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## Parents' Part C Experiences in Rural Areas: Alignment With Recommended Practices

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### Abstract

The Division for Early Childhood (DEC) clearly outlined recommended practices for the provision of Part C services. However, there may be challenges in rural areas associated with services aligning with these recommended practices. Therefore, this study focuses on how families experience Part C services and the extent to which services align with specific areas the DEC recommended practices in the large, rural state of Montana. We interviewed parents ( $N = 30$ ) about their children's Part C services. Deductive qualitative content analysis was used. Parents' reports suggest that while some aspects of their Part C services align with specific recommended practices, others do not. There were some meaningful differences regarding alignment with these recommended practices depending on type of provider being described. The environments in which services take place are discussed, as these may influence aspects of collaboration and building family capacity.

### Keywords

Part C Services; qualitative methods; family collaboration and support; disabilities and development delays; infants and toddlers

### Introduction

Early intervention (EI) comprises a multitude of programs and services (e.g., Part C of the Individuals with Disabilities Education Act [IDEA], Head Start; Early Head Start; the Maternal, Infant, and Early Childhood Home Visiting Program) all coalescing around the understanding that providing supports early in a child's life promotes optimal outcomes, despite known risk factors such as disability, poverty, or early trauma (Shonkoff & Phillips, 2000). There is clear evidence that EI services, such as Part C, are crucial to children's current and later life outcomes (Campbell et al., 2002; Center on the Developing Child at

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Supplemental Material

Supplemental material for this article is available online.

Harvard University, 2010; IDEA, 2019a). Using existing evidence and input from many stakeholders, the Division for Early Childhood (DEC; 2014) developed the DEC Recommended Practices, which are intended to guide practitioners' and support families' knowledge, skills, and dispositions. The DEC recommended practices include the topic areas of leadership, assessment, environment, family (with subtopic areas of family-centered practices [FCPs], family capacity-building practices, and family and professional collaboration), instruction, interaction, teaming and collaboration, and transition.

Young children living in rural areas are more likely to receive special education services (Grace et al., 2006) and are frequently underrepresented in national research (Capizzano & Fiorillo, 2004). Rural families may experience challenges related to travel requirements and accessibility to services (Cummings et al., 2017; Hallam et al., 2009; Haring & Lovett, 2001; Rural Health Information Hub, 2018), poverty (Hallam et al., 2009; Haring & Lovett, 2001), and a lack of information about services (Bush et al., 2015; Elpers et al., 2016). Agencies in rural areas also struggle to hire and retain Part C service providers, and very few specialized providers (e.g., physical, occupational, and speech therapists) in rural areas have pediatric back-grounds (Haring & Lovett, 2001). Presently, research focused on rural families' experiences of receiving Part C services and the alignment with specific DEC (2014) recommended practice areas is not available.

The challenges faced in rural areas, particularly around accessibility to services and highly trained professionals (Cummings et al., 2017; Hallam et al., 2009; Haring & Lovett, 2001; Rural Health Information Hub, 2018), may influence the environments in which Part C services take place. It is important to note that the Part C literature and recommended practices describe environments in ways that extend beyond the *where* and *what* of services (location, and the activities, routines, and materials used; Childress, 2004; DEC, 2014) to also encompass *how* services are provided (DEC, 2014; Shelden & Rush, 2001). *Where* services take place relates to *how* services are provided (Dunst et al., 2014). Service delivery in natural environments is intended to include aspects of family-based practices (Childress, 2004; DEC, 2014; Woods, 2008). Therefore, in this qualitative study, focused on parents living in a rural state whose children receive Part C services, we draw attention to the main topic areas of "environments" and "family" from the DEC (2014) recommended practices. Specifically, this exploratory study focuses on the *where* and *what* of environments, and the related aspects of family-based practices of collaboration and building family capacity, as these are key components to understanding *how* Part C services are delivered.

### Natural Environments

*Where* Part C services take place is important. Children with delays or disabilities greatly benefit from being included in natural environments (Childress, 2004; Odom et al., 2011; Raver & Childress, 2015; Snyder et al., 2015). Natural environments are settings common to children's daily lives and are similar to the settings in which children without exceptionalities spend time (Campbell et al., 2009). As such, Part C services are required to be provided in children's natural environments, such as their home, childcare, or other community settings, unless these services cannot be adequately provided in these environments (IDEA, 2019b). Despite evidence for and recommendations regarding service

provision within natural environments, some parents and providers may prefer clinic-based services (Fitzpatrick et al., 2007) or view clinic-based services as more supportive of outcomes for children with exceptionalities (Stewart, 2011). Families in rural communities report traveling to Part C appointments is a challenge they face (Cummings et al., 2017; Hallam et al., 2009; Haring & Lovett, 2001), which may suggest that Part C services are not taking place in children's home environments.

Natural environments also include other contexts in which services take place beyond only the physical location (Campbell et al., 2009)—*what* occurs during services also matters. For instance, the activities, routines, and materials used for Part C services can be influential to children's development (Dunst et al., 2006; McWilliam, 2010). Using everyday activities as the focus of learning can positively influence children (Dunst et al., 2006) and is in line with parent preferences (Kingsley & Mailloux, 2013). Families report a variety of routines that are important to their everyday lives (Dunst et al., 2000), but play tends to predominate during Part C visits (Campbell & Sawyer, 2007; Nwokah et al., 2013). Finally, providers are encouraged to use families' materials, rather than bringing their own (McWilliam, 2010; Williams & Ostrosky, 2019; Workgroup on Principles and Practices in Natural Environments [WPPNE], 2008).

### Collaboration

An important aspect of *how* Part C services are provided includes collaboration among providers and families (DEC, 2014). The role of Part C providers, regardless of discipline or type of team member, is to collaborate with and support each child's family and caregivers (Raver & Childress, 2015; WPPNE, 2008). Collaborative interactions build relationships and help families meet their desired goals through trust, respect, and responsiveness (DEC, 2014). Collaboration is a key component of FCP, which has been identified as the most effective EI service model (Dunst et al., 2007). FCP views children in the context of their family and aims to respectfully partner with families, respond to their unique needs, and promote their ability to make informed decisions to support their child's development (Bailey et al., 2012; Childress, 2004; DEC, 2014). Parent-provider relationships within FCP have been positively associated with parents' self-efficacy beliefs, empowerment, ability, and overall satisfaction with services (Dempsey & Dunst, 2004; Dempsey & Keen, 2008; Dunst et al., 2007; Kingsley & Mailloux, 2013). FCP has also been shown to positively influence parent and child psychological health (Dunst & Trivette, 2009) and child behavior (Dunst et al., 2007; Kingsley & Mailloux, 2013). Despite benefits of FCP, research highlights a gap between FCP recommendations and actual practices (Turnbull et al., 2007).

