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**Maternal Depressive Symptoms and Participation in Early Intervention Services**

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## **Introduction**

### ***A. Nature of the research problem***

Children ages birth to 3 years with demonstrated developmental delays or conditions known to impact developmental trajectories receive services through state-run Early Intervention (EI) programs as defined by Part C of the federal Individuals with Disabilities Education Act. Such programs are based on research documenting the importance of early life experiences on developmental pathways<sup>1</sup> and have demonstrated effectiveness in improving child outcomes.<sup>2</sup> While eligibility guidelines vary state to state (within specified federal guidelines), it is clear nationally that not all eligible children enroll<sup>3</sup> or, once enrolled, participate fully in available services.

Two factors that may influence participation in EI are race and maternal depression. Data collected by the US Department of Education show a relative decrease in the percentage of black children receiving services from 18% in 1998 to 13.5% in 2007.<sup>4</sup> Studies of children presumed eligible for EI services support this observation that black children are less likely to obtain services than white children.<sup>5,6</sup> Little is known about why black children are less likely to receive EI services. Poverty and lack of health insurance, which disproportionately affect black children, have not been shown to predict service receipt.<sup>6</sup> Several studies suggest a relationship between a child's qualifying condition and service receipt. Children who qualify for EI services based on developmental delay but do not have an easily recognizable qualifying condition, such as low birth weight or sensory impairment, appear less likely to receive services than children with such conditions.<sup>5-7</sup> This finding reflects two distinct pathways of referral and entrance into EI services, which could differentially affect black children. In the first pathway, a child qualifies for EI occurs by virtue of an obvious and easily recognized condition; the second pathway requires active screening and surveillance to identify a child's delays. With regard to maternal depression, a growing literature has documented that children of depressed mothers are at risk for a vast range of poor physical, cognitive, and emotional problems.<sup>8-17</sup> Depressed mothers are less attuned to their infants and less able to engage them in age-appropriate activities that promote optimal development.<sup>18</sup> Studies have documented elevated prevalence of depressive symptoms among mothers whose children have conditions that make them categorically eligible for EI services, such as prematurity, cardiac disease, and cerebral palsy.<sup>19-21</sup> However, these studies are small and not nationally representative.

### ***B. Purpose, scope, and methods of the investigation***

The original objective of this research was to utilize population-based data from the Early Child Longitudinal Study (ECLS) to examine a question that is a growing concern to the MCH community: the impact of maternal depression on young children. Our first research hypothesis was that unidentified maternal depression among families of children with special health care needs (CSHCN) not only adversely impacts child developmental outcomes directly, but also contributes indirectly through suboptimal family engagement in services that have the potential to improve child and family functioning.<sup>2</sup> In initial exploration of the ECLS data, we observed evidence of racial disparities in EI service receipt. We expanded our research to include an analysis exploring how differences in identification and referral as possible explanations for differences in service receipt between black and white children. Our hypothesis for this analysis was that black children without an established medical condition, such as low birthweight or Trisomy 21, which is observable or easily recognized and associated with developmental delay,

would be less likely to receive services than white children. The investigation's study questions, hypotheses, and rationale, were as follows:

1. Study Question 1: What is the prevalence of depressive symptoms among mothers of children eligible for EI services?

Hypothesis: The prevalence of depressive symptoms among mothers of children eligible for EI services will be in the range of 20-30%, exceeding national estimates that range from 6- 12% among mothers during the first postnatal year.<sup>22</sup>

Rationale: Previous research has documented prevalence of depressive symptoms between 30-40% among mothers of premature infants, a group that represents a large proportion of infants enrolled in EI.<sup>19, 20, 23-25</sup>

2. Study Question 2: Among children eligible for EI, does the presence of maternal depressive symptoms affect child participation in the program?

Hypothesis: Eligible children whose mothers report depressive symptoms will be significantly less likely to participate in EI compared with children whose mothers do not report such symptoms.

