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Understanding Barriers to Early Intervention Services for Preterm Infants: Lessons from Two States

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Abstract

Objective—To explore existing barriers and challenges to Early Intervention (EI) referral, enrollment, and service provision for very-low-birth-weight infants (VLBW; <1500g).

Methodology—We conducted 10 focus groups with parents of VLBW children (N=44) and 32 interviews with key informants from EI (N=7), neonatal intensive care units (N=17) and outpatient clinics (N=8) at six sites in two states. We used grounded theory to identify themes about gaps in services.

Results—Both parents and providers found EI helpful. However, they also identified gaps in the current EI system at the levels of eligibility, referral, family receptivity, and service provision and coordination with medical care. Inadequate funding and variable procedures for evaluation may affect children's eligibility. Referrals can be missed due to simple oversights or communication failures between hospitals, EI and families; referral outcomes often are not formally tracked. Families may not be receptive to services due to wariness of home visits, social stressors, denial about potential developmental delays, or lack of understanding of the benefits of EI. Once a child is deemed eligible, services may be delayed or terminated early, and EI providers may have little specialized training. Communication and coordination with the child's medical care team is often limited.

Conclusions—Systemic barriers, including funding and staffing issues, state and federal regulations, and communication with families and medical providers, have led to gaps in the EI

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system. The chronic care model may serve as a framework for integrating community-based interventions like EI with medical care for VLBW children and other vulnerable populations.

Keywords

Early Intervention; IDEA Part C; preterm infants; VLBW infants

INTRODUCTION

Preterm infants, especially those born very-low-birth-weight (VLBW; <1500g), are at risk for long-term cognitive,¹⁻⁴ behavioral^{1, 2} and physical limitations.^{1, 2, 4} Many face additional risk due to social factors, as preterm birth is more common among families of lower socioeconomic status.⁵⁻⁷ Because of these risks, VLBW children are often eligible for Early Intervention (EI) services through Part C of the Individuals with Disabilities Education Act (IDEA).⁸ According to recent national outcome data, 65-70% of children who enter EI with developmental delays are closer to age-expected skills when they exit EI.⁹

The American Academy of Pediatrics recommends EI referrals for all children who have or are at increased risk for developmental delays and identifies EI services as part of the medical home.¹⁰ While EI referrals and enrollment depend on state eligibility criteria,¹¹ many eligible children are not efficiently connected to services.¹²⁻¹⁴ Families of poor¹¹ and minority children¹³⁻¹⁵ may have more trouble accessing services and may be less satisfied when they do receive services.¹⁵ Budgetary constraints also have led several state EI programs to propose or institute eligibility restrictions or fees for families.¹⁶⁻²⁰ Moreover, EI typically serves children in home or community settings,⁸ which may require special efforts to integrate with the medical care system.

The chronic care model²¹ could provide a helpful framework for improving EI enrollment and services. This model describes six components of care for patients with chronic illness: organization of health care, delivery system design, community resources, patient self-management support, clinical decision support, and clinical information systems.^{21, 22} Evidence suggests that changes which address these six components can improve both quality of care and health outcomes for the chronically ill.²³

We conducted a qualitative study with parents, healthcare providers and EI providers to explore existing barriers and challenges to EI referral, enrollment, and service provision for VLBW children. We interpreted our findings in the context of the chronic care model²¹ and identified opportunities for EI and healthcare providers to work together to improve services for this population.

METHODS

We held focus groups and interviews with parents of VLBW children and interviews with key informants at six hospitals as well as state and local EI programs. We selected three sites in Massachusetts and three in South Carolina to provide socioeconomic and geographic diversity. Study approval was granted by the Institutional Review Board at each hospital site. The study's overall aim was to explore barriers to care for VLBW infants in two areas: EI

services and ophthalmologic care. Focus groups with parents explored both topics, with roughly half the time devoted to each. Interviews with key informants (e.g., EI providers, NICU providers) addressed ophthalmologic care, EI services or both, depending on the informant's role and expertise. The findings from the ophthalmologic aspect are reported separately.²⁴ Providers who exclusively discussed ophthalmologic care during their interviews are not included in this paper.

Development of Focus Group and Interview Guides

Discussion guides for focus groups and interviews (Appendix 1 and 2) were developed with input from staff in the neonatal intensive care unit (NICU), NICU follow-up clinic and local EI programs based on their experience with EI services for VLBW children. These guides were meant to be flexible to allow the focus groups and interviews to be driven by the experiences of participants. Questions were further refined as the focus groups and interviews progressed.

