

Family and Practitioner Perspectives on Prenatal Early Intervention

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Early intervention (EI) for families with infants and toddlers with developmental delays or disabilities is based on the long-held premise that developmental outcomes are optimized when supports are provided early (U.S. Department of Education & U.S. Department of Health and Human Services, 2017). Therefore, children with specific diagnoses, most frequently Down syndrome, are eligible under Part C of the Individuals with Disabilities Education Act (IDEA, 2004) based solely on diagnosis due to the "high probability of resulting in developmental delay" (632(5)(A)(ii)). While states vary in the diagnoses that meet the "high probability" definition, the expectation for intervening upon diagnosis, with or without developmental delay, is to decrease the impact of diagnosis on learning and development.

Under Part C, states provide EI to families with infants and toddlers, birth to three years. In 2007, the American College of Obstetrics and Gynecology recommended that all pregnant families be offered prenatal testing. This recommendation, paired with prenatal tests for some diagnoses becoming less invasive, could increase the likelihood families will know prenatally if their child has a high probability diagnosis (Gregg et al., 2016). At this point, there is currently no prevalence data identifying an increase or decrease in prenatal diagnoses. What is clear however is that there are families who know of such diagnoses. While waiting until birth is the standard of care for Part C EI, developmental programs for families at environmental risk (e.g., low income, adolescent parents), such as Nurse Family Partnership (NFP) and Early Head Start, begin prenatally. NFP, as well as other research-based prenatal interventions for at risk populations, focus on areas such as prenatal health and well-being, parenting self-efficacy, and attachment and responsive interactions (e.g., Gilkerson & Wechsler, 2014; Guttentag et al., 2014; Hans et al., 2013; U.S. Department of Health and Human Services, 2016). Research on Early Head Start and Bright Beginnings programs, which can begin pre or postnatally, found initiating

interventions prenatally had positive, additive effects on child development and well-care outcomes (Johnston, Huebner, Anderson, Tyll, & Thompson, 2006; Love et al., 2002). Prenatal EI for families with a high probability prenatal diagnosis might result in similar effects.

Conceptual Framework

Current research related to a prenatal diagnosis primarily focuses on the time when families are choosing whether to continue a pregnancy (Horsch, Brooks, & Fletcher, 2013). However, research post-diagnosis found the prenatal period can be a time of great stress for families (Fonseca, Nazare, & Canavarro, 2012; Horsch et al., 2013; Marokakis, Kasparian, & Kennedy, 2016; McKechnie & Pridham, 2012; McKechnie, Pridham, & Tluczek, 2016; McKechnie, Tluczek, & Pridham, 2015). The expectations and images of how to parent may be questioned (Brazelton, 1992; Galinsky, 1981; McKechnie et al., 2015). Research found families use the prenatal period to prepare for caregiving with a diagnosis, understand developmental needs common to the diagnosis, and plan pre- and post-natal services (Eidelman, Meredith, & Saul, 2015; Helm, Miranda, & Chedd, 1998; Hendrick, 2005; Hickerton, Aitken, Hodgson, Delatycki, 2012; Howard, 2006; Marokakis et al., 2016; McKechnie & Pridham, 2012; McKechnie et al., 2015; 2016). During this time, families may benefit from the specialized knowledge and skills of EI practitioners with regard to developmental delays and disabilities (Keilty, 2008). EI could help process the implications of a prenatal diagnosis on parenting preparation, which might impact parent-child interaction and subsequent child learning and development (P. M. Blasco, P. A. Blasco, & Zirpoli, 1994; Davis, 2009).

Recognizing the family ecology as the intervention context, postnatal Part C EI focuses on child development outcomes as well as family capacity-building outcomes which are directly and indirectly related to child outcomes (Bailey, Raspa, & Fox, 2012; Dunst, Trivette, & Hamby,

2007; Trivette, Dunst, & Hamby, 2010). These family-level outcomes target priorities for the entire family, parental well-being, parenting self-efficacy, and parent-child interaction.

McWilliam and Scott (2001) categorized such EI supports as informational, emotional, and resource. Based on previous research on family prenatal needs, such supports could include (a) *information* on general characteristics and inherent variability of specific diagnoses and potential implications for caregiving and developmental promotion (Carlsson, Bergman, Wadensten, & Mattsson, 2016; Kratovil & Julion, 2017; Marokakis et al., 2016), (b) *emotional* support by sharing a positive and hopeful perspective that the family can meet their prenatal and parenting goals and vision (Kratovil & Julion, 2017; Roscigno et al., 2012), and (c) *resources* such as connecting with other families with the same diagnosis (McKechnie et al., 2015).

Furthermore, a sample of Part C state administrators reported, when families contact EI programs prenatally, they are provided with initial information and asked to contact the EI program again after the baby is born (Keilty & Smith, 2018). Enrolling in Part C EI prenatally could avoid delays in services post-birth. At this point however, there is no research on whether there is a role for Part C EI prenatally (hereafter referred to as “prenatal EI”) and, if so, the desired outcomes. This study sought to contribute such research by surveying the perspectives of two EI stakeholder groups most proximal to EI service delivery – families and practitioners.

Stakeholder Perspectives

Wolf (1978) introduced the importance of involving the “consumer,” or critical stakeholders, in determining the social validity of intervention targets and compatibility between stakeholder perspectives and interventions. Stakeholder input is essential as their perspectives can provide “unique information that on occasion was at variance with conventional wisdom” (Strain, Barton, & Dunlap, 2012, p. 183). Researchers have advocated for attending to social

validity as the “tie that binds” (Odom, 2009, p. 59) practices to child and family outcomes (Odom, 2009; Strain, et al., 2012). The purpose of this study was to contribute to the knowledge base of the EI field by describing family and practitioner perspectives on prenatal EI, including potential outcomes for intervening prenatally. These perceptions offer unique insights into the importance and value of prenatal EI outcomes and potential intervention designs. This exploratory study examined the following research questions: (1) What are families’ and EI practitioners’ perspectives on the clarity and importance of potential outcomes for prenatal Part C supports? (2) How do families and EI practitioners think medical and EI practitioners should collaborate to meet potential prenatal EI outcomes? and (3) How prepared do EI practitioners feel to meet potential prenatal EI outcomes?

