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# State early intervention administrator perspectives of prenatal supports for families with high probability diagnoses

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## Abstract

Early intervention (EI) for families of infants and toddlers with or at risk for developmental delays or disabilities is federally guided to begin at birth or older. With technological advances in prenatal testing, pregnant families are increasingly learning of diagnoses that result in EI eligibility once the child is born. For these families, research is needed to determine the effects of beginning EI prenatally rather than waiting until birth. In this exploratory study, the perspectives of state EI administrators were uncovered to inform the development of a prenatal intervention to undertake such research. Participants reported strong support for prenatal EI, provided recommendations for prenatal intervention design, and offered potential systems change needs. These findings will contribute to the development and testing of a prenatal intervention that makes sense to and is compatible with one critical stakeholder group—those who administer EI programs.

**Keywords:** Prenatal diagnosis, Early intervention, Administrators, Supports design

## Background

Federal policy and regulations guide service and support provision to families of children with or at risk for developmental delays or disabilities. These guidelines evolved over time based on the best available research. One such advancement was services were provided at increasingly younger ages as research uncovered the importance of intervening earlier. In the original U.S. special education law passed over 40 years ago, now known as the Individuals with Disabilities Education Act (IDEA 2004), state provision of special education services for preschoolers aged three to five years was voluntary, while services for infants and toddlers, from birth to three years, was not included at all. Guided by evidence-based interventions, the 1986 amendments mandated that states provide special education services to preschoolers, and included an incentive for states to create an early intervention (EI) system for families with infants and toddlers with developmental delays or disabilities.

Since its inception, EI under Part C of IDEA specifies birth as the earliest time of eligibility. However, technological advances in prenatal testing have increasingly resulted in families receiving certain diagnoses, such as cleft palate, Down syndrome and other trisomies, and congenital heart disease during the prenatal period (McKechnie et al. 2016).

Depending on state EI definitions, some prenatal diagnoses have a “high probability of resulting in developmental delay” (632(5)(A)(ii)), making families automatically eligible for the EI program once the baby is born. This increase in prenatal diagnoses serves as an impetus to research the potentially additive effects of providing EI prior to birth on child and family outcomes, as was found in the Early Head Start research for low-income families (Keilty 2008; Love et al. 2002).

### **Prenatal supports in national policy**

While Part C EI has not yet recognized the prenatal period as a time for intervention, the federal early childhood programs of Early Head Start (Administration for Children and Families) and the Maternal Infant and Early Childhood Home Visiting (MIECHV) Program of 2010 (Health Resources and Services Administration) have included prenatal services since their inception. Like Part C EI, the intended goals of these programs are to enhance child health and developmental outcomes as well as family functioning as the ecology in which child development occurs.

While having a prenatal diagnosis does not preclude families from participating in these home visiting programs, and are therefore already existing support options, not all families with a prenatal diagnosis would be eligible. Additionally, current prenatal home visiting programs are focused on the needs of families with environmental risks, such as low income and/or adolescent parents, which may not be structured or readied to address family needs unique to experiencing diagnoses with a high probability of developmental delay and disability, which is the intent of Part C EI. For example, prior prenatal research found that families were in need of accurate and current information to then process the diagnosis and its implications on child development and family life, provided in a hopeful manner (Hickerton et al. 2012; Kratovil & Julion 2017; McKechnie et al. 2015; Roscigno et al. 2012). EI professionals are prepared to provide such diagnosis-specific supports. Additionally, since these families are automatically eligible for EI, having one seamless program, prenatal to 3 years, would minimize transitions for families and eliminate the need to enroll in another program at the birth of their child. Reciprocally, current prenatal programs are designed to provide supports specifically for the prenatal period, such as facilitating attachment and bonding during pregnancy and anticipatory guidance in preparation for birth. The U.S. Departments of Education and Health and Human Services (2017) jointly called for collaborative efforts between EI and other home visiting programs such as EHS and MIECHV to meet the needs of all families. Part C EI involvement in the prenatal period, in coordination with other prenatal programs, as a primary or secondary source of support, could enhance family readiness to foster positive parent–child interactions and child development.

