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"It Would Be Nice If": Analysis of Transition Experiences Through Grand Challenges

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Abstract

The adult outcomes of youth with disabilities continue to lag behind those of their peers without disabilities, especially for youth living in rural communities. Interdisciplinary teaming is identified as an important component of effective transition planning. Transition planning and collaborative teaming are challenged further in rural communities due to lack of resources, distances between services and providers, and access for youth and their families. Social workers, given their multisystem perspective on aligning youth and family needs with resources, may be well poised, though currently underutilized, to address the challenges of transition in rural contexts. Through the transition experiences of 20 families and young adults with high need disabilities from a rural southern state, this study analyzes the potential alignment between the tenets of the Individuals with Disabilities Education Act for transition and the priorities of social work described in the Grand Challenges. Implications for practice and policy for special education transition planning in rural communities are offered.

Keywords

rural special education, transition planning, collaborative teaming, Grand Challenges

Trainor and colleagues (2020) lament that despite decades of research, advocacy, new legislation, and funding ". . . too many young people with disabilities are still not experiencing outcomes aligned with their personal aspirations and priorities" (p. 1). Indeed, adult outcomes of people with disabilities, such as autism spectrum disorder (ASD) and/or intellectual disability, are worse on almost all measures than those of people with other disabilities or no identified disability (Newman et al., 2011; Shattuck et al., 2012). These outcomes appear to be even more concerning for youth with disabilities living in rural areas (Collins, 2007; Test & Fowler, 2018). The lack of resources in rural areas, travel distance, schooling based outside the rural community in which the high schooler lives, and Individual Education Program (IEP) team members not situated in the same community can pose disconnects between transition planning, implementation, and successful post-secondary education outcomes (Collins, 2007). Given the barriers transition teams face in rural areas, teams must be creative in how they support students with disabilities in these communities and fluent in the use of practices known to effectively create opportunities for youth.

Interdisciplinary teaming has been noted as crucial to the transition process (Carter et al., 2014), and social workers have been identified in the Individuals with Disabilities Education Act (IDEA) as a viable partner. Still, as discussed later, they are underutilized during this process as partners with special educators and others. This is unfortunate since social workers may be particularly well suited to address gaps in the transition experiences of youth and families in rural contexts, given their role as "a critical link between school, home, and community" (National Association of Social Workers [NASW], 2012, p. 1). Scales et al. (2014) encourage social workers in rural contexts to engage in community provider networks to assess community needs and advocate for linking families and students with formal and informal networks, such as transition teams, to reduce environmental risks and increase access to resources. Dente and Coles (2012) advocate for the inclusion of social work in transition planning for youth with ASD, given the ecological approach of the field. This study further addresses the gap in research of the partnership of social work in special education transition by exploring the experiences of transition of families and youth living in an overwhelmingly rural state. The transition experiences of participants are analyzed through the framework of the 12 Grand

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Challenges for Social Work (2020) to determine the potential alignment of the foci of social workers with the tenets of IDEA and more specifically special education transition planning. Implications are offered for transition teams integrating social work into the transition process.

Transition Services in Rural Communities

Implementation of transition-specific, evidence-based practices (Test, Fowler, et al., 2009) and predictors of positive outcomes (Test, Mazzotti, et al., 2009) in rural communities may be complicated by contextual factors, as outcome data for students with disabilities living in rural areas lag behind those living in suburban areas (Dunkley et al., 2018). Variables such as type of disability, service provision, and family demographics, including geographic location, impact transition outcomes (Test & Fowler, 2018). Test and Fowler (2018) identified barriers to successful secondary transition outcomes in rural communities in categories of expectations, opportunities, personnel, services, transportation, and cultural factors. Recommendations for reducing these barriers included integrating coordinated, seamless services across settings.

Challenges for Interdisciplinary Teaming in Rural Communities

The transition team, often led by a special educator, must include the family, youth, discipline-specific professionals, and adult service providers to assist with the transition process (IDEA, 2004). Having multiple perspectives allows transition teams to assess student needs from multiple vantage points and ultimately for better transitions to adulthood (Carter et al., 2014). Given that rural areas experience severe shortages in special education and licensed related service professionals (U.S. Bureau of Labor Statistics, 2020), the issue of interdisciplinary teaming becomes more complex.

The distances both student and service providers need to travel to provide services may further contribute to the barriers identified in rural communities (Test & Fowler, 2018). Currently, service providers may travel from outside of the community to serve on a child's IEP transition planning team (Test & Fowler, 2018) and thus may not understand the context of the community in which the youth lives. As rural areas become less populated, community schools close and are merged with those of other rural communities (Miller & Knapp, 2019), and students may be transported to a different community to receive educational services. Therefore, students must learn to generalize transition skills they learn in one setting to the community in which they live (Montague et al., 2017). IEP teams must identify critical stakeholders that can help bridge the gap between

services in a school-based setting and long-term implementation in the community. These stakeholders are the cultural brokers who can build the community support that will impact the successful transition of the student and their families. School and community-based social workers are ideal professionals to serve in this capacity on the interdisciplinary team.

The Role of School Social Workers

Social workers are perfectly poised with the skills and knowledge needed to become key transition team members as they often already serve as cultural and service brokers across communities. Social workers supporting rural communities are experts in issues facing families and youth, such as generational poverty, limited social services, restrictive cultural norms, and sheer distance (Daley, 2010). As local experts for the communities they serve, social workers often rely on informal networks as opposed to the more formal networks seen in urban communities (Daley, 2010). More formally engaging social workers into transition planning capitalizes on their expertise in generalist practice and specialization in engagement, assessment, service linkage, advocacy, and evaluation of service outcomes across micro, mezzo, and macro systems using client-based strengths perspective (Council on Social Work Education, 2015).

School-based social workers have been serving schools and families for more than 100 years (Sherman, 2016). According to the U.S. Bureau of Labor Statistics (2021), approximately 342,500 social workers were employed as child, family, or school social workers, the largest specialization. By 2029, this area of specialization is expected to add 40,100 jobs (U.S. Bureau of Labor Statistics, 2021). Because school-based social workers are generally funded by the school district, access varies from district to district. School social workers may be assigned to a specific school or they may cover several schools in a district. Historically, the school social worker was tasked with the role of working within the ecological system perspective to link home and school life while also remaining present in the community (Sherman, 2016). Over time, school-based social workers have been classified as solely mental health professionals serving at-risk and differently abled students (Sherman, 2016). However, the NASW (2012) and School Social Work Association of America (SSWAA, 2020) both define the role of the school social worker much more broadly.