Part C teams are intended to include families and providers from multiple disciplines that all work together to meet each child and family's needs (DEC, 2014), sharing information among all team members (DEC, 2014; McWilliam, 2010; Raver & Childress, 2015). This information sharing should be done in a way that is understandable to all team members, especially families (McWilliam, 2010; Raver & Childress, 2015). However, some therapists find communication and collaboration with other providers to be some of the biggest challenges they face in providing Part C services (Bowyer et al., 2017). Collaboration may

be even more challenging in rural areas due to hardships related to hiring and retaining providers (Haring & Lovett, 2001).

Part C providers' collaborative role may also include providing referrals to other providers outside of their scope of practice as well as providing information about other community resources (Frantz et al., 2018). Families' perceptions of the family-centered nature of services have been linked with their ability to gain access to other resources, supports, and services needed (Dunst et al., 1996). Collaboration is frequently a precursor or concurrent process related to building family capacity (Dunst et al., 2007).

### **Building Family Capacity**

In 1986, Congress found an “urgent and substantial need . . . to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps” (Education of the Handicapped Act, 1986, p. 1145). This greatly influenced *how* Part C services are intended to support families: by building each family's capacity. Part C providers can support families' capacity by providing opportunities for family participation, by reinforcing families' strengths in opportunities provided to families, and then supporting families to develop new skills and acquire knowledge (DEC, 2014). Helping to build families' capacity is at the core of Part C services given that two of the five identified family outcomes include “families *help* their child develop and learn” and “families know their rights and *advocate* effectively for their child” (Early Childhood Technical Assistance Center, 2019, emphasis added).

Services should be primarily directed at children's primary caregivers because learning occurs between visits and children learn from caregivers in their everyday lives (McWilliam, 2010). Participatory helpgiving, which includes family decision making and engagement to meet their goals, has been shown to help build family capacity (Dunst et al., 2007). One type of participatory helpgiving referred to as “coaching” is a structured way of building family capacity and establishing the caregiver in the role of the child's teacher (Friedman et al., 2012; Rush et al., 2003; Rush & Shelden, 2011). The use of coaching is in line with research related to adult learning styles. For example, adult learning increases when the learner is included in the planning of the program (Merriam & Leahy, 2005), which is in line with recommendations that families be viewed as “the most important decision makers” related to services (Raver & Childress, 2015, p. 34) and the development of the Individualized Family Service Plan (IFSP; IDEA, 2019c, 2019d). Additional principles of adult learning also have implications for Part C services, including helping families reflect on their knowledge and skills, and then building on these to help families meet those goals (National Research Council, 1999) by offering opportunities for them to practice, receive feedback, and apply their learning (Ambrose et al., 2010).

Despite these recommendations, a large proportion of service providers tend to use a medical model (e.g., child-focused direct intervention; Campbell & Sawyer, 2009). The research focused on rural families' Part C experiences has shown that few families felt they could follow through with their therapists' recommendations and/or incorporate these into their everyday lives (Haring & Lovett, 2001), which has implications for ways in which to build capacity of families living in rural areas.

## Perspectives on Recommended Practices

Providers and families report similar beliefs about aspects of recommended practices (King et al., 2003; Klein & Chen, 2008; McWilliam et al., 2000), yet research demonstrates that Part C practices do not always reflect these beliefs (Bruder, 2010; Campbell & Halbert, 2002; Campbell & Sawyer, 2007; Dempsey & Keen, 2008; McLean et al., 2002). Providers who rated the use of FCPs as not very important were those working in clinic-based settings who had most experience (McWilliam et al., 2000). In fact, some providers would prefer Part C services return to older models of center-based delivery (Campbell & Halbert, 2002). Related to family capacity building, providers value parental involvement but they may not fully understand or receive education/training on how to facilitate interactions during visits that support caregiver-child interactions (Campbell et al., 2009; Fleming et al., 2011). In fact, very little time may be spent during EI visits focused on the types of participatory activities that facilitate adult learning (Peterson et al., 2007). Many providers work directly with the child (Fleming et al., 2011; Klein & Chen, 2008; Sawyer & Campbell, 2012), while very few use participation-based services in line with recommended practices (Campbell & Sawyer, 2007).

## The Current Study

Taken together, this research indicates parents and providers have similar perspectives on ideal practices which align with recommendations in the field. Despite this consensus, there is variation in the use of these recommended practices. This variation warrants an in-depth qualitative approach to understand parents' experiences of receiving Part C services and how this aligns with specific DEC (2014) recommended practice areas (Rodger et al., 2008), especially for families living in rural areas as there may be unique challenges that influence the provision of services (Bush et al., 2015; Cummings et al., 2017; Elpers et al., 2016; Hallam et al., 2009; Haring & Lovett, 2001). Therefore, the overall purpose of this exploratory study is to better understand parents' experiences of receiving Part C services as related to the specific DEC (2014) recommended practice areas of (a) "where" and "what" of natural environments, (b) collaboration, and (c) building family capacity. A secondary purpose is to explore how these experiences may differ across disciplines as Part C services may include multiple specialized providers.

