

Intellectual and Developmental Disabilities

Evidence-based early home visiting for parents with intellectual disability: Home visitor perceptions and practices

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Abstract:	Evidence-based maternal, infant, and early home visiting (EBHV) is a potential strategy to support parent and child health and well-being among families headed by a parent with an intellectual disability (ID). Little is known about the capacity of EBHV programs to meet the needs of parents with ID effectively. This study examined home visitor practices and perceptions of services for parents with ID. Home visiting staff recruited from a national practice-based research network participated in web-based surveys. Practices and perceptions varied widely across sites and were associated with home visitor knowledge and self-efficacy and site implementation supports, such as policies, curricula, and community collaboration. More work is needed to understand and strengthen EBHV services for parents with ID.

Abstract

Evidence-based maternal, infant, and early home visiting (EBHV) is a potential strategy to support parent and child health and well-being among families headed by a parent with an intellectual disability (ID). Little is known about the capacity of EBHV programs to meet the needs of parents with ID effectively. This study examined home visitor practices and perceptions of services for parents with ID. Home visiting staff recruited from a national practice-based research network participated in web-based surveys. Practices and perceptions varied widely across sites and were associated with home visitor knowledge and self-efficacy and site implementation supports, such as policies, curricula, and community collaboration. More work is needed to understand and strengthen EBHV services for parents with ID.

Keywords: Home visiting, maternal and child health, parenting, intellectual disabilities

Evidence-Based Early Home Visiting for Mothers and Parents with Intellectual Disabilities:
Home Visitor Perceptions and Practices

Introduction

There are few formal services to support people with intellectual disabilities (ID) as they become parents (Lightfoot & DeZelar, 2020). This is unfortunate given that parents with ID and their children are at disproportionate risk for negative health and developmental outcomes across the life course. For example, children of mothers with ID are at increased risk for premature birth, preeclampsia, stillbirth, and low birth weight (Akobirshoev, 2017; Fairthorne et al., 2020; Mitra, 2015; Parish et al., 2015). As they grow older, children of parents with ID are at increased risk for developmental delays, behavioral challenges, and speech and language problems (Emerson, 2011).

Emerging evidence suggests that risk for adverse outcomes may be less directly related to disability status than to the myriad confounding health, economic, and psychosocial challenges that parents with ID often experience (Powell et al., 2016). Parents with ID tend to be younger, are less likely to be married, have fewer formal and informal supports, and experience higher rates of poverty, physical and behavioral health challenges, trauma, stress, and social isolation compared to parents without ID (DeZelar & Lightfoot, 2019; Emerson & Brigham, 2014; Feldman et al., 2012; Hindmarsh et al., 2015; Powell et al., 2016, 2017). In addition, fear of discrimination, stigmatization, and distrust in systems of care have been associated with reduced help-seeking and low engagement in maternal and child health services among pregnant and parenting people with ID (Homeyard et al., 2016). Although people with ID have a fundamental right to create and maintain families, discrimination is pervasive (National Council on Disability, 2012), and parents with ID may not want to be identified due to fear of losing custody of their

children (Homeyard et al., 2016). Indeed, children of mothers with ID are overrepresented in the child welfare system and are at greatly increased risk for child removal (Collings & Llewellyn, 2012; LaLiberte et al., 2017; Lightfoot et al., 2011; Slayter & Jensen, 2019).

Comprehensive, relationship-based interventions are needed to support parenting and promote parent and child health and well-being among families headed by a parent with ID (Feldman et al., 2012). Several specialized group (e.g., Glazemakers & Deboutte, 2013; Keltner et al., 1995; McGaw et al., 2002) and home-based (e.g., Coren et al., 2018; Feldman, 2004; Feldman et al., 1992; Hodes et al., 2017; Knowles et al., 2015; Mildon et al., 2008; Tymchuk et al., 2000; Wade et al., 2008) curricula and programs have been developed to strengthen parenting skills among this population. Such programs are not widely available in the United States (US), however. In addition, some programs focus on parent skills training and do not address broader ecological factors that contribute to poor outcomes (Lightfoot & DeZelar, 2020).

The Promise of Evidence-Based Home Visiting for Parents with ID and their Children

Evidence-based maternal, infant, and early home visiting (EBHV) is a promising strategy to support pregnant and parenting people with ID. EBHV is a two-generation strategy to improve health and development for expectant families and families with young children who are facing multiple, complex adversities. Home visitors assess family strengths and needs, conduct essential screenings related to family and child health and development, promote positive parenting skills, provide socialization activities for parents and children, and facilitate linkages with other needed health and social services (Adirim & Supplee, 2013; Minkovitz et al., 2016). EBHV programs assist families with improving the context in which they live by identifying and addressing concerns related to the home and social environment. By meeting with families in their homes, EBHV also improves access to services by removing barriers such as lack of transportation and

childcare. Most EBHV programs use family-centered, relationship-based approaches and tailor services to the needs and preferences of families based on self-identified goals.