According to the NASW (2012), school social workers should generally serve 250 general education students or 50 high need students, such as those served under IDEA. In the southern, rural state from which participants for the current study were recruited, on average, each school-based social worker has 450 students on their caseload (S. Gheen, personal

communication, March 7, 2021). Within this caseload, school social workers evaluate the student's history and needs, support the family and their needs, provide mental health or behavioral treatment where indicated, and connect the student and family to services in the community (NASW, 2012; SSWAA, 2020). In addition to working directly with the student and their family, school social workers collaborate with school personnel to ensure that all school personnel have critical information needed to better understand a student's individual situation or behavior including cultural, economic, and health information. School social workers often become a liaison for the greater community, wherein they secure and coordinate services for students and the school, advocate for better or more mental health resources for the school, and for innovative solutions to meet the specific needs of the school (NASW, 2012; SSWAA, 2020).

While school-based social work focuses on the aforementioned areas, these services are disproportionately offered to students based on a number of characteristics, such as age, grade, level of disability, and level of communication skills (Sherman, 2016; Wei et al., 2014). Although mental health services appear to be offered more for some middle and high school students with special needs, they are not offered equally nor focused on transition support (Wei et al., 2014). Importantly, neither the SSWAA nor the NASW, the largest organizations for school social workers in the United States, specifically cite high school transition to adulthood as a service offered to students with disabilities and their families in their descriptions of the roles of school-based social workers (see NASW, 2012; SSWAA, 2020). In fact, no current research was located which indicated that social workers are taking part in this critical part of student, family, and school planning. This further shows the compartmentalization of the school social worker being relegated to solely offering mental health and therapy services (Sherman, 2016), a service that can be supported by other school and community-based professionals (e.g., school counselor and community therapist). Relegating social workers to the role of mental health therapists minimizes their training, skillset, and expertise as cultural and community brokers (Sherman, 2016). The guiding principles of the social work profession, "the 12 Grand Challenges," provide further direction in addressing this gap in services for students, schools, and their families.

The 12 Grand Challenges of Social Work and Social Welfare

The 12 Grand Challenges for Social Work were conceptualized in 2013 by the American Academy of Social Work and Social Welfare (see https://grandchallengesforsocialwork. org). These challenges were created to bring focus to the broad field and to ensure that the articulated challenges were compelling to the public and other allied fields. The Grand Challenges are categorized into three broad areas: (a) individual and family well-being, (b) stronger social fabric, and (c) just society. Within each of these broad categories are specific objectives. *Individual and family well-being* focuses on ensuring healthy development for all youth, closing the health gap, building healthy relationships to end violence, and advancing long and productive lives. *Stronger social fabric* seeks to eradicate social isolation, end homelessness, create social responses to a changing environment, and harness technology for social good. Finally, a *just society* focuses on promoting smart decarceration, building financial capability for all, reducing extreme economic inequality, and achieving equal opportunity and justice. These efforts are directly aligned with the purpose of special education (IDEA, 2004) to "prepare (students with disabilities) for further education, employment and independent living" to ensure "equality of opportunity, full participation, independent living, and economic self-sufficiency." By understanding the experiences of people with disabilities living in rural areas within the context of the Grand Challenges, the alignment between special education transition and the social work profession may be more clearly identified and leveraged.

This qualitative study analyzed the transition experiences of young adults with ASD and/or related disabilities and their families and further analyzed these through the framework of the American Academy of Social Work and Social Welfare's Grand Challenges. Research questions guiding the development of study procedures and analysis of interviews broadly asked about the transition experiences of families and young adults. Although situated in an overwhelmingly rural, southern state, this group of participants have far more resources than most of the population of the state. While the intention of recruitment was to gather experiences of families representing the state demographics, the stories of participating families and youth who had better resources in comparison to the state's population as a whole created an opportunity to analyze the experience of families and youth who should be situated to have more positive experiences than those with less education or family income. More specifically, this study asks in what ways do their experiences reflect the expectations of the transition process as outlined in the IDEA and the Grand Challenges of the American Academy of Social Work and Social Welfare, and what implications can be drawn for the wider population in rural communities.

Method

Research design and analysis decisions are described subsequently in keeping with Trainor and Graue's (2014) call for methodological, interpretive, and narrative transparency in qualitative research. Interviews were conducted with family and youth to explore the junction between transition-related

experiences and the Grand Challenges defined by the social work field.

Participants

Participants were recruited using purposive and snowball processes initiated through emailed flyers through state-wide partners working with families and youth in transition (e.g., education department, state-level family support centers, and district special education administrators) and social media focused on professionals and families interested in disabilities and special education in the state. Each participant was encouraged to share the information about the research project through emailed flyer with others who might be interested. Participants ($N = 20$) lived across six communities in a rural, southern state. Eight young adults participated in interviews. The demographic data of two other young adults who were not able to participate (e.g., due to characteristics of disability) are not included, although their family's experiences were included in the analysis. For both of these young adults, supports provided by researchers to participate did not sufficiently address communication barriers to the extent needed for them to engage fully in the interview. One youth did join the interview with his mother and occasionally affirmed his mother's response with a verbal "yes" or "no." The other young adult did join the first author for an interview. Again, supports provided were not sufficient and the interview ended early when it appeared that she was experiencing stress as evidenced by body language and repetition of responses. All young adults had transitioned out of secondary education within 10 years of interviews and had received special education services under categories of eligibility including autism, intellectual disability, and multiple disabilities. Family and young adults were chosen to participate to ensure the perspectives of both were considered with the assumption that the same transition process would be understood and experienced differently (Miles et al., 2014).

Three-quarters of the family members ($n = 9$) and half of the young adults ($n = 4$) identified as female and all participants were White (non-Hispanic; see Table 1). More than half of the young adults had been diagnosed with ASD ($n = 7$, 58.3%). Family interviewees ranged in age from 27 to 59 years, with the average age being 49.5 years. The vast majority of family members held professional degrees ($n = 10$, 83.3%). Among family participants, most were employed full-time (75%), were married (75%), and owned their home (83%). Time in the current home ranged from 4 months to 24 years, with the average amount of time at their current address being 13 years. On average, family members reported only having one child in the home. More than half reported making $75,000 or more per year (58.3%). Note that throughout this article, participants who

represented family members of the young adults are described as "family." Each of these participants described themselves as primarily responsible for the well-being of the participating young adults. In addition to parents, "family" included one sibling who was a legal guardian.

