murphy et al., 2013). Therefore, little is known about families' broader experiences with transitions over time or the extent to which they have felt supported during these periods of change. Better understanding families' experiences of transition, including but not limited to their child's exit from Part C and/or entry into Part B services, could fill gaps in the current literature and guide practices of how families are supported during times of shifting needs or priorities. Therefore, this study aims to examine parents' perceptions of transitions when they have a child with exceptionalities, such as during formal transitions (e.g., exiting Part C services and entering Part B services) and other meaningful life transitions (e.g., child- or family-level changes such as those related to development, providers, or family structure).

Transitions During the Early Years

All families of young children experience change and transitions over time (Britto & Pérez-Escamilla, 2013; Bush & Price, 2020; McGoldrick et al., 2011). Family responses to transition depend on contextual influences and internal qualities of the family system (Bush & Price, 2020; McGoldrick et al., 2011). Adjustments to change for one family may be different for another (Bush & Price, 2020; McGoldrick et al., 2011). The ways families respond to transitions are indicative of child and family well-being and include making necessary shifts to support family members experiencing change (Bush & Price, 2020; McGoldrick et al., 2011). In addition, families with young children typically experience common transitions including the birth of a child, changes in child development, parental role changes, increasing or decreasing social support networks, and parental occupation changes (Britto & Pérez-Escamilla, 2013; Bush & Price, 2020; McGoldrick et al., 2011). However, families of children with exceptionalities may face additional types of hardships including finding access to medical services, changes in providers, beginning or

ending additional services (e.g., therapies), and entering or exiting special education services (Douglas et al., 2022; Gothberg et al., 2017; Hebbeler & Spiker, 2016; Pang, 2010; Rous & Hallam, 2012; Walsh & Taylor, 2010). The intersection of these typical family transitions with the experiences of living in a rural area and accompanying challenges, such as limited access to services or providers (Cummings et al., 2017; Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009; Murphy et al., 2013; Singh et al., 2019), is not well understood, especially in the realm of early intervention.

Families and Children With Exceptionalities

The transitions that families of children with exceptionalities face are more extensive than those of families without children with exceptionalities, and these transitions can create high levels of stress for families (Douglas et al., 2022; Pang, 2010; Waters & Friesen, 2019). These transitions include meaningful changes related to the family (e.g., relationships), environment (e.g., living situations, schools, or facilities for medical care), or amount of support received throughout these interactions (Pang, 2010; Waters & Friesen, 2019). Other major changes are also meaningful, such as formal transitions that occur related to Part C and/or Part B since this frequently leads to changes in the location, providers, and/or goals of services (Pang, 2010; Rous & Hallam, 2012; Walsh & Taylor, 2010). According to the Council for Exceptional Children's Division of Early Childhood's (DEC) recommended practices (2014), transition is defined as "events, activities, and processes associated with key changes . . . during the early childhood years" (p. 16). Therefore, transitions could include any number of changes all families may experience, as well as those related to changes that occur from hospital to home, entering and exiting Part C services, or entering preschool special education services (Part B).

The transition from Part C to Part B services marks an important change for children and their families—as this typically means that there is a major shift from home-based services that are geared toward the family to center- or school-based services where the family is not present (Douglas et al., 2022; Pang, 2010; Walsh & Taylor, 2010). Historically, parents' experiences with transitions into Part B services are fraught with challenges (Douglas et al., 2022; Podvey et al., 2010; Rous et al., 2007). Parents have reported wanting more clarification of their role(s) once entering Part B services (Podvey et al., 2013; Rous et al., 2009), with open and honest communication between practitioners and the family being a main priority for parents (Doudna et al., 2015; Douglas et al., 2022; Malone & Gallagher, 2009; Waters & Friesen, 2019). Additional barriers parents report facing include socioeconomic status, availability of resources, and rurality (Malone & Gallagher, 2009). In a

small qualitative study, parents reported feeling like "outsiders" within the context of Part B services; parents felt as if they were more involved in their child's learning and care in Part C services, as compared with their level of involvement in Part B (Podvey et al., 2013). There is a clear need for high-quality support during transitions, since this can affect both child- and family-level outcomes (Douglas et al., 2021; Murphy et al., 2013; Rous et al., 2007).

Supporting Families Through Transitions

Given the frequency with which families of children with additional support needs undergo transitions in their children's earliest years, and the stress that often accompanies these transitions, it is important to consider what types of practices best support families and children. Transitions can be a nerve-wracking experience for families, so including families in the planning and execution process is important in addressing their needs and/or concerns (Doudna et al., 2015; Douglas et al., 2022; Gothberg et al., 2017; Pang, 2010). Parents who feel supported during transitions by their providers are more likely to be involved and engage in better decision-making, resulting in better overall positive outcomes for their child and family (Doudna et al., 2015; Gothberg et al., 2017; Pang, 2010).

Successful transitions are characterized by collaboration among all members of the early intervention team (Doudna et al., 2015; Douglas et al., 2022; Gothberg et al., 2017; Walsh & Taylor, 2010). For example, indicators for a successful transition out of Part C services or from Part C to Part B services include the following: (a) the creation of transition outcomes within the child's Part C Individualized Family Service Plan (IFSP) developed by the family, service coordinator, and any other providers; (b) notification to the school district of potentially eligible children for Part B special education services; and (c) holding a transition conference between the family, the lead education agency or school district, and any other providers within the child's life (IDEA, 2004). The process of preparing for formal transition into Part B special education proves valuable in supporting families and increasing collaboration between educators, providers, and family members (DEC, 2014; Doudna et al., 2015; Douglas et al., 2022; Walsh & Taylor, 2010).