EBHV has experienced unprecedented scale-up in the US since passage of the Maternal, Infant and Early Childhood Home Visiting (MIECHV) legislation under the 2010 Affordable Care Act. By law, states and territories must spend the majority of MIECHV funds to implement evidence-based models that have undergone rigorous evaluation (Adirim & Supplee, 2013). To date, 20 models have met criteria for evidence of effectiveness and several other models are currently being evaluated (Sama-Miller et al., 2019). The most widely disseminated models are Early Head Start, Healthy Families America, Parents as Teachers, and Nurse Family Partnership (National Home Visiting Resource Center, 2019). In some states and localities in the US, EBHV is offered universally or is widely available.

There is strong theoretical support for EBHV as a strategy to help address the needs of parents with ID. Scholars and advocates assert that parent education programs for parents with ID are most effective when taught in the environment in which they will be applied (i.e., the home) and are individually tailored to parents' learning needs (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Yet, research is lacking on the prevalence of ID among parents enrolled in EBHV and the capacity of EBHV programs to reach and serve this population effectively. Perhaps the closest estimate comes from the national evaluation of federally-funded EBHV programs, which showed that 63% of enrolled parents scored below average on a subtest of the Wechsler Adult Intelligence Scale (WAIS-III) that has been associated with verbal intelligence (Duggan et al., 2018). Although not a measure of ID, per se, this finding suggests that there may be large numbers of parents enrolled in EBHV with learning difficulties, broadly defined. Of particular relevance to EBHV, Emerson (2011)

described the problem of the “hidden majority;” this term refers to people who may have struggled in school but whose disabilities have not been formally identified. Often, these individuals have been living in the community with few specialized supports. As they become parents, individuals with ID and other learning difficulties may benefit from additional supports, such as those offered through EBHV and other maternal and early childhood services.

The Current Study

To our knowledge, no studies have examined staff preparedness or the strength of current EBHV implementation supports for providing appropriate services to parents with ID. This descriptive, cross sectional study begins to address these gaps using survey data collected from a nationally representative sample of home visiting sites. The first aim was to describe EBHV site intentions, staff preparedness, site implementation supports, home visitor practices, and home visitor perceptions of services for parents with ID enrolled at their sites. The second aim was to assess multi-level factors that explain variability in home visitor practices and perceptions.

Method

Participants and Recruitment

Participants included 95 site managers and 294 home visitors from home visiting sites across the US. Investigators recruited sites from a large practice-based research network (PBRN) of the Home Visiting Applied Research Collaborative (HARC). HARC is a national research and development platform and one of the MIECHV Program’s key research initiatives; its purpose is to broaden and strengthen home visiting effectiveness through innovative research to achieve greater precision in home visiting. HARC members include hundreds of local home visiting programs, home visiting researchers, tribal organizations, states, territories, and national home visiting models. The PBRN includes sites representing EBHV models and models that have yet

to be designated as evidence-based by the Home Visiting Evidence of Effectiveness (HomVEE) review (Sama-Miller et al., 2019). Participating sites represented diverse home visiting models and geographic areas of the US (Table 1). The most frequently represented models were Early Head Start, Healthy Families America, Nurse Family Partnership, and Parents as Teachers. The number of families enrolled at each site ranged from 12 to 500 ($M = 133.4$, $SD = 102.5$).

Procedures

Survey data were collected between December 2019 and January 2020. We used a two-phase recruitment strategy. First, in collaboration with HARC, we sent an introductory email and link to an online survey to the managers of all sites on the HARC email distribution list ($N = 242$). Seven emails were returned as undeliverable. Site managers who completed the survey ($N = 95$; 40% response rate) were sent an automated email thanking them for their participation and requesting their assistance with the second phase. All 95 site managers agreed to participate in the second phase. They were then asked to forward an email to all home visitors working in their programs. The email contained an invitation and link to a parallel version of the online survey tailored for home visitors; 294 home visitors participated the survey. In each phase, investigators sent up to three follow-up reminders and offered a \$25 gift card to encourage participation. All procedures were reviewed and approved by the [Removed for Blind Review] Institutional Review Board.

Measures

Surveys were designed to assess site manager and home visitor practices and perceptions related to serving parents and other caregivers with a range of learning difficulties, such as ID, learning disabilities, and low literacy. This paper focuses on data from questions specific to practices and perceptions of services for parents with ID, or parents who showed characteristics

of ID. Survey instructions included a broad definition of ID described as *significant limitations in both intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (everyday social and practical skills)*. This definition is largely consistent with the AAIDD definition but did not include the requirement that the disability originate before age 22.