Rationale: Depressed mothers are less sensitively attuned to their infants and thus, may not appreciate lags in their child's development.<sup>26-28</sup> Depressive illness is characterized by lack of motivation and energy, which impact functional ability and make accomplishing daily tasks, such as attending appointments, difficult.

3. Study Question 3: How does race impact the participation of children with and without established medical conditions in EI services?

Hypothesis: Black eligible children without an established medical condition, such as low birthweight or Trisomy 21, will be significantly less likely to participate in EI compared with white children.

Rationale: It is widely recognized that disparities by race and ethnicity exist in access to and participation in public programs. The relationship between a child's qualifying condition and service receipt may be influenced by race or ethnicity. Black children who qualify for EI by virtue of an obvious and easily recognized condition may be more likely to be referred and enter into EI services compared to black children with delays that require active screening and surveillance for identification.

We analyzed data from the Early Child Longitudinal Study, Birth Cohort (ECLS-B). The ECLS-B is a federally-funded study designed to provide data about children's early life experiences. ECLS-B uses a nationally representative probability sample from the nearly 4 million US children born in 2001. It includes data from face-to-face parent interviews, in-person cognitive and developmental assessments, and information from birth certificates.<sup>29</sup> Children are followed longitudinally with data collection occurring at 9, 24, and 48 months after the child's birth and upon entry into kindergarten. Details of the ECLS sampling strategy are available at <http://nces.ed.gov/ecls/birth.asp>. Data used in this analysis comprise the 9- and 24-month rounds of data collection, the period when children would be eligible to receive EI services. The baseline data were collected during the fall of 2001 through 2002 and the 24-month data were collected during 2003.

### ***C. Nature of the findings***

**Maternal depression analysis:** Nearly 1 in five mothers whose children were eligible for EI services at 24 months reported clinically significant depressive symptoms at 9 or 24 months. The prevalence of persistent depressive symptoms (symptoms at 9 and 24 months) among mothers whose children were eligible for EI services at 24 months was 7.5%. Overall, our findings suggest that children whose mothers had clinically significant depressive symptoms participated in early intervention in a manner similar to children whose mothers were not depressed. Across eligibility categories, a greater percentage of children whose mothers were depressed received EI services than children whose mothers were not depressed. However, in adjusted analyses, the difference was significant among newly eligible children with the lowest scores of mental performance,  $> 2$  SD below the mean. Such children more than 9 times more likely to receive EI services compared to children whose mothers were not depressed. Despite a high burden of depressive symptoms, these symptoms did not hinder child receipt of services.

**Racial disparities analysis:** Among this nationally representative cohort of young children, less than 20% of eligible children received EI services. We found racial disparities in receipt of EI services at 24 months of age for black but not Hispanic children. Black children, who were just as likely to receive services as their white peers at 9 months, were more than 5 times less likely to receive services by 24 months. Whether or not a child had an established medical condition that qualified him for EI services affected the likelihood of service receipt, particularly among black children. In analyses that stratified children by qualifying condition, we found that compared to their white peers, the odds of receiving services were significantly smaller for black children who qualified for services based on developmental delay compared to those who qualified based on an established medical condition.

## I. Review of the Literature

### A. *Depression and Mothers of Young Children with Developmental Delays*

Depressive disorders affect between 5% and 17% of the American population.<sup>30,31</sup> They affect women twice as frequently as men.<sup>32-34</sup> Estimates of major and minor depression during the first postpartum year range from 6-12%.<sup>22</sup> Known social risk factors for depressive illness among women include low-income, single marital status, adolescent parenting, and African-American ethnicity.<sup>35-38</sup> Among certain high risk women, reports of depressive symptoms approach 50%.<sup>37</sup> Despite a higher incidence of depression among these specific populations, such women are less likely to obtain mental health care in either the primary care or specialty setting, and less likely to receive appropriate care when they do seek it.<sup>39</sup>

