Intellectual and Developmental Disabilities

To Connect and Educate: Why Families Engage in Family-Professional Partnership Training Experiences
--Manuscript Draft--

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Manuscript Region of Origin:	UNITED STATES

Abstract:	Family-professional partnerships (FPP) have been shown to positively impact children with disabilities and their families, and many training programs include experiences that feature families as mentors. However, most research on FPP has focused on professionals' experiences instead of families' experiences as mentors. The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program is a graduate-level interdisciplinary training program with sites across the country. LEND programs often include a family mentor experience (FME) in their training. This qualitative study examined the experiences of 8 family mentors in one LEND program. Overall, family mentors expressed positive experiences with FME focused on educating trainees and connecting with trainees, other families, and community resources. Interviewees also identified several facilitators and barriers to FME participation.

To Connect and Educate: Why Families Engage in Family-Professional Partnership

Training Experiences

Family-professional partnerships (FPP), sometimes referred to as family-centered care (FCC), are often defined as "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual…, and in which all the family members are recognized as care recipients" (Shields et al., 2006, p. 1318). Medical settings began to emphasize FPP by allowing parents to accompany their children and participate in their care after it became clear post-World War II that separating parents and children resulted in maladaptive psychological consequences (Jolley, 2007; Jolley & Shields, 2009; Robertson, 1970). Since then, systemic change emphasizing the family as the recipient of care has expanded to other disciplines involved in providing healthcare services (e.g., public policy makers, researchers, family support staff; Johnson, 2000). For instance, there is evidence of FPP in early intervention and special education, likely influenced by the 1986 reauthorization of the Individuals with Disabilities Education Act (IDEA), which expanded early intervention services to infants, toddlers, and their families and introduced individual family services plans (IFSPs) to guide provision of these services (Epley et al., 2010).

As more disciplines began to recognize the value of FPP, the definition expanded. In 1996, Allen and Petr conducted a comprehensive review of articles about FPP from several disciplines and developed the following definition: "Family-centered service delivery, across disciplines and settings, views the family as the unit of attention. This model organizes assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs" (Allen & Petr, 1996, p. 64). Another review of family-centered services similarly

emphasized that the inclusion of family-centeredness helped create more individualized and collaborative services between providers and families, while also highlighting the importance of treating families with dignity and respect by valuing family preferences (Dunst, 2002). The Institute for Patient- and Family-Centered Care (2007) subsequently defined FPP by the practical elements involved: (a) parent-professional collaboration, (b) recognition of familial strengths and coping strategies, and (c) flexible implementation of health care practices to be responsive to the family's cultural and developmental needs.

While subtle differences in definitions of FPP exist, family-centeredness appears to be associated with improved outcomes and increased satisfaction for children with disabilities and their families across a variety of domains, including early intervention services, early childhood special education, medicine, and adaptive functioning (Dunst, 2002; Dunst & Espe-Sherwindt, 2016; Dunst & Trivette, 2010; Kulthau et al., 2011; Turnbull et al., 2007). However, culturally and linguistically diverse individuals with disabilities and their families frequently experience additional barriers in their ability to effectively collaborate with medical and educational professionals, often due to a lack of provider understanding about the unique experiences and needs of these families (Rosetti et al., 2018; Sauer & Rossetti, 2020). As such, training in FPP for professionals working with children with disabilities and special healthcare needs and their families that specifically focuses on diverse lived experiences is generally viewed as improving outcomes across variety of life domains.

Family as Educators in Healthcare Service Provider Training

Given the benefits of FPP, many healthcare training programs have included individuals with disabilities or their family members as educators to expose future healthcare professionals to the individuals' experience of their disability or chronic health care needs. Programs that

include individuals with disabilities and families as educators vary widely in their inclusion of mentors, from single didactic sessions (Butani et al., 2020; Johnson et al., 2006), to longer rotations that include families as a primary source of expertise on the medical experience (Blasco et al., 1999; Galil et al., 1996; Rossignol, 2015). One such healthcare training program that emphasizes FPP and has been relatively widely studied is Project Delivery of Chronic Care (DOCC). Parents of children with a chronic illness or developmental disability developed Project DOCC to promote education of medical residents from a parent perspective. Project DOCC includes a parent interview with the medical provider, a home visit, and dissemination of information to other medical providers (Appell et al., 1996; Keisling et al., 2017a; Turner et al., 2011). Studies suggest that the FPP cultivated by Project DOCC positively impact the providers by increasing their understanding of the realities of raising a child with a disability, self-efficacy and communication skills, sensitivity to family issues, engagement with community resources, and active collaboration with families (Bogetz et al., 2015; Johnson, et al., 2006; Keisling et al., 2017b; Rossignol, 2015).

While the existing literature of FPP posits positive impacts for individuals with disabilities and their families across a variety of domains, the majority of FFP studies focus on the experiences and perspectives of healthcare professionals participating in FPP. Little work has examined the individuals' or family members' experience in their role as teachers and experts. In one of the few studies that have examined the experience of the individual mentor, medical students interviewed patients with chronic healthcare needs and their caregivers about how they envisioned FPP. Patients expressed the desire to collaborate with medical professionals on their care plans, inform medical professionals about the emotional impact of their medical diagnoses, and ensure that medical professionals understand the importance of listening to patients (Jackson

et al., 2003). Other work has found that when patients assume the explicit role of education, they report feeling more empowered and validated, having higher self-esteem, perceiving less of a power differential with their medical providers than if they had not assumed the role of teacher (Walters et al., 2003, see Ahuja & Williams, 2005 for review). Patients have also stated the personal benefits of knowing that they were contributing to the systemic improvement of healthcare (Coleman & Murray, 2002; Stacy & Spencer, 1999).

The benefit of FPP to patients, families, and service providers is evident (e.g., Kube et al., 2013; Kulthau et al., 2011). However, there is a dearth of literature examining the reasons why family members both become involved with and continue to participate in these training programs for providers working with individuals with disabilities and chronic health care needs. Thus, research is warranted to explore the factors that motivate families' both initial, and particularly continued, participation in training programs that emphasize FPP. This insight into individual and family mentor experiences is valuable for healthcare and service provider training programs who seek to incorporate a family mentor experience into their curriculum. Additional information can guide development of FFP training program that are mutually beneficial to participating professionals and the individuals and family members serving as educators or mentors. Additionally, it is important for training programs to better understand the unique experiences of diverse individuals and families serving as mentors, and the facilitators or barriers that may impact their continued participation.

Leadership Education in Neurodevelopmental and Related Disabilities

One such training program that emphasizes FPP through a family mentor experience is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. LEND is a graduate-level interdisciplinary leadership training program funded by the Maternal

and Child Health Bureau (MCHB) of the U.S. Department of Health Resources and Services

Administration. There are currently 52 LEND programs across the country with the goal of

promoting leaders in disciplines that serve individuals with disabilities and their families.

Although specific LEND training components can vary between programs, all programs provide

training in the areas of clinical competence, research, teaching/training, and policy/advocacy.

Individual LEND trainees include individuals with disabilities, family members, and future

professionals from a range of clinical and related disciplines (e.g., social work, psychology,

physical, speech, and occupational therapy).