Regardless of the type of changes families experience, approaching transitions using family-centered practice, a focus on understanding, supporting, and addressing families' changing needs via collaborative relationships is seen as the most supportive route (Doudna et al., 2015; Douglas et al., 2021; Pang, 2010; Rous & Hallam, 2012). Although families in rural areas may face more difficulties in accessing and receiving early intervention services (Cummings et al., 2017; Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009), little is known about what distinct

types of supports these children and families may need during transitions.

Current Study

Supporting parents of children with exceptionalities through the many transitions they may experience in the early years of their children's lives is an important component of early intervention services (DEC, 2014; IDEA, 2004). However, parents whose children receive Part C services do not always receive supportive or consistent transition services (Rous & Hallam, 2012). Existing research on transitions in Part C has traditionally focused on outcomes related to formal transitions within and between intervention systems (Douglas et al., 2021; Gothberg et al., 2017; Malone & Gallagher, 2009; Podvey et al., 2010; Rous et al., 2007), rarely also exploring the informal transitions and everyday changes that family experience during their children's early years (Hebbeler & Spiker, 2016). Furthermore, since families living in rural areas frequently face barriers to accessing services (Cummings et al., 2017; Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009; Mann & Williams, 2011; Murphy et al., 2013; Singh et al., 2019), these families may also face additional barriers during times of transitions. Therefore, this study asks: For families in a Western rural state who have young children with exceptionalities, what are parents' experiences of transitions over time?

Method

Setting

This study took place in a rural state in the Western United States (Ratcliffe et al., 2016), also regarded as frontier (Rural Health Information Hub, 2018) as many individuals must travel far distances to receive health care and other services. The state in which these data were collected is considered a "research desert" related to rural education (Thier et al., 2021, p. 9). Many counties in the state are considered medically underserved (Health Resources & Services Administration, 2018), which has implications for Part C services (Decker et al., 2020, 2021) There are regional programs in the state in which the data were collected that employ service coordinators for children's Part C services and Individualized Family Service Plans (IFSPs). The Part C team frequently includes occupational therapists (OTs), physical therapists (PTs), and speech language pathologists (SLPs), in addition to the dedicated service coordinator. In the state in which these data were collected, nearly all of these therapists work for independent agencies, clinics, or hospitals outside of the Part C system. Therefore, the child's service coordinator partners with therapists or other providers to coordinate the child's IFSP team. Once a child reaches age 3, if they are eligible, they can enter

preschool special education (Part B) services and have an Individualized Education Plan (IEP) and/or additional family-based services and continue to have an IFSP.

Sample

Data used for this study are from Wave 2 of a longitudinal, qualitative study of parents ($N = 28$) whose children had received Part C services during Wave 1 of the study. Each of the state's 5 regions was represented in Wave 2 (3 participants from Region 1; 6 from Region 2; 12 from Region 3; 3 from Region 4; and 4 from Region 5). All participants identified as the child's parent and primary caregiver, and all identified as female. One participant had three children whom they discussed as part of this study, another participant had two children, and the remaining participants each had one child; this led to a total of 31 children discussed (12 female, 19 male) in Wave 2. Twenty-three participants identified as Caucasian, 3 as American Indian and Caucasian, 1 as American Indian, and 1 as Hispanic/Latino and Caucasian. The majority of the children represented were Caucasian ($n = 23$), one child was American Indian, six children identified with more than one race/ethnicity, American Indian and Caucasian ($n = 4$); American Indian and Hispanic/Latino ($n = 1$); American Indian, Asian, and Caucasian ($n = 1$), and for one race/ethnicity information was not provided for the child; this race/ethnicity data generally reflect the demographics of the state in which these data were collected. Participants reported their information about the child/children's reason for originally receiving Part C services, including one or more of the following: developmental delays in one or more areas; diagnosed conditions (e.g., autism spectrum disorder, cerebral palsy, hydrocephalus); and other factors such as prematurity and heart or brain disorders. Children ranged between 15.8 and 49.8 months of age at the time of Wave 2 ($M = 34.8$, $SD = 11.1$ months). See Table 1 for additional parent and child demographic information.

Procedures

The following procedures were approved by a university Institutional Review Board. This study was not an official evaluation of the state's Part C services, but the principal investigator (PI) did receive support from the state's Part C agencies to help recruit participants for Wave 1. Regional Part C agencies sent fliers about the study to families who had one or more child receiving Part C services. Families who were interested in participating then contacted the PI. See Decker et al. (2020, 2021) for more information about Wave 1 of the study.

The design of Wave 2 of this study was intended to gather information from parents about changes in their needs, priorities, or services related to their child with exceptionalities that had occurred since participating in Wave 1. Participants from Wave 1 were contacted and invited to participate in Wave 2 interviews. Twenty-eight of the original 30 parents from Wave 1 participated in Wave 2. The PI worked with interested families to set up a date, time, and location for the data collection visit. Most of the interviews were led by two research assistants (RAs) trained in the interview protocol; one RA led the interview, while another RA was primarily responsible for attending to the child(ren) so that the parent could participate with fewer distractions. The interviews began with the RA outlining the purpose of the study, answering questions, and obtaining written consent from the parent. Data collection took approximately 1 to 2 h; this included reviewing information gathered at the last interview, providing an option for parents to update their demographic information collected during Wave 1 of the study, and a semi-structured interview to gather additional information regarding parents' Part C experiences and changes in the child and families' lives since the Wave 1 interview. All interviews were conducted in English, with video and audio recordings taken to be able to transcribe the data. After completion of the interview, families were given a $50 gift card and a children's book.