Survey development was informed by the conceptual framework for the study (Supplemental Content). The conceptual framework was grounded in implementation science (Fixsen et al., 2016), social ecological theory (Bronfenbrenner, 1994) and the health belief model (Rosenstock et al., 1988). The framework shows how factors at multiple levels – the home visiting model, the local home visiting site, and individual staff characteristics – are expected to influence home visitor practices and perceptions. Many items were developed by the investigators and were informed by in-depth knowledge gained from years of experience conducting applied research and evaluation in partnership with local home visiting programs. To reduce participant burden due to repetition of items, some questions asked about caregivers with learning difficulties, defined more broadly. Surveys were pilot tested by one local home visiting site manager to ensure that questions were worded in ways that local home visiting staff would understand and were subsequently revised based on feedback.

Site Manager Surveys

Site manager surveys focused on site characteristics and site expectations, supports, and services for recruiting, enrolling, and providing services for parents with learning difficulties, such as ID. The program manager survey included 111 items and was estimated to take about 25 minutes to complete.

Home visiting model (e.g., Early Head Start, Healthy Families America, Parents as Teachers) was assessed using an open text field. Sites' intentions to enroll parents with ID were

assessed categorically (*Intend/Do not intend/Do not consider as a factor for enrollment*).

Prioritization of enrollment of parents with ID was also assessed categorically (*We prioritize caregivers with ID/We prioritize caregivers without ID/We do not consider ID when prioritizing families*). Screening for ID was assessed categorically (*Yes/No/Not sure*). Finally, one item asked, “In your opinion, how important is it that home visitors know whether or not a caregiver enrolled in home visiting has a learning difficulty?” (1 = *Not at all important* to 5 = *Extremely important*).

Home Visitor Surveys

Home visitor surveys paralleled site manager surveys but included additional detailed questions about their front-line practices, perceptions of programs strengths and benefits for families, individual characteristics, and site implementation supports (e.g., supervision, case weights, curricula). The home visitor survey included 136 items and was estimated to take about 30 minutes to complete.

Outcome Variables. The three outcomes of interest were a) home visitor practices, b) home visitors’ perceptions of the strength of the program to support caregivers with ID and other learning difficulties, and c) home visitor perceptions of benefits of home visiting for parents with ID and other learning difficulties.

Home visitor practices were assessed with a set of six Likert-type items describing the frequency with which home visitors use specific practices when they work with caregivers with learning difficulties, defined broadly (0=*Never* to 5=*Always*). Items were developed by the research team and were grounded in literature describing best practices for teaching adults with ID and other learning difficulties. Items were “Check that caregiver understands content has been delivered,” “Modify the pace of visits,” “Modify content of visits to meet the needs of caregivers

with learning difficulties,” “Use a variety of methods to present information to caregivers,” “Provide caregivers with alternate ways to demonstrate what they know,” and “Offer choices of content/tools for learning.” Cronbach’s alpha was calculated to examine internal consistency reliability for the set of six items ($\alpha = .91$). Scores for the six items were then averaged to create a single continuous scale score. Higher scale scores reflect greater use of practices.

Perceptions of the strength of the program to support caregivers with learning difficulties were assessed with a set of four Likert-type items (1=*Strongly disagree* to 5=*Strongly agree*): My program... “Recognizes the unique needs of caregivers with learning difficulties;” “Supports home visitors by giving them concrete approaches to talk with caregivers with learning difficulties;” “Provides home visitors with tools/knowledge to help caregivers with learning difficulties;” and “Recognizes that working with caregivers with learning difficulties can require a lot of time.” Scores for the four items were averaged to create a single continuous scale score (Cronbach’s $\alpha = .88$). Higher scores reflect more positive perceptions of the strength of the program.

Perceptions of benefits for families was measured using a single item Likert-type item that asked home visitors to rate the extent to which they agree with each of the following: “Caregivers with learning difficulties seem to benefit just as much from our program as caregivers who do not have these challenges” (1=*Strongly Disagree* to 5=*Strongly Agree*), with higher scores reflecting more positive perceptions of benefits for families.

Explanatory Variables. Home visitor surveys assessed home visitor characteristics and perceptions of local site implementation supports to specific to addressing the needs of parents with ID and other learning difficulties.

Home visitor characteristics. *Years of home visiting experience* was assessed with a combination dichotomous variable (1 = *Under 6 months*) and an open text response (*If more than 6 months, specify number of years*). Responses were transformed into continuous values for further analyses. Specifically, respondents who selected *under 6 months* were assigned a continuous value of .42 (equivalent to 5 months of experience). Text responses were transformed to numeric responses.