Per MCHB, LEND programs are required to conduct training activities that fulfill the

Maternal and Child Health (MCH) Leadership Competencies, which were derived from theory

and evidence with the purpose of identifying the knowledge, skills, personal characteristics and

values needed to improve the lives and health of individuals with neurodevelopmental and

related disabilities and their families (Health Resources & Services Administration: MCH,

2018). Family Centered Care (or FPP) is one of the 12 MCH Competencies and is

operationalized as trainees developing relationships with families of individuals with disabilities

to promote shared decision making, developing priorities for care, connecting families to

services, tailoring recommendations, recognizing the impact on the family at the systems level,

and acknowledging the family as a support system. Several LEND programs specifically meet

the FPP competency with a family-trainee experience, where trainees are paired with a family of

a child with a disability and interact with and learn from the family through a variety of different

experiences (e.g., medical clinics, didactics, home visits). In their evaluation of a LEND

program that included this type of family-trainee partnership, Keisling et al. (2017b) found that

trainees reported increased understanding of FPP and improved confidence in their ability to

incorporate family-centered care into their own future practice at the conclusion of the training program.

Over the past decade, the Georgia LEND (GaLEND) program has included a Family Mentor Experience (FME) to meet the MCH FPP competency, where trainees are paired with a family and spend at least 10 hours over the course of an academic year interacting with and learning from a parent of a child with a neurodevelopmental disability. At multiple points in the 9-month LEND program, trainees meet with families and participate in family-led activities, which may include home visits, Individualized Education Plan (IEP) meetings, therapy sessions, social gatherings, or even everyday tasks (e.g., grocery shopping, mealtime). Mentors receive a small stipend of $100 for their participation over the course of a year. Trainees reflect on their experiences and how their engagement with the family impacts the way that they view both individuals with disabilities and their roles as future healthcare or service providers.

Our study sought to address the question of how mentors perceive the Family Mentor Experience in the GaLEND program. In asking this question, this study aims to fill a gap in the literature for understanding why family mentors choose to participate in the FME, and what potential facilitators or barriers to participation may exist. Given the lack of literature examining the benefits and perceptions of this experience from the family mentor's perspective, this study will also provide insight into ways to improve the FME that may benefit other training programs that incorporate a similar experience.

Method

In an effort to better understand the perspectives and experiences of GaLEND family mentors, we conducted semi-structured interviews that covered topics such as the mentors' experiences with trainees, overall impressions of the family mentoring process, how the

mentoring impacted mentors and their family, and suggestions for improving the FME training component.

Participants

A purposeful sample was recruited to obtain insights about family mentors' experiences. To be included, interview participants had to be a current or past GaLEND family mentor who had participated in the family mentoring process with LEND trainees from at least two annual training cohorts. The research team chose to focus on LEND family mentors with more than one year of involvement because the research objectives included a focus on factors that motivate initial *and* continued participation of family mentors. The GaLEND interdisciplinary training director and family faculty member provided the research team with a list of approximately 50 eligible mentors who met the inclusion criteria. Potential participants were then randomized and invited by phone and email to participate in the study, so as to reduce biased selection of participants from more recent LEND cohorts or those who faculty knew had particular positive or negative experiences. Once the recommended threshold of participants was reached, no further mentors were interviewed.

The recommended sample size for qualitative interview studies ranges from four (Romney et al., 1986) to 30 participants (Creswell, 1998). Other researchers have reported that qualitative code saturation typically takes place at seven to 12 interviews (Guest et al., 2006; Hennick et al., 2017). From the pool of potential participants in the current study, nine mentors agreed to participate in the interview process, although one mentor was later omitted due to unintelligibility of the recording, described below (see Table 1). Participants have been assigned pseudonyms to conceal their identities. The research team determined that a sample of nine

interviewees met the recommended threshold and that additional interviews would produce risk

of informational redundancy (Lincoln & Guba, 1985).

Data Collection

LEND faculty and staff developed the interview protocol used for this study based on

discussions about the FME. GaLEND faculty and staff, including the LEND Family Faculty

member, reviewed the interview questions, which were then adjusted based on their feedback.

The final protocol included 12 questions, with additional follow-up questions contingent on

participant answers (e.g., "Does mentoring differ based on the discipline of your trainee? If yes,

how so?"; see Figure 1). All interviews were conducted by a single interviewer who was trained

on the developed interview protocol and had no previous relationships with any of the

participating family mentors. The interview began with one introductory question, then asked

family mentors about their experiences with mentoring, the factors that influenced their

continued participation in the LEND program's FME component. Other questions addressed the

impact of the mentoring experience on interviewees and other family members and asked what

information would have been helpful prior to the first meeting with their trainee(s). The

interview concluded with an open-ended question, asking for any other information about the

family mentoring process the interview participant felt was important to share.

The interviews were conducted via Zoom video conferencing and took between 30 and

40 minutes to complete. They were audio-recorded and then transcribed using Otter.ai to

facilitate coding. Consensual Qualitative Research (CQR; Hill, 2012) framework guided our data

collection and analyses. According to Hill (2012), CQR is appropriate when researchers seek to

"study in depth the inner experiences, attitudes, and beliefs of individuals because it allows

researchers to gain a rich, detailed understanding that is not possible with quantitative methods"

(p. 14).

Procedures

The university's Institutional Review Board (IRB) reviewed and approved all research

procedures. The interviews were conducted via web conferencing in a private office and

audiotaped to allow for later review and coding. Consent was verbally obtained at the outset of

the interview prior to any data collection. All records were kept confidential and if the participant

mentioned any identifying information during the interview, the reference was deleted from the

subsequent transcript. Only the research team had access to the recording and transcripts. The

research team deleted the recording of the participants' interviews after transcription and coding.

Upon inspection, we discovered the audio recording of one participant's interview was

unintelligible, which interfered with transcription; thus, this participant's responses were not

included in subsequent analyses or reporting of the results.

Analysis

The research team consisted of three members from the GaLEND research and evaluation

team who were trained on thematic coding protocols. Only transcriptions of the interviews were

used to reduce identifiability of the mentors. Following data analysis steps of CQR outlined by

Hill (2012), all three members of the research team individually coded the first three transcripts

for thematic domains and core ideas. Then, the research team convened to reach consensus on

the domains and core ideas for these first three interviews. Engaging with these initial transcripts

allowed the team members to come to a common understanding of the coding and to reach

consensus on the domains and core ideas for the remaining interview transcripts. Following this

meeting, the first and second author coded the remaining interview transcripts and the third

author served as the auditor: examining the work of the primary coders, identifying any areas for

clarification, and suggesting possible revisions. Next the research team engaged in cross

analysis, where we reached consensus about the existence or commonality of domains across

multiple interviewees' responses. This cross-analysis process resulted in the identification of

three overarching domains that captured the major themes in the interviews.

Trustworthiness

Trustworthiness of the results was established via two core features of the CQR process:

the consensus process and an iterative engagement with the data. The consensus process ensured

that multiple perspectives were considered and debated; this process "serves as a means of

triangulating researchers' understanding of the data, thus contributing to the credibility of the

results" (Hill, 2012, p. 11). Further, the CQR process included ongoing team engagement with

interview transcripts as part of the data analysis process. When there was a disagreement

regarding a core idea or domain, team members returned to the data to read passages from the

interviews and discussed their interpretations.