The data for this study are based on the in-depth interview conducted in Wave 2. The first part of the Wave 2 interview was focused on reviewing information gathered in Wave 1 of data collection. The interview then focused on updates and/or changes to parents' goals, priorities, or needs, or changes related to their child's development or services. Parents were asked to reflect on past and current services and providers, levels of support from providers based on any changes that had occurred, and past and present transitions out of or into new services. The primary interview questions used for the current study included: *Do you feel that anything has changed over the last year related to your child's development or your family's needs or priorities? Do you feel that services have met your family's and your child's needs over the last year? What are your feelings about the professionals you and your child have worked with over the last year? Looking back, what could have made these services better?*

Analysis

We used inductive thematic analysis to analyze the data, which is appropriate when investigating an under-studied research question (Braun & Clarke, 2006). The inductive thematic process includes familiarizing oneself with the data, generating initial codes, searching for trends and patterns, reviewing codes and themes, defining and naming themes, and producing a final report (Braun & Clarke, 2006). Therefore, data analysis began with transcribing all interviews. The first and fourth authors then completed each of the next steps. The authors began data immersion

Table 1. Demographic Information for Parents and Children.

Demographic information	% (*n*) or *M* (range, *SD*)
Parent demographics (*N* = 28)	
Marital status	
Married	78.6% (22)
Single	14.3% (4)
Divorced	7.1% (2)
Employment status	
Stay-at-home parent	50.0% (14)
Working part-time	25.0% (7)
Working full-time	25.0% (7)
Education level	
High school or General Education Diploma	21.4% (6)
Some college or associate's degree	28.6% (8)
Bachelor's degree	42.9% (12)
Master's degree	7.1% (2)
Household income before taxes	
Less than $12,000	14.3% (4)
$20,000–39,999	25.0% (7)
$40,000–59,9999	17.9% (5)
$60,000–79,999	21.4% (6)
$80,000 or more	21.4% (6)
Information about children (*N* = 31)	
Age of initial diagnosis of delay or disability (in months)	10.1 (0.0-30.0, *10.3*)
Age of entry into Part C services (in months)	13.8 (1.0-30.0, *9.9*)
Age at time of Wave 2 data collection (in months)	34.8 (15.8-49.8, *11.1*)
Status of children's services	
Still receiving Part C services	25.8% (8)
Exited Part C, did not transition into Part B or additional family-based services after Part C	38.7% (12)
Exited Part C, transitioned into Part B services	35.5% (11)
Services provided by a service coordinator	100% (31)
Location of services provided by service coordinator	
Home	100% (31)
Services provided by PT, OT, and/or SLP	58.1% (18)
Location of services provided by PT, OT, and/or SLP[a]	
Home	38.9% (7)
Clinic	61.1% (11)
School	55.6% (10)

Note. Eleven of the 28 families chose not to fill out a new demographic form during Wave 2, so information in this table comes from Wave 1 demographic forms for those families. PT = physical therapist; OT = occupational therapist; and SLP = speech language pathologist.
[a]Numbers sum to more than 100% because children could have received more than one type of therapy and/or received therapies in different locations.

separately by reading each transcript and making notes about which portions pertained to the research question and which did not. Transcripts were then discussed, parts of the transcripts to be coded were agreed upon, and initial codes were generated based on participants' words and phrases. The authors coded four transcripts separately to refine and edit the coding scheme and demonstrate consistency. This resulted in a kappa score of .75, which indicates substantial agreement (Landis & Koch, 1977). The authors moved on to defining each code which included changing the names of some codes to be more concise and specific, and giving each code a description and examples. Next, the fourth author coded all remaining transcripts, and the first author reviewed each transcript. The authors met to discuss and resolve any differences, and finally, they reviewed the coded data to identify overarching themes. We then determined the number and percentage of participants whose interviews included information relevant to each theme. Each participant was only counted once per theme even if their transcript included multiple passages coded within that theme. Codes and themes can be found in Table 2.

Table 2. Parents' (*N* = 28) Reports of Their Experiences With Transitions.