Less is known about depressive illness among mothers whose children participate in EI programs. To my knowledge, no population-based studies of maternal depression in the EI population exist. Data about depressive illness can be estimated from small, condition-specific studies of children who would be presumed meet EI eligibility criteria. For one such population, premature infants, who represent 46% of children enrolled in EI in their first year of life,<sup>40</sup> estimates of maternal depression incidence ranges from 30-40%.<sup>19,20,41</sup> Literature supports increased incidence of depression among mothers of additional subgroups of children who are routinely enrolled in EI: those with cerebral palsy,<sup>42</sup> congenital heart disease, cystic fibrosis, developmental disabilities, in general,<sup>43</sup> and those reliant upon assistive technologies.<sup>21</sup> Some EI programs also enroll children at environmental risk. Environmental risk characteristics – violence exposure, poverty, early childbearing, and low maternal education, which are associated with poor developmental outcomes in children, are also associated with increased incidence of depression in

their mothers. The demographics of the EI families suggest that mothers of enrolled children are at increased risk for depressive illness, irrespective of the child's developmental or health status. Families are poorer (1 in 4 received welfare payments in the past year), mothers less well-educated, and blacks are overrepresented (21% vs. 14% as compared to the general population), reflecting known risk factors for depression.<sup>44</sup> Almost half of the infants who enter EI in the first year of life are low birth weight and have other attributes that place them at higher risk for developmental delay than their normal birth weight peers.<sup>40</sup>

Depression impairs social and physical functioning, often as severely as serious medical conditions like hypertension or diabetes.<sup>45</sup> Such disability, with its concomitant loss of income, can result in significant economic burden.<sup>46</sup> The morbidity of maternal depression exerts its influence not only on mothers, but on their children as well. Depressed mothers are less sensitively attuned to their infants, which adversely affects mother-child interaction.<sup>18</sup> Infants so affected demonstrate more frequent behavior problems<sup>8,9</sup>—often in the form of infant irritability<sup>10</sup> and eating and sleeping difficulties.<sup>11</sup> Later in life, such problems can manifest as violent behavior and emotional dysregulation.<sup>12</sup> Children of depressed mothers display impairments in social competence, problem-solving, and overall adaptive functioning.<sup>13</sup> They are at greater risk for poor physical growth,<sup>14</sup> attention deficit hyperactivity disorder,<sup>15</sup> and other school problems.<sup>16,17</sup> In a large community-based prospective cohort study, Lieb and others showed that depression in one parent is associated with a nearly three-fold greater risk of depression, a 40% greater risk of substance abuse, and a 60% greater risk of anxiety disorder among teenage offspring.<sup>47</sup> Nomura corroborated these findings in an urban cohort of children followed longitudinally over 10 years.<sup>48</sup> Although conflicting studies exist,<sup>49</sup> evidence suggests that maternal depression adversely affects childhood cognitive development, leading to long-term intellectual deficits.<sup>9,50,51</sup> Sharp and others, for example, found that three-year-old boys of mothers depressed in the first year postpartum scored a full standard deviation lower on standardized tests of intellectual attainment than boys of nondepressed mothers.<sup>52</sup> In March 2006, the STAR\*D report demonstrated for the first time that improved maternal depression symptomatology is positively associated with improved outcomes among the children of these mothers.<sup>53</sup>

### ***B. Racial Disparities in Early Intervention Service Receipt***

Data collected by the US Department of Education show a relative decrease in the percentage of Black children receiving services from 18% in 1998 to 13.5% in 2007.<sup>4</sup> Studies of children presumed eligible for EI services support this observation, that black children are less likely to obtain services than white children.<sup>5,6</sup> However, existing studies have neither investigated how the child's qualifying condition affects racial disparities in service receipt nor how this relationship changes over time.

Little is known about why black children are less likely to receive EI services. Poverty and lack of health insurance, which disproportionately affect black children, have not been shown to predict service receipt.<sup>6</sup> Several studies suggest a relationship between a child's qualifying condition and service receipt. Children who qualify for EI services based on developmental delay but do not have an easily recognizable qualifying condition, such as low birth weight or sensory impairment, appear less likely to receive services than children with such conditions.<sup>5-7</sup> As described earlier, this finding reflects two distinct pathways of referral and entrance into EI services, which could differentially affect black children. In the first pathway, a child qualifies for EI occurs by virtue of an obvious and easily recognized condition; the second pathway requires active screening and surveillance to identify a child's delays.