The study took place in a southern state that is extremely rural. The population of the state is approximately 3 million people. There is only one major metropolitan statistical area in the state, covering six counties in the central region with a population of approximately 741,000 people (U.S. Census Bureau, 2018). None of the participants lived in this area. By traditional definition, more than 44% of the population lives in rural counties (Miller & Knapp, 2019) as opposed to the United States as a whole, where 14% of people live in rural areas. More than 91% of families participating in the study indicated that they live in a rural area. Four families described moving from a rural part of the state to a more populous area: one during early school age, two during high school age, and another postgraduation from high school.

Due to the desire to include participants specifically from rural communities in the state, once sampling saturation was reached in one area of the state, recruitment in that area ceased and was refocused to other areas. Thus, interviews were conducted in various environments most convenient to individual participants (e.g., university offices, participants' homes, an adult service agency office, and by phone). Regardless of the location of the interview, participants reviewed and signed consent to participate forms approved by the university's Institutional Review Board. All participants could end the interview at any time. Participants received a $20 gift card for their time.

Researcher Roles and Reflexivity

Researchers were three White, middle-upper class women without known disabilities who are professors in special education and social work. All of the researchers are parents and have lived in rural communities in a number of states. Due to the focus on special education transition and social work, it was important that the researchers understood these disciplines. One of the researchers has focused teaching and research on transition and family/school partnerships. Another has supported school systems and families in rural communities. Processes (e.g., roles of interviewers, memo writing, member checks, and an external coder) were embedded across procedures to bring to the forefront and address the influence of researchers' assumptions (e.g., that transition is a critical process, that schools are responsible for engaging in this process, and that parents and youth are an important and integral partner in the transition process) and were based on previous experiences and knowledge throughout the data collection and analysis process.

Table 1. Family and Youth Demographic Characteristics.

Participant characteristic	*n*	%
Sex of youth interviewed		
Female	4	50.0
Male	4	50.0
Sex of family member		
Female	9	75.0
Male	3	25.0
Race of family and youth		
White, non-Hispanic	20	100.0
Youth's diagnosis		
Autism spectrum disorder	7	58.3
Asperger syndrome	1	8.3
Pervasive developmental disorder	3	25
Cerebral palsy	1	8.3
Family employment status		
Full time	9	75
Part time	1	8.3
Seeking employment	1	8.3
Stay at Home Parent	1	8.3
Family marital status		
Married	9	75
Living with partner	2	16.7
Divorced	1	8.3
Family home location		
Urban	1	8.3
Rural	11	91.6
Family housing status		
Rent home/apartment	2	16.7
Homeowner	10	83.3
Family income level		
$30,000–$44,999	1	8.3
$45,000–$59,999	3	25
$60,000–$74,999	1	8.3
$75,000 and up	7	58.3

Procedures. Semi-structured interviews broadly asked about the transition experiences of families and young adults and probed for experiences related to the transition process, future plans and fears, community-specific level of support, and any other support. By focusing questions on the transition process as described in the IDEA (Office of Special Education and Rehabilitative Services, 2017), participants told their story through the process. Follow-up questions probed for more specifics to understand the family and young adult's experiences more deeply. The first author, a faculty member in special education, interviewed all the participating young adults while the second author, a faculty member in social work, interviewed family members (i.e., parents and guardians). This process allowed for each to use their discipline-specific skills to support participants as needed. For example, some interviews with young adults required in-the-moment adaptation (e.g.,

breaking down questions into smaller segments and providing clarity on how many questions were left) to the young adult's participation in the process. Interview questions were developed across participant groups to provide opportunities for triangulation of data across family members and young adults. Table 2, Interview Questions by Participant Group, lists first-level questions. While follow-up probing questions were variable across and specific to participants, examples of more consistent probing questions are included in the table. Interviews took on average 1 hr each, were audio-recorded on two recorders, and transcribed verbatim.

Data analysis. Transcribed interview data were analyzed across a multiphase, multistep process, as illustrated in Figure 1, using NVIVO software (Bazeley & Jackson, 2014). In the first phase, interviews were coded with a focus on the transition experiences of families and young adults. Codes used at this step included those predetermined and specific to transition (e.g., IEP, connecting to adult services, and transition goals) as well as in vivo codes that emerged from the participant's words (e.g., "it would have been nice," "they were ticking boxes," and "I didn't have faith"; Saldaña, 2016). During this step, the first two authors (Miles et al., 2014) coded two family and two young adult interviews simultaneously to establish validity. Emergent codes were defined and used by researchers to independently code two more interviews from each participant group. These four coded transcripts were reviewed together by researchers. During this consensus, meeting codes were analyzed for consistency (i.e., codes used consistently in same section of transcript), variability (i.e., emergent codes added by each researcher and different codes used for same section of transcript), and presence of new in vivo codes (i.e., codes closest to the words of participants). Researchers wrote a collaborative, reflective memo about the difference in the way their disciplines informed their perspectives as they coded (Maxwell, 2013). Reflective questions used to develop this memo were "What are we beginning to learn?" "What are we unsure of?" "What are we surprised by?" and "What were we expecting that we don't hear?" This memo writing procedure led to the refinement of the codebook through the addition of codes, which included interdisciplinary perspectives and clarity of definitions.

In the third step of coding with a focus on the transition process, all transcripts were coded and recoded with this new codebook independently by both researchers. Again, researchers met to discuss variation and consistency. At this step, these transition-related codes were classified into categories that better described the groups of codes (e.g., "parent future worries" described all worries and fears parent had about child and "who he is" described mention of characteristics of young adults related to disability).

Table 2. Interview Questions by Participant Group.