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Results

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Participants were asked about their perceptions of the family mentor experience. From

these responses and utilizing the CQR process of thematic coding approach, three thematic

domains emerged:

1. Connecting with Trainees, Other Families, and Community Resources

2. Educating Trainees

3. Facilitators, Barriers, and Challenges to Participation

The thematic domains and core ideas from the interviewees' responses are presented in Figure 2

and the narrative that follows.

Theme 1: Connecting with Trainees, Other Families, and Community Services

Connecting with Trainees

In reflecting on their experience with the LEND program, the family mentors interviewed for the current study discussed the value of connecting to trainees, other families of individuals with disabilities, and high-quality professionals and services in the community. Across the interviews, forming personal connections with the trainees was among the most frequently referenced reasons for continued participation as a family mentor for LEND. One of the overarching goals of the LEND family mentor component is for trainees to learn about the experience of raising a child with a disability. However, mentors appeared to prefer when the relationships were reciprocal rather than one-sided. Ella stated, "I really enjoyed one (trainee) who…did share some about her own personal self. And so, I felt more at ease and comfort comfortable with her I guess. And we bonded on a closer level than I did with the other ones just because I felt like…I shared mine and she shared hers kind of thing. So, it was kind of nice to share that personal information with each other."

Several mentors highlighted commonalities between mentors and trainees as elements that strengthened the connection they felt to trainees. For instance, one shared point of connection between some mentors and trainees was the experience of parenting. As Ava noted, "I think we both shared some pretty interesting conversations about you know, raising children and supporting them." Further, mentors and trainees sometimes connected through a shared experience of disability. As Charlotte explained, "Well, I had one (trainee) come who had a disability himself. And he really made an impact on me…. We just really connected that way…and we still communicate on Facebook."

Several mentors reported that their relationships with trainees often continued as friendships after the program ended. As Isabella stated, "one [of] the mentees who we got very close to…she started coming to my son's basketball games on Saturdays, and we got very close. [She] was very interested in getting to know us as a family and getting to know [my child] and we stayed friends. And so that's been…really just enriching just to have that relationship." Ava echoed her sentiment, noting she often encouraged other parents of children with disabilities to participate in the program "because that's another person that comes into their individual circle. And some of them for a lifetime. You know, I still have connections with some of those people."

These friendships manifested in various ways, from occasional check-ins over the phone or social media, to a former trainee connecting with the family via Zoom to offer social support during the COVID-19 pandemic. As Charlotte stated:

> We're still in contact with most of them through Facebook and …one of the [trainees] that we mentored…saw that [my child] had been struggling since the virus and…she offered to come out and see [my child]. So, I feel like we've even built long standing relationships outside of this program, which really benefits both [my child] and I for extra support and encouragement in many ways.

Other mentors who had not kept in contact with their former mentees expressed eagerness for the LEND program to facilitate that long-lasting connection given how much they enjoyed the personal connection created with trainees during the program. As Avery expressed, "It would be really nice to reconnect again and … do something where you have LEND mentees from previous years come back and have an alumni association or a reunion or, you know, it would be really fun to reconnect with some folks."

Mentors cited several reasons for why they enjoyed making connections with trainees, including getting to meet new people and expanding their social network. For example, Ava noted, "I like getting to know the different professionals… and learn about the ways in which they might be able to help individuals with disabilities integrating to the community." Another potential benefit of participation identified by mentors was receiving emotional support from trainees. Evelyn explained, "I gotta say [the trainees] were some of my strength through some weak times, some of my emotional times." Similarly, another noted, "It just really worked out very nicely to have somebody in our lives that was a good listener."

Connecting with Other Families of Individuals with Disabilities

Mentors also discussed ways in which participating in the program not only connected them with trainees, but also connected them with other families of children with disabilities. As Evelyn indicated, "I got a chance to meet other families. That was a good thing, meeting other families and their challenges and hearing their stories. It helped me to embrace my challenges even more and figure out ways how to handle them and they were very supportive." Avery discussed participation in the program as a positive way for their child or other family members to practice their advocacy skills in a supported environment:

> I can talk to my daughter and tell her… this (trainee is) a family member, and they have a kid just like you and so maybe you can impact them by X, Y, and Z. Or… this person is psychologist and you know how psychologists have treated you in the past. This is a chance to really invite this person and help them to… figure out where it is that she can have impact.

Connecting to High-Quality Services and Professionals

Finally, interview participants frequently mentioned the impact that program participation had on their expectations for interacting with providers and services. For example, Isabella noted, "It's made me think more about the way that many health professionals or educators are lacking…because they haven't had exposure to kind of the real lived experience or family dynamics." Similarly, Evelyn mentioned that as a result of participating in the program, they now looked for different kinds of providers: "This is one of the things that, when my mentees did come to my home…I found them to be very understanding--asking questions, their presentation. So, I look for that when I go when I go places to look for [services]." Being involved with rising leaders in the disability community also provided mentors with access to information and resources that were not previously known to them. Charlotte noted that the trainees' knowledge of resources "just brings another level of support to families." Overall, all mentors discussed participation in the program being a positive experience that resulted in a number of beneficial connections.

Theme 2: Educating Trainees

Understanding the Experience of Having a Child with a Disability

A second recurring theme was that all of the mentors interviewed stated getting to educate trainees was a favorite part of the FME and that this opportunity influenced their decision for continued participation in the program. Many interviewees' responses highlighted the enjoyment or satisfaction they felt in mentoring trainees. Ella expressed the sentiment, which was echoed across several interviewees' responses, that educating people about neurodevelopmental disabilities was her "mission." In speaking about their efforts to educate trainees, mentors' comments tended to focus on two general areas: providing information to trainees and shaping trainees' thinking and perceptions.

In providing didactic education to trainees, mentors addressed basic knowledge about specific neurodevelopmental disabilities; and described the practical experience of raising a child with a disability. Specifically, they described coping with a new diagnosis, managing daily routines and stressors, family dynamics, and the economic impact of having a child with a disability.

One of the prominent stated goals the FME is for trainees to gain insight into the daily experience of raising a child with a disability. However, as Ella noted, the FME can only partially meet this objective: "I mean, just generally living with a severely autistic child, it's something that you totally cannot understand or get until you live it." Still, mentors described how they attempted to provide trainees with this understanding through variety of means, including inviting trainees to their homes, IEP meetings, extracurricular activities (e.g., sports), family outings, and therapy sessions.

Harper stated that she shared with trainees what it was like for her to receive a new autism diagnosis for her child and how that not only affected her child, but also herself, her family, and her greater community:

Because I have a son who is autistic I had to learn [about it] and then how it was diagnosed… I was really devastated, you know. So that's pretty much what we talk about that. And how we had to adjust our lives around him now. We lived in a very small town, so it was hard to find anything. To get any kind of help was so hard. And so that was one of the reasons we moved out of out of Tennessee, that we can get him more help.

Family mentors expressed their openness to sharing the logistical challenges of raising a child with a disability. Commonly identified challenges included how to cope with behavioral concerns, economic stressors, and the impact of those elements on the family dynamic. For

example, Evelyn shared with trainees about coping with elopement and other behavioral

concerns:

> What was it like to have a child that was different from others. How much rest do I get?
>
> Do I get enough? Or does the child sleep during the night? Or is the child up? You know,
>
> during that time, my son sleepwalked a lot. I put doorbells on my doors…Was it helpful
>
> to be able to do that? Yes. They keep him from walking out of the house because he
>
> would never know that he unlocked the door and will walk out.

