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Family/Caregiver Engagement in Early Intervention

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Literature Review Presented

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Abstract

Research has shown that the early years of child development and intervention that occurs during those years has a large impact on the architecture of the brain which creates a sturdy or fragile foundation for overall developmental and success later in a child's life (Shonkoff & Bales, 2011). For children with or at risk for disabilities, early intervention programs were developed to assist with increasing a child's success or closing the gap if one exists. For the purposes of this literature review, the early years and early childhood are referring to children ages birth to age 3. Early intervention services provided to this group of children involve families or adults that are caregivers. This paper examines the characteristics of early intervention home visiting programs and specifically focuses on the Individuals with Disabilities Education Act Part C early intervention services, models of the services provided and factors that have the likelihood to influence and increase the engagement of families or caretakers in these early intervention services.

Family/Caregiver Engagement in Early Intervention

Engaging families or caregivers in early intervention services is a topic that has received a great deal of attention over many years as early intervention services positively impact child development and enhance family functioning (Coogle & Hanline, 2014, p. 249). Early intervention home visiting programs vary greatly in their structure, expectations, enrollment, practices, staff, and philosophy (Korfmacher et al., 2008). There are a variety of programs available for children from birth to age 3 in the United States and around the world. These programs range from home-based to medical based to community based to center based (Dunst, Bruder, & Espe-Sherwindt, 2014). Once a referral is made, parents are voluntarily participating in screening, eligibility determination and services if warranted for the Individuals with Disabilities Education Act Part C programs. While many parents have heard the message that early intervention is important, parents of children with autism sometimes feel immense pressure to make the right decision for their child and fear what might happen if they make the wrong decision regarding early intervention services (Edwards et al., 2016, p. 205).

With limited resources and shortage of early intervention providers, all factors must be looked at for the Individuals with Disabilities Education Act Part C programs (Vail, Lieberman-Betz, & McCorkle, 2018, p. 230) if they want to stay afloat. In turn, these programs are regularly looking at their practices to increase engagement and retention and wisely spend their funding. Parent engagement in early intervention is multi-faceted. Much of the research on parent engagement has focused on enrollment, retention and involvement while other research has looked at strategies, practices and service delivery models to use to continue the involvement of parents once enrolled or participating in a program. Engagement in early intervention is taking an active role in the service being provided, being committed to improving outcomes and

continuing with services as long as their child is eligible. Engagement is a critical component when services are committed to building family capacity which is a critical feature of the Individuals with Disabilities Education Act Part C early intervention and other early intervention programs (Dunst et al., 2014, p. 38).

A wide variety of factors can influence engagement of families/caregivers with early intervention services. Location, time of day, outcomes of the program, demographics and crisis in the household, and relationships are just a few of the abundant influential factors. This literature review will focus on analyzing factors that promote engagement by reviewing what parents want and what practices have shown to increase engagement of families/caregivers.

Review of the Literature

Measuring parent engagement in early intervention services is challenging as there are a plethora of contributing factors, such as socioeconomic status, culture, context and setting to name a few (Dunst et al., 2014; Hackworth et al., 2018). Parent voice, consultation vs. coaching and direct therapy are a few other considerations. Considering all of this and more, what is known is that caregivers are the best to provide early intervention with the assistance of practitioners to coach and consult with them (McWilliam, 2015, p. 34). Early intervention services should be a partnership with the family, but building that partnership has its own challenges before providing services can be effective (Division for Early Childhood, 2014). However, if early intervention services are to be effective and efficient, it could be hypothesized that a main influential factor is parent involvement (Pretis, 2011, p. 9). Parental involvement through teaming and collaboration is evident in the guidance that the Division for Early Childhood (2014) provides in their recommended practices which connect research to practice. Therefore, since parental involvement is a main factor in early interventions programs, this paper will review more in depth some of the predictors of successful engagement including retention, enrollment, involvement, service delivery model and relationships, looking strongly at the parent perspective to indicate engagement success.