### **Focus of Part C EI as a family support program**

Part C EI starting at birth is designed with a dual and interwoven focus of child development within the context of the individual family. Meeting family needs promotes positive family functioning for all individuals involved, including but not limited to the focus child and, more specifically, that child’s developmental outcomes (Bailey et al. 2012; Dunst et al. 2007; Trivette et al. 2010). These family needs include parental emotional well-being and self-efficacy, social supports, and informational and material needs

(Bhojti et al. 2016; Brotherson et al. 2010; Dunst and Espe-Sherwindt 2016; McWilliam and Scott 2001; Trivette et al. 2010).

Research on families with a prenatal diagnosis has also identified the need for emotional, material, and informational supports. Families reported needing a balance of individual time to process the diagnosis while keeping in contact with extended family and friends as their personal support system, as well as connecting with other families who have a child with the same diagnosis and community-based resources available to meet the family's priorities (Hickerton et al. 2012; McKechnie et al. 2015). Recommended emotional supports focus on sharing a positive and hopeful perspective that the family can meet their prenatal and parenting goals and vision, including whether or how to undertake typical prenatal rituals with others, such as baby showers, pregnancy announcements, or documenting and sharing the pregnancy (Kratovil and Julion 2017; McKechnie et al. 2015; Roscigno et al. 2012). In a review of the literature on family preferences for receiving and understanding a prenatal diagnosis, Kratovil and Julion (2017) found that the type and amount of information families (mostly mothers in the studies) wanted from their healthcare providers were distinct for each family and cautioned that providing too much or too little than the family desired could increase anxiety. This research review also found that most families were seeking complete and detailed information. Therefore, researchers concluded that professionals can share information in various ways and pacing over time, and assist families in finding other trustworthy information sources (Carlsson et al. 2016; Marokakis et al. 2016; McKechnie et al. 2016). Given EI's role in family-centered supports for families with such diagnoses, EI may be uniquely positioned to provide and coordinate supports prenatally.

In addition to the research on families with a prenatal diagnosis, postnatal research has demonstrated the importance of quality parent-child interactions to positive developmental outcomes and intervention effectiveness (Guttentag et al. 2014; Mahoney et al. 1998; National Research Council 2000; Raikes et al. 2014). EI can draw on current prenatal interventions and research (unrelated to diagnoses) that focuses on bonding and responsive interactions (e.g., Bryan 2000; Gilkerson and Wechsler 2014; Guttentag et al. 2014; Hans et al. 2013) to support families as they get ready to respond to their child's communicative cues in ways that might be different from how families expected (Innocenti et al. 2013; Keilty 2008; Khetani et al. 2013; Smyth et al. 2014). All these family and interactional supports can promote the families' need to "express agency as parent" (McKechnie et al. 2016, p. 84) and develop "a sense of mastery" (Cardone and Gilkerson 1992, p. 41; Costa 2006).

Before any policy or practice recommendations can be made to Part C EI service delivery, an evidence based on whether or not prenatal EI contributes positive effects to meeting child and family outcomes must be established. This qualitative study was undertaken to understand the perspectives of state EI administrators to inform the development of a prenatal intervention as an initial step in gathering such evidence.

#### **EI state administrators as critical stakeholders**

This research was undertaken to gather preliminary evidence on whether the concept of prenatal EI, and potential prenatal outcomes, makes sense to and is compatible with EI state administrators as a critical stakeholder group (Dunst and Trivette 2009; Odom

2009; Strain et al. 2012). Collecting input in the intervention development phase can increase the likelihood that the intervention designed is socially valid and identifies contextual variables and potential implementation drivers, such as necessary practitioner competencies and systems facilitators, to be tested as to their impact on intervention effectiveness (Snyder et al. 2013; Sutherland et al. 2013). This input increases the likelihood that the intervention designed, prior to efficacy studies, can be implemented with fidelity in practice (Dunst and Trivette 2009). This study explores the perspectives of one stakeholder group, those who administer state EI programs, as part of a series of studies to understand the perspectives of various stakeholders (e.g., families, practitioners, and medical providers).