## Method

### Setting

This study took place in the state of Montana where the Department of Public Health & Human Services (DPHHS) oversees five regional agencies who provide general administration and coordination of Part C services. These five agencies employ a total of approximately 60 family support specialists (FSSs), who serve as the child's and family's service coordinator, and provide "family training, counseling, and home visits ... to assist the family of an infant or toddler with a disability in understanding the special needs of the child and enhancing the child's development" (IDEA, 2019e, section b—paragraph 3); training for FSSs is provided by their regional agency. Children also receive services from a variety of other professionals as part of their multidisciplinary team. In Montana, this most frequently includes regular contact with physical therapists (PTs), occupational therapists

(OTs), and/or speech language pathologists (SLPs) who work as “vendors” which means that while each professional is included on the Part C team, they are connected to their own individual agencies and billing structures (McWilliam, 2010). In Montana, this means therapists work as part of more than 60 agencies spread throughout the state, such as private practices, clinics, or hospitals. These therapists are not contracted through Part C agencies; most therapies are paid for through families’ private insurance or Medicaid, or in some situations, Part C agencies serve as payor of last resort and will offset these costs for families if other private or public benefit sources are not available (Montana DPHHS, 2013). Families choose their therapist(s) and FSSs then include those therapists in the IFSP process. As nearly all therapists who provide services to children in Montana’s Part C system are not employed through one of the five regional Part C agencies, these therapists are not required, or necessarily provided with an opportunity, to receive training related to Part C or the DEC (2014) recommended practice areas that are intended to guide these services. This also means that, as they are primarily employed through clinic- or hospital-based agencies, rather than Part C directly, they are not required to provide in-home services.

Montana is one of the geographically largest states in the nation (National Network of Libraries of Medicine, 2019). Montana has 56 counties, and 52 of these qualify as rural (Health Resources & Services Administration, 2018). With an average population of only 6.8 people per square mile, Montana is also one of the most rural areas in the United States and is considered “frontier” (i.e., individuals must travel far on average, in terms of distance and/or time, to receive any form of services including health care; National Center for Frontier Communities, 2014; Rural Health Information Hub, 2018). Importantly, 71.4% of Montana’s counties are considered medically underserved areas (Health Resources & Services Administration, 2019b) and 44.6% are considered primary care health professional shortage areas (Health Resources & Services Administration, 2019a).

## Sample

Parents ( $N=30$ ) who self-identified as the primary caregiver of a child (or children) receiving Part C services participated in this study. All primary caregivers identified as female. Although most parents were Caucasian, two participants identified as Hispanic or Latino, three participants identified as Caucasian and American Indian, and one participant identified as American Indian.

Two parents had two children receiving Part C services, so a total of 32 children ( $n=20$  males) were discussed; they ranged in age between 3.6 and 38.2 months at data collection ( $M_{\text{age at}} = 23.0$  months,  $SD = 11.0$  months). Twenty-three children were Caucasian, one child was Hispanic, one child was American Indian, and seven children were more than one race/ethnicity (five children were Caucasian and American Indian, one child was Caucasian and Asian, and one child was American Indian and Hispanic or Latino). Parents reported a variety of reasons for their child’s receipt of Part C services, including one or more of the following: developmental delays in one or more areas; diagnosed conditions (e.g., autism spectrum disorder, cerebral palsy, hydro-cephalus); and other factors such as prematurity and heart or brain disorders. For more information about parents, families, or children, see Table 1.

Multiple families from each of Montana's Part C regions were included in the sample (Figure 1). Our sample was largely from rural areas; 19 (63.3%) of the families in our sample had physical addresses designated as rural (United States Census Bureau, 2013). Montana has three "metropolitan areas" according to the population requirements of the U.S. Census (United States Census Bureau, 2013) but the entire state of Montana is designated as frontier based on population density (i.e., "sparsely populated rural areas"; Rural Health Information Hub, 2018, para. 3) and access to services (Rural Health Information Hub, 2018). Therefore, regardless of physical addresses, all families in our sample were living in a frontier state designated as having limited access to services on average.

## Procedures

The study procedures were approved by a university Institutional Review Board. This study was initiated by the principal investigator (PI), and while the study was supported by partnerships with Montana's DPHHS and regional Part C agencies, it was not an official evaluation of Montana's Part C services. To support this study, Montana's five regional Part C agencies sent out flyers to families whose children were receiving services, providing them with information about this study and contact information for the PI (the first author) if they were interested in participating. The goal was to recruit at least one family from each region to participate. Flyers were sent out once for regions 2 to 5 and twice for region 1 (where there were fewer families being served and no responses after a first set of flyers were sent); these flyers were staggered by region over a period of 3 months. All families who had a child within 0 to 36 months of age receiving Part C services in Montana at the time they received the flyer were eligible to participate. Upon contacting the PI, a visit was set up for a day, time, and location based on the family's preference; all families chose to meet with the PI and a member of the research team in their home. At the end of the 3-month period of sending out flyers, 31 parents had contacted the PI and a total of 30 visits had been scheduled; one parent did not follow up with the PI after being asked about specific days or times they would have available for a visit. The PI led each visit, with the research assistant helping to play with the child(ren) or with other tasks. The PI began each visit by sharing about their previous experiences of working with children with delays and/or disabilities in the school system and how this led to an interest in understanding families' earlier experiences with their children, including EI services. Participants provided written consent. The consent form outlined the purpose of the study, which was to better understand the way Part C services in Montana were being provided to families and their children, including ways in which families felt supported or how they felt services could be improved. The consent form also outlined that the information provided by participants about themselves, their children, and the specialist(s)/therapist(s) they described would be kept confidential and would not be shared with Montana's DPHHS or their Part C agency. Visits took approximately 1.5 to 2 hr and included a demographic questionnaire and a semi-structured, in-depth interview about the Part C services children received; all questionnaires and interviews were conducted in English. Families received a US\$40 gift card and a children's book for participating.

To better understand families' perceptions of receiving Part C services and how these align with the DEC (2014) recommended practice areas, the semi-structured interview included open-ended questions about FSSs and therapists (i.e., PTs, OTs, and SLPs). The same questions were asked about each type of provider (i.e., FSSs, PTs, OTs, SLPs). Questions included but were not limited to: *Tell me about what it is like during a typical visit when you see this early intervention provider; Where do services take place?; What types of things happen during visits with this provider?; What types of things do you talk about or work on?; How is it decided what will be worked on during a visit?; and What do you typically do during these visits?* A more complete list of the interview questions used to guide this study is included in the Supplemental Appendix.