Method

Determining Potential Prenatal EI Outcomes

The research team developed a preliminary set of prenatal outcomes to illustrate what prenatal EI could achieve. These outcomes were intended to elicit more specific stakeholder feedback rather than the potentially abstract concept of prenatal EI in general. The team drew from the literature on current postnatal Part C EI outcomes, current prenatal home visiting outcomes from development and public health fields, and previous research on families with prenatal diagnoses (e.g., information, time to process diagnosis, maintaining informal supports). Prenatal EI outcomes were identified by answering “What are specific family and child/parenting outcomes that could be addressed prenatally?” Researchers reviewed the exhaustive list, winnowed down, and reworded based on the following criteria:

1. The researchers defined the families expected to participate in prenatal Part C EI as those with a confirmed prenatal diagnosis that could result in Part C eligibility and already decided to continue the pregnancy.
2. The prenatal outcomes need to align with postnatal EI philosophy and nationally endorsed principles and outcomes spanning disciplinary and service coordination roles (e.g., child and family outcomes of the Early Childhood Outcomes Center; Research and Training Center on Service Coordination; Workgroup on Principles and Practices in Natural Environments, 2007; state-level outcomes), as well as current prenatal home visiting programs for families without a prenatal diagnosis (e.g., Avellar & Supplee, 2013). The family ecology and individuality of child development beyond diagnostic characteristics were emphasized.
3. Outcomes had to be “doable” prenatally, without knowing the individual characteristics of the child. Additionally, outcomes must add to, but not replace, supports already provided by health and other community-based programs.

The resulting outcomes were expected to represent the breadth of possible outcomes, not a menu for families to select.

This process resulted in 36 outcomes organized across 4 broad areas that mirror those of postnatal Part C EI: (a) Meeting their health and well-being goals (family outcomes), (b) Engaging in responsive parent-child interactions (dyadic outcomes), (c) Parenting according to their individual family culture (parenting outcomes), and (d) Navigating systems, services, and supports (coordination outcomes). A neonatologist and a maternal-fetal medicine specialist reviewed the initial outcomes as auxiliary research team members. Then, the researchers asked for feedback on the outcomes from three family members who no longer receive EI, five former state Part C coordinators, and four former EI practitioners who still have professional roles in EI.

This input resulted in wording changes to clarify how the outcomes apply to the prenatal period. See Appendix A for the resulting prenatal EI outcomes used in this study.

Participants

This exploratory study used a convenience sample of families and practitioners, derived from list serves and other electronic sources. Families were recruited from two national family organizations, one individual with a national database, and others with connections to families and family organizations. Practitioners were recruited via LinkedIn, two professional organizations, and two state EI listservs.

Eligible families were parents with children who had a diagnosis that could be identified prenatally that would result in EI eligibility. As EI eligibility definitions of “high probability” differ across states, all diagnoses that could be identified prenatally were included. Families did not need to have a diagnosis prenatally, nor did they need to have received prenatal EI. Extending the sample beyond those families who had a prenatal diagnosis allowed for an increased number of stakeholders to share their perspectives, including those who may or may not have had an opportunity to choose prenatal testing. The research team purposely did not limit study eligibility based on current age of child. As families move further away from the prenatal period, and EI (birth to three) and the early childhood (birth through 8) years, their perspectives on its contributions may change. The research team wanted to capture that variability in perspective.

Eligible EI practitioners were those of any discipline certified to and currently providing EI services under that discipline. Those fulfilling only the service coordinator role were excluded, given the variability in role and qualifications. Paraprofessionals and administrators were also excluded.

Family sample. A total of 118 respondents consented online to participate in the family survey. Forty-seven (40%) were not included in the analysis because: (a) no items were completed ($n = 28$); (b) their child's reported diagnosis could not have been detected prenatally ($n = 18$) such as preterm births, developmental delays, autism, and speech and language delays; or (c) they did not identify as a parent or legal guardian ($n = 1$). The final sample of family participants was 71, or 60.1% of the consented respondents.

Table 1 summarizes demographic information of the family sample. Respondents were from 15 states representing all geographic regions of the United States: Northeast ($n = 4$), Southeast ($n = 4$), Midwest ($n = 2$), Southwest ($n = 1$) and West ($n = 4$). The majority (76.1%) were from three states – one in the Northeast (45.1%, $n = 32$) and two in the Midwest (19.7%, $n = 14$; 11.3%, $n = 8$). All but three respondents identified as female (77.5%, $n = 55$) or declined to answer (18.3%, $n = 13$). Respondents identified as the child's mother (89%, $n = 63$), father (3%, $n = 2$), or parent (8%, $n = 6$). The sample was predominantly white and not of hispanic origin (93.0%, $n = 66$; 95.8%, $n = 68$, respectively), as were their children (93%, $n = 66$; 93%, $n = 66$, respectively). The majority (95.7%, $n = 67$) reported having one child with a diagnosis eligible for EI; most (86%, $n = 61$) citing Down syndrome. Other diagnoses (14%, $n = 10$) reported included chromosome deletion, spina bifida, hydrocephalus, and Williams syndrome.

Practitioner sample. A total of 186 respondents consented online to participate in the practitioner survey. Seventy (37.6%) did not complete any of the questions and were removed from analysis. Six (3.2%) were removed as they identified as service coordinators or administrators. The final sample of practitioners was 110, or 59.1% of the consented sample.