History

Part C of the Individuals with Disabilities Education Act, also known as early intervention programs, have been in place in the United States since the early 1990's (Vail et al., 2018, p. 229). The focus of Part C programs is to enhance child development for infants and toddlers under the age of 3 and also to build capacity of the families who provide care for these

children. The focus on building capacity and providing services in natural environments has evolved over the years and continues to take a different shape than when these services were initially enacted (Division for Early Childhood, 2014). The reason that Part C programs are critical to society, individuals, and our education system is that research has shown that brain plasticity decreases over time, which means that the earlier we get it right with children and intervene, the less costly it will be than if we try to fix it later (Shonkoff & Bales, 2011, p. 23).

Part C early intervention services varies throughout the United States as each state is allowed flexibility with who the lead agency is, eligibility criteria, use of funds, procedures and service delivery models (Cole, Oser, & Walsh, 2011). Twardzik, MacDonald and Dixon-Ibarra (2017) report that there are currently over 21 different departments serving as lead agencies for Part C programs in the United States. Some of these departments are the Department of Education, Department of Health, Public Welfare and Economic Security and it is the state's responsibility to assign a department to administer and manage the Part C services (p. 254). Part C of the Individuals with Disabilities Education Act mandates that states provide services for children birth to age 3 with physical or cognitive disabilities. In addition, some states have also chosen to add children who are at risk of a delay to be eligible for their programs (Litt & Perrin, 2014, p. 38). Therefore, if one state chooses to qualify and provide services only children with disabilities and another state qualifies those and provides services for the at risk population, the population served varies (Barger, Rice, Simmons, & Wolf, 2018, p. 12). With the flexibility in eligibility criteria, some states have narrowed the eligibility criteria due to fiscal crisis which has then diluted the programming available (McManus, Magnusson, & Rosenberg, 2014, p. 1032). These varying factors have influenced the population served based on eligibility requirements,

the frequency of services provided to children and families and the outcomes of the services (Twardzik et al., 2017, p. 253).

Bruder (2010) explains that while many early intervention programs are funded by the Part C Individuals with Disabilities Education Act, there are also programs with other federal funding sources for different initiatives. Examples of these initiatives include Early Head Start, Pre-K Now, the National Governors Association, the National Council of Chief State School Offices, and the Federal Interagency Early Childhood Consortium (p. 350). With more initiatives, these programs are sometimes competing for funding. The goal of early intervention programs is to work with children and families so that children are safe, child development is supported and parents are taught skills to provide quality environments for their children (Coogle & Hanlin, 2014, p. 250).

In order to provide quality early intervention Part C services which address families strengths, priorities, needs, and to develop outcomes for services, an Individualized Family Service Plan (IFSP) is created (Gatmaitan & Brown, 2016, p. 14). The IFSP should encompass outcomes and activities that are related to family priorities and of interest to both parent and child (Khetani, Cohn, Orsmond, Law, & Coster, 2013, p. 239). In addition, the IFSP team, which includes parents, identifies the service providers, location of services in a natural environment and how outcomes will be measured (Bruder, 2010, p. 344). Teaming and collaboration are essential in the development of the IFSP as these practices promote partnerships, relationships, and ongoing interaction (Division for Early Childhood, 2014, p. 14).

The need for early intervention programs and the enrollment of these programs, specifically Part C of the Individuals with Disabilities Education Act, has also increased. At the

same time, the funding of these programs has decreased. From Fiscal Years 2005-2015, funding was decreased or remained the same while enrollment during this time period increased (Vail et al., 2018, p. 230). With this decrease of funds, programs and agencies are having to closely analyze their allocation of funds and the services that they provide, including recruitment, enrollment, participation, involvement and their service delivery model. With that challenge also comes an increased societal expectation for early childhood intervention programs and services for children with disabilities, as our society is more aware of the importance of intervening in the first five years of life (Bruder, 2010, p. 340). All of these factors have an impact on the enrollment, retention and engagement of children and families/caregivers.

Recruitment and Enrollment

Children are referred to the Individual with Disabilities Education Act Part C programs for an assessment when a developmental concern is identified and then eligibility is determined based on the assessment and, if eligible, they are enrolled in the program with parent permission (Barger et al., 2018, p. 5). Making the referral isn't enough to enroll many families. Those that need it the most may find it difficult to be involved with an early intervention program and this is even more difficult for families with risk factors such as extreme poverty, family violence, or housing struggles (Korfmacher et al., 2008, p. 187).