Theme and code	Example
Theme 1: Change is Constant (N = 28, 100%)	
Anticipation or uncertainty of future changes or needs	"[They] told me that could indicate a cognitive delay. So, that's kind of on our radar. . . . We know he had prenatal drug and alcohol exposure, and ADHD is definitely a possibility, behavioral issues, learning delays, cognitive delays. I mean there are a lot of things that are possibilities."
Changes in child development	"[Good news] would be the fact that [my child] can do this. I mean she is not always in her bed. That killed me for months. I was like 'Gosh, I want to take her outside. I want to take her to the store. How do I let her sit in a cart when her head is so not stable and her body flops everywhere?' But she is getting better and she is not completely immobile anymore. . . . It is getting easier to hold her."
Changes in services or providers	"I'm not sure how much [our new provider] is going to see us, she doesn't know. Which kind of sucks because [our old provider] had been working with [my child] for a year and a half now."
Family-level changes	"Our priorities have changed a lot . . . as far as our needs, we want a bigger place. That's part of why I am going back to work, so that we can put some money back and get into a bigger place because our family has outgrown our apartment."
Theme 2: Positive Relationships Support Changing Needs and Priorities (N = 28, 100%)	
Appreciation of providers	"These people wanted me to succeed as a parent and wanted my kids to succeed. I always felt that way with everybody I worked with."
Collaboration among providers	"Everybody has really come together and pulled through for [my child]."
Responsiveness to child's or family's needs and priorities	"[Our provider] has done a really good job of seeking out the kind of services that we would need, and suggesting things that I wouldn't even have thought of that we need."
Support during transition from Part C to Part B	"[The Part B transition meeting] was good. It was informative and I felt like they really listened to me"
Theme 3: Parents Need More (n = 27, 96.4%)	
Lack of adequate access to resources, services, or providers	"There was a lack of [providers] to be able to come out and help, and we were supposed to get that going in September, and it took all the way until January to start services. That was a little bit of a stressor."
Lack of communication between providers and parent	"A little bit better communication [would have helped]. . . . There wasn't as much volunteered information as there could have been as far as what resources were available and stuff."
Parent did not feel adequately prepared by provider for transition	"I was [my child's] advocate and I was really the one that was calling the shots as far as, 'This is what's going on; this is what needs to happen.' But at the end of the day, the resources weren't provided to me to continue doing that to the best of my ability."
Support reduced once Part B or additional family-based services began after Part C	"[Part B services are] not as personalized as the [Part C] services were. . . . You don't have the kind of the centralized support. . . . It would have been nice to have like the same level that she received before."

Note. ADHD = attention-deficit/hyperactivity disorder.

Results

Although each parent's experience of transition over time was unique, our analysis resulted in three common themes: (a) change is constant, (b) positive relationships support changing needs and priorities, and (c) needing more. See Table 2 for information about each of the themes. Unless otherwise noted, the term "provider" refers to any early intervention professional families discussed. Quotes from transcripts are shared below to describe the findings. Brackets are used to protect parent, child, and/or provider identity or to provide contextual information.

Theme 1: Change Is Constant

All parents (*N* = 28, 100%) described transitions they experienced in their child's skills, family life, or with services and providers. Importantly, parents described these changes as a continuous process which required them to "press on, continue on." Parents were keenly aware of the fact that transitions and change over time would remain a continuous part of supporting their child.

Transitions experienced over time. Parents had much to say about their child's developmental transitions over time (e.g., "He progressed" and "I can see growth."), even if it only felt like "subtle differences." Parents attributed changes in their children's development to aging and the services they had received. These developmental transitions were meaningful to parents:

She has seriously learned so much in this amount of time. And that makes me happy because I have had doctor after doctor tell me, 'She's not gonna walk, she's not gonna talk, she's not

gonna eat, she's not gonna be doing this.' . . . It can't be working out any better—you want to prove the doctors wrong, and that's what she's doing.

Not only did parents discuss the ways in which their child had changed, but they also described many transitions their families had experienced. For example, parents described divorce, moving, and mental health crises. Some parents shared multiple changes that had affected their family system, which had in turn influenced their child. One parent shared, "His biological dad. . . moved away and it caused a lot more behavioral shifts [for my child]." Some of the changes parents mentioned were positive or supportive of the child or family (e.g., "I adopted [my child]," and "I don't have to work anymore, so I can stay with him. That's helped a lot.").

Many parents also experienced transitions between providers, sometimes due to retirements, which services a child was receiving (e.g., ending private therapy services and beginning school-based therapy when transitioning from Part C to Part B), or because parents were not happy with a provider (e.g., "We're currently in transition for physical therapy [PT]. I was butting heads with our PT."). However, changes in providers most often occurred due to staff turnover. Some parents talked about having multiple providers within a few months that was unrelated to a child starting or ending services. Parents said, "[The clinic] went through three different therapists during the short time we were there," and "One of the things that I found was a hard transition, was when [our first service coordinator] was replaced. They did n't go directly to [our current service coordinator]. They had [a different service coordinator] come for a month."

Expected transitions in the future. As part of parents' discussions of the transitions and changes they had already experienced, each parent also discussed the future. Parents described their anticipation or uncertainty for what the future might hold for their child. For instance, parents regularly described some aspect of developmental progress their child had recently made and then quickly followed this by talking about the next skills their child was working toward (e.g., "I think she's a lot more confident. But she's still, I think, behind on developmental skills," and "She's definitely making progress. Compared with peers the same age, I don't think she's caught up."). Parents described anticipation for these changes to continue as part of their child's progression over time. Parents shared: "Goals might change within six months, because kids develop and grow," and "We haven't achieved all of our goals yet, but they take time. You know, development doesn't just happen overnight because of these services. . . . But I think everything's headed in the right direction." While some parents seemed more certain of what they anticipated in the future (e.g.,

"[My child] shouldn't have long term issues"), others described this anticipation in more uncertain terms (e.g., "It could never be an issue or it could be a huge issue, but we won't know until he starts talking."). When discussing the future, another parent said,

There is a good possibility that my daughter won't ever be able to go to school. I mean that is real shit. And it is not fun. It's scary and it makes you want to cry all the time, but if you did that then you wouldn't be present and you wouldn't be able to enjoy what she's doing now. She is definitely the light of my life. That smile just slays me.