## Data Analysis

The purpose of this study was to understand parents' experiences with Part C services in relation to specific DEC (2014) recommended practice areas. To accomplish this, a deductive qualitative content analysis (QCA) approach was selected (Elo & Kyngäs, 2008). A deductive QCA approach is used when there is existing research or frameworks in the topic area, and this approach was selected because there are established DEC (2014) recommended practice areas for providing EI. As indicated in the literature review, some of the DEC (2014) recommended practice topics that may be most influenced by rurality are captured in the major areas of (a) "where" and "what" of natural environments, and "how" services are provided, including (b) collaboration and (c) building family capacity. Consistent with the analytic approach (Elo & Kyngäs, 2008), the existing research and DEC (2014) recommended practice areas (i.e., "where" and "what" of natural environments, collaboration, and building family capacity) were used as the categories from which to code the data (Table 2). This process began with transcription of each interview by members of the research team. Per the deductive QCA (Elo & Kyngäs, 2008), the first two authors then read all transcripts to familiarize themselves with the data and identify aspects of interviews that were relevant to the study aim. Given the way in which Part C services are provided in Montana, prior to coding the researchers determined to note whether families were discussing a FSS or therapist during the coding process. The two researchers independently created a list of possible codes, using parents' own words, that fit within the categories. The first two authors then met, compared possible codes, and created an initial coding scheme.

The coding process began with the first two authors separately coding three transcripts to begin establishing intercoder agreement and to make any adjustments to the coding scheme. Two additional transcripts were then coded separately to establish interrater agreement and substantial agreement was achieved (Cohen's  $k = 0.79$ ; Landis & Koch, 1977). Remaining transcripts were coded by the second author. The first author then checked each transcript and the two researchers met to discuss and resolve any questions or disagreements. For presentation and transparency purposes, the number of families whose transcripts included each code (from one of the predetermined categories) was counted, and it was noted whether each code was related to a FSS or therapist. Each family was only counted once per code even if they shared the sentiment more than once. This allowed determining the percentage of families in our sample whose transcript included specific codes and to differentiate this based on whether the code pertained to FSSs and/or therapists. In the presentation of the

results, quotes were designated by whether the parent was discussing a FSS or therapist and when describing parents' experiences that were similar, regardless of whether they were describing a FSS or therapist, we use the term "provider."

## Results

Based on the qualitative analysis, results in three deductively based categories include (a) the "where" and "what" of natural environments, (b) collaboration, and (c) building family capacity (see Table 2). Participant quotes are provided throughout the results. Brackets are used to provide clarifying information and/or to omit information to protect participant confidentiality.

### The "Where" and "What" of Natural Environments

All parents ( $N = 30$ ) reported that their FSS met with the family in their home or a community setting, and only nine parents reported that therapist visits occurred in these environments. Of these nine families, seven consistently saw a therapist in their home, and two indicated that a therapy visit had been at their home or a community setting at least one time. One parent described how receiving services in their home helped to meet the specific needs of their child: "I really love that [the FSS] will come to your house it makes it so much easier. Especially with him; he would not be cooperative in another atmosphere." Some families also reported that services took place in a community setting such as a local park or at childcare: "[The therapist] comes to day-care about every other month."

Twenty of the 23 families who were seeing a therapist reported that visits took place in a clinical/office setting and indicated the clinical setting was the only option offered for these services. A parent described a therapist's reasoning for preferring clinic-based services:

[The therapist] goes, "I will only see [your child] when we're in the clinic because I prefer a clinical setting because at the end of the day I am trying to get these kiddos ready for school, and they are going to have to be used to that type of setting."

In some instances, parents described how it would be ideal to have a therapist visit their home or other community locations, but it may not be realistic. When discussing if services could take place somewhere outside of a clinic, one parent said, "It's hard when you live in such a rural area." Parents also spoke to how the availability of providers influenced where services take place, saying: "I would love a therapist to come to my home, but I know that they don't have therapists available to do that. There aren't enough, especially serving rural Montana," and "There is no such thing as home-based services in rural Montana ... let's face it you cannot get specialists who come into these communities and stay, it's not worth their while." Parents also talked about how travel distances influenced where services take place because a therapist may have to travel to a clinic to see multiple children in one day. They said, "So we live in complete rural Montana ... once a month the therapist comes from [one town] to the [clinic in our town, 135 miles away]," and "It's such a rural area and spread out ... [therapy] has to be a certain day."

In terms of the use of materials and tools, more providers used their own materials rather than those already accessible to the family. Parents indicated this professional practice could

be discouraging because they felt they could not meet their child's needs without these, often expensive, materials. For example, a parent disclosed, "I don't have the [therapy] equipment necessary on some of this muscle building and sensory input, you know, I can only have so much I can afford, it's not like I'm going out and buying like ball pits, you know." In contrast, parents recognized when providers prioritized materials in their homes and expressed appreciation for this practice. A parent shared, "[The FSS] uses the same tools that I have here at home." Concerning accessible materials, a parent explained it was "great because I didn't want to go out and have to buy a bunch of stuff."

Parents mentioned their providers had discussions about and/or worked directly with them during daily routines such as "playing," "dressing," "feeding," "reading," "cooking dinner," "bath time," and "bedtime." Parents recalled specific suggestions their providers made related to their daily routines: "[The therapist] gave great ideas of you know when to work with him [during a specific routine] so it wasn't so much of a burden," or "[The FSS] pointed out things I can do during diaper changes." Approximately half of the time that parents mentioned specific routines they discussed services taking place in the context of a play routine, but families mentioned other routines as well. For instance, a parent shared,

[The therapist] did mealtimes and I was surprised cause I was used to therapists just doing playtime and then telling us about things about the rest of the day. But she said, "Next time I come, serve up the food!"

Parents recognized the importance of services aligning with a child's routine and saw this as a strength when providers did this in practice. While talking generally about integrating various interventions into the child's daily life, one parent said, "Since we're in rural Montana and we get one half an hour of therapy per month, it needs to be stuff you can do at home obviously. It can't be stuff that's just 'drop what you're doing.'"