## II. Study Design and Methods

### A. Study design

Both analyses were cross sectional cohort studies.

### B. Population studied

For both studies, we analyzed data from the Early Child Longitudinal Study, Birth Cohort (ECLS-B). The ECLS-B draws from a nationally representative probability sample of the nearly 4 million US children born in 2001. It includes data from face-to-face parent interviews, direct cognitive and developmental assessments, and information from birth certificates. Children are followed longitudinally with data collection occurring at 9, 24, and 48 months after the child's birth and upon entry into kindergarten. Details of the ECLS sampling strategy are available at <http://nces.ed.gov/ecls/birth.asp>. Data used in the analyses were collected during the 9- and 24-month rounds of data collection, the period when children would be eligible to receive EI services.

### C. Sample selection

The ECLS-B study population included 10700 children at the 9-month time point and 9850 children at the 24-month time point. In each analysis we included in our sample children who had both parent interviews and developmental assessments and met the eligibility criteria for EI services (described below).

Eligibility for services was determined independently at 9 and 24 months using the following criteria. Children ages birth to 3 years with demonstrated developmental delays or a diagnosed physical or mental condition known to increase risk of developmental delay are entitled to receive services through state-run EI programs as defined by Part C of the federal Individuals with Disabilities Education Act. We included in our analyses children whom we presumed would be eligible for Part C services almost all states.<sup>54</sup> The four criteria used for study inclusion were 1) birth weight < 1000 grams; 2) medical conditions associated with developmental delay, such as blindness, deafness, and mental retardation, determined from parental self-report at the 9 month and 24 month interviews; 3) genetic and congenital conditions associated with developmental delay, such as Down syndrome, spina bifida, fetal alcohol syndrome, and major congenital anomalies such as cleft lip and palate, rectal atresia, and omphalocele, ascertained based on information from the birth certificate; and 4) developmental delay, evaluated through direct assessment at the 9 and 24 month interviews using the Bayley Short Form – Research Edition (BSF-R) Mental Scale and Motor Scales. The BSF-R, which can be administered in a home setting, includes a subset of items from the Bayley Scales of Infant Development, 2<sup>nd</sup> Edition (BSID-II).<sup>55</sup> The BSF-R scores are similar to those obtained from the full BSID-II.<sup>56</sup> We used the BSF-R Scale Scores, which do not adjust for gestational age. In the racial disparities analysis we included children who scored > 2 SD below the mean on Mental Scale or > 2 SD below the mean on Motor Scale.<sup>8, 57</sup> In the depression analysis we also included children who scored > 1.5 SD below the mean on both scales.<sup>58</sup>

Race was coded as Hispanic, black non-Hispanic, or white non-Hispanic according to US Census categories.<sup>59</sup> Children of other races were excluded from analyses due to insufficient numbers.

In the depression analysis, we included the ~ 1200 children who were eligible for services at 24 months and had complete maternal depressive symptom data (described in section D, Instruments used). We stratified the sample by the age at the time the child first became eligible to receive EI services: children eligible for EI services at the 9 month interview who continued to meet eligibility criteria at 24 months (n~ 600) and children newly eligible at the 24 month assessment, based on their developmental performance (n~ 600).

In the disparities analysis, our sample included 1050 eligible children at the 9 month time point (300 black, 500 white, 250 Hispanic) and 700 eligible children at the 24 month time point (200 black, 300 white, and 200 Hispanic).

#### ***D. Instruments used***

As noted, ECLS-B study data were used for all analyses. ECLS-B data are comprised of information from face-to-face parent interviews, direct cognitive and developmental assessments, and birth certificates. EI eligibility was assessed as described above, using information from birth certificates and the results of direct assessments of developmental delay.