State administrators are in a unique position to contribute as interpreters and overseers of evidence-based policies through procedures, funding foci, and professional development that, in turn, influences practice (Buysse et al. 2005; Hebbeler et al. 2012). The purpose of this study is to inform prenatal intervention by understanding the perspectives of state EI administrators. This research sought to understand:

- What are state EI administrators' perspectives on the need for and compatibility of prenatal EI within the intended goals of Part C EI?
- What do state EI administrators recommend are included in a prenatal intervention which can then be tested for efficacy?
- What are potential systems considerations if prenatal EI is found to positively contribute to child and family outcomes?

## **Methods**

A focus group was the primary method used to conduct this research. Given the newness of the topic of prenatal EI, a focus group provided participants the opportunity to engage with their peers and build knowledge through their various thoughts and ideas that might not arise without such interactions (Madriz 2003; Patton 2015).

### **Researcher positionality**

Both researchers have prior professional preparation and practice in Part C EI, as well as experiences in hospital-based settings where many families with prenatal diagnoses begin their developmental supports. Additionally, both researchers recognize the potential for prenatal interventions and are, therefore, interested in prenatal research to determine its effectiveness. These positions are made explicit so that the data can be analyzed with a focus on the research purpose.

### **Participants**

The population under study was the 58 lead administrators of U.S. state and territory Part C EI systems. All administrators were emailed an invitation to participate; a second follow-up invitation was emailed 1 week later. Once an agreed upon date for the focus group was scheduled with administrators who contacted the project to participate, the researchers shared this date with all lead administrators as a final invitation to participate. In total, five state EI administrators (8.6%) participated in this study via either a

focus group interview ( $n = 4$ ) or an individual interview ( $n = 1$ ). The interview was conducted separately from the focus group to accommodate the participant’s schedule.

Participant demographic characteristics are summarized in Table 1. Four participants worked in EI for over 20 years. This significant experience can provide a historical perspective and insight into system facilitators and barriers. One participant has been in EI for 3 years, which could lend a newer perspective to the focus group discussion. Particular to their current role, two participants led their state’s EI system for 9 years, while three participants were in their current position for 2.5–3 years. The five participants represented the primary lead agencies (education, health, and human services) responsible for administering EI at the state level and spanned the northeast, southeast, midwest, and western regions of the U.S. While the sample represents a small percentage of the population, the sample’s diversity lends support to the data derived.

**Data collection**

Both the focus group and individual interview were audiotaped and facilitated by one of the authors, using the same semi-structured interview. One set of questions asked participants to consider the concept of prenatal EI in general to prompt discussion on:

1. Current prenatal service provision in their state;
2. Support for and questions about prenatal EI;
3. Similarity and differences between pre- and post-natal EI;
4. Systems considerations including infrastructure, professional development, and policies and procedures; and
5. Collaborations with medical, social, and other developmental programs.

The second set of questions asked participants about a series of project-developed prenatal outcomes (see Additional file 1: Appendix S1). Currently available state and

**Table 1 Demographic information of participants ( $n = 5$ )**

Participant characteristics	<i>n</i>
Gender	
Female	4
Male	1
Age	
40–49	1
50–59	2
60–70	2
Race	
White, non-hispanic	3
Black, non-hispanic	1
Education level	
Master degree	3
Doctoral degree	1
Area of study	
Education	3
Nursing	1
Social work	1

program postnatal EI outcomes, as well as expected outcomes of other home visiting programs, were examined. The researchers considered if the outcomes could be addressed prenatally and were in the purview of Part C EI. The outcomes were divided into four areas: (1) meeting family health and well-being goals, (2) engaging in responsive parent–child interactions, (3) parenting according to their individual family culture, and (4) navigating systems, services, and supports. Similar to postnatal EI, the identified prenatal outcomes were not expected to be areas all families would seek support, but reflect the range of outcomes possible. The intention was that each particular family would individually identify specific outcomes. Study participants were asked to review the outcomes and share their perspectives on (1) the importance of particular outcomes, (2) how families might respond to the outcomes, and (3) system considerations.

Five former state EI administrators reviewed the questions and outcomes, and provided feedback on clarity and content. This feedback was integrated into the versions used in this study. During the focus group and interview, participants were asked to suspend concerns related to funding issues currently facing EI nationally. The researchers emphasized that this study was not seeking to make any policy or practice recommendations at this time, but to develop an intervention for research purposes as a preliminary step toward determining evidence for prenatal EI over time.