Parent Focus Groups and Interviews

We recruited a convenience sample of parents and guardians of VLBW children via an opt-out method. Study staff at each site provided contact information for families of VLBW children discharged from the NICU during the previous year. The research team then mailed families an introductory letter which explained the study and asked them to return a stamped postcard if they preferred not to be contacted. Families who did not opt-out were contacted by the research team via telephone and invited to attend a focus group at the site from which their child was discharged. Those who declined to participate or could not be contacted after 3 attempts were excluded from participation. Only one parent from each family could participate. Because of staff language constraints, we recruited only English and Spanish-speaking parents. However, we were unable to recruit enough Spanish-speaking participants for a focus group. Focus groups lasted approximately two hours and were conducted by trained study staff using a semi-structured guide (see Appendix 1 for focus group guide). Subjects provided verbal consent and demographic information before participating. They were compensated \$30 and received reimbursement for transportation and child care costs.

Key Informant Interviews

Study staff at each site provided contact information for providers who care for VLBW infants in 3 settings: (1) EI programs (e.g., state and local coordinators, direct service providers); (2) NICUs (e.g., neonatologists, nurses, discharge planning staff), and (3) outpatient clinics (e.g., NICU follow-up clinic staff, physical therapists). In some cases, we also obtained contact information for state and local EI coordinators from publically available online resources. We sent recruitment emails to eligible providers. Interested stakeholders gave verbal consent and participated in 30-minute interviews with trained research staff, either in person or via telephone, again using a semi-structured interview guide (see Appendix 2 for interview guide).

Data Analysis

Audio recordings of focus groups and interviews were transcribed by research assistants who were present during data collection, which helped to ensure accuracy of transcription. Data were analyzed using grounded theory. Grounded theory is an analytic method which begins without an a priori hypothesis or organizational framework. Investigators identify themes as data are collected. New data are either classified under existing themes or new themes are created as necessary. Themes are then used to build an explanatory model. Examples of direct quotes which best represent each theme are presented in the manuscript.^{25, 26} For this study, two research staff independently read each electronic transcript and marked relevant quotes with descriptive codes. Using the constant comparative method, they continued to refine the list of codes as data collection progressed. They then met with a third team member to reconcile disagreements and generate a final list of codes. Each quote was then reclassified using the final list of codes, and codes were organized into major themes. Quotes were stored in an excel file alongside their corresponding themes to allow the data to be easily sorted. Theme saturation was achieved when quotes from each new transcript could be classified using the existing set of themes. Findings are reported using Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.²⁷ While multiple quotes supported each theme, the results section includes the quote which best captured the essence of each underlying theme.

Data Credibility

We used the following strategies to ensure data validity:^{28, 29} (1) Investigator triangulation: Investigators from different disciplines independently read and coded transcripts before the codebook was developed. (2) Expert triangulation: Results were reviewed by investigators familiar with health services research, neonatology, and EI. (3) Parent-provider triangulation: Themes were cross-checked by comparing statements from parents and providers. We did not use a qualitative research software package; such tools help with data management but not analysis.²⁸

Development and Organization of Policy Recommendations

After organizing data into major themes, we sought to derive policy recommendations from our findings. For some identified problems with EI services, parents and providers directly made suggestions for improvement or gave examples of strategies used at their institution. We included these as participant-derived recommendations. In other cases, parents and providers described problems but did not give any suggestions for improvement. The research team then used our results to identify possible solutions and included them as investigator-derived recommendations. We organized these recommendations based on the chronic care model.²¹

RESULTS

Characteristics of Participants

Parent Focus Groups and Interviews—We held 10 focus groups at five sites (two groups per site). Each group had three to seven participants. One site did not recruit enough

participants for a focus group. A total of 44 parents participated. Most were female (96%) and identified as Black/African-American (45%) or White (40%) (Table 1). Sixty-nine percent reported that their children were currently enrolled in EI.

Key Informant Interviews—We interviewed 32 providers from the six study hospitals and EI programs in both states. Participants included 7 EI informants, 17 NICU providers, and 8 outpatient clinic providers (Table 1). EI informants included state and local program coordinators as well as EI service providers. Two NICU providers and one outpatient provider also had previously worked as EI service providers.

Key Findings

Below, we discuss ways in which EI can be helpful to parents and providers. We then identify gaps in the current EI system (Figure 1) which may limit EI's ability to achieve its potential. In order to aid in the interpretation of our findings, we have included a figure which shows basic EI eligibility criteria and outlines the processes for referral, evaluation and service provision in Massachusetts and South Carolina (Appendix 3).

How EI Can Help Families and Providers

Several parents described how EI providers help them understand their children's medical and developmental needs. One parent explained: “Sometimes we don't really [understand] the doctor, and then [the EI provider] comes and explains it.” (Parent, MA) In some programs, EI staff attend doctor visits with families: “We go as support systems, and... to make sure we have information correct. A lot of our families' educational levels make it hard for them to... talk about what their doctor explained.” (EI Local Coordinator, MA) EI providers also develop supportive relationships with families: “[My wife] says how... [the EI providers] relate to her, kind of help her out more... mentally than physically.” (Parent, MA) Moreover, EI can connect families with other community resources to address unmet needs: “[EI providers]... know that you can get [supplemental security income] benefits... special vouchers for private day care... Had I not gone through [EI], I would've had no idea after I left this hospital.” (Parent, SC)