Maternal depressive symptoms were measured using validated scales administered during the parent interview. Symptom scales differed by time point due to changes in the survey questionnaire. At 9 months, depressive symptoms were measured by an abbreviated form of the Center for Epidemiologic Studies Depression Scale (CES-D),<sup>60</sup> which has been widely used in populations including new mothers.<sup>61-63</sup> The short form used in the ECLS-B asks about 12 symptoms and their occurrence within the past week; each item is coded on a 4-point scale (0, rarely or never to 3, most or all of the time). The range of total scores is 0 to 36 and the index has an alpha reliability of 0.85 for women.<sup>64</sup> For analysis, total scores were categorized into symptom severity using suggested cut-points from the Department of Education ECLS research team: no clinically significant depressive symptoms (none or mild symptoms, score 0-9, comparable to a score of 0-15 on the full CES-D) or clinically significant symptoms (moderate or severe symptoms, score 10-36, comparable to a score of 16 or higher on the full CES-D).<sup>65</sup> At 24 months, depressive symptoms were determined from responses to the World Health Organization short form Composite International Diagnostic Interview (CIDI-SF) questions.<sup>66</sup> The interview uses a stem-branch structure to assess for major depressive episodes. Two stem questions evaluate the respondents' experience of depressed mood or anhedonia. If the respondent has experienced either of these conditions for two or more weeks in a row, she is asked additional questions about the duration and intensity of the symptoms, the presence of associated symptoms, and the degree to which the endorsed problems interfered with overall functioning. The CIDI-SF used in the ECLS-B assessed symptoms since the last interview (on average, during the previous 15 months). For analysis, responses were categorized into symptom severity as follows: no clinically significant depressive symptoms or clinically significant depressive symptoms (at a minimum, depressed mood or anhedonia for at least a two-week period).

Receipt of EI services was determined based on parent response to the interview question regarding whether or not their child was participating in an early intervention program or regularly receiving services to help with their child's special needs from their local school district, state, health or social service agency, health care provider, or some other source. Receipt of services was coded independently at 9 and 24 months.

#### ***E. Statistical techniques employed***

Both analyses: All analyses were performed using Taylor Series estimation,<sup>67</sup> applying individual level weights to yield valid national estimates, to accommodate the ECLS-B complex sampling design. We performed all analyses using SAS v9.1.<sup>68</sup>

Maternal depression analysis: By child eligibility we compared the child risk and demographic characteristics of children whose mothers were depressed to those who were not. On weighted data, we used the  $X^2$  test of independence to study associations between these characteristics and categorical outcome data. We used multivariable logistic regression models to examine associations between maternal depressive symptoms and receipt of EI services. Separate models were estimated for children who became eligible for EI services as infants and the newly eligible children. To assess confounding and effect modification by child condition, four domains of child risk: medical risk, developmental risk, child temperament and health status were included in the models based on their documented or theoretical association with maternal depressive symptoms and receipt of EI services. All models were adjusted for child race, insurance, single or dual parent household, and family socioeconomic status.

Racial disparities analysis: With weighted data, we used  $X^2$  tests of independence to study associations between a child's qualifying condition, dichotomized as established medical condition versus developmental delay, and race. We examined this relationship among all eligible children and the subset of children who received services. We used weighted multivariable logistic regression to estimate odds ratios for the association between receipt of services and race. To address confounding by possibly collinear variables, while preserving degrees of freedom to enhance statistical power, we estimated propensity scores<sup>69-71</sup> representing the conditional probability of belonging to a specific racial/ethnic category given the observed covariates included in the model.<sup>71</sup> We used child, maternal, and family demographic characteristics to calculate propensity scores for the 9 and 24 month models independently. We imputed missing demographic data required to calculate the propensity score, inserting the race-specific mean value for the missing data point. Missing data was limited to < 1% of the sample for all variables. Separate propensity scores were generated for non-Hispanic black vs. non-Hispanic white children and Hispanic vs. non-Hispanic white children. Our approach allowed the effects of variables included in the propensity scores to differ at the two time points and by race comparison. Propensity scores were included in multivariable regression models to balance observed covariates across racial groups and to infer the association of race with receipt of early intervention services. To examine racial disparities in service receipt by child age, we estimated separate multivariable models for the 9 and 24 month time points. Models were estimated for subgroups of the study sample comparing black and white children and Hispanic and white children to appropriately accommodate propensity scores. Based on results from bivariate analyses suggesting a significantly different relationship between qualifying condition and race among children receiving EI services, we stratified multivariable analyses by qualifying condition (established medical condition versus developmental delay-only) to examine differences in receipt of service by race at the two time points. To determine if the stratified models were significantly different, we tested the significance of a race X qualifying condition interaction term in the whole sample multivariable model.

