Toolkit to Support Home Visiting Services for Caregivers with Learning Differences

Conceptual Model and Resource Compendium

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Toolkit Overview

❖ WHY the Toolkit was developed…

Researchers are doing a lot of work in home visiting right now to understand "what works" best for which families and under what circumstances. One group of families that has received little attention are those in which a **parent or caregiver has an intellectual disability or other learning difference.**

❖ WHO is the Toolkit for…

This toolkit is **for home visiting staff, home visiting programs, and home visiting models and policymakers** who are seeking information about how to provide services for caregivers with learning differences.

❖ HOW to use the toolkit…

The toolkit includes **important background information, a conceptual model, and a resource compendium.**

- Key background information includes:
    - ✓ Why parents with learning differences may benefit from home visiting
    - ✓ Why it is important for home visiting to provide services in ways that work with ALL parents' communication and learning styles
    - ✓ Why support is needed at multiple levels, not just by home visiting staff
- The conceptual model lists and describes:
    - ✓ The supports that influence the quality of services received by parents with learning differences
    - ✓ The outcomes that are anticipated to occur if the supports are carried out with sufficient quality
- The resource compendium contains:
    - ✓ A list of resources on a range of topics for those seeking information about how to provide services for caregivers with learning differences
    - ✓ Resources are organized to align with the levels of support described in the conceptual model

Part A: Background and Conceptual Model

Introduction

Evidence-based early home visiting is a strategy to improve health and development for expectant families and families with young children. Home visiting serves families facing adversities that may compromise caregivers' ability to provide a safe, nurturing, and stable home environment. Yet, research shows that all families do not benefit equally from home visiting services. Many families disengage from services far earlier than intended, and average home visiting effects are modest.[1] More work is needed to understand "what works" best, for which families, and under what circumstances. One group of families that has received little attention includes those in which a parent or caregiver has an intellectual disability or other learning difference.

This set of documents was developed as product of a Maryland MIECHV evaluation to:

1. Provide important context for understanding the unique challenges facing caregivers with learning differences and the potential benefits of home visiting,
2. Present a conceptual model that describes supports home visiting stakeholders can use to strengthen services for caregivers with learning differences, and
3. Share a compendium of resources for models, programs and home visiting staff interested in learning more about how to improve services for caregivers with learning differences.

We intend for the conceptual model and resources to be used to raise awareness and provide information, and as the basis for self-assessment, quality improvement, program evaluation, and research.

What do we mean by "learning differences"?

We use the term *learning differences* as an umbrella term to describe a broad range of challenges (Figure 1) in areas such as:

- Comprehension
- Memory
- Problem solving
- Communication
- Reading or math literacy
- Adaptive skills or problems in daily living (self-care; child-care; literacy, number, and conceptual skills; social skills; other practical skills)
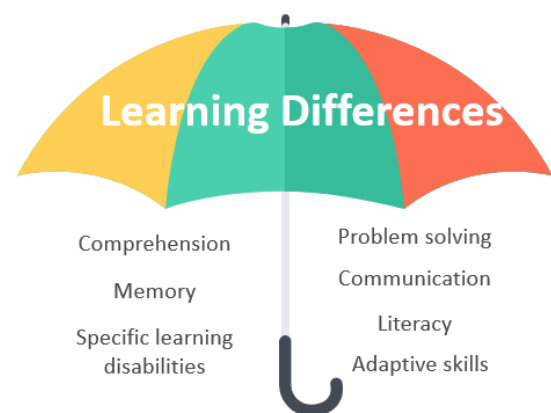

Figure 1. Examples of learning

These challenges may result from intellectual or developmental disabilities, specific learning disabilities, traumatic brain injury, environmental stressors, or other causes. Some parents who enroll in home visiting have been diagnosed with a learning or intellectual disability and may have received specialized services. However,

evidence suggests that many learning differences are undetected. **Learning differences may affect a caregiver's ability to engage in and benefit fully from home visiting services, especially if a program is not designed to meet the needs of parents with a range of abilities.**

Background

In this section we offer some important background information and a rationale for home visiting stakeholders to consider the unique needs of caregivers with learning differences.

Point 1: Caregivers with learning differences may benefit from home visiting

There are many reasons why parents with intellectual disabilities and other learning differences would benefit from home visiting. Research shows clear disparities in birth outcomes for women with intellectual disabilities.[2,3] In part, such disparities may be related to the finding that parents with intellectual disabilities frequently have co-occurring adverse life conditions such as poverty, serious health and behavioral health issues, and poor social support.[4–6] Mothers with intellectual disabilities also tend to be younger and less likely to be married than mothers without intellectual disabilities.[4] Due to these confounding risks, children of women with intellectual disabilities are at increased risk of removal by child protective services.[7,8] However, many parents with intellectual differences are capable of taking care of themselves and their children with support. Home visiting is well situated to provide that support. For these reasons, parents with learning differences may be ideal candidates for home visiting.

There is strong support for home visiting as a strategy to address the needs of caregivers with learning differences. Home visiting aims to *increase parenting assets* by:

- teaching parenting knowledge and skills,
- conducting mental health and other essential screenings,
- identifying and addressing parenting concerns,
- providing socialization activities for parents and children,
- providing referrals to help families meet basic needs, and
- coordinating services with other essential health and related service providers.