Home visitor knowledge and self-efficacy related to supporting parents with ID and other learning difficulties were assessed using two sets of items. One set of three Likert-type items was adapted from a survey designed to assess home visitor's perspectives of knowledge and efficacy to address maternal substance use and depression (Dauber et al., 2017). Home visitors responded to the prompt: "Please rate the extent to which you agree with each of the following statements." Items were, "I am familiar with the signs of a learning difficulty"; "I have adequate knowledge and skills to effectively serve caregivers with learning difficulties", and "I feel comfortable talking about learning difficulties with caregivers" (1=*Strongly disagree* to 5=*Strongly agree*). A second set of 7 Likert-type items was developed by the research team to assess home visitors' confidence to do specific tasks. Home visitors responded to the prompt: "How confident are you that you can do the following tasks effectively, on your own, in most situations, without first checking with your supervisor?" Example items were "Recognize if a caregiver has a learning difficulty, such as through formal or informal screening" and "Modify the content of visits to meet the needs of caregivers with learning difficulties" (1=*Not confident* to 7=*Very confident*). Because the two sets of items were on different scales, the ten items were standardized using z-scores and averaged to create one continuous scale score for use in analyses

(Cronbach's $\alpha=.92$). Higher mean scores reflect higher levels of knowledge and self-efficacy in supporting parents.

The amount of *specialized training* a home visitor had received in how to work with parents with ID and other learning difficulties was assessed using a single item with five categorical response options (0=*None*; 1=*1-3 hours*; 3=*Half a day*; 4=*One day*; 5=*Multiple days*). Data were recoded as a dichotomous variable (0=*No specialized training*; 1=*Any specialized training*).

Finally, one item asked, "In your opinion, how important is it that home visitors know whether or not a caregiver enrolled in home visiting has a learning difficulty?" (1 = *Not at all important* to 5 = *Extremely important*).

Local site implementation supports. The availability of *program policies and procedures* was measured via a single Likert-type item that asked whether the program "Has implemented staff policies and procedures regarding caregivers with learning difficulties" (1=*Strongly disagree* to 5=*Strongly agree*). Higher mean scores indicate stronger agreement.

A single categorical item assessed *whether the site considers caregivers' learning difficulties when deciding caseload assignments or case weights* (1=*Never*, 2=*Sometimes*, 3=*Always*). This is because many home visiting models and sites will adjust home visitors' caseloads to accommodate families with particularly complex needs who may need higher levels of support. Responses were dichotomized for ease of interpretation (0=*No, does not consider when assigning caseloads/use case weights* or 1=*Yes, considers when assigning caseloads or case weights*).

Helpfulness of one-on-one supervision related to working with caregivers with learning difficulties was assessed with a single Likert-type item (0=*Not helpful* to 3=*Very helpful*). Higher scores reflected more perceived helpfulness of program supervision.

Perceptions of curriculum supports for parents with ID was assessed using a set of three Likert-type items: “Our program materials (e.g., recruitment and enrollment materials, curriculum materials, handouts) are written at a level all caregivers can understand,” “Our curriculum offers flexibility regarding the timing, pace, and way in which curriculum content is delivered for families with varying learning abilities,” and “Our curriculum provides clear and specific guidance on how to tailor delivery for caregivers with intellectual disabilities” (1 = *Strongly disagree* to 5 = *Strongly agree*). The three items were averaged to create a continuous scale score (Cronbach’s $\alpha = .79$). Higher scale scores indicate greater perceived strength of program curriculum supports for parents with ID.

Community collaboration was assessed with a single categorical item: “Does your program collaborate with other community-based agencies or organizations that have expertise or experience working with caregivers with learning difficulties?” (1=*We do not know of other agencies with which to collaborate*; 2=*We do not currently collaborate*; 3=*We collaborate somewhat*; 4=*We have strong collaborations*). Responses were transformed into a dichotomous variable (0=*No, we do not/We do not know if we collaborate with other agencies*; 1=*We collaborate somewhat/We have strong collaborations*).

Data Analysis

All analyses were conducted using Stata version 17 (StataCorp, 2021) and SPSS version 26 (IBM, 2019). Data from a single site that was located outside of the US was considered an outlier and was removed from analyses. All but one variable had minimal missing data (Range: 0

- 4.1%); missing data on these variables were handled with multiple imputation. One variable, home visitor years of experience, had 12 missing values. Sensitivity analyses showed that attempts to impute missing values for this variable resulted in unstable parameter estimates. Consequently, the 12 cases were removed using pairwise deletion, resulting in a final analytic sample of 293 cases.

To address the first aim, we calculated frequencies, means, and standard deviations for all survey items as appropriate. To address the second aim, we first used bivariate Pearson (continuous) and biserial point (categorical) correlations to examine associations between independent and dependent variables. We selected variables for inclusion in multivariate models balancing theory, prior research, and bivariate correlations with outcome variables. For ease of interpretation, we used the same set of explanatory variables in all models. We constructed three two-level fixed effects generalized hierarchical linear models (HLM) using maximum likelihood (ML) estimation to estimate the effects of home visitor characteristics, site implementation supports, and perceived levels of community collaboration on a) home visitor current practices, b) perceived program strength, and c) perceived benefits for families. HLM was used to account for home visitors (Level 1) being nested within local home visiting sites (Level 2). All explanatory and outcome variables were measured at Level 1. Each site at Level 2 was represented with a unique identifier. Site characteristics at Level 2 were used for descriptive purposes only and were not included in multivariate models. We provide regression equations as supplemental material.

