



Exploring the Appropriateness of Home Visitation Models for Parents with Intellectual and Learning Disabilities

Paula Merlino, MS, Lauren Percodani, Aryel Simonelli, & Sasha Stok, MA, Team Leader: Trupti Rao, Psy.D.

Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program Westchester Institute for Human Development and New York Medical College



Background

Evidence-Based Home Visitation Models (EBHV) are used to provide parenting support and education about maternal health, child safety, and development. Currently, there is considerable funding for these programs at the federal and state level.

Individuals with intellectual and learning disabilities (ID/LD) are increasingly being integrated into communities and becoming parents. Parents with ID can be successful parents when given appropriate support. A literature review completed last year showed that these EBHV programs are not being used to support these parents and parents with ID/LD are often not referred for any support until a report of abuse or neglect arises.

Project Goal

To explore EBHV Programs to assess their ability to appropriately support the needs of parents with ID/LD.

Community Partnerships

Nurse Family Partnerships
Parenting Skills
Mental Health Screenings
Bonding between Mother & Child

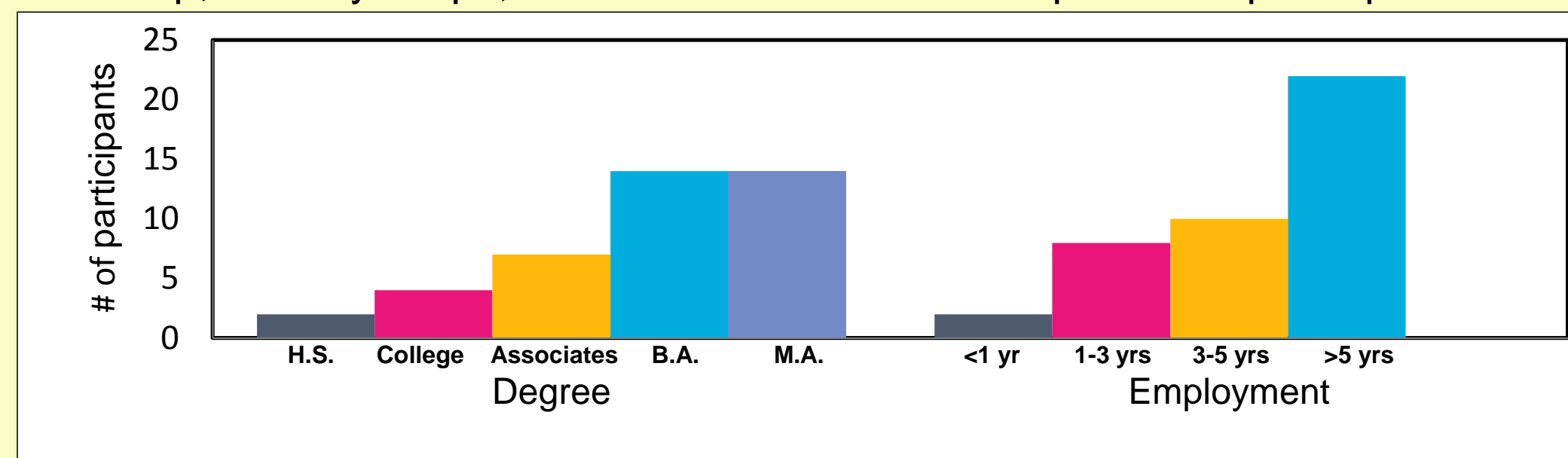
Parent/Child Home Program
Increases Literacy Skills
School Readiness

Methods: Procedure

- Received IRB approval.
- Contacted 8 EBHV programs with a letter of intent and request to participate in survey
- Interviewed community partners associated with EBHV programs.
- After consent was received, link to survey was emailed to program administrators in order to disseminate link among staff.
- Followed up with programs as needed.
- Data compiled and analyzed online.