Topic	Family	Youth
Transition process	Ways in which the school worked with you to prepare you and your child. • What was the process? • Who was involved? • How were needs assessed? In what ways was/wasn't child prepared for adulthood?	When you were in high school what did you want to do after graduation? What did you like/not like about high school? Who helped you? What did they do? What were the best things that you learned during high school?
Community	How would you describe your community? In what ways, does/doesn't your community support you?	Where do you go in your community? What do you do there?
Future	What are your hopes for your future for you and your child? What will need to happen for these to come about? What supports will you and your child need?	What do you like about your life now? What do you wish was different?
Support	In what ways have your needs/available supports changed as your child as moved through school age to adulthood?	Who gives you help for what you want to do in your life? When you want to share something special or a secret who do you go to? Who do you spend time with?

After the fourth step, the second phase was initiated to analyze the coded and categorized transition experiences across the Grand Challenges. In the second phase, a trained social work graduate student recoded all transcripts using codes specific to each of the Grand Challenges (e.g., "close the health gap" and "eradicate social isolation"). This new coder minimized the impact of the emerging theories of the first two researchers on this round of coding, given their familiarity with the transcripts. Again, as in Step 2 of Phase 1, to ensure coding was consistent, two transcripts were coded first and then a consensus meeting was held with the third coder and the first author to review discrepancies and again to consider discipline-specific influence of the researchers. Finally, all transcripts were coded and recoded. After coding, NVIVO query tools were used to constantly compare categories and codes to develop themes that organized transition experiences across Grand Challenges as described in the findings subsequently. These queries included comparing young adult and family code and category density and variability across Grand Challenge codes.

As themes emerged through this constant comparison process, researchers continued to "weigh the evidence" and check for internal validity (Miles et al., 2014) by asking each other: "What are the stories and what do they mean?" "What data do we have to corroborate this story?" and "What data contradicts this story?" In addition to checking to understand with each other, researchers checked in with each participant during their interview (i.e., "I think I'm hearing you say . . .," "It sounds like . . . is that correct?"). Once analysis reached the final phase, a summary of themes was described to a sample of participants (2 family members and 1 young adult) verbally (i.e., "We are finding the following across interviews . . . "). Participants' reactions to these findings in relation to their individual experiences were considered in further evaluating the validity of researchers' conclusions. For example, the member check clarified the importance of recognizing the initiative of families and changes made to their lives to support goals for adulthood. Emerging themes were also described during focus groups of other families and young adults living in the same communities in an aligned study. Researchers used reactions from these participants to check for researcher bias in interpretations. Finally, findings and themes were presented at a national special education conference. Presenters (the first two authors) invited a conversation with participants who overwhelmingly identified as family members and special educators. This discussion led to a reframing of the "interdependent" interdisciplinary relationships between transition team members. The member checks with participants and exploration of findings with broader groups of families and young adults helped researchers to consider possibilities for misunderstanding. Validation of conclusions was further supported through triangulation by the use of multiple investigator perspectives on the data, multiple informants in the stories of participants, and theoretical triangulation (Miles et al., 2014).

Findings

The findings below illustrate aspects of the transition experiences of families and youth associated with social work's Grand Challenges of *individual and family well-being*, a *stronger social fabric*, and *just society.*

Individual and Family Well-Being

The health gap is of particular concern, as people living in rural areas face significant barriers and challenges related to
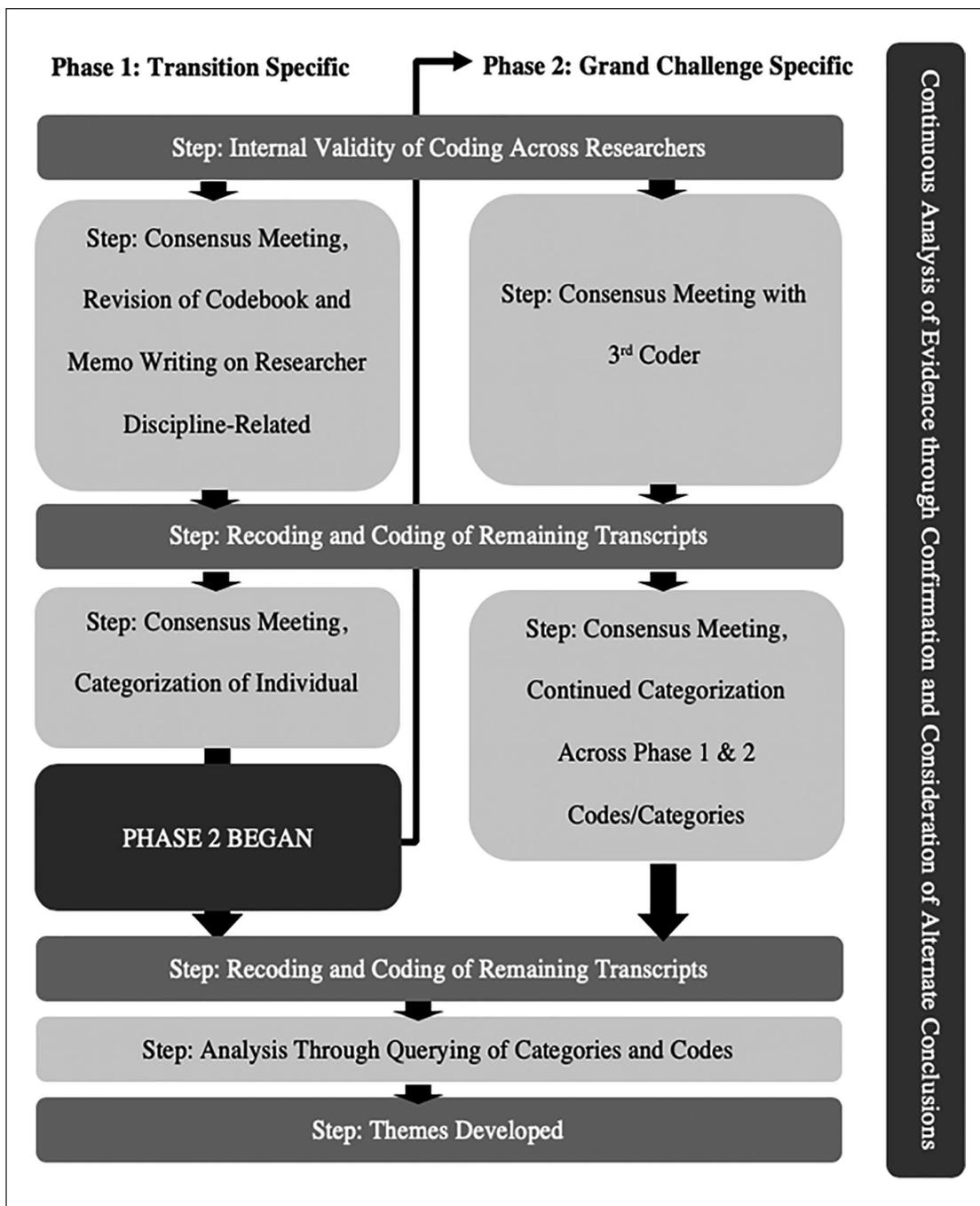
Figure 1. Data analysis process across two phases.