Continuous variables were centered prior to analysis. Variability associated with clustering of home visitors within sites was assessed by calculating the unconditional intraclass correlation coefficients (ICCs) for each outcome of interest. Multivariate models with

explanatory variables were built incrementally and assessed against the null model using AIC and Chi-Square criteria, and by comparing unconditional (for null models) and conditional (for hypothetical models) intraclass correlation coefficients (ICC) at the 95% confidence interval (CI) following the addition or subtraction of explanatory variables. These fit indices assess incremental improvement in fit across models, with the smallest value representing the best fitting model (Byrne, 2012).

Results

Sample Characteristics

Site characteristics. Over half of the site managers ($n=52$; 55%) reported that their sites intended to enroll caregivers with ID. Most others ($n=38$; 40%) reported that their sites did not consider whether a caregiver had ID as a factor for enrollment. Only two sites did not intend to serve this population. Many sites ($n=38$; 40%) prioritized caregivers with ID for enrollment when their program had a wait list.

Most site managers ($n=79$; 83%) and home visitors ($n=254$; 87%) reported that it was either “extremely” or “very” important to know whether an enrolled caregiver had a learning difficulty, yet few sites ($n=15$; 16%) screened for ID. In all sites that screened for ID, a staff member other than the home visitor conducted the screen. Of note, although home visitors were not expected to screen, some home visitors reported that they were expected to gather information about caregivers informally in the first 1-2 visits, such as the caregiver’s ability to read (56%), understand simple and complex information (51%), follow multi-step directions (37%), learning style (36%), preferred ways of receiving information (verbal, visual, written; 68%), and pace for learning new material (45%).

Home visitor characteristics. Most home visitors described themselves as non-Hispanic White ($n = 199$; 70.6%), held at least a bachelor's degree ($n = 155$; 55%), and had several years of experience in home visiting ($M = 6.74$, $SD = 6.66$; Range = 0.42-29.0 years). The vast majority reported having at least one caregiver with some type of learning difficulty on their caseload ($n = 270$; 91.8%). Knowledge and self-efficacy varied widely; standardized scores on this scale ranged from -2.02 to 1.24. Most home visitors reported that they had *not* received any specialized training in how to work with caregivers with learning difficulties, such as ID ($n = 221$; 78.3%).

Implementation supports. Most home visitors reported that their site did not consider caregivers' learning difficulties when deciding caseload assignments ($n = 183$, 64.9%). Home visitors varied in the extent to which they agreed that their site had implemented policies and procedures regarding caregivers with learning difficulties ($M = 2.89$, $SD = 0.97$, Range = 1.0-5.0), the degree to which they found supervision around working with these caregivers to be helpful ($M = 2.04$, $SD = 0.87$, Range = 0.0-3.0), and in their perceptions of curriculum supports for caregivers with ID ($M = 2.91$, $SD = 0.94$, Range = 0.0-5.0). Most home visitors indicated that their site collaborated with community-based organizations that serve adults with learning difficulties ($n = 164$; 58.2%).

Home visitor practices and perceived program efficacy and benefits. Home visitors showed marked variability in their use of practices to support caregivers with learning difficulties ($M = 3.66$; $SD = 1.01$; Range = 0.0-5.0), their perceptions regarding the strength of the program to support caregivers with learning difficulties ($M = 3.40$; $SD = 0.91$; Range = 1.0-5.0), and their perceptions of program benefits for caregivers with learning difficulties ($M = 3.61$; $SD = 0.92$; Range = 1.0-5.0).

Factors Explaining Variability in Practices and Perceived Program Efficacy and Benefits

Bivariate correlations showed that visitor knowledge and self-efficacy, program policy/procedures, and curriculum supports were positively associated with visitor practices, perceived program strength, and perceived benefits for families (Table 2). Home visitor years of experience, specialized training, use of case weights, perceived helpfulness of supervision, and community collaboration showed no associations with any of the three outcomes of interest. Visitor practices, perceived program strength, and perceived benefits for families were all positively associated with one another; the strongest correlation was between perceptions of program strengths and benefits for families ($r=0.56, p<0.01$).

Model 1: Home visitor practices. As shown in Table 3, the final model for home visitor practices showed superior fit compared to the null model as evidenced by lower estimates for each of the three fit indices (unconditional ICC=0.12, 95% CI, 0.05-0.30 vs. conditional ICC=0.004, 95% CI, 0.00-0.09). Results show that, after controlling for home visitor years of experience, higher levels of home visitor knowledge and self-efficacy related to working with caregivers with ID was the only variable associated with home visitor practices ($\beta = 0.849, p < .000$). As knowledge and self-efficacy increased, home visitors' use of practices also increased.