Several mentors talked about the economic impact on their family. Ella explained, "I don't think

people realize that we spend … a good $125,000 a year out of pocket… on everything for him in

terms of school… People don't realize how expensive it is".

Finally, some mentors focused on how the experience of raising a child with a disability

impacted their family dynamics and the importance of sharing that with trainees. As Harper

noted, "I go to work when my husband works from home. So, it's always someone with the kids,

but a lot of families don't have that. But some families, maybe they have a one parent home, you

know, or both parents are working."

Shifting Trainee Perspectives

In addition to providing information, most mentors indicated they also try to help trainees

shift their thinking and perspectives towards more family-centered and disability advocacy

frameworks. Mentors indicated they did this by attempting to reduce the stigma associated with

neurodevelopmental disabilities. As Ella explained:

> There's so many judgments out there in terms of what [autism] actually is and what it
>
> looks like and what it feels like. [It's] nice to have them walk out of the situation and
>
> maybe have a little bit more respect for what the families go through and have a little bit

more understanding of just autism in general…. Getting rid of any preconceived, you

know, notions that they had about it.

Avery referenced a specific situation in which she saw one of her trainee's views on the potential

of children with disabilities in the future shift throughout their time together:

I really felt like when she came into that program that she had somewhat I thought maybe

lower expectations for her daughter than I would have liked to see. And so, I felt like that

that was a way we could positively influence her…. Both of our daughters are non-

speaking, use communication devices to talk and so to be able to…look at what my

daughter is doing and all the amazing things she's been able to accomplish despite this.

And I think sometimes people just need to see something similar to give them some hope

and they give them 'Oh, that's what that really could look like,' you know? So that that

was a very positive experience for both myself, my daughter too.

Families also provided education with the goal of moving trainee thinking towards

family- and person-centered care by viewing the person with a disability as an individual rather

than simply a collection of characteristics or traits associated with a certain diagnosis. As

Charlotte noted, "For the person, the trainee, I think, just having that experience and really

getting to know someone was the main [thing]." Additionally, family mentors often encouraged

and modeled for trainees how to be empathic when working with families with children with

disabilities given the many stressors which they face daily. Sophia explained that one thing she

"talked a lot about is empathy, being conscious of the challenges that the family may have to go

through that kind of thing."

When mentoring trainees who were future disability-serving professionals, mentors

emphasized the value of bringing flexibility and creativity to working with children with

disabilities and their families. Sophia advised that, "[trainees should not] get locked into a certain

protocol of how to handle things. Just be open and, and creative when it comes to dealing with

the challenges of each individual. Accept each person or each patient or each client as an

individual."

To illustrate the importance of flexibly and providing family-centered care to trainees,

mentors provided examples of challenges they faced with their families, communities, and

providers. Harper stated that members of her extended family and cultural community did not

understand why her son exhibited behavioral problems. She told a story about a community

leader who "made a comment like, Oh, this boy has no kind of like no manners. Maybe not in

those words, but that's what she meant, you know, like, he's not well behaved, or well trained."

Other mentors shared difficult experiences they had with providers in the hope that trainees

could learn from these challenges to improve their future care for children with disabilities and

their families. Ava, an experienced family mentor shared:

> [A big challenge] is to get professionals to listen to slow down just enough to hear my
>
> side of it and the way I think about what I'm seeing, to take--to trust--my word when I say
>
> that I'm seeing… something that maybe they think is odd or it's not true, or it's just their
>
> disability, and I'm just an overbearing parent. So, a lot of times I think I felt like I was not
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> a part of, of the decisions that have been made for her. And that sometimes people's
>
> minds were already made up. And a lot of times to professionals, I think with her, they've
>
> already made their mind up about how they're going to before they even actually look at
>
> her. Some have not looked at her thoroughly. They don't…. Some have not even felt
>
> comfortable coming near her or touching.

Finally, Isabella articulated how she attempted to teach the importance of advocacy for people with disabilities and to encouraged trainees to think about they infuse advocacy into their future careers and into their personal lives. She added:

I feel like I have this moment as an advocate to help shape, in the same way that the LEND program does, how they will use that advocacy moving forward. … It's having an impact on this whole generation of professionals who are moving out into these different disciplines with this this underpinning of disability advocacy and how that would make a difference and hopefully… It'll become more of a framework for all types of professional work…and that's…so beneficial.

Theme 3: Facilitators, Barriers, and Challenges to Participation

Facilitators to Participation

A final recurring theme present across interviews was that mentors identified a number of program features that either facilitated their participation in the program or served as barriers to successful mentoring. In terms of facilitators, mentors indicated the small stipend provided for participation was a positive incentive for continued participation. As Ella stated, "I feel like I'm doing them a favor, and I'm getting paid for it. So, it's kind of nice… I guess I should say, they're kind of doing me a favor too. And I'm getting paid for it." Similarly, others mentioned the flexibility of the program as facilitating their continued engagement, as families were able to participate on their own time and schedule. For example, Isabella indicated, "the fact that we pick and choose when we do something and what we do, so it's just that idea that…you can have a big impact by starting with small." Harper mentioned she appreciated the family mentor process and "didn't feel like it was an interruption [to] normal life."

Barriers and Challenges to Participation

While the mentors conveyed generally positive experiences and perceptions, some

mentioned specific barriers or challenges and ways they felt the program could improve for

family mentors. The primary challenges mentioned by mentors related to a poor match between

the trainee and the mentor, trainees' lack of information about the family prior to the initial

meeting, insufficient clarity around overall goals and expectations for the mentoring relationship,

and limited feedback from the LEND program.

While the LEND program worked to match trainees and mentors in a way that would be

mutually beneficial, there were times when mentors believed the match was not as effective. As

Sophia noted:

> My child is visually impaired and I thought that for them to give me a visually impaired
>
> trainee, was not a good match… because she was already living that life. She didn't need
>
> to come here and watch ours. If anything, she may have needed to get experience from a
>
> different viewpoint to give her insight…. The challenges that we had were not new to
>
> her…. I just thought that it would have been better for them to pair her with someone
>
> else.

Other mentors indicated that even when the match with the trainee was good, there were

sometimes logistics or scheduling issues where the family and the trainee had difficulty aligning

their schedules or finding appropriate transportation. As Avery stated, "It was supposed to be

(the trainee) initiating, but it was not always that way. And so, then we felt like it was our

responsibility, and then it fell back on us."

Mentors often stated that they felt that trainees did not have enough information about the

child and/or family prior to their initial meeting. LEND trainees were provided very limited

information about the family or the child prior to the initial meeting. The program's decision to

provide limited background information reflects (a) our hope that trainees would go into first visits with the family with limited assumptions about the child, their diagnosis, or the family dynamics; and (b) the belief that families should control how and when this information is shared with trainees. However, mentors noted that, as a result of trainees having a limited knowledge about their child or their diagnosis, they had to spend the initial visits providing background and context to the trainee instead of focusing on daily living experiences, which some mentors found to be problematic. As Ella observed, "I think the first couple of times, I just assumed that they knew he was autistic. And that I have a son, but like, they didn't know anything." However, others were fine with the basic information presented. For example, Sophia explained, "Not knowing too much, I think allowed them to not to draw a conclusion before meeting us. I think the only thing they need to know is that we had, you know, maybe what the disability of my son was. And then they just responded accordingly."