social determinants of health (Rural Health Information Hub [RHIhub], 2021). Those living in rural communities face significant barriers and differences in overall social determinants of health, such as access to adequate community infrastructure, safe and healthy housing, transportation (self and public), and health care (RHIhub, 2021). More specifically to the participants of the current study, the state in which they reside is ranked in the top three states with the highest rates of heart disease, chronic lower respiratory disease, diabetes, and kidney disease (Centers for Disease Control and Prevention, 2017). The *individual and family well-being* Grand Challenge emphasizes healthy development of youth, closing the health gap, building healthy relationships to end violence, and advancing long and productive lives. Many of these were evident in the experiences of participants.

Close the health gap. Families and young adults described significant concern for their health and well-being. Health needs described stemmed primarily from mental health concerns related to depression and anxiety, although almost half the young adults also had medical needs specific to their disability. Families shared mental health issues during high school, ongoing concerns as youth entered adulthood, and fears for the future related to their health. Furthermore, families described ways in which changes to activities related to their young adult's transition heightened mental health concerns (e.g., increased anxiety due to change in the provision of services) and ways in which adult-focused activities were negatively impacted by changes in mental health (e.g., couldn't continue working). To illustrate, one family described a turning point when the school's focus shifted toward post-secondary education:

> We had a comprehensive assessment, and this was a whole year (that was) stressful for (young adult) too because I don't think she knew herself what was really going on and so for her to be at those meetings was very traumatizing. And for the very first time she realized that she was different from the rest of the sisters. There are six of us and the oldest have gone to college and graduated and had jobs. In her mind, she was going to do the same thing but when she realized that was why she was in resource (special education setting) and that was why she was not like her other peers in other rooms, it was so significant she had suicidal thoughts. That's why we have the mental health services.

This same family described how transition-related experiences both triggered and impacted the young adult's anxiety:

> So, I got connected with (state's vocational rehabilitation program) because they were out of (name of town) that was the nearest town that they had a facility in and my parents drove her to that and she would have her intake they would get to know her skills because in the town you either work at Pilgrim or you work at Walmart or you work at McDonald's. There's really nothing else because everything else requires some type of certification or degree. So, we got her a case manager or caseworker and they assigned her to someone else to kind of be like her counselor and they were going to take her in and shadow first. But when she got there she had extreme anxiety and she had a meltdown. She couldn't even walk in. So, they took her back to the center and she couldn't stay so my dad had to go pick her up. After that they tried it again and she realized that she couldn't do it so that her counselor thought that perhaps that is not the right time. She's just not ready. That was three years ago.

This family underscores challenges inherent in rural communities as they relate to the social determinants of health particularly, with limited employment opportunities for young adults without training and education beyond high school and where services are limited and often situated outside the boundaries of the community (RHIhub, 2021). This family's experience encapsulates the shared experiences of participants in the way that concerns for the young adult's mental health impacted their transition. Mental health concerns were a barrier to continued transition, and services did not directly address these concerns.

Ensure healthy development for all youth. In addition to health concerns, families and young adults shared ongoing stress and fear for the future related to behavioral health problems described in the Grand Challenge on ensuring healthy development for all youth. These worries were predominantly centered on risky behavior or lack of understanding of risk.

One family shared concerns about their son's risky behavior:

> He admitted he did drugs and he drank a lot and hired prostitutes. It was just not good. There is part of autism that's not understanding risks and consequences in a way that you would expect maybe someone who didn't have autism to do more of. Although that age is tricky too. But then lots of kids do risky things. When you're out on your own and you have money. Because at that time he had a consistent 40 hour a week job. Because he did draw the line because somebody brought meth to his apartment and he called us. I think a lot of it is just out of loneliness. Wanting to be accepted. I think that's why (he) does most of what he does.

Another family shared their fears related to their daughter:

> We never were able to get her to understand that there is danger. And the other thing the information, she will give you her address or phone number or Social Security number if you ask. We can't make her understand someone could hurt her. She sees the good in everybody, she doesn't realize that there is somebody that might hurt (her). Or do damage.

Experiences of risky behavior or lack of understanding of risk shaped family decisions for their young adult's future. Families acknowledged making decisions for their transition from high school to adulthood based on their fears for their safety, such as choosing adult service providers based on safety measures, limiting youth independence in the community, and determining when to support their child's learning to drive. These decisions were informed by perceptions of resources related to the ruralness of their communities. For example, one family shared

> He would have to walk 2 miles to the bus stop and another quarter-mile is his work. It's not the best. It's not as nice as it is here in (town where interview took place). So that's one of the (concerns) I guess is transportation. I just don't know about him driving a car. I think there needs to be more job opportunities for kids with disabilities.

Families recognized that at times these decisions minimized their child's experiences and independence.

Advance long and productive lives. The Grand Challenge to advance long and productive lives addresses supporting "fuller engagement in education and paid and unpaid productive activities to generate a wealth of benefits" throughout the lifespan (Grand Challenges for Social Work, 2020). Family members especially, but also young adults, described family-driven action related to the well-being of the youth and the family unit and motivated by hopes and fears for their young adult's future. These actions included making a significant change in the life course and parents taking responsibility and initiative linked to the family's productivity.

Descriptions of changes to the life course of the family included evidence that family significantly shifted their plans related to their child's disability and needs. Families described moving from their less populated communities to an area of the rural state they believed to have better resources (e.g., more choices of service providers). Some families left employment to support their children at home. Some families changed career paths to careers that were more closely aligned with their child's experiences (e.g., family support center advocate, related service provider, teacher, home-schooler). These decisions were not only based on their child's specific needs but also because many of the resources and service providers their child needed were limited by the ruralness of their communities and the state.