For medical providers, EI can complement care by helping to identify developmental issues early: “My doctor didn't notice... my daughter's problem, her neck. Early Intervention did. And then I started to notice it, too. So she has two therapists, one for the neck and one to help her play.” (Parent, MA) EI providers may encourage parents to attend important follow-up appointments: “[EI has] helped us out a lot... in terms of prompting parents to come back to the [NICU follow-up] clinic.” (Clinic Provider, SC) Because they have access to the home environment, EI providers also may make salient observations about the child's development and the family's social situation: “[EI] is the eyes and ears for pediatricians and school systems, and everybody.” (EI Local Coordinator, MA)

Gaps in the EI System

Gap #1: Child is not eligible or loses eligibility—Some VLBW children qualify for EI services based on birth weight or gestational age cutoffs, which vary by state. Those who do not meet these criteria may be eligible based on developmental evaluation. The

assessment tool used can have variable effects on eligibility. In South Carolina, the required tool may delay enrollment for VLBW infants: “We can’t score [our assessment tool] if they’re under four months age. You can tell some of them, they’re probably going to need [EI]... Then [we] have to go out and do [the assessment] again...” (EI Local Coordinator, SC) In contrast, Massachusetts uses a tool which favors enrollment of VLBW children: “The [assessment tool] does not take into account the... adjusted age. So we usually catch them on [developmental delay]... even though the preemie may be doing fantastic for a 34-weeker...” (EI Local Coordinator, MA)

Several EI providers expressed concern about restrictions on eligibility criteria due to insufficient funding: “We’re spending... about \$1.5 million more than we have... Our only choice is to... decrease the number of children served, and to [do that], our only choice is to change eligibility requirements.” (EI State Coordinator) Budgetary inadequacies may be compounded by federal requirements to evaluate programmatic outcomes: “That’s a very expensive proposition... If you don’t have enough money to go around, then [measuring outcomes] just decreases the number of children we can serve...” (EI State Coordinator) Other providers had concerns about loss of eligibility due to more frequent re-assessment of the need for services: “At six months, the preemie may be doing great, even though there may be other [concerns], but since there’s no official diagnosis, we’re going to lose the preemie.” (EI Local Coordinator, MA)

Gap #2: Child is eligible, but referral is missed or unsuccessful—Most families reported that they were referred to EI by the NICU on or around the day of discharge. However, referrals can be missed due to simple oversights or staff coverage issues. Navigating EI eligibility criteria can also be quite complicated for providers. One EI provider said: “I think most pediatricians, and most people who refer to EI don’t quite understand how children get qualified for services.” (EI Local Coordinator, MA) Even when clinicians successfully make EI referrals, establishing the initial connection between EI programs and families can be difficult (Figure 1). One NICU follow-up provider stated: “We find it usually takes two to three times... A lot of my time is re-referring.” (Clinic provider, SC) While some hospital providers received fairly regular feedback from EI about the status of referrals, others relied on updates from families: “I never hear back from [EI] as to what’s happened... If [a parent says], ‘[EI] never called me...’ then here we’ve gone another six months and the child is still delayed.” (Clinic provider, SC) None of our study sites had formal systems for monitoring referral outcomes: “[I] try to, in my head, keep track of who the kids are when they come back to follow-up clinic. If I get the [referral outcome] letter [from EI]... I usually try and put the letter in [the chart].” (Clinic provider, SC)

Gap #3: Referral is successful, but family is not receptive to EI services—Most parents perceived that EI was beneficial to their children and were eager to accept services. However, many factors may decrease family receptivity, including wariness of home visits, social concerns and denial about potential developmental delays (Figure 1). One EI program used brief screening assessments to help parents recognize the need for services: “Some [parents]... might say, ‘I think my child’s fine’ ... We’ll do that [Ages and Stages] screening on the phone... if it shows a slight delay... then they’ll usually let [EI] come out.” (EI Local

Coordinator, SC) Families who are overwhelmed after discharge also may not notice if their EI referral has failed. One parent suggested: “Don't throw [EI] in that pile of paperwork they give you when you have a preemie. They give you... piles and piles of pamphlets and paperwork... And, you know, you just can't...” (Parent, SC)

After services are started, some families struggle to understand the role of the EI provider and how services promote the child's development. Others gave examples of how EI providers keep them engaged in their children's care. One stated: “[The EI therapist] writes... what we did and what needs to be worked on and what was the improvement. And I get a [carbon] copy of that every visit...” (Parent, MA) Another explained: “Some [providers] have diagrams... it shows you how to do [the exercise] step by step... I couldn't ever get these poses, how to hold [my son]... So I got my [video] camera and I was like... [to EI therapist]: ‘now tell me what I need to do.’” (Parent, SC)

Gap #4: Family is receptive, but services are delayed, unavailable, of poor quality, or poorly coordinated with medical care—Most families stated that the referral and evaluation process happened quickly, but some experienced significant delays in the start of services (Figure 1). One parent suggested that referrals should occur before NICU discharge: “I'm thinking for EI to get involved [before discharge]. So when you get home, you don't wait three weeks... for the evaluation and all that.” (Parent, MA) However, a NICU provider explained: “[EI] will not take a referral before [the child's] discharge date, because... that starts a clock for them [to complete the referral and evaluation process within the time allotted by law].” (NICU provider, MA) After a successful referral, procedures for evaluating the child's needs and providing services are variable. For example, in Massachusetts, each child is evaluated by a multidisciplinary team, but this was not always the case in South Carolina.