### **Data analysis**

Participant data were coded through inductive, thematic analysis using the constant comparative method with the purpose of informing the design of a prenatal intervention. (Merriam 1998; Patton 2015). The focus group and interview audio recordings were transcribed. Each of the authors independently read the transcriptions and identified preliminary themes and codes. Individual data units were specified so researchers were coding from the same data unit. Researchers then independently coded each data unit into one of the codes. Researchers conducted two rounds of coding independently, revising and refining themes in between. Researchers then came to consensus on the themes and codes. A third researcher with expertise in EI but unfamiliar with the study conducted a peer audit as a validity check and shared potential implications of the findings. Reassembling the data (Yin 2016) resulted in the final themes and codes summarized in Table 2 and described in the findings below (Yin 2016).

### **Findings**

The participating state administrators shared their perspectives on prenatal EI in general as well as project-identified prenatal outcomes. Overall, the participants held positive views of prenatal EI. They focused the discussion on considerations for designing an intervention to be tested, including related personnel competencies and interagency collaboration needs. Participants also identified system changes necessary to implement any prenatal interventions should research find those interventions to be effective in the future.

**Table 2 Qualitative themes and codes (n = 5)**

Themes	Codes
Current state of prenatal EI	EI starts at birth Provides referrals to other resources Shares information
Fit/understanding prenatal EI	Benefits families Aligns with postnatal EI purpose and practices
Direct intervention service factors	What would prenatal EI look like? Project outcomes clarity, usage, and changes
Personnel and professional competencies	Professional development needs Professional disciplines needed
Interagency collaboration (medical, mental health and home visiting programs)	Recognized expertise of other programs/new partners EI professionals' scope of practice defines role in collaboration Formalize collaborations
Future systems design	Eligibility criteria Funding/system of payment Statutory/regulatory language

**Current state and fit of prenatal EI**

The participants described what was currently occurring when families with prenatal diagnoses contacted EI, as well as the alignment of prenatal EI to postnatal EI philosophy and practice.

All five participants reported their state EI program had no specific policies or procedures around prenatal intervention. Any supports provided were identified as “informal” and would occur at the local level as the child and family would not be formally enrolled into the state program until birth. Some participants identified that, should families call the EI program while pregnant, resources provided would most likely be “connecting with...parent organizations,” and/or “giv[ing] information [about the EI program] and prepar[ing] for the family to contact again after the child was born”.

While EI programs were not formally providing EI supports, there was consensus among participants that providing services prenatally could be a positive evolution in EI. Participants specifically discussed how the concept of prenatal EI was aligned with the purposes and practices of postnatal EI, including the focus on prevention, use of coaching models, and “family guided...supporting the family”.

Four participants specifically articulated the potential benefits of prenatal EI for families; one participant cited that EI “could alleviate parental fear and...give them a realistic perspective”. Another participant further outlined the benefits of prenatal EI:

*[EI could] support [the family] and provide information and parent-to-parent support...and that it could potentially open up an entire community to a family... they may not even know exists....That excites me about how much knowledge and support and information that we could impact an individual family.*

While another participant agreed that prenatal EI could be valuable to provide information to families and answer their questions, that participant also identified prenatal EI has its limitations as, “[families] are not going to know everything they

wish they had known after the fact”. This divergent perspective is important to consider in intervention design as, while all participants agreed that prenatal EI could be beneficial to families, any supports provided must fit within the family’s currently articulated priorities, resources, and needs.

Participants acknowledged that not all families may want prenatal EI, and emphasized the importance of how prenatal EI is described. One participant compared this to current EI:

*I think we face the same issues even with a postnatal diagnosis. It's how you describe the [EI] service; in that it is intended to educate the family and support the family and increase their capacity. It's not about teaching the babies things necessarily.*

Another participant suggested “understanding the cultural implications...[due to] significant differences in how people view...or how people would accept or consider intervention at this [prenatal] stage”. The participants emphasized the importance of how prenatal EI is articulated to individual families.

### **Prenatal intervention components**

Participants provided their perspectives on three components of designing a prenatal intervention—direct intervention service factors, personnel and professional competencies, and interagency collaboration. Considering these perspectives at the forefront of research design can inform both the intervention itself and testing for potential active ingredients of intervention effectiveness.