### **III. Detailed Findings**

Please refer to the two study manuscripts (attached/Appendix I and II) for the detailed findings.

## IV. Discussion and Interpretation of Findings

### A. *Conclusions to be drawn from findings*

**Maternal depression analysis:** Overall, we found that mothers of children who are eligible to receive EI services and mothers of children who receive such services have elevated depressive symptoms compared to mothers of typically developing children. Across eligibility categories, a greater percentage of children whose mothers were depressed received EI services than children whose mothers were not depressed. However, the difference was significant among newly eligible children whose scores of mental performance were  $> 2$  SD below the mean. Such children whose mothers had clinically significant depressive symptoms were more than 9 times more likely to receive EI services compared to children whose mothers were not depressed. As expected, child risk factors were significant predictors of service receipt. In analyses that tested for effect modification, we found that scores on the mental scale of the BSF-R had a different effect on the likelihood that a child whose mother was depressed would receive services. However, this differential association was only observed among the children who were newly eligible to receive services at 24 months.

**Racial disparities analysis:** Among a nationally representative cohort of young children, we found racial disparities for black but not Hispanic children in receipt of EI services at 24 months of age. Overall, less than 20% of eligible children received EI services. In the study population, racial disparities in service receipt did not emerge until 24 months after birth and were significant for black but not Hispanic children. Black children, who were just as likely to receive services as their white peers at 9 months, were more than 5 times less likely to receive services by 24 months. Whether or not a child had an established medical condition that qualified him for EI services affected the likelihood of service receipt, particularly among black children. In analyses that stratified children by qualifying condition, we found that compared to their white peers, the odds of receiving services were significantly smaller for black children who qualified for services based on developmental delay compared to those who qualified based on an established medical condition.

### B. *Explanation of study limitations*

The analyses have several limitations. First, the studies rely on parent report of receipt of early intervention services. Given the varied models of early intervention service delivery, parents may be unclear of whether they are receiving Part C services or developmental services provided through other mechanisms. Second, children may be eligible for Part C services based on delays in social-emotional development; our measure of developmental functioning does not capture children with delays in this developmental domain. Third, we examined the experience of children born 2001. It is possible that participation in early intervention services has changed during the intervening period. Last, as is typical of cohort studies, the associations reported in the analyses are not necessarily causal, and residual confounding may exist.

In the depression analysis, although we documented depressive symptoms at 9 months and the interval between the 9 and 24 month interviews, we were not able to quantify the duration or number of depressive episodes or address the issue of whether or not depressed mothers received treatment for their condition. Further, ECLS-B used different measures to ascertain depressive symptoms at 9 and 24 month interviews, making it difficult to ensure symptom severity equivalence at the two time points.

### *C. Comparisons with findings of other studies*

Racial disparities analysis: Our results are consistent with and extend the findings from previous research, which reported low levels of EI service receipt among young children with developmental delays, particularly black children.<sup>5, 6, 72</sup> We believe we are the first study to identify a differential effect of race on receipt of services over time. Our results suggest how child's qualifying condition may contribute to this disparity. Receipt of EI services is the outcome of a process that requires identification of developmentally at-risk children, referral, and confirmation of eligibility. Given that all children in our study are presumed eligible, we focused on differences in identification and referral as possible explanations for differences in service receipt between black and white children. Previous studies have documented that children without a diagnosed medical condition are less likely to be identified and referred to services.<sup>5, 73</sup> Detection of at-risk children requires proactive identification by the child's parents or a clinician. It is possible that clinicians, who play a major role in identifying children with developmental delay and referral to EI services, are less likely to identify such delays in Black children. Studies of racial differences in the identification of children with specific developmental disabilities, such as autism, offer support for this hypothesis.<sup>74</sup> There is additional evidence that clinicians respond differently to patients based on gender, clinical training, and child's behavior<sup>75, 76</sup> and that they may be less sensitive to recognizing developmental delays when they coexist with social and economic adversity, which was more common among black children in this sample.<sup>77</sup>