The availability and quality of EI services is affected by the ability of programs to offer competitive salaries to hire and train experienced providers (Figure 1). One EI provider stated: “We get a lot of young clinicians, fresh out of college... They don't have as much experience in the field, may not recognize signs...” (EI Local Coordinator, MA) Another had concerns about her own qualifications for conducting evaluations: “We just get a brief training on [the developmental assessment tool]. And we don't feel really qualified doing this full assessment, because we don't have... the intense training I think you need to have.” (EI Local Coordinator, SC) In addition, services for special populations, such as rural families, may be unavailable (Figure 1).

Even when children receive high-quality services, communication between EI and medical providers is often limited. For example, hospital staff may hear little from EI about referral outcomes, services received or the child's progress (Figure 1). Conversely, EI providers sometimes experience delays in obtaining medical records, which are important for developing the child's individualized family service plan (IFSP): “Some places are quicker, and it goes more smooth than other places, and sometimes we have to do re-requests, but...eventually we get what we want.” (EI Local Coordinator, MA)

Recommendations for improvement

Table 2 lists recommendations for each component of the chronic care model. Of the 22 recommendations, 11 are participant-derived (marked “a”). Of these, 8 had been implemented by at least one site at the time of data collection (marked “b”). Table 2 also specifies the anticipated time frame (short-term, intermediate, long-term) and the stakeholders responsible for implementation (state/federal government, EI programs, healthcare providers, families).

DISCUSSION

We identified gaps in the EI system at the levels of eligibility, referral, family receptivity, and service provision and coordination with medical care. Our qualitative findings suggest that while EI has tremendous potential to help both families and medical providers, it is difficult to achieve these goals consistently for VLBW children in the current system.

Gaps in EI enrollment for VLBW children have been documented previously,^{12, 13} yet few studies have explored the underlying causes. Some have identified groups less likely to receive services, including poor children,¹¹ racial minorities¹³⁻¹⁵ and those living in disadvantaged neighborhoods.³⁰ However, it may be difficult to increase enrollment without a better understanding of families’ experiences with EI. In one small survey, parents whose preterm children no longer received EI services cited reasons including loss of eligibility and unreliability of EI programs. Some also felt services were unnecessary, and many families whose children did receive EI were unsure which services were being provided.³¹ These results are consistent with our findings about systemic barriers within EI as well as variable understanding of EI services among families. A qualitative study of primarily low-income parents referred to EI also confirms some of our findings – in particular, the perceived concern about EI’s relation to child protective services and the logistical difficulties in establishing connections between EI and families. However, the authors note that “motivated” families were able to access services in spite of these issues.³²

Ensuring access to high quality EI services for eligible children and coordination with their medical care is an important goal. The American Academy of Pediatrics (AAP) recommends that pediatric medical homes strengthen connections with EI programs, to include tracking referral outcomes, monitoring services and updating programs about medical diagnoses.³³ As the Affordable Care Act moves forward, community programs like EI also may be an important resource for pediatric accountable care organizations as they strive to improve quality of care and contain costs.³⁴ Below, we suggest ways in which gaps in the current EI system might be addressed by different components of the chronic care model.^{21, 22} Some sites already used these strategies at the time of data collection (marked “b”), and it is possible that others have been implemented at other locations.

Gap #1: Child is not eligible or loses eligibility

For VLBW children who qualify for services based on developmental delay, eligibility criteria are partially related to funding, which we considered to be an organizational issue. While enhanced budgetary support for EI is needed, systems to more efficiently capture

outcomes data and demonstrate effectiveness also may help sustain adequate funding (clinical information systems). Eligibility must be determined by trained staff (delivery system design) and with appropriate assessment tools (decision support). It is also important to create systems to identify and refer children who initially were ineligible if new developmental concerns arise. Flowcharts for EI eligibility could help general pediatricians determine which children might qualify for services (decision support). Families also could be provided with contact information for EI programs and encouraged to self-refer if they become concerned (community resources).