#### ***Direct intervention service factors***

The participants identified many questions to consider in intervention design. These questions centered on intervention duration (when to start prenatally) and intensity (how often and how many professionals involved) and considerations for specific populations, such as those with a false positive prenatal diagnosis and those with limited life expectancy. One participant described how different diagnoses would require a different approach:

*If you discover your unborn child has a diagnosis of Down syndrome, that might take you to a different focus than discovering your child has a medical condition that's going to cause a wide variety of physical and medical conditions that will [be] part of that whole early intervention experience.*

Reciprocally, the question of how much a diagnosis informs intervention was also raised:

*There is such a range of...[the] kind of issues a child with Down syndrome can have and some may have it and some may not...a heart condition or hearing impairment....One child with Down syndrome is one child with Down syndrome. So how do you adequately prepare families based on a prenatal diagnosis when you don't know how that particular diagnosis is going to present until the child is born?*

These direct service factors can be proactively integrated into the prenatal intervention research design as research questions to inform future implementation in practice



on the active ingredients needed should the intervention be found effective. For example, duration and intensity can be investigated by comparing child and family outcomes for families who start prenatal EI earlier in pregnancy and differing intensities. These analyses would need to take into account the multiple variables impacting both decisions, such as gestational age of diagnosis, family choice of when to begin prenatal EI, and individually determined intervention frequency. Multivariate and qualitative methods can be used to understand these multiple influences and the kinds of information used (e.g., diagnoses, family and known child factors) in making intervention planning decisions.

With regard to the project-identified prenatal outcomes, all participants reported the outcomes made sense prenatally and were written such that they can be individually interpreted for particular family priorities. Participants agreed that, rather than all outcomes be addressed, specific outcomes targeted in intervention would need to be identified for each family. One participant described this in the following manner:

*Some families might choose one [outcome] from each [outcome area. Another family] might choose a whole bunch of goals from each category. Others might be very focused on, "I've got six months, I've got to take care of my house and I've got to make sure I understand the services because my child is going to need the service system when the time comes". Or, "I'm really, very...unsure about how I should be relating [to] my child who has a disability. Is it different? Is it the same? I need some advice about...how to have that positive relationship as we get started".*

Participants clearly endorsed the individual nature expected in postnatal EI to be applied to prenatal EI by recognizing the need for a range of possible prenatal outcomes that are then specified to family priorities.

Focus group participants recommended changes to the outcome areas under which the specific outcomes were categorized. One participant suggested that outcome area 4—navigating services and supports—be listed as the first outcome area and explained why:

*It'd be nice to think that one of the benefits of having prenatal early intervention was that you felt more confident talking about your needs, telling the team what's important to you, objecting if it's going in a direction you're not comfortable with...*

This statement suggests that those areas that directly influence the prenatal experience [i.e., health and wellness (outcome area 1) and navigating supports and services (outcome area 4)] take immediate priority. Those influencing what happens when the baby is born (parent–child interactions (outcome area 2) and parenting within one's culture (outcome area 3)) may be a focus nearer to the time of birth. The participants also discussed whether, and came to consensus that, there were differences between outcome areas 2 and 3. One participant described this difference as outcome area 2 was “more about the child and parent connection and relationship” while outcome area 3 was “broader parenting”. Another participant affirmed that the areas represent different “circles...of the eco map”. Finally, some participants questioned the use of the stem *Families are confident and competent in...* prior to each outcome area, wondering “I don't know if, prenatally, if they would be confident [in these outcomes]. They may still be anxious just

to a certain degree”. Similar to the importance of language and approach used to communicate prenatal EI to families in general, this feedback demonstrates the need to consider the order of outcome areas, clearly articulate the differences among outcome areas, and use language that reflects the prenatal period as a beginning to meeting outcomes that continue in the postnatal period.

#### ***Personnel and professional competencies***

One implementation driver to utilize evidence-based practices with fidelity is the competence of professionals using those practices (Snyder et al. 2013). Aligned with the need for clearly articulating the active ingredients of any intervention, participants recognized and encouraged further development of “a clear [prenatal] framework... that then you can determine... the professionals who could best carry it out”. Working from the broad construct of prenatal EI, participants discussed three aspects necessary to ensure an EI workforce ready to support families prenatally—professional development needs, disciplines involved, and consistency of professionals.