Hackworth et al. (2018) reviewed three types of engagement and how they influence early intervention. The three types of engagement that the study reviewed were participant enrollment, retention and participation. Looking only at these factors is not sufficient as demographics, socioeconomic status, psychosocial factors and other factors can play a large role as well (Cho, Terris, Glisson, Bae, & Brown, 2017, p. 3204).

Enrolling families in early intervention can be one of the biggest challenges as the system for referring families is not streamlined (Twardzik et al., 2017, p. 255). Along with data collection issues for Child Find, federal regulations for these activities are minimal with results in a wide variety amongst different states in the Child Find efforts (Barger et al., 2018, p. 12). Physicians sometimes take a “wait and see” approach before making a referral for early intervention even when parents have concerns, which can result in months of lost early intervention services for children and families (Barger et al., 2018, p. 4). Families are many times offered a wide range of services for their children who have disabilities or who are at risk for a disability. These services are many times from a variety of agencies. Parents then have to discern what is best for them, their child and family. Transportation, cost, convenience, work schedules, child care and time are at the top of the list for reasons parents choose to enroll. Hackworth et al. (2018) found that up to two thirds of families do not enroll in programs that are offered to them and over half do not complete the program for various reasons (p. 881). While some of the above mentioned factors related to demographics and economics may be thought to predict program involvement, Korfmacher et al. (2008) suggests that these may be proxies for factors more directly related to participation and engagement, such as life circumstances and parent characteristics (p. 187).

As mentioned before Vail et al. (2018) stated funding for early intervention programs is low. States have turned to other funding sources other than the Part C Individuals with Disabilities Education Act funds that they receive to try to supplant the difference between what they receive federally and the cost to run the program. Litt and Perrin (2014) report that Medicaid and private insurance are also used and that children with Medicaid coverage had higher enrollment than those who are privately insured. States have also taken actions such as

increasing family fees, requiring prior approval for services, and creating fee schedules for parents (Vail et al., 2018, p. 231). While these situations are not ideal for state Early Intervention Coordinators, Vail et al.'s (2018) research through a survey of Early Intervention Coordinators showed that there is a need for further inquiry into funding and how it can positively or negatively affect early intervention programs. Another area that is lacking in the Part C system is systematically collected information to assess the efforts of Child Find in identifying children in need of early intervention services (Barger et al., 2018, p. 5). More detailed Child Find information could assist in more referrals for children who could qualify for services.

In order to try to get to the root of why parents may not enroll or stay enrolled in early intervention programs, Pellecchia et al. (2018) completed a systematic study of engagement to identify what strategies have the strongest effect. The study looked into underrepresented families receiving psychosocial services for their children (p. 3141). For all families, and especially those from underrepresented populations, research has shown that to engage parents, we must not only consider if the child is benefiting, but also if the parents are benefiting. Pellecchia et al. (2018) reviewed 24 studies on parent engagement and then analyzed this data using a social-network analyses to determine which strategies are most commonly used, which strategies are most effective and how are these strategies being combined to increase engagement (Pellecchia et al., 2018, p. 3148). Upon the systematic review of the articles, it was discovered that cultural acknowledgement, accessibility promotion and goal setting, assessment and problem solving were the strategies most often used and paired with other strategies. Tran, Luchters, and Fisher (2016) also acknowledged cultural factors and researched the relationship among poverty and child development in many countries. Their research showed a consistent link between household wealth and early childhood development (p. 422). Recruitment efforts should take into

consideration the factors mentioned above if the goal of Child Find is to recruit and enroll the children and families who need intervention the most.

Involvement

Korfmacher et al. (2008) defines involvement as parents connecting with and using the program to the best of their ability and includes two dimensions: participation and engagement.

Participation refers to the quantity of services and engagement is the emotional quality of interaction with the program (p. 171). Parents engagement in creating outcomes for early intervention services that are functional and important to them will help increase the chances of participation when providers are not at a home visit (Gatmaitan & Brown, 2016).