Table 2 summarizes demographic and professional information of the practitioner sample. The sample represented 15 states across all regions of the United States: Northeast ($n =$

3), Southeast ($n = 3$), Mid-west ($n = 6$), Southwest ($n = 1$) and West ($n = 2$). The majority ($n = 88$, 80%) were from two states – one in the Southeast (44.5%, $n = 49$) and one in the Midwest (34.5%, $n = 38$). One respondent reported residing outside the U.S. All participants identified as female. The sample was overwhelmingly white and not of hispanic origin (92.6%, $n = 100$; 98.2%, $n = 108$, respectively). About 60% of the sample reported working full-time in EI, either as an employee (52.7%, $n = 58$) or contract provider (10%, $n = 11$).

Instrumentation: Family and EI Practitioner Surveys

The researchers designed two online surveys – one for families and one for practitioners. Both surveys collected participant demographic information, then asked about each of the prenatal outcomes twice – once on clarity and once on importance. Each outcome statement was paired with a four-point, forced-choice Likert-type scale chosen to better estimate participants' responses without a neutral response option (cf. Hutman et al., 2010; Musselwhite & Wesolowski, 2018; Wesolowski, 2017). Both surveys also asked about collaboration between EI and medical communities. All “other” choices provided space for respondents to elaborate. The two surveys were similar in content and form, with certain topics specific to a particular respondent group, such as family desire for prenatal EI and practitioner perceived preparation. The survey questions were worded differently on the two surveys. For practitioners, the questions focused on the importance of prenatal EI outcomes for families in general. For families, the questions were worded specifically to their own experiences and support needs.

Clarity was defined as how understandable and doable the outcomes were prenatally. Both surveys asked, “How well do you understand what each statement means as an outcome during pregnancy?” The family survey included a prompt of, “Does each outcome make sense?” Response descriptors ranged from 1 = *Not at All* to 4 = *Completely*.

Importance was defined as how vital each outcome was to begin prenatally. Families were asked, “Thinking about when you were pregnant, how important would it have been to know that each outcome was an option to put on the IFSP or work on during EI?” Practitioners were asked, “How important is it for families to meet, or begin to meet, each outcome prenatally?” Response descriptors ranged from 1 = *Not at all important* to 4 = *Extremely important*. Any outcomes rated as “Not at All Important” resulted in the follow-up question, “Why do you think [specific outcome statement] is not at all important to address prenatally?” Forced choice responses were “the family might: (a) be overwhelmed, (b) have other things to worry about prenatally, (c) not know what to do/work on prenatally, (d) not be ready to work on this outcome prenatally and (e) other.” Families had an additional choice response of “it would have been too hard to work on until after my child was born” and practitioners had “families would not be capable of doing the outcome prenatally.” The family survey specifically asked about families’ desire for EI to begin prenatally (“How much do you wish early intervention started during pregnancy to help you with each outcome?”). Response descriptors ranged from 1 = *Not at all, I had all the supports I needed* to 4 = *A lot*.

Collaboration was defined as relationships and supports across EI, medical, and other communities. For each outcome area, families were asked, “Thinking about these outcomes, who would you most like to help you meet these kinds of outcomes during pregnancy?” Response options were: “(a) an EI professional, (b) a medical professional, and (c) other (please specify).” For each outcome, practitioners were asked, “What role should the Part C EI program play in supporting families as they seek to meet each outcome during the prenatal period?” Response options were: “(a) EI should take the lead with the medical community as collaborators, (b) the

medical community should take the lead with EI as collaborators, (c) none; families have all the supports they need prenatally to meet this outcome, and (d) other (please specify).”

Preparation needs were practitioners’ perceived ability to help achieve the outcome area. Practitioners were asked twice; first, “If EI took the lead in meeting, or beginning to meet, the above outcomes, how good do you think you could be at helping families meet these outcomes prenatally?” and second, “If the medical community took the lead in meeting, or beginning to meet, the above outcomes, how good do you think you could be at collaborating with medical services as they support families in meeting these outcomes prenatally?”. Response options were: “(a) I could be pretty good at it now, (b) I could be pretty good at it with more training/guidance, and (c) I don’t think I could be good at this even with more training/guidance.”

The surveys included two open-ended questions. Family questions were, “What other outcomes do you think are important if Early Intervention started during pregnancy?” and “Is there anything else you'd like to share about Early Intervention supporting families during pregnancy?” Practitioner questions were, “What other outcomes would be important to support families prenatally?” and “Is there anything else you'd like to share about EI supporting families prenatally?” Both surveys took about 45 minutes to complete and any items could be skipped.

Technical adequacy. Both surveys were piloted for content validity with the same families ($n = 3$) and former EI practitioners ($n = 4$) who reviewed the prenatal EI outcomes. Both surveys were revised from the feedback which primarily focused on general issues (e.g., editing, formatting, length of time to complete). Family respondents suggested specific wording changes so they were responding to their personal experiences rather than for all families.

Procedures. The researchers used Qualtrics® (2014) for survey creation, dissemination, and data collection. After IRB approval, the convenience sample was recruited through the organizations and online forums described above. For those forums in which the researchers could not post directly, the researchers shared a study description and survey link to forum contacts who agreed to post. The researchers asked the same contacts to post periodic reminders.

Data Analysis

Data were managed and analyzed in SPSS Version 22 (IBM, 2013). Descriptive statistics (means and standard deviations) were used to analyze data within each sample. Comparative (*t*-tests) statistics analyzed any significant differences in family clarity and importance responses when their child's age fell in the early childhood age range (8 years and younger) or above that range (9 years or older). To quantify open-ended responses, the researchers reviewed those responses and identified coding categories. Each researcher independently coded the responses into those categories and then compared codes. Any disagreements were reconciled between researchers and then frequencies of categories were calculated.

Results

Clarity and Importance

No significant differences were found for clarity of outcomes between families whose children were in the early childhood age range (birth to 8 years) and those who were older at the time of survey completion. In comparing importance responses, only three outcomes yielded significant differences between the groups ($p < .05$): (a) Identify health and well-being goals, (b) Discuss and are confident in vision of parenting, and (c) Convey confidence in parenting. Families in the older child group rated each of these outcomes significantly more important than

families in the younger age group. Since only 3 of the 36 outcomes identified significant differences, all analyses were conducted for the entire sample.