When envisioning prenatal interventions, participants identified multiple areas for professional development. These areas included active listening, cultural diversity and family systems, understanding infant mental health, anticipatory guidance of family and child needs, community resources, family assessment, impact of diagnosis, and collaboration with other support programs (e.g., home visiting, medical community, family organizations). Participants emphasized the emotional aspect of intervening during the prenatal period, recognizing that, for families, this is “a time in their life that could come with lots of different emotions”. Participants identified both the competencies needed to provide such emotional supports during “a critical point” and to provide informational and resource supports:

*Just letting families talk about where they are and then being able to identify and work with them to identify the resources they want and need. And [professionals] may need some information about how to prepare the family, like anticipatory guidance and what the hospital will be like and those kinds of things.*

While acknowledging that the overarching professional development skills identified are also expected postnatally, participants identified that utilizing these competencies prenatally, “may be a different set of skills” given how different the prenatal period is from a parenting perspective and the way those “skills and knowledge to support families in this kind of fragile state” would be applied. Participants suggested there may need to be a paradigm shift for some EI professionals to recognize themselves as “home visitors,” and the related roles that entails, in addition to those roles usually considered by their professional discipline.

Participants identified “a broader pool of providers” that may be involved prenatally than those disciplines who usually take on the primary provider role postnatally. Participants specifically identified the disciplinary expertise of psychology, social work, nursing, and counseling as needed during the prenatal period. At the same time, participants also advocated for professionals from more traditional EI disciplines to provide

prenatal supports specific to their expertise and according to family priorities, when well prepared:

*It's about the skills, not the background. So...a physical therapist, for example, or an occupational therapist could be extremely helpful in this role, with the right skillset. And maybe [from research] will emerge that it is often a psychologist or social worker or even a service coordinator, but there could be a decision, because of the particular medical condition that...we want a teacher of the hearing impaired or physical therapist or an OT to be focused on providing that support...because of the issues that will come later.*

Another participant identified the potential role of motor therapists prenatally to provide “an in-home assessment...so that you have all the equipment and adaptations that you need”. Participants appeared to agree that both disciplines more usually aligned with infant mental health provision and those who usually provide EI supports would be necessary to address families’ prenatal priorities and prepare for the postnatal period.

Two participants also emphasized the importance for consistency of professionals between the pre- and postnatal periods. One participant described this as follows:

*[In postnatal EI] a family could experience several interventionists throughout their enrollment period and I just think that there need to be careful considerations during such a time when a family is understanding about a diagnosis and getting support that we are cognizant of how much consistency is important.*

This suggests that pre- and postnatal EI be viewed as a cohesive intervention rather than provided by separate programs, in coordination with the services and supports provided by other programs, such as those currently providing prenatal home visits. In summary, participants identified any prenatal intervention should include well-prepared professionals from disciplines who usually provide postnatal EI, as well as those professionals who usually take on a secondary role in postnatal EI, but are primary providers in other family and child programs.

### **Interagency collaboration**

Participants emphasized that any prenatal supports undertaken by Part C EI would require close collaboration with current home visiting programs and the medical community to determine “how might there be some intersection with [those] team[s] of professionals in early intervention”. As one participant identified, this collaboration would prevent those in programs that already provide prenatal supports from thinking, “we do a lot of prenatal work and support with families and now you are stepping on that”. Participants described collaboration across agencies at both the practice and systems levels.

On a practical level, participants recognized the expertise brought by nursing and mental health providers already available in other programs. While one participant identified that, in their state, there is a “small [EI] program that is starting to expand and grow for early childhood mental health specialists,” another participant acknowledged that these types of supports may “not [be] coming from EI necessarily”. Another participant questioned:

*Could that be an option...you're developing an IFSP for a family participating in this [EI] program...and it could be that the service is actually one of the existing home visiting programs...that are sort of outside of early intervention?*

Taking advantage of already existing prenatal resources could further delineate the particular role EI can provide prior to birth.