Another possible explanation for the observed racial differences in receipt of EI services is that differences in family beliefs and cultural values may underlie differences in what triggers a concern about atypical development. A strong literature exists supporting the sensitivity of parental concerns to detect developmental delays among young children.<sup>78-81</sup> Only one of the studies considered racial differences in parental concerns and reported no differences between non-white and white subjects in either likelihood to report concerns or discuss such concerns with their child's pediatric provider.<sup>82</sup>

Maternal depression analysis: Our findings suggest that children of depressed mothers participated in EI services in a manner similar to children whose mothers were not depressed. A mother's depressive symptoms did not interfere with receipt of EI services. Based on research supporting decreased health management skills among depressed women<sup>83</sup>, one might expect to find decreased participation among children whose mothers experienced depressive symptoms as a result of the lack of energy, motivation, and organization associated with depressive illness. However, in supplemental analyses (available from authors on request) that looked specifically at women with severe depressive symptoms and those with persistent depression, a mother's depression did not appear to compromise child receipt of services. This finding is not inconsistent with previous research, including reports of increased use of selected child health services among depressed mothers compared to nondepressed peers.<sup>84-85, 86</sup>

Our findings document the high symptom burden among mothers of children who receive EI services, in particular the extremely elevated prevalence (53.8%) of depressive symptoms among mothers of the children who were newly eligible for EI services at 24 months and were receiving such services. Children who enter EI programs as toddlers generally fall within two main groups – children with expressive language delays and children with impairments in social interaction and communication, many of whom receive autism spectrum diagnoses. Mothers of children who fall in either category have increased depression risk. Among mothers of children

with expressive language delay, increase risk is conferred by virtue of the association between lower SES, early childhood language delay, and maternal depressive symptoms.<sup>87, 88</sup> Among mothers of children with impaired social communication, the high levels of parenting stress and depressive symptoms are well documented in the autism literature.<sup>89-92</sup>

#### ***D. Possible application of findings to actual MCH health care delivery situations***

**Maternal depression analysis:** Understanding the prevalence of maternal depressive symptoms among mothers of EI eligible children has practical implications. Identifying and treating depressed mothers represents an opportunity to not only improve service delivery to women, but also to improve developmental and behavioral outcomes for their children. In 2009, the Institute of Medicine (IOM) published a landmark report, *Depression in Parents, Parenting, and Children*.<sup>93</sup> In this report, the IOM called for the development of innovative, community-based initiatives to reduce barriers to care for parents experiencing depressive symptoms. The IOM specifically called for interventions that take place in venues capable of integrating services for parents and children. Early intervention programs represent such a setting. EI is well-liked by families and non-stigmatizing,<sup>94, 95</sup> making it a promising context for engaging women who are reluctant to seek and receive mental health services.<sup>96</sup> While ultimately the efficacy of EI rests on improving child outcomes, there is increasing recognition of the importance of family outcomes for young children with disabilities. Beginning in 2004, all states were required to report on activities related to supporting family capacities in their EI performance report.<sup>95</sup> The exact content of family outcome measures is still under debate but the conceptual framework, which focuses on providing a developmentally supportive environment and supporting the overall quality of family life, is consistent with an effort to identify maternal depression. Finally, EI has systems in place to promote the longitudinal management of chronic disease, which could be extended to maternal depression. EI represents an alternative venue for case finding and depression care management. If EI programs have an increased awareness of the existence of maternal depressive symptoms and their impact on family participation, such programs may be motivated to implement formal screening protocols and represent a relatively untapped resource to reach at-risk mothers.