Model 2: Perceived program strength. As shown in Table 3, the model estimating perceived program strength also showed improved fit with the addition of explanatory variables (unconditional ICC=0.19, 95% CI, 0.09-0.33 vs. conditional ICC=0.0, 95% CI, 0.0-0.0). After controlling for home visitor experience, higher levels of knowledge and self-efficacy related to working with caregivers with ID ($\beta = .195, p = .001$), the presence of policies and procedures ($\beta = .473, p < .00$), curriculum supports ($\beta = .215, p < .001$), and perceptions of greater community collaboration ($\beta = .234, p = .004$) were positively associated with perceived program strength.

Model 3: Perceived benefits for families. As shown in Table 3, fit also improved with the addition of explanatory variables for the model estimating perceived benefits for families (unconditional ICC=0.22, 95% CI, 0.11-0.37 vs. conditional ICC=0.03, 95% CI, 0.001-0.46). After controlling for home visitor experience, site policies and procedures ($\beta = -0.104, p = .012$) and curriculum supports ($\beta = 0.842, p < 0.00$) were the only variables associated with home visitors' perceptions that the program was beneficial for families headed by a caregiver with learning difficulties. Stronger curriculum supports were associated with more positive perceptions. In contrast, the presence of policies and procedures related to working with caregivers with learning difficulties were associated with less positive perceptions.

Discussion

Key Findings

This study fills critical gaps in our understanding of maternal, infant, and early home visiting services for pregnant and parenting people with ID and other learning difficulties. Findings show that parents with ID are a priority population for many local sites, yet there was marked variability in levels of staff preparedness and implementation supports specific to their needs.

Findings show that very few home visiting programs use validated tools to screen for ID. Prior research has shown that *early* identification and engagement is one of the most persistent challenges for maternal and child health service providers in supporting the needs of parents with ID (MacIntyre et al., 2019; Weiber et al., 2016). Although many home visitors indicated that they were *expected* to gather information about learning ability and style informally, *whether* and *how well* they do this is likely to vary in the absence of formal tools, specific guidelines, or training.

Home visiting programs that are interested in using screening tools must decide, at the outset, how screening results will and will not be used. Screening tools are typically used to determine whether an individual is *likely* to have ID, but they cannot provide a formal diagnosis. Thus, screening results may be useful for identifying parents who may learn differently, and who may benefit from increased time, flexibility, and thoughtful adaptations or enhancements to teaching strategies and materials. Of note, parents with ID may wish to avoid being identified due to the stigma and increased risk for discriminatory practices it may carry. A positive screen may invite scrutiny of parenting ability, and home visitors may wrongly conflate risk factors related to the social or physical environment with a parent's disability (Booth, 2005; McConnell & Llewellyn, 2000, 2002). Because home visitors are mandated reporters, it is important that they understand the purpose of screening tools and receive training to reduce risk of bias and ensure that all parents are valued and respected. Importantly, screening should only be considered when evidence-informed adaptations or services are available (McConnell et al., 2008).

In multivariate models, knowledge and self-efficacy were associated with home visitor practices and perceived program strength but not perceived benefits for families. Curiously, home visitors' knowledge and self-efficacy were not associated with having received specialized training or perceived helpfulness of supervision. This may be because few visitors received specialized training, and the quality of training they received may have varied. Evidence suggests that training is most effective when grounded in principles of adult learning and when there are opportunities for ongoing reinforcement to facilitate transfer of skills to practice (Schultz et al., 2018).

Implementation supports such as policies and procedures, curricula, supervision, and consideration of family needs when assigning caseloads and case weights are known to support adoption of intended practices (Fixsen et al., 2009). Most sites in our sample intended to serve caregivers with ID, yet few had supports in place to ensure that home visitors could fulfill their roles effectively and with confidence. Results showed that the presence of policies and procedures for working with caregivers with ID and other learning difficulties was positively associated with perceived program strength but negatively associated with perceived benefits for families. This suggests that home visitors may appreciate some aspects of policy yet may view the policies as falling short of having direct positive benefits for families.

Perceptions of having curricula supports that are well suited for parents with ID were associated with perceived program strength and perceived program benefits for families. Given that home visitors rely heavily on verbal and written communications (e.g., worksheets and handouts) with parents, these findings emphasize the importance of using curricula that incorporate universal design principles to ensure that materials are usable by ALL parents, to the greatest extent possible (King-Sears, 2009). Universal design also reduces the need for individual service tailoring. This is important, given the finding that variability in home visitor *practices* was most strongly associated with home visitor knowledge and efficacy. Thus, the extent to which a home visitor checks for parents' understanding of information, modifies the pace or content of visits, or offers varied methods or choices of content and tools for learning may depend heavily on individual judgement. The marked variability in home visitors' knowledge and self-efficacy and limited specialized training raises concerns about their capacity to make informed judgments.