Theme 2: Positive Relationships Support Changing Needs and Priorities

All parents ($N = 28$, 100%) described ways in which they felt supported over time. Many parents shared their deep appreciation for their services overall (e.g., "It was a really positive experience.") and their providers, in particular. Providers were described as collaborative and responsive as children's or parents' needs and priorities transitioned over time.

Providers' support and expertise. Parents described many positive aspects of providers' interpersonal skills, saying things like, "They're never gonna judge. . . . I really appreciate having people that are real, down to earth, that I can be honest with," and that providers were "really kind, warm people, who are easy to welcome into your home." More specifically, parents' comments about appreciation focused on feeling genuinely cared for by their providers. Parents summarized this by saying: "They truly did care," and "It felt like they were interested in her, like specifically as an individual versus just a kid with [a specific need]." Parents perceived that their providers were deeply committed to helping (e.g., "Everybody has been flexible and open, and never rigid in their thoughts. . . always willing to do something different for her because it's probably going to take something different for her."). Parents discussed feeling cared for by providers who they viewed as responsive, which included being listened to, validated, and supported during times of shifting needs or priorities for the child, parent, or family. One parent said, "People on the team have always been very good about listening to our concerns . . . and that's very nice because then you feel like your concerns are validated, they're working with the team, and they're really listening to you."

Parents viewed their providers as experts whose advice they valued, and this provided them with reassurance when transitions caused uncertainty. Most of parents' comments about providers' expertise focused on therapists. Parents shared: "I need their expertise, I need their. . . specialized training to meet his needs," and "We've made huge strides

in the last year and I am a firm believer that if we didn't have these therapies none of this would be happening." Parents described feeling reassured by their providers that they "were on the right path with everything." One parent said, "[Our provider] made me feel like I wasn't crazy! That there was reason to believe what I was saying and that it wasn't all in my head." Many parents were grateful when their providers had specialized expertise specific to their child's needs, such as resources, referrals to other providers, and advice. Parents described receiving information about "helpful tips and tricks and stuff to do," as well as opportunities to build their skills or understanding (e.g., "There are all kinds of classes and stuff for me to do. They are phenomenal at giving me the opportunity to gain the knowledge I need.").

Collaboration among providers. Parents also described collaboration among their providers as an important part of how they were supported via positive relationships. Some aspects of collaboration overlapped with areas of appreciation parents had mentioned, such as valuing providers who demonstrated expertise (e.g., "We all work really closely together. [They] are people I feel comfortable with, people that I trust, and I'll listen to.") or commitment to helping (e.g., "They're learning from each other, they're willing to try unconventional methods. They're willing to work outside the box, and that means a lot."). Parents also described that collaboration included providers communicating and cooperating in ways that then led to better support for their child. Examples of this type of collaboration included providers working as "a team," frequently across disciplines (e.g., "Our PT is working really hard at some sensory stuff to be able to get [my child] to calm himself down before he gets to speech that day.").

Cross-discipline collaboration was mentioned most often by parents who felt supported when their child had transitioned from Part C to Part B services. This type of teamwork helped parents begin to form positive relationships with new providers and feel reassured that everyone who would be supporting their child was involved; this included many individuals, such as their service coordinator, therapists, and transportation professionals. Parents felt most supported through this type of transition when they were informed and involved with the transition process (e.g., "It was a really easy transition. They knew what we were working on, what [my child] needed to work on, and so we had all that documented [in the IEP].". A positive transition experience frequently included providers giving parents an ample amount of information regarding the process, paperwork, and changes to come (e.g., "It was very informational. . . . They went over everything"). When parents had a positive Part C to Part B transition, they regularly mentioned their child's service coordinator. One parent said, "It was pretty seamless. We had all the meetings set up

a month before. . . . [Our service coordinator] kind of handled everything and she had everybody there."

Theme 3: Needing More

Despite feeling supported in a variety of ways, most parents (*n* = 27, 96.4%) also described feeling like they needed more from services or providers. Parents most often described needing additional support, information, or access to services or providers as their child's or family's needs and priorities transitioned over time.

The need for more information. Many parents reported feeling shocked, confused, or unprepared when their child transitioned out of or between programs (i.e., Part C, Part B, and/or family-based services after Part C) because proper information had not been provided to them. One parent described feeling like they had been "dropped off" by their provider when Part C services ended. Other families described similar feelings when their child no longer qualified for Part C. One parent shared, "I didn't really know what I was supposed to be doing. [Our provider] just told us he should go to Head Start and I had to figure it out from there." Some parents whose children exited Part C services and were not eligible for other services felt that their child was still in need of services, but only one child continued to receive therapy services after exiting Part C. Parents shared the following about transition out of Part C: "He no longer qualified even though he did really need it," and "It was a little bit depressing because then he was not eligible to go to the [Part B] preschool and he missed the cutoff for Head Start by two days."

Some parents felt that there was not enough information provided about various programs or services available, including information about eligibility criteria, processes, or differences between programs. For parents whose children had entered Part B services, some described feeling most in need of additional support by their providers during the qualification and transition process. Some parents reported receiving little to no information about this qualification and transition process. One parent described the initial process of being told about Part B services as: "It was kind of like, 'Here's some brochures. Here's some pamphlets.'" Another family felt that they had been given false information about the Part B starting age:

> The superintendent led the [IEP] meeting. . . and explained that [my child] was not ready for preschool. The entire team said he was not ready for preschool, and I said, "Well, what do you mean he's not ready for preschool?" They said, 'He's not [age] four,' and I said, "But state and federal law says that the age is three and that's why we are doing this meeting." And they said, "Well, no. It's [age] four."