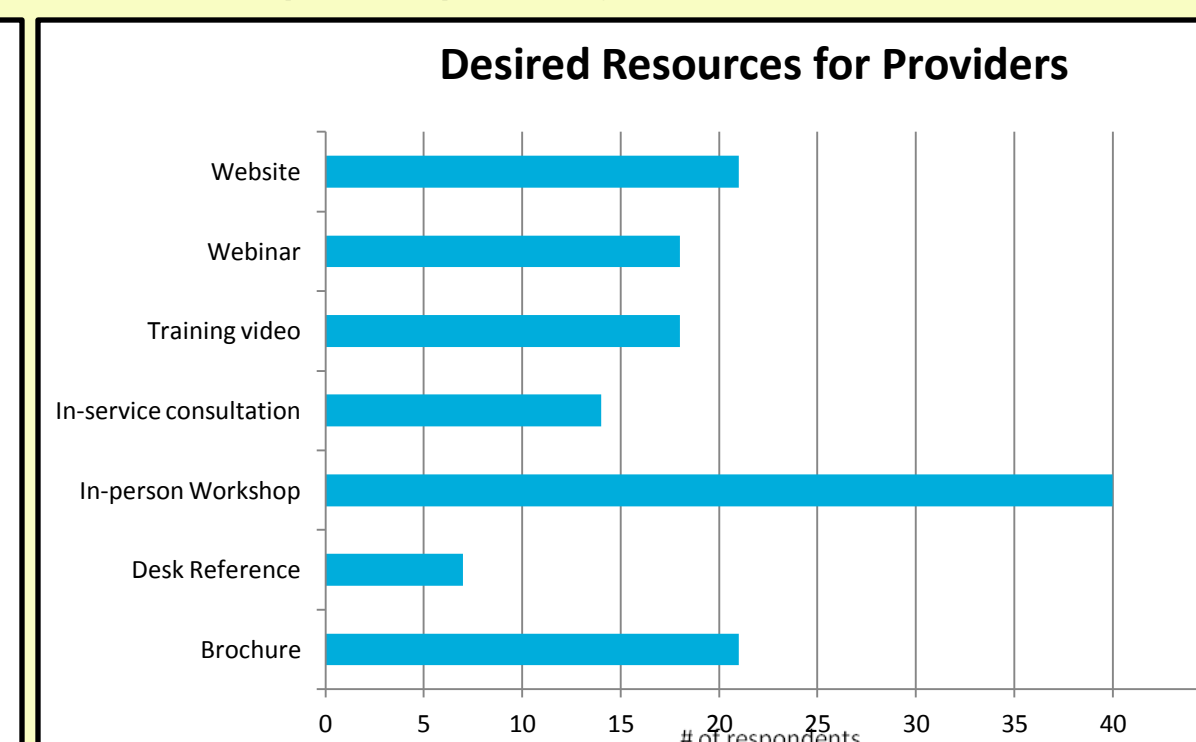
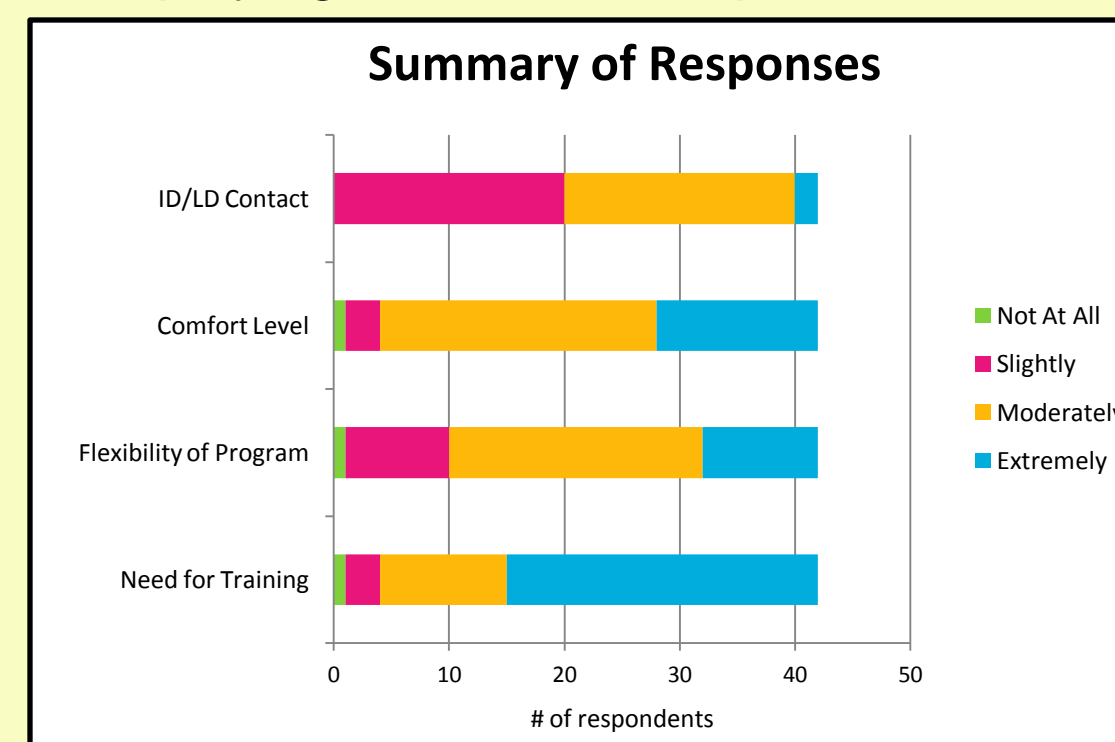
Methods: Participants