Means and standard deviations of clarity are presented in Table 3. For both family and practitioner groups, mean *clarity* responses fell between understanding the outcomes “pretty well” and “completely.” Mean clarity ratings were slightly lower for families.

Means and standard deviations of importance ratings are presented in Table 4. Mean responses for importance fell between “important” and “very important” for each outcome, and were slightly lower for families. Of the six highest rated outcomes for the family sample, four fell in the outcome area of *Navigating systems, services, and supports*. These outcomes were: (a) Make informed medical decisions, (b) Have knowledge of EI services, (c) Have coordinated services across systems, and (d) Discuss EI, medical and other preferences. Families rated two other outcomes highest; one in outcome area 3 (understand accurate diagnostic information) and one in outcome area 1 (have access to financial resources).

The six outcomes rated highest by practitioners were spread out over three outcome areas. These outcomes were: (a) Know and ready to initiate and respond during interactions, (b) Promote learning, and development, (c) Understand accurate diagnostic information, (d) Recognize child’s unique strengths, (e) Navigate being an active member of the health care team, and (f) Make informed medical decisions. No outcomes in outcome area 1, *Meeting health and well-being goals*, were represented in the highest rated outcomes by practitioners.

All outcomes were rated “not important” by at least one family; 20 outcomes by only one family. Fifteen outcomes were rated “not important” by two (7 outcomes) to four (2 outcomes) families. One outcome, have relationships with informal (e.g., friends) social resources, was rated “not important” by six families. Families chose the following reasons: might become

overwhelmed (6 outcomes), would not know what to do/work on prenatally around this outcome (6 outcomes), had other things to worry about prenatally (4 outcomes), too hard to work on until the baby is born (2 outcomes), not ready/prepared to work on this outcome prenatally (1 outcome) and other (34 outcomes). While 61% ($n = 21$) did not specify a reason for selecting “other,” the open-ended responses were coded into already having the resource/support (e.g., “I already had a great network of friends”) or were not worried or concerned (e.g., “I would have not worried about interacting no matter the diagnosis” and “I wanted time to just enjoy being pregnant. It might have been overwhelming to have so many people swooping in before the baby was even born.”).

One or two practitioners rated nine (25%) outcomes as “not important.” Practitioners selected the following reasons: too hard to work on until the baby is born (7 outcomes), families have other things to worry about prenatally (5 outcomes), families are not prepared to work on this outcome prenatally (4 outcomes), families wouldn’t know what to do/work on around this outcome prenatally (4 outcomes), families might become overwhelmed (4 outcomes), and families are not capable of doing this outcome prenatally (2 outcomes). An “other” response was: “[prenatal EI] would depend on the temperament of the family; some may need time to mourn. Aggressively seeking resources/contacts may cause them to skip the emotional adjustment. But--again, it depends on individual temperament.” Other responses conveyed intervention needed to be “... based on individual child needs and family priorities” which “may be difficult to determine as points of intervention until the post-natal period” and “This is an overwhelming time for families ... there are so many unknowns during a high-risk pregnancy.”

Families and practitioners identified other prenatal outcomes, which were coded into the categories: (1) professional practices/attributes, such as special training, avoiding judgment (“do

not assume anything”), and relationship-based approaches ($n = 7$ for families; $n = 6$ for practitioners); (2) accurate and current information ($n = 10$ for families; $n = 1$ for practitioners) including the timing as “once our baby was born we were so busy...it was just that much more information we could have processed prior,” and (3) connecting with others including introducing the diagnosis to family and friends ($n = 5$ for families; $n = 2$ for practitioners).

For each outcome, families responded to the item, “How much do you wish EI started during pregnancy?” The range of mean responses primarily fell between families desired prenatal EI “a lot” and prenatal EI “could have been helpful” (see Table 5). Mean ratings for three outcomes in the area of *Meeting health and well-being goals* and two outcomes in the area of *Parenting according to their individual culture* were slightly below “could have been helpful.” These outcomes were the following: (a) Have informal (e.g., friends) social resources, (b) Identify health and well-being goals, (c) Know their strengths for a healthy pregnancy, (d) Discuss and are confident in vision of parenting, and (e) Recognize the many influences on learning and development.

Collaboration

Table 6 presents the results of family and practitioner preference for professional lead. Across all outcome areas, the majority of families reported a preference for EI to take the lead. The highest ratings for EI practitioner lead were in the outcome areas *Navigating systems, services, and supports* (87.5%) and *Engaging in responsive parent-child interactions* (72.5%). EI practitioners varied in their preference for taking a primary or secondary role to meet particular outcomes. *Engaging in responsive parent-child interactions* was the only outcome area in which the majority of the practitioners clearly indicated EI should take the lead for every individual outcome in that area (range = 81 – 89%). The outcome area with the widest range was

Navigating systems, services, and supports. The percentage of practitioners who suggested EI take the lead ranged from 12 to 98% depending on the specific outcome. The percentage of practitioners who suggested the medical community take the lead ranged from 0 to 85% depending on the specific outcome. Within this outcome area, the overwhelming majority of EI practitioners reported EI should take the lead in meeting the following prenatal outcomes: (a) Know their Part C IDEA rights (96.4%, $n = 80$), (b) Have knowledge of EI services (96.4%, $n = 81$), (c) Understand intention of EI (97.6%, $n = 80$), and (d) Feel comfortable with EI services (95.2%; $n = 79$).