## Collaboration

Parents described aspects of their partnership with their providers, or their providers' partnerships with other professionals. Personal qualities of the provider were mentioned most frequently by the parents. They described providers' personal characteristics as "warm," "welcoming," "kind," "caring," "passionate," "personable," and "non-judgmental." These personal qualities and relational skills allowed parents to feel "reassured," that they had an "ally," and they were empowered "to do what I need for my kids." There were parents who described feeling supported, empowered, or more confident because of their relationship with their provider. One parent said, "[The FSS] is the best part of my team ... if I also need somebody to talk to, especially with as stressful as this is." Parents also appreciated the knowledge, reliability, and experience of their providers. A parent elaborated, "[The FSS] is just very willing to either figure it out, research it, ask somebody, and do whatever we need to do to get where we're going."

Parents reported that providers connected them with specific materials needed to ensure their child's progress (e.g., "high-density foam," "orthotics," and "a 100-day tool kit [related to autism]"). Tangible resources providers gave to them included information (e.g., "different milestones," "pictures of exercises," or "a visual schedule") or reminders (e.g., "[The FSS and therapist] are good about leaving notes about what we should be working on"). Parents

also reported their providers referred them to other professionals and provided information related to a variety of additional services such as “preschool,” “Medicaid,” and “insurance concerns.”

In contrast, parents did explain some undesirable characteristics within their interactions with providers. Parents explained that some providers guided their visits (e.g., “[My FSS] has her ideas of what she wants to do and we do it”), which led to some parent concerns going unaddressed or unresolved. Some of these concerns included feeling like the provider had unrealistic expectations, feeling uncomfortable or concerned, and questioning the purpose of certain aspects of services. When parents experienced this type of interaction they were left feeling overwhelmed (e.g., “How do I squeeze it all in,” “[The therapy exercises] just weren’t feasible”), confused (e.g., “I just don’t have any idea of how to apply it”), or deflated (e.g., “Nothing I was doing was good enough”). Parents did wonder about the purpose or value of some of the services (e.g., “I don’t know what [FSSs] do, I just got thrown a bunch of brochures”), which led to frustration. Some parents also questioned the level of knowledge or experience of their providers. One parent divulged, “[FSSs] don’t necessarily have the training or the experience base and because they don’t get paid a professional wage so these people don’t stay very long.”

Finally, parents described professional relationships and partnerships among different providers with whom they were working. Some parents were unaware whether their FSS or therapists ever communicated with each other or any other provider involved in services (e.g., pediatricians, specialists) saying, “Not that I know of ... it is separate.” On the contrary, some families described that their FSS or therapist consulted with one or more other providers or attended one another’s sessions. Parents who had this experience stated, “[The FSS] likes to watch what [the therapist] is doing with him to learn new stuff, too, and see if we’re all kind of on the same page.”

### **Building Family Capacity**

Parents described their visits with providers consisted of a combination of discussion, observation, and various types of involvement. Most reported services focused more on the child than the parent or other family members. However, across visits providers used discussion as a primary way to engage parents. Discussion included checking in and/or engaging in collaborative goal setting: “[The FSS and I] basically sit down together and work on developing the goal together.” In addition, some parents reported other ways of being included in Part C services. Parents most commonly explained receiving ideas and suggestions from a provider and occasionally mentioned being shown how to do something to help their child: “[The therapist] will show me how to do it and I’ll take pictures of her doing it.” Beyond sharing or showing techniques, providers sometimes also provided opportunities for parents to practice what they learned in their visit and receiving feedback from the provider: “[The FSS] pointed out at the end, she goes, ‘I like how you made him look at you every time that you talk to him.’” Parents also indicated that they were also engaged in interactions with the provider and their child during visits. A parent described working with their child with the provider and said, “[the therapist] will be like, ‘okay, you can come stand over here, get her to step over these things to come to see you.’ You know, a

lot of times I'm the reward, which is kind of funny." Furthermore, some parents discussed that their providers tailored services to their specific wants or needs of their "whole family." For example, one parent mentioned gratitude for their therapist including the child's siblings (e.g., "It's not just me working with [my child], it's me and his four older siblings you know?") while another talked about the FSS providing more holistic support to the entire family (e.g., "looking at the family too not just specifically [my child])."

More often parents described the provider in the role of working directly with the child and themselves in the role of an observer. Observation occurred in the same room (e.g., "most of the time it was him and the therapist and me observing") or outside the room (e.g., "[The therapist] prefers that we step outside and we view from her little window") where the therapist was working with the child. Some parents discussed it was difficult to see what a therapist was doing or know what they were doing through observation alone. Some parents indicated they were not present at all when their child was receiving services from a therapist in a clinical setting but felt like this was justified practice. These parents explained it was important to have the child work uninterrupted with the therapist. For example they said things like, "[The therapist] has us stay out in the waiting room ... just to see if they can do it away from mom basically, which that makes sense to me," "I'm not going back there because I want him to engage with [the therapist]," and "I would actually prefer to be outside [of the therapy room] ... kids behave so much better for other people than they do for you." However, a few parents indicated not being present could be a challenge. One parent explained when her child was expected to work one-on-one with a therapist, "[My child] is just super reluctant to do it, just screaming and I try to help and then [the therapist] will ask me to leave, so I'll step out and that makes it like ten times worse."

## Discussion

The purpose of this study was to gain an understanding of parents' experiences of receiving Part C services in a large, rural state. Children living in rural areas may be more likely to receive special education services (Grace et al., 2006) but are underrepresented in research (Capiznanno & Fiorillo, 2004), and families in these areas may face specific challenges related to receiving adequate Part C services such as travel requirements, lack of accessibility or information about services, and hiring and retaining Part C service providers (Bush et al., 2015; Cummings et al., 2017; Elpers et al., 2016; Hallam et al., 2009; Haring & Lovett, 2001). This is the first study to investigate how Part C services in a rural state align with specific DEC (2014) recommended practice areas which can inform professional development and subsequent improvements in services and in the lives of children and families.

### Alignment With Specific DEC (2014) Recommended Practice Areas

Broadly speaking, parents' reports indicated that services provided by FSSs were better aligned with the specific DEC (2014) recommended practice areas investigated in this study than services provided by therapists. Parents' reports of services reflect the division in the provision of Part C services in Montana. EI service systems vary widely across the United States; in Montana, FSSs are employed through the Part C system directly, whereas

therapists are employed through individual clinics or agencies and often provide lifespan services. FSSs in Montana may be better equipped to provide services aligned with the DEC (2014) recommended practice because they are more directly connected to the Part C system in their state than the therapists on their team.