Received consent from 4 programs: Parent-Child Home Program, Nurse-Family Partnership, Healthy Steps, & Parents as Teachers. 41 providers participated in survey.



Results Regarding EBHV Programs

- Top 3 services provided: parenting support, child health education, & child literacy
- 76% of parents are referred from other community providers, 25% from social services, 21% from medical clinics, 11% from schools, 7% from developmental disability system, and 3% from adolescent special education programs.
- 57% of providers acknowledged that working with parents with ID/LD is moderately more challenging and 4% identified it as extremely more challenging as compared to working with parents without ID/LD
- Successful strategies identified in the literature for working with parents with ID/LD are also routinely used by EBHV providers (e.g., assisting with completion of paperwork, simplifying information, & positive reinforcement for participation).



Qualitative Themes from Participants

Theme	Quotes
Adapting to parent's pace	"...Home-Visitor can let the parent's ability level dictate the pace and level of involvement with reading and playing to their children" "Parents with cognitive/learning disabilities require more work hours to achieve the same goals as our "nondisabled" clients. I wish funding would take that into account and/or caseloads could be adjusted to reflect the extra work required for this type of client."
Working collaboratively	"It would be great to have a collaborative team: hospital, Public health, OPWDD, agencies serving this population meet routinely to network and learn about what each agency offers to this population."
Educating and advocating for families	"It starts now ... giving parents more information and preparing them on how to help and advocate for their children. We need to learn more about how to help parents and children with disabilities"
Staff training needed	"I am definitely interested in a work-training to refresh and learn more about working with parents with cognitive and/or learning disabilities." "I have noticed that staff who have not been exposed to this population tend to be cautious and unsure of themselves. More training in this area would be a plus."

Discussion

Some programs were difficult to reach, which was a major barrier to our study. Nonetheless, information collected from participating providers resulted in several main themes:

- EBHV providers are inadvertently already working with this population.
- EBHV providers acknowledge that working with this population is moderately more challenging.
- EBHV providers are already using many strategies found to be successful with this population.
- Given that EBHV programs are increasingly available and funded in communities, they should be formally considered for this population.

Based on these findings, recommendations include:

- Encouraging cross-systems collaboration and referrals between EBHV and disability-focused organizations.
- Offering in-person training to EBHV programs so providers feel more comfortable when working with parents with ID/LD.