In examining the project-identified outcomes, participants cautioned EI professionals must remain within their scope of practice, facilitated by clearly articulated roles, most particularly within outcome area #1, prenatal health and well-being. In reference to the outcome around the coordination of a healthy pregnancy, one participant stated that “the role of the early interventionist would be minimal there” with the medical community taking the lead. Additionally, participants agreed that EI professionals’ roles related to depression would be limited to “know[ing] there are maternal depression screenings...and maybe knowing how to complete a screening and referring a family depending on the results”. Participants appeared to agree that, for outcomes outside their scope of practice, EI professionals’ roles would focus on coordination with other professionals (e.g., home visiting, mental health, medical) while those professionals support the family “and then just monitor and be available as needed”. When considering collaboration with the medical community, participants identified the need for “pretty robust outreach” to new specialists, such as OB/GYNs, and while “we already work with geneticists...it would be different now. This would be earlier than we’ve ever done before”. One participant suggested using the medical home model to coordinate such supports. Participants recommended these collaborations could be formalized at the systems level “so there’s a clear, joint understanding of coordination versus just trying to work it out family by family”.

Participants identified various mechanisms for formalizing interagency coordination, such as the maternal and child health collaborations occurring at the federal level and the Help Me Grow model. One participant described how their state’s home visiting consortium could support:

*[The consortium] would be a prime opportunity to share and discuss and it probably could address some of those concerns we’ve talked about for early intervention... maybe some of the other programs could incorporate information from us and help us to deal with some of the barriers.*

Participants identified that those home visiting supports are “already done by other programs and is it a matter of expanding eligibility” to include all families with prenatal diagnoses. These systems level considerations may be beyond the development of a prenatal EI evidence-base, yet identifying future systems needs as implementation drivers can be tested for if efficacy research demonstrates prenatal interventions have promise in effecting family and child outcomes.

### **Future systems design**

While participants recognized that prenatal EI is currently at the conceptualization phase and first requires the development of an evidence base, they discussed specific needs in order to ready EI systems for prenatal support provision. This discussion

further demonstrated the participants' interest in, and appreciation of, prenatal EI, by looking ahead to designing such a system. Participants described necessary changes that affected eligibility, funding, and related procedures to shift the focus from postnatal to prenatal supports. Most particularly, participants emphasized that current federal and state rules identify *birth* as the onset of EI, requiring changes in "statutory language and regulatory language". With regard to eligibility procedures, participants identified the need for a "rethinking of child find activities" and evaluation processes, including "what families should be eligible for prenatal early intervention?" Participants questioned the source of funding prenatal supports as services are currently funded through the child's private health insurance and Medicaid as well as the child's special education rights for a free and appropriate education in birth mandate states. Participants also identified more detailed administrative changes needed, such as "calculating the age of the child" upon system entry in state databases and "what's relevant and what's not" related to due process and other procedures. While participants identified these systems questions, as well as current funding and personnel constraints, they further emphasized the alignment of prenatal supports to current initiatives: "[Our state] is really focusing heavily ... on prenatal on up. So, I think it's a great idea, and just trying to think of...the difficulties or barriers we would face to be able to do that".

## **Discussion**

The purpose of this study was to inform the development of a prenatal intervention by soliciting input from state EI administrators, a stakeholder group responsible for leading the implementation of evidence-based practices. Study findings demonstrate strong support for undertaking such research and outlined considerations for intervention design and testing.

Study participants confirmed that the concept of prenatal EI supports is aligned with the philosophy and intent of EI, as well as state initiatives occurring across early childhood and mental health. While tempered by the small sample size and potential bias of those who chose to participate, participant support extended beyond the abstract as they provided explicit feedback on intervention design as well as the impact on EI administrative systems. These formative data suggest pursuing this line of this research has merit in accordance with the EI goals of intervening as early as needed, maximizing primary and secondary prevention approaches, and building family capacity.

Findings resulted in considerations for ensuring effective "messaging" of prenatal EI purpose, intent, and outcomes within the intervention design, including the consideration of cultural conceptions of the prenatal period and prenatal diagnoses. The authors conducted survey research on families as another stakeholder of prenatal EI and found most families thought the prenatal EI outcomes were clear and important. Future research can draw on the processes outlined by Shonkoff and Bales (2011) to translate scientific knowledge. First, the broad concept of prenatal EI can be made concrete and then gather data from a more diverse group of families to capture understandings and misunderstandings to identify how best to communicate prenatal EI to a wider audience.