When parents feel competent in supporting their child grow and develop, feel emotionally supported and feel like the program is working for their child, they are more likely to be engaged. Location of the service also plays a role in the engagement of parents. Hackworth et al. (2018) also looked at the intensity of the services and defined two levels of intensity as group session with home coaching and group sessions without home coaching. The community based program *smalltalk* was utilized to help parents enrich their home learning environment (Hackworth et al., 2018, p. 883). The program length and intensity varied on the age of the children. All programs involved a group component and then one group received additional home coaching sessions. The coaching sessions alone were not a predictor of retention, but rather parent/family factors played the biggest role.

Other research has focused solely on specific measures affecting involvement once parents are enrolled in an early intervention program. The research has reviewed family and program barriers, characteristics of the early intervention program and community influences.

With all of these characteristics being influential in engaging parents, it is critical to engage parents early when attitudes are positive and so are their intentions for the program (Gonzalez, Morawska, & Haslam, 2018, p. 416).

Families of children living in rural communities face different circumstances regarding program availability and support compared to those in more urban areas. These circumstances correlate to sustained parent engagement. Cummings, Hardin, and Meadan (2017) focused on investigating the perspectives of parents and what ecocultural features enhanced or prevented their sustained engagement (p. 116). Best practice for early intervention programs is for parents to be actively engaged in the intervention versus the therapist or provider working only with the child and not coaching the family to build their skills to help their child. However, ecocultural factors can hinder parent involvement and then they make accommodations in one of the 12 ecocultural domains (Cummings et al., 2017, p. 117). Pulling from the ecocultural theory, Cummings et al. (2017) noted the 12 ecocultural domains and stated that when these factors interrupt the learning experiences, families will make accommodations in these domains to sustain learning opportunities. The twelve domains include family financial base, accessibility to services, work, domestic and child care tasks, marital relationships and role of parents in care for the child, cultural influences and involvement in organizations and networks in the community. Results from this study found that some of the ecocultural factors and accommodations made varied among parent participants on whether they were positive or negatively affecting their involvement and engagement in the early intervention program and engagement with their children. For example, whether the parents work or do not work did not affect engagement with their children, but it does limit the types of activities they were able to do with their child (Cummings et al., 2017, p. 119).

Having a child with a disability can create major stress on the lives of parents and families, including siblings. The stress impacts the dynamics within the home and relationships within the family. This is especially true if the child has challenging or disruptive behaviors. When this happens, parent engagement or involvement in early intervention services can be affected as well. Champine, Whitson and Kaufman (2018) found that when parents are involved in services to help their child with behavior or disruptive disorders it tended to show a decrease in the families stress. Also, when families were overall satisfied with services, more active engagement occurred (p. 332). When families feel supported and understood, engagement increases and stress decreases.

Community-level social determinants can also influence participation in early intervention programs. Cho et al. (2017) cited that these determinants can be negatively associated with all aspects of program engagement (p. 3210). Job opportunities, safety of the neighborhood, families in need of assistance and children with health risks all play a role in engagement. While these factors are not necessarily able to be controlled by early intervention programs, service coordination and other assistance provided may increase parent involvement if they feel like there is some help relieving some of the stress from these circumstances.

Pellecchia et al. (2018) defined cultural acknowledgment as the use of strategies to acknowledge or explore the cultural factors of the family. Accessibility promotion is strategies used to make the early intervention program convenient and accessible. Goal setting, assessment and problem solving is setting goals to achieve a certain skill, assessing barriers and needs and problem solving is defined as training staff to problem solve with families and find solutions (Pellecchia et al., 2018, p. 3147). When looking at accessibility for all families, language barriers can present additional questions regarding involvement in early intervention programs. Olmsted

et al. (2010) concluded through their research suggests that the needs for families who speak Spanish may have different needs due to the functional challenges that occur when providers and families speak a different language (p. 54). For increasing engagement from underrepresented groups, traditional engagement strategies may not be the most effective as they do not take into consideration the varied needs of under-resourced or ethnic minority families (Pellechia et al., 2018, p. 3151).