Gap #2: Child is eligible, but referral is missed or unsuccessful

Algorithms and checklists could help NICU staff identify eligible children and document referrals; they could also help outpatient providers identify missed referrals after discharge (decision support). Connecting families with EI before NICU discharge could help prevent problems reaching families at home (delivery system design). However, this may not be feasible without adjustments to federal timelines (e.g., 45 days to develop IFSP) for referrals made from inpatient settings (organization of health care). As some initial referrals will inevitably fail, it may be helpful to designate a NICU staff member to monitor referral outcomes (delivery system design). Because primary care pediatricians have close follow-up with families after discharge, providing EI-specific information in the NICU discharge summary (e.g., general eligibility criteria, date of initial referral, federal timelines for evaluation, contact information for the child's local EI program) also could help eliminate missed opportunities for referrals (decision support). In the long term, a shared clinical information platform could facilitate communication by allowing providers in different settings to share real-time updates on referral status and families' contact information (clinical information systems). Giving families personalized tools to manage their child's health information, along with contact information for local EI programs, could also prompt families to follow-up when referrals are unsuccessful (self-management support).

Gap #3: Referral is successful, but family is not receptive to EI services

Our results suggest that vulnerable families, who may benefit most from EI, sometimes decline services because of social concerns or wariness about home visits. By meeting families in the NICU, EI could capitalize on the trust that the NICU staff has built with families, which might increase receptivity (delivery system design). Providing families with a list of community resources to address unmet needs might alleviate some stressors and help families prioritize their children's care (community resources). Other families may stop services because they perceive that EI providers merely “play” with the child. Strategies to engage families, such as written updates on the child's progress and targeted online resources, might help clarify the importance of EI and enhance its utility for families (self-management support).

Gap #4: Family is receptive, but services are unavailable, of poor quality, or poorly coordinated with medical care

Increased funding for EI would allow programs to offer experienced providers more competitive salaries (organization of health care), which could help address concerns about staff availability. It may also help ensure that EI programs keep experienced providers who

have the skills to treat medically complex children, which would promote both the effectiveness of treatment and families' confidence in EI services. Programs also could explore innovative ways to incorporate technology into service provision models, which might also reduce costs.³⁵ While video technology could never replace in-person visits, it could facilitate specialty consultation during IFSP development or allow EI providers to participate in doctor visits, especially in areas with provider shortages (delivery system design). An online library of resources could also help reinforce teaching by EI providers (self-management support). Technology could also help improve coordination of EI services with medical care. A common electronic clinical information platform would allow EI providers, healthcare providers and families to share real-time updates about care plans and progress toward developmental milestones (clinical information systems).

These recommendations are based on the chronic care model, which was developed for use in clinical settings. As much of the work of EI occurs outside the traditional health care system, this model provides an imperfect framework for addressing certain issues related to EI. For example, information sharing presents a greater challenge because EI providers may have limited access to electronic medical records and share patients with multiple hospitals and pediatric practices. This is one reason why we believe the development of a shared clinical information platform is an important long-term goal. In the interim, creating a portal/conduit for EI programs and primary care pediatricians to share basic information electronically (e.g., families' contact information, date of referral, status of services) could be an important first step in establishing communication and sharing data. Another challenge is the ability to evaluate the effectiveness of our recommendations. While clinical settings have used information available in medical records,^{21, 23} evaluation of our recommendations would require EI programs to select and measure appropriate outcomes (e.g., enrollment rates, developmental outcomes, quality of life or caregiver stress).

Our study has several limitations. First, our findings are derived from parents and providers of VLBW children in two states. VLBW infants represent a subset of all children served by EI, and funding, eligibility and insurance coverage for EI vary by state. However, several of our findings are consistent with national data about challenges EI programs are facing, including offering competitive salaries, establishing contact with families, and communicating with medical providers.⁹ Second, participants were recruited by convenience sampling and their perceptions about EI may not accurately represent the experiences of all parents and providers. Still, their perceptions and experiences are important, as they identify potential areas of miscommunication and reasons why parents might decline services. Participating parents also had working telephones and access to transportation; families without these resources might face additional challenges in accessing EI services. Third, while we recruited a diverse sample, we were unable to discern differences in the experiences of families from various socio-demographic groups, and we were unable to recruit a Spanish speaking focus group or other groups with limited English proficiency. Future research is needed to optimize EI services for specific populations, particularly families of lower socioeconomic status. These children may have more difficulty accessing services,¹¹ but may benefit most from early childhood programs.^{36, 37}

Despite these limitations, we have identified gaps in the current EI system and used the chronic care model to suggest potential opportunities to improve services for VLBW children. While derived from VLBW infants, many of our findings may apply to other children who qualify for EI services. Indeed, because of their many medical and developmental needs, the VLBW population may serve as a model for the coordination of EI services and health care for other medically complex children. Our recommendations can serve as an initial framework for stakeholders to initiate changes in the current EI system for these vulnerable populations. We hope that communities will test and refine these and other strategies based on their own priorities for improvement.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