All families described taking on significant responsibility and initiative in ways that were qualitatively different from what they had expected for their life course. Related to transition planning, guardianship concerns and state waiver programs were described by multiple family members as requiring a significant change in responsibility and roles. One father described changes he and his wife made:

> She qualifies for 24-hour staffing. So, an eight-hour shift is provided by (adult service provider) plus transportation time. (My wife) works 40 hours a week as a caregiver after hours and now that I'm retired our youngest daughter who is 27 now she has been (daughter)'s legal guardian for the last year, year and a half, and I am staff as well for (our daughter).

A young adult talked about the lengths his parents went to prepare him for transition to post-secondary settings. When asked what supports he received in high school through conversations with teachers and others about his future, he shared:

> Not like a whole lot really. A lot of it was just done by my own parents at times. And so it really wasn't anything done with the teachers, it was of our own doing. We just went out and looked around.

Stronger Social Fabric

Elements of the *stronger social fabric* Grand Challenge most prevalent in the experiences of families and young adults were eradicating social isolation and a lack of harnessing technology for social good. Issues of social isolation and the digital divide are of particular concern in primarily rural states, such as the state in this study, where persistent poverty, infrastructure deficiency, and limited access to high-speed internet (Miller & Knapp, 2019) impact access to information and deepen isolation (RHIhub, 2021).

Eradicate social isolation. As described on the Grand Challenge website, "social isolation is a silent killer." Young adults described social isolation experiences such as bullying and challenges in maintaining friendships as well as expressed desire for more friends and time spent with friends. Most of the young adults, without direct prompting, described bullying that they experienced or observed during their schooling. One young adult described the steps he took that he felt made a difference in the way he was treated by peers in his early education and later in work settings:

> One of the things was that I just had to learn to get along with people. I just had to learn to get along and not be a crazy kid like I used to be. When I was in grade school I used to get all up in people's space and stuff and so I just kind of stepped back and just sat and listened and just brought it down. What I've had to do the trial and error process. I just go like okay, that was a situation that I probably shouldn't do that, or oh that seem to work so I'll try that out. So it's really a lot of trial-and-error process. Which got me in a lot of trouble and some of my older jobs because one year I went to like four or five jobs because again my bluntness was getting the trouble all the time.

Another young adult shared the challenge experienced in maintaining a friendship that, similar to the previous quote, illustrates self-awareness and understanding of the way that their disability impacted their behaviors and, in turn, relationships:

> I don't know if you know about people with autism but they get obsessive on people. And I have a friend that I really liked being friends with and I talked to her all the time but sometimes . . . I do this a lot like if I'm upset like feeling something, or if I'm upset, if I miss her . . . that I try to talk to her a lot. But she's the kind of person that doesn't like to talk to people sometimes. And sometimes I get too overwhelming to her because a lot of times, well actually, all of the time I don't know when to quit because I just want to talk to her because she makes me feel better. So it could be considered maybe stalking at a later age because most people I have been told don't do that constant need to talk. That would be my biggest difficulty because I still struggle with it.

All young adults shared, and families concurred, that they wished for more friendships and experiences with friends. The following exchange between the interviewer (I) and young adult (Y) describes this desire:

I: If you could do anything lots and lots and lots, what would it be?
Y: I wish I could do a lot with my friends.
I: What would you need help to do to spend more time with your friends?
Y: Get out more.
I: Would you call your friends or would you need somebody else to call your friends?
Y: I call my friends yes.
I: Do you text with your friends?
Y: I don't have the numbers.

Young adults and family members generally described their nuclear families as their primary support, with a few family members also acknowledging support from their own parents. Importantly, while supports were held close, no family described education or adult professionals as critical supports. Interestingly, when asked directly "who was involved in the transition process?" none of the participants described a team, let alone an interdisciplinary team. When families described relationships and interactions with school members, these were primarily special educators, with a few describing speech-language pathologists and district special education administrators. No other disciplines were described. When adult service providers were discussed, these relationships were described as initiated by the family and not the school.

Harness technology for social good. Part of creating a stronger social fabric is understanding whether people have access to technology, a common issue in rural states, and if so, how they are harnessing that technology. As such, participants and their families were asked about their use of technology. Specifically, they were asked about using technology for "community support" for themselves or their child, for finding information, or for reducing their own social isolation. Virtual forms of social support for young adults or families (e.g., social media, online gaming, disability-specific online support groups) were nearly absent from the interviews. When prompted, families did not note that these were particularly important to them, and when brought up, these were not described as the researchers expected (i.e., for building social networks of people with common experiences). When family members brought up groups such as family and disability-specific Facebook groups, these were not described as helpful or useful. Families did mention technology in building their own education related to their child's needs, disability, or services as in this example: "I think we just kind of looked for what we needed and if it

didn't exist I looked for it in a book or on Google or whatever or I created it."

Just Society

The Grand Challenge *just society* includes building financial capability for all, reducing economic inequality, and achieving equal opportunity and justice. Participants live in a state where in 2016 the median income was 77% that of the national median and in its most rural counties only 65% of the national median (Miller & Knapp, 2019). An important purpose of effective transition planning (Office of Special Education and Rehabilitative Services, 2017) is to develop and pursue goals for adult life, including "ensuring that **all students and youth with disabilities** are equipped with the skills and knowledge to be engaged in the 21st-Century workforce" (p. iv). Elements of the *just society* Grand Challenge are evident in the data of participants' experiences related to transition planning, which is meant to build financial capability for all, reduce economic inequity, and achieve equal opportunity. Families overwhelmingly shared stories marred by disappointment, as they reflected on their experiences of transition from high school services to adulthood. Two core themes emerged: (a) effective transition requiring "secret knowledge" and access and (b) a misalignment between the family and/or young adult's priorities and transition planning goals of the school system.

Families described frustration with a lack of knowledge about the process, lack of relevant resources and services, and not knowing what questions to ask during the process. One family member summarized both the need for resources and acknowledged their access to knowledge, given their profession, when asked what would have made the biggest difference for her child and family:

> I think just resources. Having a case manager that I could just call and say, "Hey I need this where do I go, or who do I talk to about this?" We often find ourselves talking to the (primary care provider). Luckily, since I'm in the special ed department, we know other things. I will go to (professionals in the special education department) and see if she qualifies (for adult services).

Professionals described by families as part of their high-school to adult-life experiences were special education teachers, district administrators, speech and language pathologists, and adult service providers (e.g., vocational rehabilitation counselor and adult service case manager). Social workers were not directly mentioned by families or young adults nor did they confirm working with a social worker upon prompting.