Similarly, for parents whose children transitioned out of Part C and into the state's additional family-based services,

some found the process to be unclear. One parent shared that their child was initially not considered for family-based services because they had entered into Part B services, though children can receive both services at the same time:

> I got like a letter after he transitioned [into Part B] saying, "Well, since you've indicated you don't want services anymore, we're taking you off our list." So, I called and was like, "Whoa whoa whoa whoa! I never indicated I didn't want services anymore." And they were like, "Well, when you transition to Part B, we take you out."

Other parents also experienced confusion about their child exiting Part C and entering into the state's family-based services that can continue past Part C, when children are eligible. One parent said, "I really don't understand what the difference between this program and that program is. . . . They didn't really go into depth." This lack of communication about programs and services also was evident when one parent did not know any additional programs existed to serve children over the age of 3 years after they exited Part C.

For parents whose children had exited Part C services and begun Part B and/or additional family-based services, many of them felt that the support they received had drastically reduced. In general, parents' comments indicated that their expectations for Part B and/or additional family-based services were not being met. Some parents stated these services were not as personalized as the services they received when in Part C. More specifically, parents stated that their providers made less frequent visits, they felt less knowledgeable about their child's progress, and that services were less comprehensive. Parent said, "I really liked [Part C services]. They were way more involved," and "[The services] are there if I need it, but it isn't as interactive. . . . When she was younger it was way more involved. Now it's just kind of, 'We're here if you need us.'" Some parents felt that the additional family-based services provided after Part C, in particular, were generally less supportive than Part C services had been. One parent said that these services were "definitely a step backwards more than helping," while another receiving family-based services after Part C said, "Now that she turned three. . . they are not really helpful."

Related to the reduction of support provided to parents via Part B and/or family-based services after Part C, some parents commented on how the goals outlined for these programs were not in line with realistic needs of their child. Some parents discussed how the process of creating goals, for Part B IEPs or IFSPs for the additional family-based services after exiting Part C, became less meaningful. Many of the parents felt that the providers created goals that were unrealistic for the child or the school, or that were not in line with parents' priorities. One parent said, "The goals need to be rewritten. . . they were unattainable at the [local] school district level. . . . So I think some of those goals were maybe cookie cutter," while another shared "[My child] is not anywhere near ready to work on [the goals set]. . . . [The provider did not ask], 'Are you okay with it?' But like kind of said, '[Your child] will be ready.'"

The need for better communication. Parents also described a need for better communication. Some parents indicated that they experienced tension, misunderstandings, or felt uninformed about their child's services in general. One parent summed this up by saying, "You don't know what you don't know." Another parent said, "There's been surprises along the way like, 'Oh, you should do this.' 'Really? I would have liked to know that five years ago!'" Parents felt that there should have been more regular information provided about the services that their children were receiving, especially related to services that the child received while the parent was not present (e.g., therapy provided in clinics for Part C services, therapy in the school for Part B services, or Part B services more broadly). Some parents' concerns about the lack of communication were broader, such as wanting better communication with their provider:

> Well the biggest [challenge] was the communication. . . . Appointment changes, being late. Like the point in time would come and I hadn't heard from her and then got worried that something had legitimately happened. Well, "Oh, I'm on my way." [I thought,] "Well, you could've sent that to me when our appointment actually was!"

Parents whose children had transitioned into Part B shared that they wanted more communication and transparency about what was occurring during services. For example, "What happens at school I have really no idea about, because that's not really communicated. . . . They'll discuss how she's doing toward meeting her goals or whatever," and "This is her school notebook. This is the communication from the school. It doesn't really give me any information. . . . From this I don't really know what she did. I don't know what they're working [on]."

Many parents also commented on their need for better access to resources, services, or providers after frequently experiencing waitlists or a general lack of services available. Some parents made broad statements about the lack of resources: "There's just not the resources here that we need," and "There isn't really much for support around here. . . . There weren't resources really." Other parents talked about how they felt there was a lack of funding for programs and that led to a lack of resources being available as part of their services (e.g., "Funding! . . . The things we couldn't get was because of funding."). Parents mentioned having to start "paying for speech services" when their Part C agency stopped doing so, needing "adaptive equipment" for their child but being told it was not necessary, and not being able to receive respite care.

Many parents commented on the lack of adequate access to providers and how this influenced the services they received. Parents perceived there were not as many providers available as were needed, which led to challenges with availably and waitlists; this was true for families living in some of the most densely populated areas of the state and was even more challenging for those living in more rural areas. Parents shared that it was "hard to get an appointment" with various types of providers, mostly pediatric therapists. Sometimes rurality led to challenges with finding pediatric therapists (e.g., "We're in [a] rural [state]. . . . We have a doctor in [a town ~250 miles away], so they have no idea what we do or don't have up here."), especially ones who have specialized areas of expertise (e.g., "There isn't another speech therapist that does feeding and swallowing. . . . It's a problem in [our area]. . . . At this point we don't have anyone"). One parent said, "They need to hire a speech therapist. . . . I just don't think they can get anyone to come to [our small, rural town]. . . . I think the closest OT is [approximately ~115 miles away] and they're booked." Many parents also talked about very long waitlists, saying: "It took a while to get into [SLP services] because they have such huge caseloads and they didn't have enough availability." This challenge of waitlists was exacerbated for parents who would have had to travel long distances to receive those services. Parents said: "It was over a six month wait to get into [a clinic ~350 miles away for] pediatric speech and OT services," and "I called in October and they said, 'Well, the first thing we have is in January, but we could put you on our cancel list.' Well that's fine and dandy but we're [~220 miles away]."