1. Behrman, RE.; Butler, AS., editors. Preterm Birth: Causes, Consequences, and Prevention. National Academy Press; Washington, D.C.: 2007.
2. McCormick M, Litt J, Smith V, et al. Prematurity: an overview and public health implications. *Annu Rev Public Health*. 2010; 32:367–379. [PubMed: 21219170]
3. Aarnoudse-Moens CSH, Weisglas-Kuperus N, van Goudoever JB, et al. Meta-analysis of neurobehavioral outcomes in very preterm and/or very low birth weight children. *Pediatrics*. 2009; 124:717–728. [PubMed: 19651588]
4. Hille ETM, Weisglas-Kuperus N, van Goudoever JB, et al. Functional outcomes and participation in young adulthood for very Preterm and very low birth weight infants: the Dutch project on preterm and small for gestational age infants at 19 years of age. *Pediatrics*. 2007; 120:e587–e595. [PubMed: 17766499]
5. Smith LK, Draper E, Manktelow B, et al. Socioeconomic inequalities in very preterm birth rates. *Arch Dis Child Fetal Neonatal Ed*. 2007; 92:F11–F14. [PubMed: 16595590]
6. Blumenshine P, Egarter S, Barclay CJ, et al. Socioeconomic disparities in adverse birth outcomes: a systematic review. *Am J Prev Med*. 2010; 39:263–272. [PubMed: 20709259]
7. Luo Z-C, Wilkins R, Kramer MS, et al. Effect of neighbourhood income and maternal education on birth outcomes: a population-based study. *CMAJ*. 2006; 174:1415–1420. [PubMed: 16682708]
8. Public Law 108-446: Individuals with Disabilities Education Improvement Act of 2004. [US Copyright Office website]. December 3, 2004. Available at: <http://www.copyright.gov/legislation/pl108-446.pdf>. Accessed March 22, 2013.
- 9.

- The Early Childhood Technical Assistance Center. Part C SPP/APR 2011 Indicator Analyses - FFY 2010. 2012 March 22, 2013 Available at: http://ectacenter.org/~pdfs/partc/part-c_sppapr_12.pdf. [The Early Childhood Technical Assistance Center website].
10. AAP Council on Children With Disabilities. Role of the Medical Home in Family-Centered Early Intervention Services. *Pediatrics*. 2007; 120:1153–1158. [PubMed: 17974754]
  11. McManus B, McCormick M, Acevedo-Garcia D, et al. The effect of state Early Intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics*. 2009; 124:S368–S374. [PubMed: 19948601]
  12. Wang C, Elliott M, Rogowski J, et al. Factors influencing the enrollment of eligible extremely-low-birth-weight children in the part C Early Intervention program. *Acad Pediatr*. 2009; 9:283–287. [PubMed: 19482532]
  13. Barfield W, Clements K, Lee K, et al. Using linked data to assess patterns of Early Intervention (EI) referral among very low birth weight infants. *Matern Child Health J*. 2008; 12:24–33. [PubMed: 17562149]
  14. Rosenberg S, Zhang D, Robinson C. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*. 2008; 121:e1503–e1509. [PubMed: 18504295]
  15. Bailey DB, Hebbeler K, Scarborough A, et al. First experiences with early intervention: a national perspective. *Pediatrics*. 2004; 113:887–896. [PubMed: 15060241]
  16. Grant R. State strategies to contain costs in the Early Intervention program: policy and evidence. *Topics Early Child Spec Educ*. 2005; 25:243–250.
  17. Texas Department of Assistive and Rehabilitative Services. Message from Commissioner Debra Wanser About Changes in ECI Eligibility. 2011 March 22, 2013 Available at: <http://www.dars.state.tx.us/announcements/20110818.shtml>. [Texas Department of Assistive and Rehabilitative Services website].
  18. Illinois Department of Human Services. Official Early Intervention Task Force Report - Recommendation #10. 2010 March 22, 2013 Available at: <http://www.dhs.state.il.us/page.aspx?item=50793>. [Illinois Department of Human Services website].
  19. Massachusetts Department of Public Health. Notice of Public Hearing for Early Intervention Services. Dec. 2010 March 22, 2013 Available at: http://www.eiplp.org/documents/Public_Hearing_2011.pdf. [Massachusetts Department of Public Health website].
  20. State of Hawaii Department of Health. S.B. 2595 S.D. 1, Relating to Early Intervention Services - Testimony of Loretta J. Fuddy, Director of Health. Feb 28. 2012 March 22, 2013 Available at: http://www.capitol.hawaii.gov/session2012/Testimony/SB2595_SD1_TESTIMONY_WAM_02-28-12.pdf. [State of Hawaii Department of Health website].
  21. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA*. 2002; 288:1775–1779. [PubMed: 12365965]
  22. Changes to Improve Chronic Care. 2011 August 4, 2013 Available at: <http://www.ihl.org/knowledge/Pages/Changes/ChangestoImproveChronicCare.aspx>. [Institute for Healthcare Improvement website].
  23. Coleman K, Austin BT, Brach C, et al. Evidence on the chronic care model in the new millennium. *Health Aff (Millwood)*. 2009; 28:75–85. [PubMed: 19124857]
  24. Wang CJ, Little AA, Kamholz K, et al. Improving preterm ophthalmologic care in the era of Accountable Care Organizations. *Arch Ophthalmol*. 2012; 130:1433–1440. [PubMed: 22777426]