In addition to lack of transition-specific resources, families experienced great frustration in the transition process.

Families described a "secret knowledge" that they perceived would open up opportunities for the young adults if they were able to decode the process. Some, years after their child left high school, were still unaware that a specific transition process was expected under IDEA. One family member reflected on her limited knowledge of transition nearly a decade after her son's graduation from high school:

> And remember, he's 27, so I don't know if (transition planning) was just such a newer thing, or you know what I mean, I don't know. At that time, I don't know. Or if it was just it being a rural school, or an older teacher, or a combination, but that's what happened.

Most families described a feeling that the school personnel or IEP team were "ticking boxes"; that transition planning was a paperwork process, as in this example:

> I honestly don't remember having those kinds of discussions with them. They may have vaguely asked things like, "Do you think she'll go to college" and I think I said "yes." Sort of vaguely, "Do you think she'll live independently?" And I probably said "yes." It felt more like a form at a doctor's office. "Have you ever had this problem?" "No." And just ticking boxes. I don't remember there ever being a plan. Nobody ever referred us to vocational rehab or anything like that. And I called them myself, but I don't remember the high school even doing anything like that.

Another family member considered the impact that cultural and language differences might have had on the transition process: "It could have been that, cultural language barriers. And then lack of education really. Just not knowing the terminology and having make that connection. My parents have a third-grade education and they just know basic reading and writing."

The impact of this lack of comprehensive, interdisciplinary planning and process was a perceived misalignment between student needs, family priorities, and transition goals. One family shared that:

> I remember there were things that he would say a career goal and they would write it down. But often they were just ridiculous things that I want to make movies or just silly things that were clearly not going to happen for him. But they were also not in any position to help him work towards. In many ways it felt to me like they were just ticking boxes they would ask you this question and will just write down your answer.

Another family underscored this experience in the following:

> I kept asking for academics because he had waiver services at the time. So, I didn't feel like the school needed to be teaching functional skills because he was learning that at home with

waiver status. We didn't need to spend 12 years learning how to unload the dishwasher. He was already doing it at home.

Still another family addressed frustration with lack of progress and planning for the future by moving from their small town to a larger town in the rural state. She shared:

> They were helping her and they had goals and objectives but they were very limited because it was a small town and so that's the reason why we moved her out to (another town). So, she can have a better opportunity and preparation for life.

This family believed that the larger community would provide special education opportunities lacking in their small town. Another family summarized well this theme of misalignment and lack of understanding of the process as well as the need for family-driven action in describing their feelings upon leaving IEP meetings:

> What I do remember is always being discouraged when I left. Feeling, you know, to just see the low scores and really no kind of encouragement or we can maybe do this, this might help. Because obviously, I mean, I didn't think he was going to go to college, but I mean maybe a tech school or just voc-tech or something, you know with . . . I don't know. There just was really, I mean, . . . I was just kind of out there to figure it out.

Largely, families had little faith in the school systems to transition their youth. One family member shared: "I don't know. It didn't really occur to me that they would have things that would be helpful to me. So, I never asked for anything. I didn't have that much faith in them."

Discussion

The transition experiences of young adults and families were analyzed across the social work Grand Challenges to determine alignment between the expectations of the IDEA specific to transition and the focus of social work as a field. Several notable findings emerged, including opportunities for social workers in rural communities to become robust partners in the transition process. These findings indicate that school-based social workers, as experts in working with individuals and systems, would be an invaluable resource for educators in not just elementary school, where their presence is strongest, but also in middle and high school to assess the needs of youth and their family, link families to resources in the community, demystify the transition process, educate others on the transition process, and collaborate on policy issues at the micro, mezzo, and macro levels. Interestingly, harnessing technology, which the researchers proffered as an invaluable resource, did not pan out, perhaps due to (a) the age of family members and the newness of social media as a support system during their

Table 3. Threads Across IDEA and Social Work Policy, Participants' Experiences, and Implications.

IDEA 2004	Grand challenges	Themes	Interdisciplinary implications
Education employment Independent living	Individual and family well-being	Health concerns Risky behavior Family-driven action	*Engage social work as transition partner through*: • Assessment of family and youth needs • Linkages to community resources • Telehealth and support
Equality of opportunity Full participation Independent living	Stronger social fabric	Social isolation Social skills Bullying	• Greater transparency of transition process • Education of community and individual on the transition process and access to work and community • Increase presence of H.S. social worker
Economic self-sufficiency	Just society	"Secret" process Misalignment of goals Ticking boxes	• Interdisciplinary collaboration on policy issues • Interdisciplinary programs include transition services as content

Note. IDEA = Individuals with Disabilities Education Improvement Act.

high school years or (b) the ruralness of the community and access to reliable internet. Although no family specifically said access was an issue, we did not address this directly in the interviews. Given the digital divide experienced by people with disabilities (U.S. Department of Commerce, 2010), and its impact on school practices (Sundeen & Sundeen, 2013) and health (Cortelyou-Ward et al., 2020), research on the impact of technology in rural communities during special education transition is needed.

Table 3 further illustrates the threads connecting IDEA 2004, social work policy as indicated in the Grand Challenges, and interdisciplinary implications. Analyzing these experiences through the lens of the Grand Challenges offered an innovative perspective for a field of potentially underutilized, interdisciplinary partners particularly suited to understand individual needs in relationship with community-based resources. Implications for policy and practice for fields of special education and social work are offered.

It is important to underscore that families in a rural state indicated the transition process was often minimal or non-existent, students were not being prepared for adulthood with the priority skills needed for success, families felt that transition planning was fragmented and compliance-driven, and families made significant life changes to address the complex learning and health needs of their youth. The description of transition experiences as missing or inadequate are consistent with Miller-Warren's (2016) findings from surveyed parents in a small rural school district. Of the barriers to successful transition outcomes in rural communities noted by Test and Fowler (2018), families and young adults interviewed most directly spoke of low expectations, lack of services/opportunities, and unprepared education personnel. Collet-Klingenberg and Kolb (2011), in their research of teacher perspectives on transition programming in rural Wisconsin, described parents as a wealth of information and potential resources. Families interviewed confirmed that they had leveraged their resources for their own

education and seeking of services and supports. Unfortunately, they experienced their relationship with schools as disconnected and did not describe school-initiated steps for leveraging their resources for the transition needs of their youth.