We were surprised that neither consideration of learning difficulties when assigning caseloads or case weights nor perceived helpfulness of supervision were associated with any of the outcomes. Home visitor caseload sizes vary by model. Additionally, a few programs have “tiered” systems that adjust the frequency of visits depending on family needs. We viewed the assignment of higher case weights to families headed by a parent with a learning difficulty as a “support” because we felt it acknowledged that such families may require additional time and attention. However, it would be impossible to assign case weights in the absence of tools to identify parents with potential learning difficulties. As a result, we suspect that participants may have found it difficult to answer this question. On average, home visitors described supervision as only moderately helpful in supporting their work with parents with suspected learning difficulties. It is important to note that national home visiting models set many standards for implementation supports; thus, some decisions are not under the purview of local sites.

Home visitors’ perceptions of the extent to which sites collaborated with other service providers were associated with more positive perceptions of program strength, but not current practices or perceived benefits for families. Again, home visitors may view strong collaboration as an indicator of overall program strength, but not in direct relation to family outcomes. Referral and coordination with community-based organizations that support parents with learning difficulties is only possible when such needs are able to be identified.

Implications

Findings highlight several potential avenues for further work. First, research is needed to assess the prevalence of parents with ID who are eligible for and enroll in EBHV. Prevalence estimates may help policy makers, program developers, researchers, and practitioners understand how to allocate, coordinate, and leverage scarce resources. There may be opportunities for

EBHV to partner with agencies and organizations that specialize in services for adults with ID, for example. Such partnerships may benefit from shared expertise and financial resources. Research is also needed to assess whether EBHV, as currently implemented, is effective in improving outcomes for this group of families. As we learn more about effectiveness, the field may find it helpful to partner with stakeholders to develop and test EBHV adaptations or enhancements. In a related project, our team is partnering with stakeholders – including parents with ID – to develop a conceptual framework for addressing the needs of families with learning difficulties in home visiting. The framework emphasizes universal design features and identifies touchpoints where development and testing of adaptations or enhancement may be useful. Involving stakeholders in research and development ensures that products are relevant, acceptable, and useful (Greenhalgh et al., 2016). Finally, although our survey findings offer an first glimpse into the strengths and need of EBHV programs, qualitative research involving home visitors, supervisors, and pregnant and parenting people with ID who have taken part in EBHV services may help provide more nuanced information regarding barriers and facilitators to providing services effectively.

Strengths and Limitations

Strengths of this study include use of a national sample of home visiting sites, which promotes generalizability of the findings. Limitations include the use of cross-sectional survey data, which does not permit causal inferences. Home visiting staff are not qualified to identify ID; therefore, the data are based on staff perceptions only. The convenience sample of PBRN member sites may be more highly motivated or have stronger supports in place than sites that chose not to respond to the survey. This potential for bias seems a reasonable tradeoff given that this is the first national study of parental ID in EBHV. Because we did not have data on the

number of home visitors within each site, we were unable to calculate a valid home visitor response rate. We were also unable to explore differences by home visiting model due to the disproportionate number of responses across models. Thus, it may be that some models are more prepared than others to address the needs of parents with ID. Many of the items used the survey were developed by the research team and have not been well validated. Finally, this study focused on a limited number of explanatory variables. Implementation supports such as policies, use of case weights, and supervision were assessed based on home visitor perceptions. We felt this was appropriate and useful given the variability in perceptions across frontline providers, even within a given site. Collecting these data at the site-level in future studies would allow for more accurate estimates of the effects of these supports.

Conclusions

EBHV is well positioned to support expectant families and families with young children headed by a parent with ID. To our knowledge, this the first study to assess EBHV practices and perceptions of services for this population. Expansion of federally-funded home visiting presents an opportunity to serve more parents with ID; however, research is needed for EBHV to maximize reach and optimize positive outcomes. Findings from this study call for a critical analysis of the assumptions that guide EBHV practice for all families. Findings also contribute foundational knowledge that will help EBHV achieve greater precision in services for parents with ID.