**Racial disparities analysis:** Child age and qualifying condition are significant factors affecting racial disparities in EI service receipt. Whether or not a child had an established medical condition that qualified him for EI services affected the likelihood of service receipt, particularly among black children. This information can be used to inform efforts to increase enrollment in EI services and to reduce disparities in service receipt.

#### ***E. Policy implications***

**Maternal depression analysis:** Maternal depressive symptoms are widely acknowledged to negatively impact child development. To our knowledge, this study is the first to use population-based data to examine the prevalence of maternal depressive symptoms among mothers of EI-eligible children and explore its effects on child participation. Findings from the study will be valuable to states that are conducting needs assessment and planning programs to meet the needs of EI-eligible and -enrolled children. It is encouraging that despite a high burden of depressive symptoms, these symptoms did not hinder child receipt of services. These data can be used as evidence to support policies to include maternal mental health services within EI programs.

**Racial disparities analysis:** Despite an increase in the percentage of children obtaining EI services, studies suggest that many young children who have or at risk for developmental delays

fail to receive them. Studies indicate black children are less likely to obtain services than white children.<sup>5, 6</sup> We believe ours is the first study to identify a differential effect of race on receipt of services over time. Our results suggest how child's qualifying condition may contribute to this disparity. The findings indicate the need for improved policies to promote active screening and surveillance among black children to identify children with qualifying conditions that are not easily recognizable. Policies are also needed to ensure children with these conditions enter into EI programs after being identified.

#### ***F. Suggestions for further research***

**Maternal depression analysis:** The demographic characteristics of EI families suggest that mothers of enrolled children are at increased risk for depressive illness.<sup>97, 98</sup> Despite a higher incidence of depression among these specific populations, such women are less likely to obtain mental health care in either the primary care or specialty setting, and less likely to receive appropriate care when they do seek it.<sup>39, 96</sup> Additional research is warranted to better understand the unexpected findings from the present analysis indicating maternal depressive symptoms did not interfere with child receipt of services. Other studies have reported increased use of selected child health services among depressed mothers compared to nondepressed peers;<sup>84-85,</sup><sup>86</sup> additional analysis of the use of EI services among depressed mothers is warranted, particularly among the group of mothers of new entrant children into EI services at 24 months.

**Racial disparities analysis:** Studies of black mothers identify factors such as stigma, fear of blame and child protective services involvement as factors affecting the willingness such mothers to discuss their own emotional health concerns with their child's health care provider.<sup>99,</sup><sup>100</sup> Future studies are needed to determine if these same factors influence the willingness of black parents to discuss concerns related to their young children and thus contribute to differences in EI service receipt between black and white children.

### **V. List of products**

#### **Manuscripts in Preparation**

Feinberg E, Silverstein M, Young R. The Impact of Race on Participation in Part C Early Intervention Services. Submitted to Pediatrics; under review.

Feinberg E, Donahue S, Young R, Silverstein M. Maternal Depressive Symptoms and Participation in Early Intervention Services for Young Children. In preparation.

#### **Conference Presentations**

Feinberg E, Silverstein M, Young R. Racial Disparities in Receipt of Early Intervention Services: The Effect of Child Age and Qualifying Condition. Pediatric Academic Societies' Annual Meeting, May 2, 2010, Vancouver, BC (presentation).

Feinberg E, Donahue S, Meisner A, Silverstein M. Maternal Depressive Symptoms and Participation in Early Intervention Services for Young Children. Pediatric Academic Societies' Annual Meeting, May 4, 2010, Vancouver, BC (presentation).

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Appendix 1:

Proofs of Manuscript:

The impact of race on participation in Part C early intervention services

[NOT FOR CIRCULATION]

Appendix II:

Manuscript Draft:

Maternal Depressive Symptoms and Participation in  
Early Intervention Services for Young Children

[NOT FOR CIRCULATION]

Appendix 3

Presentations to Pediatric Academic Society Annual Meeting 2010