Learning From Privileged Participants

Although a significant limitation of the study was the lack of diversity in the group of participants, the findings in relationship with participants' demographics are telling. Participants were overwhelmingly White, employed, English-speaking, and educated. Four of these families had the opportunity to move to less rural parts of the state with more resources in hopes of finding communities with greater services for their youth. Still, overwhelmingly, these families and youth described minimal access to or benefit from the transition process described by the IDEA. It is remarkable to consider the implications for ineffective transition experiences for families less privileged: those who do not benefit from being White, English-speaking, and having access to educational or financial resources in a rural state. If these participants would benefit from the perspective of social workers on their teams, the possibilities for less privileged families are significant and important to consider in future research.

Transition as a Shared Grand Challenge

When transition is viewed through the lens of the current findings, it is clear that beyond the interdisciplinary practices as described in the IDEA, intentional, coordinated, and interdependent practice across disciplines is needed to better serve youth and their families during transition. The Grand Challenges of Social Work and the IDEA speak directly and cohesively to these implications for shared practice in rural communities. Social work as a profession is well poised to further the work already being done by

special educators and others and to expand school social work practice to directly include transition services and programming.

The transition process is a natural fit for school-based social workers in that they come prepared with the knowledge and skills needed to understand and work within multiple systems, which is what both educators and families need. They are versed in understanding individual and family needs, school and educator needs, resources or lack thereof in the community, and the case management that is often needed beyond high school for young adults with high need disabilities. Moreover, the findings clearly indicate the experiences of participating families and youth of transition to adulthood highlight that their lives are deeply and directly impacted by most of the Grand Challenges described by the field of social work. Significant concerns were expressed for youth health and *well-being*. Families described lives greatly changed through unexpected moves, lost employment, and changes in role toward their children as they entered adulthood (e.g., shifting from parent to service provider). Families and youth experienced a precarious *social fabric*. Families attributed their isolation to a lack of services and youth longed for friendship and social skills supportive of friendship. Finally, if transition is meant to be a *just* process to ensure youth are well prepared for the adult lives they desire through work, community engagement, and independent life, it must be transparent and equally accessible for all. As noted across the findings, the alignment of Grand Challenges to the purpose of special education transition services is particularly critical in rural states with communities experiencing high poverty, low wages, significant health concerns, and diminished access to services.

Engaging Social Workers in Transition in Rural Communities

Transition is a time of great need and change, especially for those in rural states and communities, full of challenges outlined as priorities by the social work field. Given social work's focus on attending to the gap between individual and group needs and community resources, social workers are perfectly poised to directly support the transition of youth and their families in rural communities. The findings of the current study are a call to action for rural-based school social workers to redefine their current roles in schools and for transition teams to advocate for their inclusion in the process. Social workers could be incorporated in the transition process in the following ways. First, direct engagement in the transition process would allow social workers to assess family and youth needs, provide linkages to community resources, provide counseling, and community education in support of increased well-being and reduction in

economic inequality. These roles engage the social worker's unparalleled understanding of how systems are interrelated and connected (Sherman, 2016). Second, social workers have the ability to help harness technology through teletherapy, teleservices, support groups, resources, and individual and community education in ways that the participating families and youth did not experience. Such services may be especially impactful in under-resourced rural communities, where distances can limit access to supports and services (Sundeen & Sundeen, 2013). Third, participants noted worries about health concerns, risky behaviors, social isolation, social skills, and bullying. While addressing risky behaviors and mental health issues are areas in which school-based social workers are utilized (Sherman, 2016); unfortunately, none of the participants noted social workers as part of their transition experiences or support services. Fourth, participants expressed their longing for the key to the "secret knowledge" of transition that seemed to be unavailable to them. Social workers, with their generalist approach to systems and specialization in the context of rural communities, should be given that key to share with families and youth in their support of their full engagement in the special education transition process.

The implications for policy are threefold. First, to become an interdependent team working toward the goals of transition, social workers must be aware they are needed and must be present in the schools. This means the social work profession must redefine their roles in schools and advocate for changing policy and funding streams to include school social workers in high schools and at each student's transition planning table (Sherman, 2016). The current literature (Teasley, 2018) clearly shows that social workers are needed in every school across the United States, not solely for mental health care but also as cultural and community brokers, especially in rural communities where services are harder to find and access. Second, district and school-level policy should include social workers in transition planning processes, given their expertise in evaluating family and individual needs and their expertise in community culture and resources (Sherman, 2016). Policies at the school level should be created that include a trained team of professionals that work interdependently, across their fields' priorities, with the youth and family to create and implement a successful transition plan. Special educators should be prepared to partner with social workers by linking families to these professionals and communicating specific family and youth needs and priorities with social workers. Third, to support the inclusion of social work in the transition process, not only should professional preparation programs (i.e., special education, social work, education leadership) offer cross-discipline learning opportunities, but school administrators should be prepared to support ongoing interdisciplinary collaboration.

Limitations

The purpose of qualitative research is not to generalize findings but to deeply understand how people make meaning of experiences to more fully explore the complexity of those experiences (Maxwell, 2013). Still, rural communities vary, as do families and youth living in these communities. Although some participants straddled both lower resource and higher resource communities, this study is limited by the breadth of these communities. The communities as described by participants were not consistent with wider understandings of rural and nonrural communities in the United States. Future research should particularize the experience of families across communities with shared characteristics to more fully understand these experiences. Furthermore, as already discussed, the participants involved in this study were not diverse. While studying the experiences of participants with such shared demographics can shed light on a group of families and youth with resources in a rural state, the experiences of more diverse families may suggest not only transitions that are even less effective but also simply different. These differences are important to consider in suggesting changes to practice and policy.

Conclusion

Interviewed family members and youth situated in a rural, southern state described their experiences of transition as secret, misaligned with their priorities, lacking support and isolated, and requiring family-driven action and resources. Their experiences and needs align with the core challenges identified as priorities for the field of social work as well as the purpose of special education transition planning as described in the IDEA. Implications for practice and policy suggest that engaging social workers on interdisciplinary transition teams could be the missing link in current transition services provisions for students with disabilities, especially in rural communities, as their role is to deeply understand both the family and the community in which the youth will live and work.

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