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Table 1. *Home Visitor Characteristics (N = 282)*

	<i>n (%)</i>
Home Visiting Model	
Healthy Families America	78 (27.7)
Parents as Teachers	93 (33.0)
Nurse Family Partnership	9 (3.2)
Early Head Start	53 (18.8)
HIPPPY	6 (2.1)
Other	43 (15.2)
Race	
Black	33 (11.7)
White	199 (70.6)
Asian	3 (1.1)
American Indian/Native American	3 (1.1)
Mixed race	44 (15.6)
Hispanic/Latina	48 (17.0)
Education	
Less than bachelor's	85 (30.1)
Bachelor's	155 (55.0)
Master's	41 (14.5)
Doctoral	1 (0.4)
Estimated # of families on caseload with a learning difficulty ^a	
None	23 (8.2)
1-20%	156 (55.3)
21-40%	57 (20.2)
41-60%	31 (11.0)
Over 60%	15 (5.3)

^a“Learning difficulty” was defined on the survey as *a broad array of difficulties that may impact a caregiver's ability to understand, process, remember, and use or communicate information or manage tasks of daily living. This includes intellectual disabilities, cognitive impairments brought about by injury or disease, specific learning disabilities, and problems with conceptual skills or math or reading literacy. Such difficulties may have originated before birth or at any point during the life course.*

Table 2. *Bivariate Correlations among Explanatory Variables and Outcomes*^a

	Explanatory variables							Outcomes			
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
<i>Explanatory variables</i>											
1. Years of experience as a home visitor	-										
2. Specialized training	.08	-									
3. Policy/procedures	.01	.04	-								
4. Knowledge/efficacy	.14*	-.01	.01	-							
5. Use of case weights	.12*	.02	-.04	-.02	-						
6. Helpfulness of supervision	.15*	.24**	-.02	.04	.17**	-					
7. Curriculum supports	-.07	.31**	.11	.48**	-.05	.06	-				
8. Community collaboration	.05	.22**	.0	-.03	.19**	.16*	.25**	-			
<i>Outcomes</i>											
9. Home visitor practices	.07	.03	.22**	.63**	-.10	-.01	.26**	-.02	-		
10. Perceived program strength	-.02	-.03	.70**	.42**	-.04	.07	.59**	.06	.26**	-	
11. Perceived benefits for families	-.01	-.00	.38**	.43**	-.01	.01	.80**	-.04	.15*	.56**	

Note. N = 286 to 294; * $p < .05$, ** $p < .01$; ^aResults for Pearson correlations for continuous variables and point biserial correlations for dichotomous variables.

Table 3. HLM Results for Home Visitor Practices, Program Strength, and Benefits for Families (N=293)

		Model 1: HV Practices		Model 2: Program Strength		Model 3: Benefits for Families	
		Block 1	Block 2	Block 1	Block 2	Block 1	Block 2
		β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
		<i>p</i>	<i>p</i>	<i>p</i>	<i>p</i>	<i>p</i>	<i>p</i>
Intercept		0.016 (0.073)	0.057 (0.081)	-0.001 (0.074)	-0.077 (0.068)	-0.004 (0.078)	-0.009 (0.063)
		0.820	0.484	0.985	0.255	0.957	0.885
Level 1 main effect: HV characteristics	Specialized training	-	0.078 (0.117)	-	-0.122 (0.099)	-	0.0564 (0.088)
			0.507		0.217		0.525
Level 1 main effect: Implementation supports	Knowledge/efficacy ²	-	0.849 (0.697)	-	0.195 (0.058)	-	0.096 (0.053)
			<0.00		0.001		0.070
	Policies/procedures	-	0.084 (0.553)	-	0.473 (0.046)	-	-0.104 (0.041)
			0.126		<0.00		0.012
	Use of case weights	-	-0.185 (0.992)	-	-0.052 (0.082)	-	0.067 (0.073)
			0.062		0.525		0.362
	Helpfulness of supervision	-	-0.052 (0.056)	-	0.035 (0.047)	-	-0.030 (0.042)
		0.349		0.449		0.473	
	Curriculum support	-	-0.101 (0.064)	-	0.215 (0.053)	-	0.842 (0.048)
			0.114		<0.00		<0.00
	Community collaboration	-	-0.004 (0.098)	-	0.234 (0.082)	-	-0.004 (0.073)
			0.962		0.004		0.947
Deviance statistics¹	N	292	247	293	248	292	248
	ICC (95% CI)	0.12 (0.05-0.30)	0.004 (0.00-0.99)	0.19 (0.09-0.33)	0.0 (0.0-0.0)	0.22 (0.11-0.37)	0.03 (0.001-0.46)
	Likelihood ratio test ³		<0.001		<0.001		<0.001
	AIC	807.6	561.5	766.8	477.5	765.2	422.0

¹Smaller is better when comparing two models

²Indicates a standardized (z-score) average composite variable

³Chi-square comparison between intercept only model (block 1) and final model (block 2).

Note. HV = home visitor; ICC=intraclass correlation coefficient.

Bold font indicates factors significantly associated with the outcome after introduction of all Level 1 (home visitor) explanatory variables: Years of experience (included across models), program policies/procedures, HV knowledge/efficacy, helpfulness of supervision, curriculum supports were all continuous; Specialized training (0=no; 1=yes), use of case weights (0=no; 1=yes), and community collaboration (0=no community collaboration; 1=community collaboration) were all dichotomous.