Another concern that was commonly mentioned by mentors was a lack of clarity regarding the goals and expectations of the program. Although both trainees and mentors are provided written guidance on the expectations for the FME, several mentors mentioned being unsure about what exactly should be shared with trainees, or what trainees were supposed to be getting out of the family mentoring experience. Ella indicated, "It would help me direct what I'm teaching them… to know what they need exactly. So that I don't sit there and give them a whole bunch of stuff that they don't need." Isabella suggested having a clearer and more transparent set of goals and activities for mentor-trainee pairs: "It'd be helpful to have some suggestions, even at the beginning of the semester. Yeah. Here's your mentee. Try to connect and have three meetings, here's some ideas for things that you could do. Things that mentees in the past have said or particular school types of things. And that would just help a little bit."

Another common challenge discussed during the interviews was how much personal information to disclose to trainees. For instance, Ella noted that what she shared with trainees changed over time and with experience: "I think I think at first I would share way too much and I could tell they're like, 'Okay, stop.' And then since then, I think I've cut back a lot and just kind of been like, you know, share a little bit and then say, 'Okay, what else do you need to know?'" Others stated that they were constantly trying to decide if they were sharing too much or too little.

Although trainees were expected to give a short presentation at the end of the year about their experience with the family, multiple mentors noted they were not provided information or access to the presentation. Several mentors indicated that they would like to be able to participate in the presentation activity, in particular to get a better sense of how they were being portrayed. As Ella stated, "I just kind of curious to see what they come up with. I think that would also kind of help me to understand like maybe if they presented some information that is not exactly what I was meaning to portray. Maybe they'll help me to get that information more accurately next time." In particular, Ella further noted wanting more transparency about the presentations: "I want to know, are they going to do a presentation to talk about my child? Are they going to go out in the community and, you know, utilize this information? Like what are they doing with that information? I guess would be helpful." Some mentors also mentioned that they would have appreciated feedback at the end of the year about the trainees' experiences. Isabella stated, "It would be helpful as a mentor to know how the mentee's experience was like, if they did any kind of like evaluation at the end… like, you know, this was an activity that really helped me or I was really grateful to have the chance to do this."

Discussion

The value of family professional partnerships for healthcare service providers has been

well documented (e.g., Dunst, 2002; Dunst & Espe-Sherwindt, 2016; Dunst & Trivette, 2010;

Kulthau et al., 2011; Turnbull et al., 2007); however, little work has examined FPP from the

perspective of the family members serving as mentors. The current study aimed to examine the

perspective of the family mentors participating in a FPP in a multidisciplinary training program

for future professionals who want to work with individuals with neurodevelopmental disabilities.

Qualitative interviews were conducted with the goals of understanding the family mentors'

reasons for continued participation and avenues for continued program improvement. Three main

themes emerged across the eight interviews: the value of connection and support, the ability to

educate others, and other barriers and facilitators of continued participation. The first two themes

provide insight into *why* family members participate in experience, while the third provides

greater insight for other training programs on ways to better support participating family

mentors.

Connection

The first theme that was evidence as a reason for the mentors' continued participation in

the FME was the sense of personal connection created with trainees. These connections, which

ranged from making professional connections, to developing support networks, and to creating

lifelong friendships, were discussed as one of the major factors that contributed to family

mentors having a positive overall experience and motivated their continued participation with the

program.

This emphasis on connection seems to suggest that the relationships that family mentors

formed with trainees, even over a relatively short timeframe, went beyond a standard

practitioner-patient relationship. One of the main reasons for this may be that these partnerships

were guided and shaped by the family mentors. They determined how much they wanted share

and what aspects of their daily lives they wanted the trainee to observe and experience. This is

consistent with previous literature examining outcomes of other FPP in training programs, that

families report feeling high level of self-efficacy (Bogetz et al., 2015). This sense of personal

efficacy may have allowed family mentors to be more vulnerable and authentic in sharing their

daily experiences, stressors, and struggles with a future health service professional while

maintaining comfortable boundaries. The family-driven experience appeared to empower

mentors to see themselves as the experts in their own experiences and view the relationship with

future healthcare professionals in a different light.

Social capital theory may also help explain, at least in part, the benefits associated with

forming personal connections and relationships for the family mentors. While social capital is a

large, amorphous construct, two subtypes have emerged in research across a variety of

disciplines: bonding and bridging social capital (Putnam, 2000). Bonding social capital describes

connections within homogenous groups, which result in benefits like emotional support and

sense of community; conversely, bridging social capital refers to connections between members

of different groups that can result in access to new information and resources (Burke et al., 2010;

Putnam, 2000). Interview responses indicate that both bonding and bridging social capital are

present in the connections formed in the FME. Several mentors reported that establishing

supportive connections to other family members (an instance of bonding social capital) was one

benefit of participating in the FME. Additionally, family mentors reported the connection to

future and current disability-serving professionals and greater awareness to community resources

(both instances of bridging social capital) were also beneficial. These instances of bridging social

capital may be particularly noteworthy as they suggest participating in the FME helps families

connect with service and supports that facilitate their child's inclusion and well-being across multiple life domains.

Further, social capital theory generally posits that networks of relationships among people increase effective functioning with a group (Putnam, 2001). This relationship has been found to be facilitated by a shared sense of identity, a shared understanding of challenges and values, trust, cooperation, and reciprocity (e.g., De Silva et al., 2005; Dika & Singh, 2002; Islam et al., 2006). Mentors reported feeling more connected to trainees when the relationship was reciprocal rather than one-sided, which positively influenced their decision to continue to be family mentors. Additionally, family mentors shared their challenges and values with trainees, which they often cited as a facilitator to the formation of these personal connections. Thus, increased social capital may be one possible explanation as to why connections with trainees were one of the most frequently cited reasons for continued participation in the FME.

Education

The second theme that family mentors frequently noted as a benefit of participating in the LEND program was the opportunity to help educate future healthcare and service professionals on the real-life experiences of individuals and families with disabilities. Family mentors frequently expressed this ability to educate future professionals as their "mission," providing them with an opportunity to give back to the community and make a difference for future families. Several family mentors noted negative experiences with professionals, and cited participation in the FME an opportunity to influence how future professionals treat individuals and families in the future.

This emphasis on this family-mentor relationship as a means of education might be explained, as least in part, through Contact Theory. Contact Theory suggests that contact

between groups can promote tolerance, acceptance, and a reduction in prejudice, particularly

under conditions where the groups are working towards a common goal (Allport, 1954;

Pettigrew & Tropp, 2006). In previous studies, FPP have been shown to improve practitioners'

understanding of family experiences, sensitivity to family issues, and active collaboration with

families (Bogetz et al., 2015; Johnson, et al., 2006; Keisling et al., 2017b; Rossignol, 2015).

Findings from the current study suggest that mentorship experiences also provided families with

the opportunity to create positive relationships with healthcare professionals, even in cases where

families have reported having negative past experiences. By providing families and future health

service professionals the opportunity to interact in a goal-directed mentorship experience,

families are able to shape the way that they share information to be more meaningful and

purposeful in educating future professionals about the daily experiences of individuals with

disabilities and their families. This access to and understanding of the families' lived experiences

may strengthen LEND trainees' commitment to policies and practices that facilitate greater

inclusion and self-determination.