Given the challenges with the lack of availability of providers, parents felt that this also influenced the frequency and location of services provided. Parents described receiving some services weekly and other services monthly. Some parents commented on how they felt that there was a need for their child to receive "more frequent" services, and that their children were not "getting worked with as much as [they] should." One parent said, "My expectations were too high. I thought they'd be here every week, but they're here every month." While some of these services were provided in their homes, many parents were required to travel long distances for their child's therapy services (e.g., "We sometimes have to travel four and a half hours or three hours."). A few parents commented on their desire to have in-home therapy services, but that it was not realistic given the lack of availability of providers more generally. One parent said,

> I want [our state] to do better. I don't know what the answer is as far as recruiting more therapists or paying them better, but I wish we could get in home services. . . because it's the most natural environment for my baby to learn, and it's easiest for our family to have a therapist come here but there aren't any.

Some parents also commented on how they felt the general lack of providers available led to their Part C service coordinators being overworked or underqualified. So while many parents commented on valuing the expertise of their providers—primarily therapists—they also felt that they were sometimes missing out on specialized knowledge, information, or advice, specifically from their Part C service coordinators. Parents said, "I think they are just very understaffed and too much is expected of one person," and

> [Our service coordinator] is definitely spread very thin. She's getting done what's needed to get done and what is expected to get done. . . . Their job is to bring different ways and ideas and things, and I don't think she has time to think of different ways and ideas.

Parents described their concerns regarding not always getting the personalized support and help they needed. One parent said, "I think I expected them to be more therapeutic than they are. So, more of the technical training piece, like helping parents learn new strategies with their kids and I personally haven't felt like I've received that." Some parents commented on the lack of specialized education or training of their service coordinators, and how this may contribute to feeling that they needed more support than they were receiving. One parent summarized this:

> I think that's probably my main concern with early intervention in [our state], is that we're not hiring professionals who have degrees in early intervention, early education, or special ed, because we're paying them poorly. . . . So, there isn't a huge depth to the services that they're providing.

Discussion

The purpose of this study was to gain an understanding of rural parents' experiences of transitions over time when they have a young child with exceptionalities. The findings of this study included three common themes in parents' interviews. First, parents reported many transitions they experienced related to their child, their family, and/or aspects of their services; they viewed these transitions as a constant part of parenting their child, which included anticipation or uncertainty about future changes or needs their child may experience. Second, parents described how positive relationships, including those with their providers or among their providers, helped provide necessary support during periods of transition. Finally, though parents described many ways in which they had been supported, they also mentioned many ways in which they needed more support. Parents reported needing more communication and support from their providers to feel informed and prepared for transitions, especially transitions out of Part C services that had felt more personalized and inclusive of the family.

In addition, parents needed overall better access to services and highly trained providers.

One of the most salient messages communicated from parents in this study was that change is ubiquitous as they move across the timeframe of their child's early years, which is consistent with and extends existing family systems research on early developmental changes (Britto & Pérez-Escamilla, 2013; Pang, 2010). In this study, we interacted with parents during a period of many and significant transitions—such as becoming parents for the first time, expanding their family, and learning about relevant systems and support networks. Many of these transitions are experienced by all families, including uncertainty or joy experienced in their child's early years (Bush & Price, 2020; McGoldrick et al., 2011). However, families of children with exceptionalities, especially those in early intervention services, face far more transitions and changes in early development years; in sum, the challenges and uncertainty of transitions are amplified for these families (Douglas et al., 2022; Gothberg et al., 2017; Hebbeler & Spiker, 2016; Malone & Gallagher, 2009; Podvey et al., 2010; Rous & Hallam, 2012; Waters & Friesen, 2019). In this study, parents described a variety of experiences similar to all families of young children, but they also described unique experiences that were intensified given their child's additional needs. It is not that parents identified change as bad per se, but rather, the uncertainty and disempowerment that often came along with some transitions were difficult for some families to weather.

It is notable that much of what parents identified, both in the realm of change and in what they identified as "good" practice, was operating at the child level. For instance, while parents described change as constant, much of the change they referenced happened as part of everyday rhythms of family life (e.g., getting a new job and moving), but most change they attributed to the early intervention process itself happened to the child (e.g., the child learning new skills and being able to talk more). It is significant that parents did not talk about changes within themselves, their parenting, or family processes or well-being as a result of early intervention services, especially as this contrasts with the tenets of family-centered practice and parent empowerment in early intervention (DEC, 2014). It also may contribute to the sense of loss some families described as their child moved into Part B services out of the home setting—these families may have internalized that it is the provider working with the child, rather than the parents themselves, who are the most important drivers of development for their children.

Regardless of how parents in this study viewed their own role in early intervention services, it was clear they valued their relationships with providers. Similar to the findings of other studies, parents felt as if communication and collaboration were essential in bridging the gap between important transitions (Douglas et al., 2022; Waters & Friesen, 2019), which is recommended to increase positive outcomes in times of transition (DEC, 2014; Doudna et al., 2015; Malone & Gallagher, 2009). It is encouraging that parents in this study identified numerous examples of these types of supportive practices. Parents described feeling supported not only as they transitioned through everyday informal changes, such as moving or welcoming a new sibling, but also as they experienced through more formal changes, such as getting a new provider or entering special education services from home-based services. Many parents described providers who listened, validated their experiences, and really took an interest in helping, which supported parents during times of uncertainty and/or change. Feeling that their provider cared for, and really knew, their child and family was important to parents. Cultivating caring relationships is an evidence-based recommended practice (Murphy et al., 2013). Based on parents' reports, this was a strength of providers in this study.