25. Glaser, B.; Strauss, A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine Publishing Co; Chicago, IL: 1967.
26. Bernard, H. *Research Methods in Anthropology*. 4th ed.. Altamira Press; Lanham, MD: 2006.
27. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007; 19:349–357. [PubMed: 17872937]
28. Giacomini M, Cook D. Users' guides to the medical literature: XXIII. Qualitative research in health care: A. Are the results of the study valid? *JAMA*. 2000; 284:357–362. [PubMed: 10891968]
29. Giacomini M, Cook D. Users' guides to the medical literature: XXIII. Qualitative research in health care: B. What are the results and how do they help me care for my patients? *JAMA*. 2000; 284:478–482. [PubMed: 10904512]
30. McManus BM, Robert S, Albanese A, et al. Predictors of receiving therapy among very low birth weight 2-year olds eligible for Part C early intervention in Wisconsin. *BMC Pediatr*. 2013; 13:106. [PubMed: 23845161]
31. Keller-Margulis MA, Abrahamson CW, Llorens AV, et al. Early intervention service utilization among children born preterm. *Clinical Practice in Pediatric Psychology*. 2013; 1:344–354.
32. Jimenez ME, Barg FK, Guevara JP, et al. Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Acad Pediatr*. 2012; 12:551–557. [PubMed: 23159037]
33. Adams RC, Tapia C, Murphy NA, et al. Early Intervention, IDEA Part C services, and the medical home: collaboration for best practice and best outcomes. *Pediatrics*. 2013; 132:e1073–e1088. [PubMed: 24082001]
34. Long T, Antonelli R, Burton O, et al. Accountable Care Organizations (ACOs) and pediatricians: evaluation and engagement. *AAP News*. 2011:32.
35. Kelso GL, Fiechtl BJ, Olsen ST, et al. The feasibility of virtual home visits to provide Early Intervention: a pilot study. *Infants Young Child*. 2009; 22:332–340.
36. Ramey CT, Ramey SL. Early intervention and early experience. *Am Psychol*. 1998; 53:109–120. [PubMed: 9491742]
37. Brooks-Gunn J, Gross RT, Kraemer HC, et al. Enhancing the cognitive outcomes of low birth weight, premature infants: for whom is the intervention most effective? *Pediatrics*. 1992; 89:1209–1215. [PubMed: 1375731]

WHAT's NEW

Very-low-birth-weight children may encounter gaps in the EI system at the levels of eligibility, referral, family receptivity, and service provision and coordination with medical care. The chronic care model may provide a framework to address these barriers to services.

Figure 1.
Gaps in the EI system for VLBW children

Table 1

Demographic characteristics of sites, parents and providers

Site Characteristics(N=6)	VLBW births per year (approximate)
Boston Medical Center Boston, MA – Urban	40
Brigham and Women's Hospital Boston, MA - Urban/Suburban	110
Tufts Medical Center Boston, MA - Urban/Suburban	140
Medical University of South Carolina Charleston, SC - Suburban/Rural	225
Self Regional Healthcare Greenwood, SC – Rural	20
Spartanburg Regional Healthcare System Spartanburg, SC - Suburban/Rural	50

Parent Characteristics (N=44)	n (%)	Key Informant Characteristics (N=32)	n (%)
Site		Site	
Boston Medical Center	7 (16%)	Boston Medical Center	2 (6%)
Brigham and Women's Hospital	11 (25%)	Brigham and Women's Hospital	2 (6%)
Tufts Medical Center	6 (14%)	Tufts Medical Center	8 (25%)
Medical University of South Carolina	14 (32%)	Medical University of South Carolina	5 (16%)
Self Regional Healthcare	0 (0%)	Self Regional Healthcare	4 (13%)
Spartanburg Regional Healthcare System	6 (14%)	Spartanburg Regional Healthcare System	4 (13%)
		Early Intervention	7 (22%)
Gender		Gender	
Male	2 (5%)	Male	2 (6%)
Female	42 (95%)	Female	30 (94%)
Race		Role	
White	18 (41%)	El Coordinator/Service Provider ^c	7 (22%)
Black/African-American	21 (48%)	NICU Provider ^d	17 (53%)
Other	5 (11%)	Clinic Provider ^e	8 (25%)
Ethnicity^a			
Hispanic/Latino	4 (9%)		
Non-Hispanic/Latino	39 (91%)		
Age^a			
<25 years	7 (16%)		
25-34 years	23 (53%)		
35-44 years	12 (28%)		
45 years	1 (2%)		
Education			
High school graduate/GED or less	11 (25%)		
Some college or 2 year degree	16 (36%)		
4-year college graduate or more	17 (39%)		

Parent Characteristics (N=44)	n (%)	Key Informant Characteristics (N=32)	n (%)
Child currently enrolled in EI ^b	28 (67%)		

MA: Massachusetts; SC: South Carolina; GED: General Equivalency Diploma; EI: Early Intervention; NICU: Neonatal Intensive Care Unit

^aFor the variables “Age” and “Ethnicity”, N=43.