Lessons for Training Programs

The final intended outcome of the interviews with family mentors was to better

understand the ways that the FME could be improved to support family mentors. In addition to

the ability to connect with and to educate others, several mentors also indicated that the inclusion

of a small stipend or incentive was a motivator for continued participation. This financial

incentive appeared to act more as a token of gratitude, recognizing the value of mentors'

knowledge and experience. This is consistent with literature from social psychology, which finds

that even a small sum of money can increase participation and perceived value (e.g., Stajkovic &

Luthans, 2001). Moreover, multiple mentors reported feeling as though they were receiving the stipend for doing something they were already passionate about and committed to supporting.

Interviewees described barriers or challenges that could be addressed in order to improve the mentoring experience and facilitate continued participation from families. One area for improvement that frequently emerged was increased transparency across several aspects of the program. While the family mentors often mentioned the value of sharing their experiences, they also frequently noted they did not always have a clear understanding of program goals, which made it more difficult to determine exactly what information to share. Some mentors worried they were over- or under-sharing because they were unsure about trainees' program requirements and trainees' needs and future goals. In addition, some family mentors wished trainees entered the initial mentoring interactions with more knowledge about their family, so that mentors felt less compelled to spend the initial visits presenting medical history and diagnoses. This transparency was also requested at the end of the mentor-trainee partnership, when trainees present about their experiences with families to their training cohort. Several mentors expressed wanting to be a part of that presentation or, at minimum, to have more information regarding what was being presented about their family. As one mentor noted, after being vulnerable and sharing about their personal life, they wanted to know how they were being portrayed in trainees' presentations.

Mentors noted a few additional instances when they would have appreciated clear communication about LEND program practices and goal, including understanding the factors that guided mentor-trainee matches and clear identification of a contact person to help problem solve when issues arose. This suggests that, although the program provides mentors information regarding the FME structure and expectations, more explicit communication and on-going

dialogue about program goals and procedures may help support successful experiences for both trainees and family mentors.

Limitations

One of the primary limitations of this study was the small sample size, as only eight interviews were included in the final coding. Despite this small sample, the use of CQR as a qualitative coding method allowed for in-depth thematic coding that was extremely consistent across interviews, suggesting that the experiences and perspectives of the family mentors may be generalizable to other experiences within this particular family mentor experience. Similarly, in order to get a deeper understanding of why family mentors continued to participate, only those who had at least two years of participation were interviewed. As such, we did not get the perspectives of those family mentors who chose to discontinue their participation after one year, and it is possible those mentors' viewpoints may have differed from those described in the study. Finally, due to the continued relationship of several of the family mentors with the GaLEND program, there is the risk that their answers were influenced by social desirability in wanting to appear supportive of the program. However, as many of the families did express barriers or challenges in participating with the LEND program, they appeared willing to express both positive and negative feelings regarding their participation in the family mentor experience.

Future Directions

The majority of the research on FPP focuses on the outcomes and experiences of the professional in the dyad; thus, additional investigations are needed to achieve a richer understanding of families' perspective on these programs. To that end, one potential next step would be to facilitate a survey of family mentors across multiple LEND programs that incorporate a similar FME. A multi-LEND project survey determine trends across family mentor

experiences and needs. A survey of this type could serve as a benchmark regarding the facilitators and barriers to continued family mentor participation and might help shape future efforts by programs to support and serve both LEND trainees and the family mentors.

Conclusions

Overall, these interviews shed light on the previously unexplored family perspective regarding FPP training experiences, despite their common use across a variety of healthcare and health service professional training programs. In the current study, family mentors expressed many reasons for ongoing participation in these types of experiences, including personal connections, the opportunity to train and educate future professionals to provide more family-centered services, and small financial incentives that served as acknowledgement of the mentors' expertise and knowledge. Moreover, our results provide some insight into ways to enhance the FPP training experience for families, including a focus on transparency in both goals and practices to help the family mentors tailor their sharing in a way that is mutually beneficial for both families and trainees. Participation in FME is often described by trainees as an essential particularly impactful component of their LEND training. Continued evaluation and enhancements to this training element is important to insure future professionals are positioned to develop and implement supports that enhance outcomes and quality of life for individuals with neurodevelopmental disabilities and their families.

References

Ahuja, A. S., & Williams, R. (2005). Involving patients and their carers in educating and training practitioners. *Current Opinion in Psychiatry*, *18*(4), 374-380.

Allen, R. I., & Petr, C. G. (1996). *Toward developing standards and measurements for family-centered practice in family support programs.* In G. H. S. Singer, L. E. Powers, & A. L. Olson (Eds.), *Family, community & disability series, Vol. 1. Redefining family support: Innovations in public–private partnerships* (p. 57–85). Paul H. Brookes Publishing Co.

Allport, G. W. (1954). The nature of prejudice. Cambridge/Reading, MA: Addison-Wesley.

Appell, D. J., Hoffman, M. W., Speller, N. B., Weiner, P. L., & Meryash, D. L. (1996). Parents as teachers: an integral component of a developmental and behavioral pediatrics curriculum. *Journal of Developmental & Behavioral Pediatrics*, *17*(2), 105-106.

Blasco, P. A., Kohen, H., & Shapland, C. (1999). Parents- as- teachers: design and establishment of a training programme for paediatric residents. *Medical Education*, *33*(9), 695-701.

Bogetz, J. F., Rassbach, C. E., Bereknyei, S., Mendoza, F. S., Sanders, L. M., & Braddock, C. H. (2015). Training health care professionals for 21st-century practice: a systematic review of educational interventions on chronic care. *Academic Medicine*, *90*(11), 1561-1572.

Butani, L., Sweeney, C., & Plant, J. (2020). Effect of a patient-led educational session on pre-clerkship students' learning of professional values and on their professional development. *Medical Education Online*, *25*(1).

Burke, M., Marlow, C., & Lento, T. (2010). Social network activity and social well-being. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1909-1912).

Coleman, K., & Murray, E. (2002). Patients' views and feelings on the community-based

　　　teaching of undergraduate medical students: a qualitative study. *Family Practice*, *19*(2),

　　　183-188.

Creswell, J. A. (1998). Five qualitative traditions of inquiry. *Qualitative inquiry and research*

　　　design. Choosing among five traditions, 47-72.

De Silva, M. J., McKenzie, K., Harpham, T., & Huttly, S. R. (2005). Social capital and mental

　　　illness: a systematic review. *Journal of Epidemiology & Community Health*, *59*(8), 619-

　　　627.

Dika, S. L., & Singh, K. (2002). Applications of social capital in educational literature: A critical

　　　synthesis. *Review of Educational Research*, *72*(1), 31-60.

Dunst, C. J. (2002). Family-centered practices: Birth through high school. *The Journal of Special*

　　　Education, *36*(3), 141-149.

Dunst C.J., Espe-Sherwindt M. (2016) Family-Centered Practices in Early Childhood

　　　Intervention. In: Reichow B., Boyd B., Barton E., Odom S. (eds) *Handbook of Early*

　　　Childhood Special Education. Springer, Cham.