**Variation by discipline.**—While parents reported visits with FSSs consistently took place in their homes or community settings, there was more variation in environments for services provided by therapists, with most parents reporting visits with therapists took place in a clinic. This finding is in line with others who have also found that families living in rural areas must travel to receive some or all Part C services (Cummings et al., 2017; Haring & Lovett, 2001). The provision of Part C services outside of natural environments is not in line with the DEC (2014) recommended practices (Childress, 2004; Odom et al., 2011; Raver & Childress, 2015; Snyder et al., 2015), yet it is possible that challenges faced in rural areas (e.g., limited access to services, and hiring and retaining of pediatric specialists; Cummings et al., 2017; Hallam et al., 2009; Haring & Lovett, 2001) could contribute to why this is occurring. In fact, the rural context in which families lived was perceived by parents to influence the Part C services they received. The finding related to where services took place could also be related to aspects of services that spanned all three categories. For example, though the use of families' materials is recommended to positively support parent-child interactions (Dunst et al., 2006; McWilliam, 2010; Williams & Ostrosky, 2019; WPPNE, 2008), parents mentioned the use of providers' materials much more commonly when referring to a therapist than a FSS; this may be due to the fact that services were taking place more often in clinic settings with therapists.

Research indicates the most experienced providers who work in clinic settings tend to have lower standards for the use of FCPs (McWilliam et al., 2000), which may provide some insight into why some reports of therapists' collaboration and family capacity building practices in our study do not align with the DEC (2014) recommended practices. For example, a few families in this study described collaborative relationships among their providers; however, many families were unaware of whether their FSS and therapist had ever communicated. Recommended practice emphasizes the importance of teaming and collaboration among service providers and families (DEC, 2014; IDEA, 2019e); however, parents' reports of a lack of communication align with other research indicating that providers find collaborating with other professionals to be one of the biggest challenges in Part C (Bowyer et al., 2017). In this study, this challenge may also be related to rurality given likely differences between the environments in which they interacted with families, and likely vast geographic distances between these providers.

**One-on-one services predominate.**—Parents reported that providers frequently worked directly with their child, and this occurred much more often for services provided by therapists. While others have also found that Part C services tend to focus directly on the provider-child interaction (Campbell & Sawyer, 2007; Fleming et al., 2011; Klein & Chen, 2008; Sawyer & Campbell, 2012), it is possible that rurality is exacerbating this issue by influencing the environments in which services are taking place and, subsequently, how families are involved in services. For example, many more parents in our study reported

observing services (i.e., either from inside the room or through a one-way mirror) or not being present (i.e., remaining in a waiting room) when referring to their services with a therapist, whose services tended to be provided in a clinic. This finding is in line with what others have found—*where* Part C services take place can influence *how* families are included, and when services are clinic-based families tend to be less involved (Dunst et al., 2014). In addition, while some parents reported various ways of being involved, the ways in which they are included does not necessarily reflect principles of adult learning that can build family capacity (Ambrose et al., 2010; Dunst et al., 2007; Merriam & Leahy, 2005). Some parents reported being asked to participate in therapy sessions to act as the “reward” to keep their child motivated or because their child was upset or uncomfortable without them. Recommended practices suggest parents should be actively involved from the very beginning as the primary focus of sessions and in the role of teacher to the child (Friedman et al., 2012; Rush et al., 2003; Rush & Shelden, 2011), rather than being invited to participate to support the interaction between the child and therapist. Recommended practices, which are informed by adult learning styles (Ambrose et al., 2010; Merriam & Leahy, 2005), would seek to reverse the roles of the parent and provider in this situation—the provider should be supporting interactions between the parent and child, regardless of where services take place.

**Commonalities across geographic areas.**—Importantly, some of our findings demonstrate there are also similarities in alignment with DEC (2014) recommended practice areas regardless of the geographic regions in which families live, particularly related to collaboration and building family capacity. The majority of families in this study described being supported by both FSSs and therapists to understand how the information discussed as part of visits could be integrated into their daily lives. While much of this focused on the routine of play, which is a common limitation in Part C across all types of geographic areas (Campbell & Sawyer, 2007; Nwokah et al., 2013), parents also commented on learning about or discussing other routines that could also support their child’s development which is ideal (Dunst et al., 2000; McWilliam, 2010). Parents in this study were primarily engaged in services via discussions with their providers, and sometimes their provider would model how to do something or occasionally provide opportunities for them to practice. While these types of interactions between parents and providers align with building family capacity (Bailey et al., 2012; Childress, 2004; DEC, 2014), families should be actively participating in Part C services in a manner that goes beyond discussion and observation (Dunst et al., 2007; McWilliam, 2010) but similar to other studies conducted in diverse geographic areas (Campbell & Sawyer, 2009; Sawyer & Campbell, 2012), we found this does not always occur.

## Implications

The findings of this study have implications for professional development, tools used for collaboration, and policy. Given the vast distances between families in large and/or rural states and the challenges of limited providers to meet with these families in their homes or community settings, it may not be reasonable to expect practices to change regarding the environments in which services take place. However, the results of this study and others indicate that therapists may prefer clinic- or center-based services (Campbell & Halbert,

2002; Fitzpatrick et al., 2007; Stewart, 2011), and it may not only be rurality that is influencing where services take place. Providing services in families' homes is costly for therapists in terms of time and travel costs (Cason, 2009), especially for those who work outside of the official Part C system, as is the case in Montana. The provision of Part C services in natural environments should be encouraged whenever possible, if not required, and should be considered as part of policy decisions, including supporting higher reimbursement rates for therapists willing to travel to families' homes.