Service Delivery Model

For many years early intervention services were delivered more like a medical model in various settings (McWilliam, 2015). Teach the child, work only with the child and family involvement was minimal. This often mirrored special education services for students in schools (McWilliam, 2015). Home intervention services have made great changes in the 15-20 years. There has been a swing in the pendulum to provide services in natural environments with children learning from their caregivers with the assistance of professionals specific to the areas of need for the child (McWilliam, 2015). This empowers parents to have a greater impact in working with their child and assisting the child with transferring skills to other settings (Bell, Corfield, Davies, & Richardson, 2009, p. 145). The child will receive more dosages of the service than if the professional provider only comes two times per month for an hour.

The team models vary throughout early intervention programs as well. There are multidisciplinary, interdisciplinary, and transdisciplinary/primary service provider models (Vail et al., 2018, p. 234). The main difference in the models is the number of providers, or disciplines, working with a child and family. Bruder (2010) states that the primary service provider model has been identified as being the most efficient for use in early intervention programs. This model

focuses on one provider or discipline providing service to the family across all developmental domains while teaming with other disciplines to ensure the design of interventions is developmentally appropriate (p. 343). In order for transdisciplinary/primary service provider model to be effective, frequent team meetings are needed to assist the primary care provider and for the rest of the team to help develop the plan and implementation of services (Boyer & Thompson, 2013, p. 23). The result of using the primary care model for early intervention is that it integrates the developmental needs of the children and families as well as provide more efficient and comprehensive assessment and intervention services when team expertise is integrated and brought together (Bruder, 2010, p. 343).

Transdisciplinary teams use collaboration and a willingness to work together and have knowledge of different disciplines (Boyer & Thompson, 2013, p. 19). This model had challenged thinking of providers and requires a shift in mindset. In turn, this shift of thinking in the way services are provided has forced programs and providers to look at adult learning principles as well as collaborative consultation and coaching (McWilliam, 2015, p. 35). Practitioners talking to parents about their goals for their child, sharing knowledge, jointly solving problems, and planning for and implementing interventions is best practice (Division for Early Childhood, 2014, p. 14). and then finding natural routines or times of the day to work on these skills has assisted parents to feel more confident and competent to make a difference and help their child with or at risk for a disability.

As McWilliam stated (2015), what has not been looked at deeply enough is the diversity amongst families and how services are provided. Through his research, McWilliam (2015) states that while family centered coaching is the best model, providers may neglect to consider cultural beliefs and expectations, socioeconomic status and educational level to name a few (p. 36). If

services are to truly be effective for all families that the services must look at more than just a coaching model that works and also focus on the quantity and quality of the intervention, family structure, needs and beliefs.

One of the goals of Individuals with Disabilities Education Act Part C early intervention services is to build family capacity so that parents may help their children throughout their daily routines, even when providers aren't there. Dunst et al. (2014) decided to complete an analyses to determine if settings and contexts in which providers worked with children and families influenced the way the providers involved the families and to determine if the parent participation had features that would promote family capacity building which is the intent of Individuals with Disabilities Education Act Part C services.

Parents were surveyed using a rating scale which was designed for families to choose a rating from 1-5 which described the level of how they were involved with the service provider. The survey also collected data on the location of the service whether it was in the family's home, center-based location or a combination of the family's home and center-based location. Results from this analyses showed that the parent involvement scores were significantly lower when services were provided outside of the family home (Dunst et al., 2014, p. 41). It also showed that this involvement was not capacity-building for families. Where early intervention services are located can have an effect on parent involvement and family capacity-building.

Relationships

The basis of early childhood intervention is all about interaction. Interaction between the child and family and interaction between the professional and the child/family system (Pretis, 2011, p. 14). With that interaction comes the building up of families/caregivers' competence

which occurs when home visits are perceived as helpful and there are positive family relationships (Crossman, Warfield, Kotelchuck, Hauser-Cram, & Parish, 2018, p. 599).

Developing these healthy, collaborative relationships with families benefits the family, child and professional (Brotherson et al., 2010, p. 33).