Dunst, C. J., & Trivette, C. M. (2010). Family-centered helpgiving practices, parent-professional

　　　partnerships, and parent, family and child outcomes. In S. L. Christenson & A. L.

　　　Reschly (Eds.), *Handbook of school-family partnerships* (pp. 362-379) Routledge.

Epley, P., Summers, J. A., & Turnbull, A. (2010). Characteristics and trends in family-centered

　　　conceptualizations. *Journal of Family Social Work*, *13*(3), 269-285.

Galil, A., Glick, S., Flusser, H., Lubetzky, H., Law, Y., Kaplan, S., Martine Chen, M. C., &

　　　Margolis, C. Z. (1996). Teaching medical students about disability: a community-based

　　　approach. *Medical Teacher*, *18*(4), 333-337.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment

        with data saturation and variability. *Field Methods*, *18*(1), 59-82.

Health Resources & Services Administration: Maternal and Child Health. (May 2018). MCH

        Leadership Competencies. https://mchb.hrsa.gov/training/leadership-00.asp

Hennick, M.M., Kaiser, B.N., & Marconi, V.C. (2017). Code saturation versus meaning

        saturation: How many interviews are enough? *Qualitative Health Research, 27*(4), 591-

        608.

Hill, C. E. (2012). *Consensual qualitative research: A practical resource for investigating social

        science phenomena*. American Psychological Association.

Institute for Patient- and Family-Centered Care. (2007). About Us. Institute for Patient- and

        Family-Centered Care. https://www.ipfcc.org/about/index.html

Islam, M. K., Merlo, J., Kawachi, I., Lindström, M., & Gerdtham, U. G. (2006). Social capital

        and health: does egalitarianism matter? A literature review. *International Journal for

        Equity in Health*, *5*(1), 1-28.

Jackson, A., Blaxter, L., & Lewando- Hundt, G. (2003). Participating in medical education:

        views of patients and carers living in deprived communities. *Medical Education*, *37*(6),

        532-538.

Johnson, B. H. (2000). Family-centered care: Four decades of progress. *Families, Systems, &

        Health*, *18*(2), 137-156.

Johnson, A. M., Yoder, J., & Richardson-Nassif, K. (2006). Using families as faculty in teaching

        medical students family-centered care: what are students learning?.*Teaching and

        Learning in Medicine*, *18*(3), 222-225.

Jolley, J. (2007). Separation and psychological trauma: a paradox examined. *Paediatric*

    Nursing, *19*(3), 22-25.

Jolley, J., & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric*

    Nursing, *24*(2), 164-170.

Keisling, B. L., Bishop, E. A., Kube, D. A., Roth, J. M., & Palmer, F. B. (2017a). Long-term

    pediatrician outcomes of a parent led curriculum in developmental disabilities. *Research*

    in Developmental Disabilities, *60*, 16-23.

Keisling, B. L., Bishop, E. A., & Roth, J. M. (2017b). Integrating family as a discipline by

    providing parent led curricula: impact on LEND trainees' leadership

    competency. *Maternal and Child Health Journal*, *21*(5), 1185-1193.

Kube, D. A., Bishop, E. A., Roth, J. M., & Palmer, F. B. (2013). Evaluation of a parent led

    curriculum in developmental disabilities for pediatric and medicine/pediatric

    residents. *Maternal and Child Health Journal*, *17*(7), 1304-1308.

Kuhlthau, K. A., Bloom, S., Van Cleave, J., Knapp, A. A., Romm, D., Klatka, K., Homer, C. J.,

    Newacheck, P W., & Perrin, J. M. (2011). Evidence for family-centered care for children

    with special health care needs: a systematic review. *Academic Pediatrics*, *11*(2), 136-143.

Lincoln, Y. S. & Guba, E. G. (1985). Naturalistic Inquiry. Newbury Park, CA: Sage

    Publications.

Pettigrew, T. F., & Tropp, L. R. (2006). A meta-analytic test of intergroup contact

    theory. *Journal of Personality and Social Psychology*, *90*(5), 751-783.

Putnam, R.D. (2000) Bowling Alone. New York: Simon and Schuster

Putnam, R. (2001). Social capital: Measurement and consequences. *Canadian Journal of Policy*

    Research, *2*(1), 41-51.

Robertson, J. (1970). *Young children in hospital* (Vol. 57). Routledge Kegan & Paul.

Romney, A. K., Weller, S. C., & Batchelder, W. H. (1986). Culture as consensus: A theory of

      culture and informant accuracy. *American Anthropologist*, *88*(2), 313-338.

Rossignol, L. (2015). Relationship between participation in patient-and family-centered care

      training and communication adaptability among medical students: Changing hearts,

      changing minds. *The Permanente Journal*, *19*(3), 54-58.

Shields, L., Pratt, J., & Hunter, J. (2006). Family centered care: a review of qualitative

      studies. *Journal of Clinical Nursing*, *15*(10), 1317-1323.

Stacy, R., & Spencer, J. (1999). Patients as teachers: a qualitative study of patients' views on

      their role in a community- based undergraduate project. *Medical Education*, *33*(9), 688-

      694.

Stajkovic, A. D., & Luthans, F. (2001). Differential effects of incentive motivators on work

      performance. *Academy of Management Journal*, *44*(3), 580-590.

Turnbull, A. P., Summers, J. A., Turnbull, R., Brotherson, M. J., Winton, P., Roberts, R., ... &

      Stowe, M. (2007). Family supports and services in early intervention: A bold

      vision. *Journal of Early Intervention*, *29*(3), 187-206.

Turner, T. L., Hime, E. J., & Ward, M. A. (2011). Impact of a Parent Directed Teaching Program

      in Family Centered Chronic Care. *Academic Pediatrics*, *11*(4), e6.

Walters, K., Buszewicz, M., Russell, J., & Humphrey, C. (2003). Teaching as therapy: cross

      sectional and qualitative evaluation of patients' experiences of undergraduate psychiatry