Importantly, related to "how" (Shelden & Rush, 2001) services take place, even when it is absolutely necessary that Part C services are provided in clinic-based settings, there are still important ways services can align with other aspects of the DEC (2014) recommended practice areas. For example, there should be a deliberate attempt to include families' own materials or those they have access to into visits whenever possible; using materials the family does not have access to limits the effectiveness of Part C services. Furthermore, though it may not be possible for all providers on the team to see one another in large and/or rural states, it should not limit providers' communication with one another; collaboration can take on many forms such as joint phone calls or the use of video services when possible. The use of technology to provide Part C services via telehealth has been shown to be supportive of families and potentially be a cost-effective way to overcome challenges with provider shortages in rural areas (Cason, 2009, 2011). Telehealth may support efforts to help build family capacity and support collaborative relationships between families and providers, as well as providers across disciplines (Cason, 2011). Regardless of where services take place, it is still possible to draw upon principles of adult learning styles (Merriam & Leahy, 2005) and practices that build on families' strengths and help them learn new skills (e.g., Dunst et al., 2007; Friedman et al., 2012;; Rush et al., 2003; Rush & Shelden, 2011). Many parents in this study reported that they observed services while the provider worked directly with their child. There is a need to use more engaging styles of involvement, whether face-to-face or via telehealth, that can promote families' capacity.

Based on the findings of this study and others (Campbell et al., 2009; Campbell & Sawyer, 2007; Fleming et al., 2011; Peterson et al., 2007), providers may need support and specialized training to feel comfortable engaging with both the parent and child together, and to not only provide suggestions or model something for parents, but to then invite the parent to practice a new skill and receive feedback; this may be especially true for therapists in rural areas who may typically provide lifespan services and have less training or experience related to pediatric populations (Haring & Lovett, 2001). In states where Part C services are provided in a more "fragmented manner" (McWilliam, 2010, p. 125) with providers spread across various agencies and funding mechanisms, there should be more deliberate policies put in place to guide expectations for service delivery and provide incentives and professional development opportunities focused on the DEC (2014) recommended practices.

### **Limitations and Future Research**

This study relies on parents' reports, which may not include all aspects of the services delivered by providers. Furthermore, many parents reported they were not present for their

children's therapy services, which may limit the information parents were able to provide about those services. Although this is a limitation, it also demonstrates that, in these situations, services do not align with aspects of the DEC (2014) recommended practices. Another limitation of this study was the use of a convenience sample. However, our sample included families from each of the five regional agencies providing Part C services in Montana, variability in the nature of children's delays and/or disabilities, and certain demographics (child and parent race/ethnicity, and family income) that are representative of Montana (United States Census Bureau, 2018).

The results of this study lead to further questions about services provided by therapists and ways in which to strengthen this in rural areas. It should be noted, however, that due to the nature of OT, PT, and SLP services, there are likely differences in how these services are provided, as well as the extent to which they align with specific DEC (2014) recommended practice areas. To better understand ways in which to strengthen alignment with recommend practices, future research should examine each type of therapy individually. Furthermore, for states using a Part C model that includes therapists as vendors or independent contractors who operate outside of the Part C system, future research should continue to investigate how to better support professional collaboration and unified services for families.

## Conclusion

This study adds to the limited existing research related to rural Part C services and is the first to investigate parents' reports of how services align with specific DEC (2014) recommended practice areas. There may be significant challenges to providing Part C services in large and/or rural states, such as distances required for travel, limited availability of professionals, and how these influence one another (i.e., it may be harder to provide services in families' homes or community settings when there are already limited professionals, and travel time for these professionals would further limit their availability to serve clients). However, there are ways in which Part C services can align with DEC (2014) recommended practices regardless of the environment in which services take place. Providers in rural areas should be held to the same standards as those in more urban areas, including their collaborations with all members of the Part C team and the ways in which they engage with families, though the means by which they do this may need to be more flexible.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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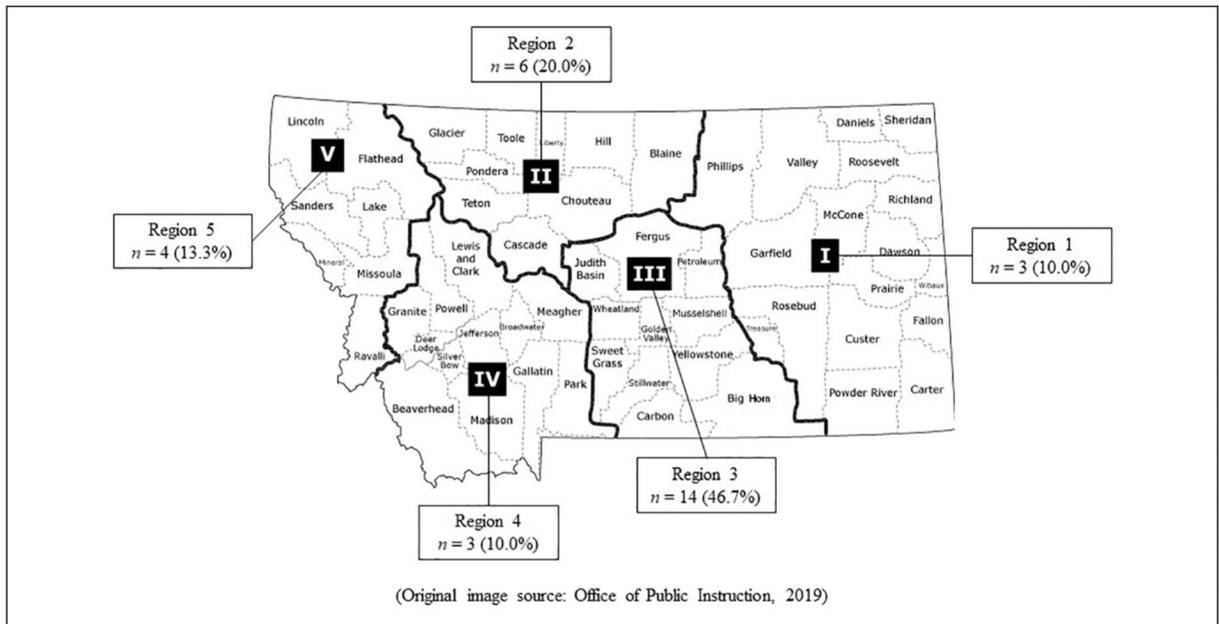
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**Figure 1.** Map of Montana’s five regional agencies and sample sizes for each region ( $N = 30$ ).