Strong relationships are a necessary foundation, but insufficient on their own for providing high-quality early intervention services (Foster et al., 2020). The current study demonstrated that regardless of strong provider–family relationships, parents continued to identify significant barriers to supportive services that ultimately undermined children's, parents', and/or families' well-being. Similar to others' findings (Douglas et al., 2021; Podvey et al., 2013; Rous et al., 2009; Waters & Friesen, 2019), some parents needed more from their providers, including more communication, expertise, access to services, and information related to transition into or out of services. Most notable was parents feeling disempowered and uninformed during times of formal transitions between services.

The importance of the context of rurality for these families cannot be overstated—the large, rural nature of a state may have direct implications for the types of providers available for children and their families, how many or how often providers are available, and the locations or distance required to travel for services. Research on rural parents' perceptions of early intervention services is limited yet, as demonstrated in this and other studies, families in rural areas may face more difficulties in accessing and receiving services (Cummings et al., 2017; Decker et al., 2020, 2021; Elpers et al., 2016; Hallam et al., 2009; Mann & Williams, 2011; Singh et al., 2019). In this study, parents validated the challenges of living in a rural state and were willing to travel long distances to accept any services available, prioritizing their child's needs over the stresses caused by these barriers. While certain approaches like telehealth might mitigate the need for travel in rural states and thus increase availability of services (Rooks-Ellis et al., 2020), these approaches may introduce new challenges or may not be feasible for all families. For instance, some families, especially those in the most rural areas, may not be able to afford or have access to high-speed Internet.

Limitations and Future Directions

This is a qualitative study based on a small sample from one state; this limits the ability to generalize the findings to other rural areas or states. A further limitation of this study is that most parents and children were Caucasian. While this is not reflective of a more diverse national population, it does reflect the demographics of the state in which these data were collected and other large, rural states. Moreover, although this study utilized a sample from each of the regional Part C agencies in the state, the experiences of the parents included may not accurately represent all parents' experiences of transition across the state. These findings may not represent parents' experiences in other rural areas or in other states and regions. Furthermore, this study relied on parent's reports of their perception on their child's services and the family's experiences, and as such, the data may not fully represent the complete nature of the early intervention services, such as quantitative child or family outcomes or providers' perspectives. However, understanding parents' experiences is critical to informing family-centered practice and, as a broader concept of transitions over time, it is not well studied in the current literature. One important strength of this study is that families were able to comment on the changing nature of their services, as many families had experienced months and years of services, rather than provide data relative to one point in time. In addition, while the qualitative nature of this study leads to natural limitations in generalizations, it did allow for a deep understanding of parents' experiences, informed by the voices of parents themselves. Building on this study, future research should investigate how providers view transitions with children and families, how they are trained to administer transition support, and the barriers they may face. The importance of rurality in these parents' experiences should also be explored further, especially as the rural context relates to access, communication, and transitions within families and between providers and systems.

Conclusions and Practical Implications

This study adds to the limited existing research related to parents' experiences with transitions over time, which includes but is not limited to exiting Part C early intervention services and/or entering into Part B special education services. Change is a unifying aspect of parenthood, but this study adds to our understanding of some of the possible unique needs of parents of children with exceptionalities as they experience transitions over time. This study also provides insight into the additional needs that families living in rural areas may experience. Parents' relationships with providers, a relative strength in our sample, are critical for parents to feel supported throughout the many changes they and their children experience. However, parents in this study also indicated that these supportive relationships are a necessary but insufficient ingredient as they navigate through important life transitions. Based on recommended practices that are intended to guide services for children with exceptionalities, the work of others, and our findings, there should be concerted efforts to:

- Address the specific needs related to the context of rurality, specifically regarding access to providers, reducing waitlists, and enhancing collaboration and communication between all members of the early intervention team, especially as services change and evolve (Decker et al., 2020, 2021; Mann & Williams, 2011; Singh et al., 2019).
- Recruit, hire, and retain providers with specialized training (and/or provide that training), specifically aimed at how to work with families throughout transitions (Douglas et al., 2022; Murphy et al., 2013; Podvey et al., 2013). DEC (2014) identifies numerous recommended practices to this end (e.g., see recommended practices TR1 and TR2).
- Provide training and education of providers, with the specific aim of bolstering the use of family-centered practices and family capacity building (e.g., see DEC, 2014 recommended practices F1-F10; Doudna et al., 2015; Pang, 2010; Rous & Hallam, 2012).
- Empower families and reduce the uncertainty that accompanies transitions, by better preparing them for the qualification process/entry into Part B and other services, and/or the end of Part C or other services (Douglas et al., 2022; Murphy et al., 2013; Podvey et al., 2013). Although change is an expected part of life, providers should expect that families are not always prepared for these changes. Providers have a special role to play in mitigating stress and uncertainty, and maximizing success and empowerment, during these times.

This study offers insight regarding early intervention practices that may be working well as services unfold over time—communication, collaboration, and relationships—and also gives us direction into what may need to be tackled head-on—empowerment, family-centered services, and access—to best support families and children.

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