EI practitioners indicated a clear preference for the medical community to take the lead on two outcomes. These were “navigate being an active member of the health care team” (84.5%; $n = 71$) and “make informed medical decisions” (83.3%; $n = 70$). Family and practitioner “other” responses were coded as (1) other families as “a positive role model peer” ($n = 8$ for families and $n = 1$ for practitioners), (2) a variety of professionals, including medical and/or EI practitioners with training across both medical and EI ($n = 6$ for families and $n = 20$ for practitioners), (3) social service professionals such as social workers and mental health professionals ($n = 6$ for families and $n = 10$ for practitioners), and (4) diagnosis-specific organizations ($n = 3$ for families and $n = 1$ for practitioners). Families and practitioners identified the importance of individualizing who should take the lead for each family.

Preparation Needs

For each outcome area, the majority of EI practitioners reported they could be “pretty good at it now” or “pretty good with more training” regardless of who (i.e., EI, medical community) took the lead (see Table 7). A majority of EI practitioners (71%) indicated they could be “pretty good at it now” for the outcome area of *Engaging in responsive parent-child*

relationships. Approximately half of respondents reported they could be “pretty good at it now” for the outcome areas of *Parenting according to their individual family culture* and *Navigating systems, services, and supports* (56.5%, 45.7%, respectively). The majority (60.7%) of respondents reported a need for more training to meet the outcome area of *Meeting health and well-being goals* if they were to take the lead. Almost the same percentage (56.1%) reported they could be “pretty good at it now” if the medical community took the lead. A very small percentage (0 – 4.7%) reported they would not be competent even with more training. Specific training content categories coded from the open-ended responses were: (1) relationships and infant mental health ($n = 13$), (2) collaborating with medical and other professionals ($n = 7$), (3) specific information on prenatal development and diagnoses ($n = 10$), (4) available community resources ($n = 6$), and (5) insurance/financial ($n = 3$). Outside of training, 16 practitioners identified needed systems supports, coded into categories of funding (“While I agree that this would be helpful, I wonder how this will be funded?”) and structure (“a new level of cooperation and coordination would need to be established between the EI and medical community”). Two practitioners identified that past experiences influenced perceived readiness.

Throughout the open-ended responses were 14 family comments and 18 practitioner comments coded as positive support for prenatal EI in general. A practitioner example was, prenatal EI “would greatly benefit long term parenting; setting up these important goals and helping parents plan and ... process their own thoughts.” A family example was, “We feel confident that parents can benefit from information and education and believe having our EI team in place prior to our son’s birth would have been beneficial.” One practitioner reported a shift in thinking about EI: “When I started the survey, I wasn’t sure how prenatal services could be provided by EI. This survey has expanded my concept of EI service delivery.”

Discussion

Given the focus of Part C EI on family and child outcomes, Part C EI may be uniquely positioned with the expertise, principles, and outcomes to support families who know prenatally their child has a diagnosis with a high probability of a developmental delay once born. This exploratory study examined family and practitioner perspectives of prenatal EI as a preliminary step in understanding the value and focus (i.e., expected outcomes) of prenatal EI.

Overall, family and practitioner samples reported the project-identified prenatal outcomes were clear and important to address prenatally. Additionally, the majority of families wished their EI began prenatally. The findings suggest the need for prenatal EI is supported among these EI stakeholders most proximally involved. A small sample of state Part C administrators echoed this support (Keilty & Smith, 2018). This critical stakeholder affirmation, backed by research on the needs of families with prenatal diagnoses and positive outcomes of prenatal home visiting programs for families at environment risk, could build a case for earlier intervention.

Mean importance ratings were high for families and practitioners. While infrequent for both groups, more families rated more outcomes as “not important” than practitioners. This is expected as EI practitioners were asked to envision the breadth of priorities and needs across families, while families were asked to envision their personal support needs. When families commented on why an outcome was not important, they stated the outcome already was met or not a priority. Therefore, prenatal EI could benefit from following the same approach as postnatal EI where families identify their individual outcomes. At the same time, EI practitioner ratings of importance suggest that the project-identified prenatal outcomes have merit in addressing family needs across family, dyadic, parenting, and coordination outcome areas.

In examining the most highly rated outcomes, particular results are noteworthy. First, the highest rated family outcomes primarily focused on *navigating systems and services* (outcome area 4) that are coordinated and based on their preferences. These outcomes identified family information needs to decide upon medical procedures and EI services and understand their child's diagnosis. Families also identified the need for supports in accessing financial resources. The top-rated outcomes by practitioners also included information related to the diagnosis, as well as two outcomes in area 4 – families actively teaming with professionals and making informed medical decisions. These findings suggest there may be a valuable role for service coordination prenatally, currently provided to all families in postnatal EI, to assure families are informed and can actively participate in and advocate for their child and their family.

Second, three of the practitioners' highest rated outcomes focused on parent-child interactions across outcome areas 2 and 3 – responsiveness, promoting learning, and holding a strengths-based perspective. These findings are aligned to previous literature citing prenatal families may question how they will parent with the particular diagnosis (P. M. Blasco et al., 1994; Davis, 2009). Given their knowledge of development and diagnosis impact, as well as a focus on supporting families in their parenting role, EI practitioners might see these outcomes as a particular specialty Part C EI can bring to prenatal supports.

It is less clear why families might have rated these outcomes lower. It might be that families think parent-child interaction could be difficult to focus on before the baby is born. However, bonding and responsive interactions are a focus of some current prenatal interventions and research (e.g., Gilkerson & Wechsler, 2014; Guttentag et al., 2014; Hans et al., 2013). Or, families may think there are no differences in responsive caregiving during the newborn period, whether or not the child has a diagnosis. EI practitioners might weave anticipatory guidance on

newborn development and ways to promote learning into the diagnosis-specific information families identified as needed (Combs-Orme, Nixon, & Herrod, 2011; Dworkin, 2000; Keilty, 2008; Lewallen & Côté-Arsenault, 2014). Alternatively, families may have rated information and systems navigation needs higher given their urgency during pregnancy, with parent-child interaction more distal considerations. These family perceptions would need to be considered in any prenatal intervention design.