**Table 1.**

## Demographic Information for Parents, Families, and Children.

Demographic information	% ( <i>n</i> ) or <i>M</i> (range, <i>SD</i> )
Parent demographics ( <i>N</i> = 30)	
Marital status	
Married	80% (24)
Single	13.3% (4)
Divorced	6.7% (2)
Employment status	
Stay-at-home parent	43.3% (13)
Working part-time	26.7% (8)
Working full-time	26.7% (8)
Currently unemployed	3.3% (1)
Education level	
High school or General Education Diploma (GED)	20.0% (6)
Some college or associate's degree	26.7% (8)
Bachelor's degree	43.3% (13)
Master's degree	10.0% (3)
Family demographics	
Household income before taxes	
Less than US\$ 12,000	10.0% (3)
US\$12,000–US\$ 19,999	3.3% (1)
US\$20,000–US\$39,999	23.3% (7)
US\$40,000–US\$59,999	23.3% (7)
US\$60,000–US\$79,999	20.0% (6)
US\$80,000 or more	20.0% (6)
Information about children's services ( <i>N</i> = 32)	
Age of diagnosis of delay or disability (in months)	10.1 (0.0–30.0, 10.2)
Services provided by a family support specialist	100.0% (32)
Child age at which these services began (in months)	13.7 (1.0–30.0, 9.7)
Frequency of services (times/month)	1.6 (0.5–4.0, 0.8)
Services provided by a speech language pathologist	53.1% (17)
Child age at which these services began (in months)	19.1 (0.0–35.0, 11.1)
Frequency of services (times/month)	3.5 (1.0–8.0, 1.6)
Services provided by a physical therapist	46.9% (15)
Child age at which these services began (in months)	7.9 (0.0–30.0, 9.7)
Frequency of services (times/month)	2.8 (0.5–4.0, 1.4)
Services provided by an occupational therapist	25.0% (8)
Child age at which these services began (in months)	16.3 (6.0–33.0, 9.0)
Frequency of services (times/month)	3.7 (2.0–4.0, 0.8)

**Table 2.**

Parents' ( $N=30$ ) Reports of Their Experiences With Part C Services: Results From a Deductive Qualitative Content Analysis.

Category and code	FSS: $n$ (% of 30)	Therapist: $n$ (% of 24)	Example
<i>The "Where" and "What" of Natural Environments</i>			
Visits took place in the child's home or a community setting	30 (100.0%)	9 (37.5%)	"I like that [the FSS] comes here because they get to see him interact in his home environment."
Supported integration into daily life or specific routines	25 (83.3%)	24 (100.0%)	"The most important part of therapy, to me, has been things you can incorporate right into your day because there's no time to stop and do therapy at home."
Used families' materials or those they had access to	10 (33.3%)	6 (25.0%)	"[The FSS will say], 'okay well I know [your child] has this toy, so why don't we use this?'"
Visits took place in a clinic	2 (6.7%)	19 (79.2%)	"[The therapist] gets things out of [my child] in her setting and it's completely different than what I can get at home."
Used providers' materials	7 (23.3%)	15 (62.5%)	"[There are] tons of balls there and then the big giant swing that [the therapist] works on."
<i>Collaboration</i>			
Parent felt supported, empowered, more confident	26 (86.7%)	20 (83.3%)	"[The FSS] is like, 'follow your heart, if you don't think something is right or you're not comfortable with something then, it's up to you, you have the control,' so she's very empowering."
Parent appreciated relational skills	25 (83.3%)	22 (91.7%)	"[The therapist is] very personable so I think that's probably the best part about it."
Provider was knowledgeable or experienced	22 (73.3%)	21 (87.5%)	"[The therapist will] talk to me about why he's having difficulty in terms of specific issues. She kind of explains more of the reasons behind why it's happening."
Provider consulted with or attended joint sessions	20 (66.7%)	14 (58.3%)	"I'm really kind of impressed with both [the FSS] and [therapist]. I like how well they both work together."
Helped family gain access to other services, providers, or needed information	26 (86.7%)	16 (66.7%)	"I don't think that we would know what we'd do without [the FSS] getting us hooked up with the right people"
Parent felt concerned about provider's knowledge, experience, or approach	12 (40.0%)	12 (50.0%)	"Sometimes [with the therapist] it's a little jargony ... I know what to work on but sometimes it's maybe just a little bit much."
Parent unaware if providers communicated	10 (33.3%)	11 (45.8%)	"I'm sure we signed a release, but whether or not [the FSS and therapist] actually spoke I really don't know."
<i>Building Family Capacity</i>			
Visits included checking in and/or goal setting	30 (100.0%)	18 (75.0%)	"[The FSS asks], 'How are things going? How was last week?'"
Tailored to the family	26 (86.7%)	18 (75.0%)	"[The FSS has] been receptive to our concerns."
Provider gave suggestions and/or modeled techniques	24 (80.0%)	21 (87.5%)	"[The therapist] gave us tips on how to strengthen the muscles in his mouth."
Included interaction with child(ren) and parent together	9 (30.0%)	10 (41.7%)	"If [the therapist] notices [my daughter is] being a little more obsessed with mom today, they try to incorporate me into the therapy."
Provider facilitated opportunity for parent to practice, gave feedback	8 (26.7%)	9 (37.5%)	"[The therapist] demonstrates ways to play with toys and then I'll do it and she watches to tell me, 'Maybe add this in.' She does a lot of, 'Add this next time' kind of stuff."
Provider worked directly with child	14 (46.7%)	22 (91.7%)	"[It included the therapist] being able to get their hands on her and work with her."
Provider guided session	20 (66.7%)	20 (83.3%)	"[The therapist] comes in with the ideas ... she'll say, 'This week I thought we should work on this area.'"
Parent observed	4 (13.3%)	17 (70.8%)	"We just sit on this chair thing and we just watch [the therapist] interact with her."

Category and code	FSS: <i>n</i> (% of 30)	Therapist: <i>n</i> (% of 24)	Example
Parent was not present	2 (6.7%)	9 (37.5%)	"I'm not going back there [into the clinic] because I want [my child] to engage with [the therapist]."

*Note.* Percentages exceed 100% because participants individually contributed to more than one code.

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