^bFor the variable “Child currently enrolled in EI”, N=42.

^cEI coordinators and service providers included state level coordinators, local coordinators, direct service providers

^dNICU service providers included physicians, nurses, PT/OT/speech therapists, social workers/discharge planners

^eClinic providers included physicians, PT/OT/speech therapists, clinic coordinators

Table 2 Opportunities for innovation in the EI system based on the Chronic Care Model²¹

Recommendations by Component of Chronic Care Model	Time Frame ^c	Stakeholders Responsible ^d
Organization of Health Care: Develop an organizational structure and reimbursement model to promote high quality chronic care for patients with chronic illness		
• Enhance state and/or federal funding for EI; include funding for staff who connect children to services, travel expenses to EI home visits, and assessment of programmatic outcomes ^a	L	1
• For EI referrals made from inpatient settings, consider revising federal time limits (e.g., 45 days for IFSP development) so the clock starts ticking from the date of hospital discharge rather than date of referral	I	1
Delivery system design: Create practice teams to support acute care, patient self-management and appropriate follow-up		
• Establish contact between EI and families prior to NICU discharge, in person or via video chat ^a	I	2, 3, 4
• Designate a hospital staff member who is responsible for monitoring EI referral outcomes	I	3
• Provide formal training on assessment tools to all EI staff who conduct evaluations ^{a,b}	I	1, 2
• Consider conducting evaluations with a multidisciplinary team ^{a,b}	L	2, 3
• Consider including input from specialists connected with the child's medical home when EI specialists are unavailable to participate in the multidisciplinary team	L	2, 3
• Consider using video technology to facilitate consultation from the child's medical team	L	2, 3
Decision support: Integrate evidence-based guidelines into daily practice through reminders		
• Create a discharge planning checklist for the NICU which includes an EI referral and provides contact information for local EI programs; ^{a,b} also include this information in the NICU discharge summary	S	3
• Incorporate EI eligibility criteria into a flowchart for providers to easily determine whether and how children qualify for services	S	3
• Use standardized eligibility criteria and developmental assessment tools across all states	L	1
Clinical information systems: Capture and use critical information to promote compliance with guidelines and plan patient care		
• Create an patient-owned, HIPAA-secure electronic platform for EI providers, medical providers and families to share information, including the referral status, contact information, observations from the home environment, and EPSDT screening data from pediatric visits	L	1, 2, 3, 4
• Offer EI providers mobile electronic devices to document home visits in real time	I	1, 2
• Develop electronic tools for EI providers to capture data needed for program evaluation (e.g., enrollment/disenrollment rates, measures of child's functional abilities)	L	1, 2
Community resources: Facilitate behavior change and self-management through linkages with community-based resources		
• Offer all VLBW families contact information for local EI programs upon discharge	S	3, 4
• Encourage families who are ineligible or lose eligibility to self-refer if developmental concerns arise ^{a,b}	S	2, 3, 4
• Offer VLBW families personalized materials to organize the child's medical information, follow-up needs and referrals, including EI services ^{a,b}	I	3, 4
• During the initial referral, address families' concerns about EI services and conduct a brief assessment (e.g., Ages and Stages) to encourage families to accept a full evaluation ^{a,b}	S	2, 4
• Maintain an updated list of available community resources (e.g., SSI, fuel assistance, day care)	S	2, 3

Recommendations by Component of Chronic Care Model	Time Frame ^c	Stakeholders Responsible ^d
Self-management support: Help patients and families develop skills to manage chronic illness		
• When possible, EI providers can attend doctor visits (in person or via video chat) to help families understand medical information and advocate for their children ^{a,b}	I	2, 3, 4
• Offer families written summaries of EI sessions to help them track the child's progress toward IFSP goals ^{a,b}	S	2, 4
• Create an online library of resources to help families learn about their children's medical conditions and practice skills learned during EI sessions, e.g., physical therapy exercises ^a	L	2, 3, 4

^aRecommendation made directly by parent or provider (versus investigator-derived)

^bRecommendation already implemented by some parents, EI programs or medical providers

^cTime frame: S, Short-term; I, Intermediate; L, Long-term

^dStakeholders responsible: 1, State/Federal Government; 2, EI programs; 3, Healthcare providers; 4, Families EI: Early Intervention; EPSDT: Early Periodic Screening, Detection and Treatment; HIPAA: Health Insurance Portability and Accountability Act; IFSP: Individualized Family Service Plan; NICU: Neonatal Intensive Care Unit; SSI: Supplemental Security Income; VLBW: Very-low-birth-weight (<1500g)