While all outcome areas were rated important, families and practitioners differed in who would best support achieving those outcomes. Practitioners identified EI taking the lead on many outcomes. However, there was a clear preference for the medical community to take the lead on outcomes with a medical focus. Additionally, while practitioners overall reported readiness to support families prenatally, the majority of practitioners identified a need for more training in the outcome area, *Meeting health and wellbeing goals*, if they were to take the lead. This outcome area includes medical and social resource outcomes. EI practitioners may feel these outcomes are beyond their scope of practice. Collaboration among EI, medical, and other supports to meet family needs have been nationally endorsed (Adams, Tapia & The Council on Children with Disabilities, 2013; U.S. Departments of Education and Health and Human Services, 2017). This same collaboration appears needed for prenatal EI as well.

Family respondents, however, clearly conveyed a preference for EI practitioners, rather than the medical community, as the primary support for all four prenatal outcome areas. Given the intimacy of EI, situated within families' homes, it may be families' relationships with EI superseded who could provide the best content expertise. Further insight into family preferences are needed, which could uncover currently available prenatal supports, their perceived effectiveness in meeting family needs, and supports unmet.

Limitations

These findings contribute to current literature on family support needs when there is a prenatal diagnosis. However, study limitations, such as sample characteristics and survey constraints, are acknowledged. Both participant populations represented samples of convenience. The homogeneity of the family sample limits the ability to generalize findings. The sample was comprised of families who had and did not have a prenatal diagnosis. Therefore, some families were responding on what they thought they would have wanted. Future research is needed to obtain perspectives of more diverse families, including ethnicity and prenatal diagnosis, and particularly with solely families who experienced a prenatal diagnosis firsthand. Additionally, the survey provided a summative picture of family and practitioner perspectives related to prenatal EI and specific prenatal outcomes. Further insight into families' desires for prenatal EI and practitioners' professional development and systems needs requires more in-depth analysis. This current research provides foundational findings upon which future research can be built.

Implications for Future Research and Practice

Study findings uncover implications for future research and practice. Replication with a more diverse family sample, including satisfaction with postnatal EI, is needed. Qualitative research with families who had a prenatal diagnosis could provide a deeper understanding of prenatal supports families feel they already had and supports Part C EI could provide. Insight into the perspectives of other professional stakeholders, such as medical professionals who provide prenatal supports, is also needed. These studies could elevate the knowledge base on prenatal EI to inform future interventions. Intervention models can be designed and tested to see if the additive effects of intervening prenatally found in other developmental programs (e.g., Early Head Start) hold for families eligible for Part C EI (Love et al., 2002).

While the current knowledge base on prenatal supports does not yet warrant prenatal Part C EI, these and earlier study findings lead to specific implications for current postnatal Part C EI. First, EI practitioners can recognize and affirm that families come to postnatal EI already thinking about and preparing for the unique needs of their baby. EI practitioners, in partnership with the family, can identify and provide informational, emotional, and resource supports families desired, but might not have received, during the prenatal period (McWilliam & Scott, 2001). This discussion can be a part of assessment and planning to craft and implement interventions aligned to families' already existing knowledge and competencies.

Second, EI eligibility processes can be streamlined so EI can begin at birth. In this sample, the majority of families knew their child's diagnosis either prenatally or at or shortly after birth. The majority of families did not begin EI until 1-3 months post-birth. EI could use the algorithm for eligibility determination created by the *Tracking, Referral, and Assessment Center for Excellence* (Dunst, 2006). Namely, if a child meets the state eligibility definitions of either an "identified condition or diagnosis that has a high probability of resulting in a developmental delay" or "one or more biological at-risk conditions" (p. 2), eligibility has been established without further evaluation. Using these criteria, eligibility can then be established prenatally if families contact EI, even if services do not begin until birth. Utilizing such decision-making processes can accelerate eligibility so supports can begin as soon as possible.

Conclusion

The technological innovations in prenatal testing result in the need to revisit whether Part C EI starting at birth is early enough. This research examined family and practitioner perspectives for beginning EI prenatally. Results found both stakeholder groups were positive about such a possibility. This study is an initial step in building a prenatal EI knowledge base.

Future research can further understand these and other stakeholder perspectives and, in particular, the desired supports of families. While more research is needed, practitioners and administrators can use the findings to recognize and appreciate that families have been already processing and preparing for their child, inclusive of the child's diagnosis, and identify ways to begin postnatal EI as soon as possible after birth.

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PRENATAL EARLY INTERVENTION

Table 1

Demographic Information for Family Participants

Characteristic	<i>n</i>	%
Age (<i>N</i> =71)		
18 – 34	12	16.9
35 – 44	34	47.9
45 – 54	16	22.5
55 or over	9	12.7
Education Level (<i>N</i> = 71)		
High School or GED	4	5.6
Some College	9	12.7
Associate Degree	6	8.5
Bachelor Degree	28	39.4
Post Graduate	24	33.8
Annual Household Income (<i>N</i> = 68)		
\$20,000 - \$49,999	8	11.3
\$50,000 - \$74,999	21	29.6
\$75,000 - \$99,999	16	22.5
\$100,000 - \$150,000	14	18.7
Over \$150,000	9	12.7
No Response	3	4.2
Learned of Diagnosis (<i>N</i> = 70)		
Prenatally	27	38.0
At birth/within days	38	53.5
Within 6 months of birth	3	4.2
Child was 6 – 36 months of age	2	2.8
No Response	1	1.4
Enrolled in EI (<i>N</i> = 71)		
At birth or within days	10	14.1
Within 1 – 3 months of birth	50	70.4
Within 3 – 6 months of birth	7	9.9
Child was 6 – 24 months of age	3	4.2
Did not receive EI	1	1.4
Child's Gender (<i>N</i> = 71)		
Male	37	52.1
Female	34	47.9
Child's Current Age (<i>N</i> = 70)		
0 – 2 years	21	29.6
3 – 5 years	14	19.7
6 – 8 years	8	11.3
9 – 14 years	12	16.9
15 – 21 years	11	15.5
Over 22 years	4	5.6
No Response	1	1.4