The study findings also identified specific variables to be tested as potential active ingredients for intervention effectiveness, including prenatal EI frequency and

intensity, in general and specific to family characteristics, such as child diagnosis. These same variables have been cited as next steps toward research-informed postnatal EI design (McWilliam 2015, 2016). Building these variables into the design of efficacy research at the outset will provide the detailed data necessary to inform effective program implementation should prenatal EI be determined to add value to effecting family and child outcomes.

Participants affirmed that all the researcher-identified outcomes made sense to address prenatally in EI. They discussed the order of outcome areas—whether outcomes around navigating systems and supports should come first—as well as the differences between the outcome areas of parent–child interaction and parenting within one’s individual culture. While consensus was not reached regarding changing the order of outcome areas, the participant’s rationale for moving navigating systems and supports first suggests a chronological prenatal priority. Upon receiving a diagnosis, families are frequently faced with multiple services and supports that require coordination and decisions needing family advocacy to ensure their voices are included. The effects of intervening toward these outcomes can be seen immediately. Preparing for responsive interactions and parenting may be considered more ongoing outcomes during the pregnancy, with the full impact harder to ascertain until closer to, or after, the child’s birth. In EI, families determine which outcomes to address. Future research can uncover whether, and at what gestational ages, families prioritized certain outcomes over others. Participants did reach consensus that parent–child interaction and parenting are distinct outcome areas to be addressed prenatally. The value they placed on these outcome areas are reflected in their stated need for qualified personnel and interagency collaboration.

Findings identified potential implementation drivers of qualified personnel and, relatedly, interagency coordination to meeting all the prenatal outcomes. Participants articulated specific areas of professional development for those providing prenatal EI. Broadly, these competencies are also expected in postnatal EI to address family-level outcomes and partner with families. Since the child is not yet born, these family-based practices rise in prominence in prenatal EI. Future research can determine the similarities and differences in applying these competencies pre- and postnatally to fully ensure EI professionals are prepared for such work, as well as inform the selection of EI team members based on disciplinary expertise.

Participants recognized and valued the expertise other agencies bring to prenatal intervention, envisioning EI taking different roles depending on the specific prenatal outcome. While interagency coordination of services and supports are important in postnatal EI, collaboration among agencies may be further emphasized prenatally where “who takes the lead on which outcomes” needs to be specified in ways that maximize the resources and capacities available across agencies. By designing prenatal EI research attuned to needed professional competencies and roles of EI and other prenatal support programs, the findings from the research can better inform practical implementation in the future.

While prenatal EI is still in a conceptual phase, the findings from this study suggest that prenatal EI is aligned with the philosophy and intent of Part C EI, and could evolve into a beneficial source of support for families with prenatal diagnoses. The

next step is to commingle the results across stakeholder studies (i.e., state EI administrators, families, EI professionals, and medical providers) to create and test an intervention to determine efficacy.

## Additional file

**Additional file 1: Appendix S1.** Project-identified prenatal early intervention outcomes.

### Authors' contributions

BK and JDS collaboratively designed and implemented all aspects of the research reported above, as well as outlining this manuscript based on the research findings. BK took the lead in writing the manuscript and JDS reviewed and provided feedback on content and clarity. Both authors read and approved the final manuscript.

### Authors' information

BK is an associate professor in the Department of Special Education at Hunter College, City University of New York and coordinates Hunter's Early Childhood Special Education program. BK's work focuses on early intervention practices and policies that support the family in their parenting role and promote infant-toddler development, and prepare professionals to provide that support. She is author of *The Early Intervention Guidebook for Families and Professionals* (2016), which is currently in its second edition, and *Seven Essentials for Family-Professional Partnerships in Early Intervention* (2017). BK is a former president of the Division for Early Childhood of the Council for Exceptional Children.

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### Competing interests

The authors declare that they have no competing interests.

### Availability of data and materials

The data reported in this manuscript are qualitative and, therefore, not made available as such data are context specific and, per IRB and associated consent procedures, will solely be reported in aggregate form.

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