In order to know how these relationships with families are best formed and the characteristics and qualities of a good relationship, gathering information from families seems to be a logical place to start. Family perceptions of early intervention services are important as the early intervention services have the ability enhance child development and family functioning (Coogle & Hanline, 2014, p. 249). The reason that these relationships are critical is that the most relevant interactions with young children take place in their daily routines with their families/caregivers, not with the professionals (Pretis, 2011, p. 14). This practice of building family capacity through participatory opportunities to strengthen and develop new parenting knowledge and skills to enhance self-efficacy beliefs and practices is just one of many recommended practices for early intervention/early childhood special education from The Division for Early Childhood of the Council for Exceptional Children (Division for Early Childhood, 2014, p. 9).

Relationships that are not strong can create negative experiences for families and cause interpersonal conflicts with professionals and an increase in stress for families (Coogle & Hanline, 2014, p. 250). However, when the emotional issues of families align with the needs and skills of the provider, the result is likely to be more effective partnerships (Brotherson et al., 2010, p. 36). Crossman et al. (2018) also noted through their research that positive relationships with families is associated with increased maternal competence (p. 603). It is likely then that focusing on relationships and addressing the emotional needs of families and providers will

empower families and providers as well as improve the quality of home intervention programs

(Brotherson et al., 2010, p. 43).

Application

Working in the field of early intervention on a daily basis, the information gained from this research and literature review will influence my thoughts and practices related to Part C early intervention services. As I oversee the Early ACCESS (Part C early intervention) program at our agency I am now more equipped to support staff working in the field providing home visiting services. Engagement with families is a consistent topic with my department members. They tend to have beliefs that families are not engaged or do not want to be engaged. The information regarding relationships gleaned from this research will be critical to share with them, not only individually, but with the department as a whole. If families are volunteering for services and taking time out of their lives to allow staff to come into their home, that is showing initiative to help their child. I will now be able to coach staff create a more positive attitude regarding these families and guide them in building relationships to hopefully provide a better outcome during home visits and the services being provided.

While not information that I expected to find, the content regarding funding for Part C early intervention programs and the variety of eligibility criteria in different states is intriguing. The population of children being served due to these eligibility differences varies a great deal from state to state. With states receiving the same amount of money for their Part C programs, this poses a question of how states that are serving not only those with disabilities, but also those at risk, are supposed to fully fund their Part C early intervention programs the same as others that only serve those with disabilities. Before having conversations with others regarding this, I would first like to complete more research in this area to be better informed. At the department level and not an administrator, I have not thought much about the financial side of Part C

programming. After gathering more information, I will be able to utilize it to have further conversations at the agency and state level to continue to be an advocate for early intervention.

Conclusion

A vast amount of research has been conducted regarding recruitment and enrollment, involvement and service delivery models for early intervention programs. While there are many common themes in each one of these areas to promote and retain families in early intervention, most studies and research have concluded that more research needs to be done. One of the major difficulties in finding what works for parental engagement in these programs is the differences in the way the programs are designed. In order to make data-based decisions to improve Child Find systems and evaluate their effectiveness, systematic data is needed to follow children from monitoring and screening to the entrance to early intervention services (Barger et al., 2018, p. 13). This would be an area for further research for Part C early intervention systems in the United States.

Major themes that are prominent in the literature are that building relationships with families when they are initially invested and focusing on their goals and outcomes for their child and family will increase engagement. Services that are accessible and at no cost or low cost to families are also determining factors for families enrolling and staying involved in the programs. Therefore, funding sources must also be a topic of discussion and action taken to financially fund these programs.

In order to keep improving early intervention programs, gathering more research from families and providers would be a next step on the path to improving early intervention programs so that children with disabilities or at risk for disabilities can grow and develop in the early years in the hopes to prevent or minimize the need for services in their future years. Another topic for future research should focus on exploring and analyzing the quantity and quality of caregiver-

mediated interventions and also look deeper at the types of children and families enrolled in early intervention (McWilliam, 2015, p. 37) to make sure that the population that needs services the most are receiving them.

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