PRENATAL EARLY INTERVENTION

Table 2

Demographic Information for Practitioner Participants

Characteristic	<i>n</i>	%
Discipline (<i>N</i> = 110)		
Occupational Therapist	11	10.0
Physical Therapist	12	10.9
Social Worker	9	8.2
Special Instructor	67	60.9
Speech-Language Pathologist	9	8.2
Other	2	1.8
Age (<i>N</i> = 107)		
18 – 34	16	14.5
35 – 44	24	21.8
45 – 54	32	29.1
55 – 64	27	24.5
65 or over	8	7.3
No Response	3	2.7
Education Level (<i>N</i> = 109)		
Associates Degree	1	0.9
Bachelor Degree	28	25.5
Master Degree	58	52.7
Doctoral or Post-graduate	22	20.0
No Response	1	0.9
Years of Practice in Discipline (<i>N</i> = 109)		
Less than 1 year	3	2.7
1 to 5 years	8	7.2
5 to 10 years	16	14.5
10 to 20 years	20	18.2
Over 20 years	62	56.4
No Response	1	0.9
Years of Practice in EI (<i>N</i> = 107)		
Less than 1 year	3	2.7
1 to 5 years	17	15.5
5 to 10 years	23	20.9
10 to 20 years	34	30.9
Over 20 years	30	27.3
No Response	2	2.7
Hours Worked Per Week in EI (<i>N</i> = 110)		
Less than 10 hours	10	9.1
10-20 hours	28	25.5
20 to 40 hours	28	25.5
40 or more hours	44	40.0

PRENATAL EARLY INTERVENTION

Table 3

Means, Standard Deviations, for Clarity of Outcomes for Families and Practitioners

Prenatal Outcome	Group					
	Families			Practitioners		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
<i>Meeting Health & Well-Being Goals</i>						
1.1 Informal Social Resources	71	3.55	0.63	110	3.56	0.63
1.2 Formal Social Resources	71	3.48	0.63	109	3.50	0.69
1.3 Family Health & Well-Being	71	3.39	0.77	109	3.46	0.75
1.4 Choice of Perinatal Supports	71	3.45	0.81	110	3.59	0.65
1.5 Strengths for Healthy Pregnancy	71	3.49	0.83	110	3.59	0.70
1.6 Access to Financial Resources	71	3.48	0.75	109	3.54	0.75
1.7 Advocate Health & Well-Being	71	3.48	0.67	110	3.57	0.73
<i>Engaging in Parent-Child Interactions</i>						
2.1 Interact with Newborn	63	3.44	0.78	99	3.62	0.68
2.2 Understand Communicative Cues	63	3.48	0.84	99	3.65	0.64
2.3 Initiate & Responsive Interactions	63	3.48	0.84	99	3.65	0.61
2.4 Promote Learning & Development	63	3.54	0.78	99	3.70	0.60
2.5 Newborn Strengths and Needs	63	3.48	0.74	98	3.63	0.65
2.6 Promote Newborn Self-Regulation	63	3.44	0.84	99	3.55	0.70
2.7 Include in Everyday Interactions	63	3.52	0.84	99	3.61	0.67
<i>Parenting According to Culture</i>						
3.1 Vision of Parenting	59	3.47	0.73	88	3.56	0.64
3.2 Parenting Effect on Development	59	3.73	0.55	88	3.52	0.74
3.3 Communicate Child Diagnosis	59	3.59	0.65	88	3.64	0.65
3.4 Influences on Development	59	3.68	0.63	88	3.68	0.62

(table continues)

PRENATAL EARLY INTERVENTION

Prenatal Outcome	Group					
		Families			Practitioners	
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
<i>Parenting According to Culture Continued</i>						
3.5 Accurate Diagnostic Information	59	3.73	0.52	87	3.68	0.67
3.6 Unique Diagnostic Impact	59	3.59	0.65	88	3.58	0.78
3.7 Parenting & Diagnosis	59	3.66	0.66	87	3.62	0.69
3.8 Family & Community Activities	58	3.52	0.78	88	3.61	0.72
3.9 Confidence in Parenting	59	3.53	0.73	88	3.64	0.66
3.10 Child's Unique Strengths	58	3.71	0.56	88	3.64	0.66
<i>Navigating Systems, Services, & Supports</i>						
4.1 Navigate Health Care Team	50	3.70	0.54	85	3.56	0.68
4.2 Know Part C EI Rights	50	3.52	0.76	85	3.66	0.78
4.3 HIPAA and FERPA Rights	50	3.44	0.81	85	3.60	0.78
4.4 Informed Medical Decisions	50	3.70	0.54	85	3.58	0.76
4.5 Child Care Decisions	50	3.62	0.70	84	3.57	0.78
4.6 Choosing Healthcare Provider	49	3.67	0.59	84	3.61	0.78
4.7 EI, Medical & Other Preferences	50	3.67	0.59	84	3.60	0.79
4.8 Coordination Across Systems	49	3.60	0.70	85	3.56	0.84
4.9 Knowledge of EI Services	50	3.66	0.72	84	3.63	0.80
4.10 Understand Intention of EI	49	3.54	0.68	83	3.53	0.86
4.11 Comfort with EI Services	49	3.71	0.54	84	3.63	0.85
4.12 Financial Resource Information	50	3.70	0.65	85	3.54	0.83

Note. * $p < .05$; 1 = Not At All; 4 = Completely.