      teaching in the community. *British Medical Journal*, *326*(7392), 740-746.
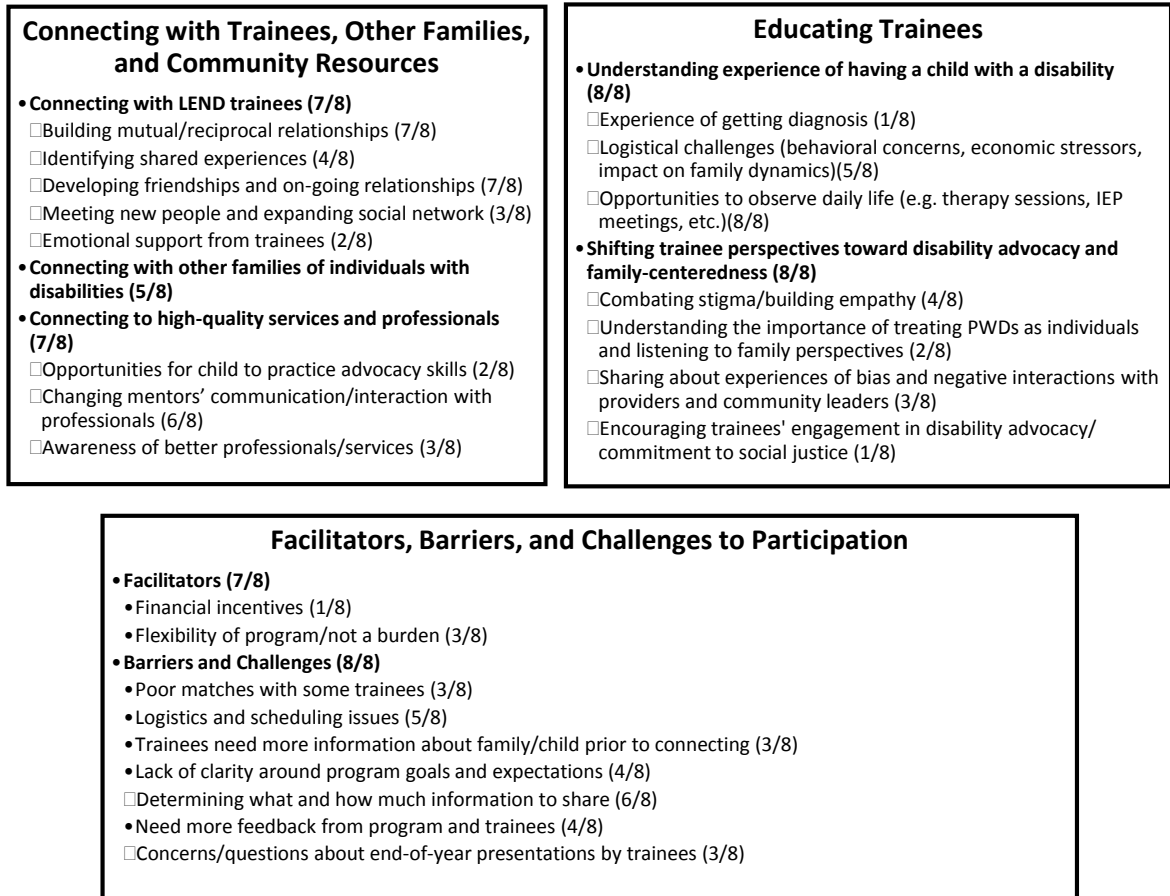
Zajicek-Farber, M. L., Lotrecchiano, G. R., Long, T. M., & Farber, J. M. (2015). Parental

perceptions of family centered care in medical homes of children with

neurodevelopmental disabilities. *Maternal and Child Health Journal, 19*, 1744–1755.

Figure 1

Semi-structured Interview Protocol

1. How did you learn about the family mentor experience?
    a. How long have you been involved? If not currently involved, when were you involved?
2. Describe your overall experience as a family mentor.
    a. Did your experience differ based on the discipline of your trainee? If yes, how so?
    b. What worked well?
    c. What did not work well?
3. Describe the types of experiences have you had with trainees.
    a. How did you communicate with trainees?
    b. How did you decide what to do with trainees?
    c. Give examples of experiences you had with trainees. How much time did you spend on average with trainees?
    d. Are there experiences you wish you had gotten to share with trainees that you were unable to share for whatever reason? Why?
    e. Did you think about your trainees' discipline when deciding on experiences to share with them?
4. What kinds of things have you discussed with trainees?
    a. What are some conversations that stand out to you?
5. What have been the most valuable experiences you have had with trainees?
    a. What do you think was the most valuable experience for you and/or your family?
    b. What do you think was the most valuable experience for the trainee?
6. What is/was your favorite part(s) of the family mentor experience?
7. What would you change about the family mentor experience?
    a. Logistical changes? (e.g., mode of communication, trainee you were paired with, amount of time spent with trainee)
    b. Changes in communication/support from GaLEND team regarding the program?
8. What are the factors that contribute to your continued participation with the family mentor program?
    a. If you are not currently a family mentor or you are considering not serving as one next year, what are the factors that contributed to that decision?
9. How has your participation as a family mentor impacted the way you see or interact with health/service professionals?
    a. Describe any impact on interactions with professionals in the same field as your trainee(s).
    b. What about interactions with professionals in different fields?
10. How do other members of your family (e.g., your children, partner/spouse, grandparents, extended family) feel about the family mentoring experience?
    a. What about other people involved in the experiences that you shared with the trainees (e.g., teachers, close family friends, direct support professionals)?
11. What do you wish GaLEND trainees knew before they met your family?
    a. Were there things that they did not know about you or the family mentor program that would have been helpful for them to know before the initial meeting?
    b. What do you wish you knew before meeting the trainees?
    c. What would you want to share with family mentors who are going to be in the program for the first time?
12. What else do you think would be important for us to know that we have not talked about?

Figure 2

Themes and Core Ideas in Participant Responses

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Connecting with Trainees, Other Families, and Community Resources

- **Connecting with LEND trainees (7/8)**
  □ Building mutual/reciprocal relationships (7/8)
  □ Identifying shared experiences (4/8)
  □ Developing friendships and on-going relationships (7/8)
  □ Meeting new people and expanding social network (3/8)
  □ Emotional support from trainees (2/8)
- **Connecting with other families of individuals with disabilities (5/8)**
- **Connecting to high-quality services and professionals (7/8)**
  □ Opportunities for child to practice advocacy skills (2/8)
  □ Changing mentors' communication/interaction with professionals (6/8)
  □ Awareness of better professionals/services (3/8)

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Educating Trainees

- **Understanding experience of having a child with a disability (8/8)**
  □ Experience of getting diagnosis (1/8)
  □ Logistical challenges (behavioral concerns, economic stressors, impact on family dynamics)(5/8)
  □ Opportunities to observe daily life (e.g. therapy sessions, IEP meetings, etc.)(8/8)
- **Shifting trainee perspectives toward disability advocacy and family-centeredness (8/8)**
  □ Combating stigma/building empathy (4/8)
  □ Understanding the importance of treating PWDs as individuals and listening to family perspectives (2/8)
  □ Sharing about experiences of bias and negative interactions with providers and community leaders (3/8)
  □ Encouraging trainees' engagement in disability advocacy/ commitment to social justice (1/8)

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Facilitators, Barriers, and Challenges to Participation

- **Facilitators (7/8)**
  - Financial incentives (1/8)
  - Flexibility of program/not a burden (3/8)
- **Barriers and Challenges (8/8)**
  - Poor matches with some trainees (3/8)
  - Logistics and scheduling issues (5/8)
  - Trainees need more information about family/child prior to connecting (3/8)
  - Lack of clarity around program goals and expectations (4/8)
  - □ Determining what and how much information to share (6/8)
  - Need more feedback from program and trainees (4/8)
  - □ Concerns/questions about end-of-year presentations by trainees (3/8)

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Note. The number of the family mentors (n=8) whose statements matched each thematic code is listed.

Table 1

Participant Information

Participant	Gender	Race/ Ethnicity	Child Diagnosis	Number of Years as a Mentor	Number of Mentees
1. "Ella"	Female	White	Autism	3	4
2. "Sophia"	Female	Black	Visual Impairment	3	3
3. "Ava"	Female	White	Autism	3	3
4. "Charlotte"	Female	Black	Autism	5	5
5. "Avery"	Female	White	Cerebral Palsy	8	8
6. "Isabella"	Female	White	Autism	3	4
7. "Evelyn"	Female	Black	Learning Disability, ADHD, and Autism	3	3
8. "Harper"	Female	Black	Autism	3	4