PRENATAL EARLY INTERVENTION

Table 4

Means, Standard Deviations, for Importance of Outcomes for Families and Practitioners

Prenatal Outcome	Group					
	Families			Practitioners		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
<i>Meeting Health & Well-Being Goals</i>						
1.1 Informal Social Resources	70	3.19	0.97	110	3.61	0.59
1.2 Formal Social Resources	70	3.51	0.74	110	3.52	0.62
1.3 Family Health & Well-Being	69	3.32	0.85	109	3.42	0.60
1.4 Choice of Perinatal Supports	70	3.60	0.71	110	3.69	0.60
1.5 Strengths for Healthy Pregnancy	70	3.34	0.81	110	3.67	0.58
1.6 Access to Financial Resources	70	3.60	0.71	109	3.83	0.47
1.7 Advocate Health & Well-Being	69	3.59	0.75	110	3.68	0.59
<i>Engaging in Parent-Child Interactions</i>						
2.1 Interact with Newborn	63	3.35	0.79	99	3.68	0.55
2.2 Understand Communicative Cues	63	3.37	0.81	99	3.67	0.52
2.3 Initiate & Responsive Interactions	63	3.37	0.89	99	3.78	0.46
2.4 Promote Learning & Development	63	3.57	0.73	98	3.70	0.54
2.5 Newborn Strengths and Needs	62	3.45	0.78	98	3.69	0.55
2.6 Promote Newborn Self-Regulation	62	3.34	0.89	98	3.64	0.56
2.7 Include in Everyday Interactions	60	3.35	0.90	99	3.66	0.56
<i>Parenting According to Culture</i>						
3.1 Vision of Parenting	59	3.12	0.87	86	3.35	0.65
3.2 Parenting Effect on Development	58	3.45	0.71	86	3.51	0.65
3.3 Communicate Child Diagnosis	59	3.47	0.68	86	3.48	0.59
3.4 Influences on Development	59	3.39	0.72	87	3.53	0.57

(table continues)

PRENATAL EARLY INTERVENTION

Prenatal Outcome	Group					
	Families			Practitioners		
	<i>n</i>	<i>M</i>	<i>SD</i>	<i>n</i>	<i>M</i>	<i>SD</i>
<i>Parenting According to Culture Continued</i>						
3.5 Accurate Diagnostic Information	59	3.64	0.58	86	3.70	0.51
3.6 Unique Diagnostic Impact	58	3.48	0.73	86	3.63	0.58
3.7 Parenting & Diagnosis	58	3.31	0.78	86	3.47	0.63
3.8 Family & Community Activities	57	3.33	0.83	87	3.44	0.66
3.9 Confidence in Parenting	58	3.26	0.76	87	3.37	0.73
3.10 Child's Unique Strengths	58	3.53	0.68	86	3.70	0.51
<i>Navigating Systems, Services, & Supports</i>						
4.1 Navigate Health Care Team	50	3.52	0.68	84	3.74	0.52
4.2 Know Part C EI Rights	50	3.44	0.81	85	3.40	0.73
4.3 HIPAA and FERPA Rights	50	3.36	0.83	85	3.49	0.68
4.4 Informed Medical Decisions	50	3.66	0.59	83	3.89	0.35
4.5 Child Care Decisions	50	3.32	0.82	85	3.56	0.59
4.6 Choosing Healthcare Provider	49	3.39	0.64	85	3.62	0.53
4.7 EI, Medical & Other Preferences	50	3.60	0.67	85	3.48	0.65
4.8 Coordination Across Systems	49	3.65	0.63	84	3.62	0.60
4.9 Knowledge of EI Services	50	3.66	0.63	84	3.54	0.63
4.10 Understand Intention of EI	49	3.41	0.71	83	3.42	0.78
4.11 Comfort with EI Services	49	3.49	0.68	84	3.67	0.59
4.12 Financial Resource Information	50	3.58	0.64	82	3.66	0.55

Note. * $p < .05$; 1 = Not at All Important; 4 = Extremely Important.

PRENATAL EARLY INTERVENTION

Table 5

Means and Standard Deviations of Outcome Areas for Families' Desire for Prenatal EI

Outcome Area	<i>M</i>	<i>SD</i>
1. Meeting Health and Well-Being Goals	2.90-3.51	1.06-0.81
2. Engaging in Responsive Interactions	3.22-3.53	0.09-0.78
3. Parenting according to Family Culture	2.88-3.57	0.99-0.68
4. Navigating Systems, Services, and Support	3.02-3.61	0.95-0.69

Note: 1 – Not at all, 4 = A lot

PRENATAL EARLY INTERVENTION

Table 6

Distribution of Family and Practitioner Preference for Professional Lead Across Outcome Areas

Outcome Area	<i>n</i>	Family			<i>n</i>	Practitioner		
		EI %	Medical %	Other %		EI %	Medical %	Other %
1. Meeting Health and Well-Being Goals	67	62.7	17.9	19.4	106-107	32.7-80.2	5.7-57.0	4.7-16.8
2. Engaging in Responsive Interactions	58	69.0	17.2	13.8	93-94	80.9-89.4	3.2-13.8	4.3-7.4
3. Parenting according to Family Culture	51	72.5	11.8	15.7	85-87	19.8-87.4	1.1-76.7	3.5-8.0
4. Navigating Systems, Services, and Support	48	87.5	8.3	4.2	82-84	11.9-97.6	0-84.5	1.2-12.2

Note: Families were asked who should take the lead for each outcome area; practitioners were asked who should take the lead for each outcome.

PRENATAL EARLY INTERVENTION

Table 7

Distribution of Practitioner Perceived Competence of Outcome Areas

Outcome Area	Group											
	If EI Took the Lead						If Medical Community Took Lead					
	Pretty Good Now		With More Training		Don't Think So		Pretty Good Now		With More Training		Don't Think So	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
1. Meeting Health and Well-Being Goals	37	34.6	65	60.7	5	4.7	60	56.1	46	43.0	1	0.9
2. Engaging in Responsive Interactions	66	71.0	27	29.0	0	0.0	56	59.6	38	40.4	0	0,0
3. Parenting according to Family Culture	48	56.5	36	42.4	1	1.2	47	56.0	36	42.9	1	1.2
4. Navigating Systems, Services, and Support	37	45.7	44	54.3	0	0,0	40	48.2	43	51.8	0	0.0