Moreover, experts suggest that parent education programs for parents with learning differences are most effective when taught in the environment in which they will be applied – *in the home* - and are individually tailored to parents' learning needs.

Most home visiting programs are already serving parents with learning differences. Findings from the national MIHOPE evaluation of home visiting suggest that many parents enrolled in home visiting may have learning differences. In fact, 63% of parents in MIHOPE scored below average on a validated test of verbal intelligence.[1,9] Results from another study, the 2018 US Behavioral Risk Factors Surveillance System phone survey, showed that between 11-17% of women of childbearing age (18-44 years old) reported a cognitive disability. Moreover, other research shows that many parents have learning differences that have not been detected or diagnosed.[10] The term "hidden majority" refers to potentially large numbers of adults who may have been "slow" in

school and yet did not benefit from specialized supports because their challenges were never identified.[10] These high estimates of prevalence suggest a need for home visiting models, programs, and staff to examine more closely how they can provide high quality services to parents with learning differences.

Point 2: Home visiting must consider caregivers' unique learning needs

To improve outcomes, home visiting must provide services in ways that work with ALL parents' communication and learning styles and capacities. Parents vary in how they understand, process, remember, and use information that may be offered in a typical home visit. Programs that rely on one approach to serve all families may fall short of fully engaging parents with unique learning needs. They may also inadvertently marginalize parents who feel stigmatized or ashamed and who then may disengage from services.

Families benefit most when home visiting programs and staff have the supports and competencies to serve ALL families effectively. HRSA Centers for Excellence emphasize the need for *linguistic competence*, a term that refers to "the capacity of an organization and its personnel to *communicate effectively and convey information in a manner that is easily understood* by diverse audiences," including individuals with learning differences.[11] Linguistic competence includes structures, knowledge, skills and attitudes that support communication with caregivers with a range of abilities. It also refers to awareness and understanding of how learning differences can influence access to and quality of health care and family support. Linguistic competence is a core component of family-centered care and an essential home visitor competency.

> *Linguistic competence refers to the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse audiences.*

Point 3: Reducing health disparities will require change at multiple levels

Home visiting programs and staff should consider four levels of change to promote equity in outcomes and in early childhood systems for families in which a caregiver has a learning difference: *personal, interpersonal, institutional, and structural* (Figure 2).[12]

Personal: Requires that home visiting staff consistently work to understand their own values, beliefs, implicit biases, actions, and privileges which may contribute to inequities in outcomes, and strive to develop relevant competencies.

Interpersonal: Requires that home visiting staff relate effectively to others not like themselves, actively include those typically excluded, share power, openly acknowledge issues of inequity, and act to support positive change.

Institutional: Requires that models and programs apply a social justice lens to policies, practices, regulations, and work culture to dismantle policies that perpetuate inequality. Home visiting models and programs must develop policies and practices that advance opportunities, fairness, and access to resources.

Structural: Requires that individuals and groups recognize that structural arrangements are interconnected and resist change.
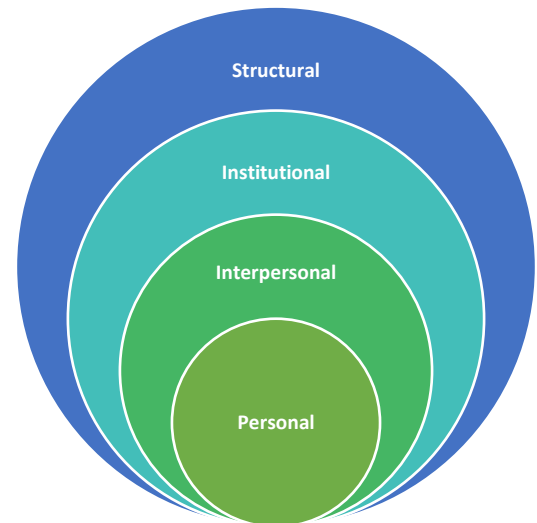

Figure 2. Levels of change

Overview of the Conceptual Model for Supporting the Needs of Caregivers with Learning Differences in Home Visiting

The Conceptual Model describes supports at multiple levels that influence the quality of services parents with learning differences receive. The Model also describes outcomes that are anticipated to occur if supports are implemented with sufficient quality. Evaluators developed the Model using data from four sources: literature reviews, key informant interviews, stakeholder and consultant feedback, and home visitor focus groups (see Appendix A). The Model can be used to inform practice or as the basis for self-assessment, quality improvement, program evaluation, and research.

The most important lesson learned from our evaluation was the need for a more intentional focus on equitable access and inclusion in HV for ALL families, including those headed by caregivers with learning differences. Findings also emphasize the need for systems and organizational changes, such as incorporating validated screening tools, implementing case weights, increasing flexibility around and timing for assessments and curriculum delivery, and integrating **universal design** principles in all aspects of service delivery. Currently, efforts to promote accessibility often occur at the level of the individual home visitor, and this is time consuming and duplicative. Finally, federal, state, and local home visiting programs should identify and partner with related service systems (i.e., health care, social services, disability services) to leverage funding opportunities, increase efficiency, reduce gaps in services, and ensure coordinated service delivery.

Universal design refers to ways of designing environments and instructional strategies and materials to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.
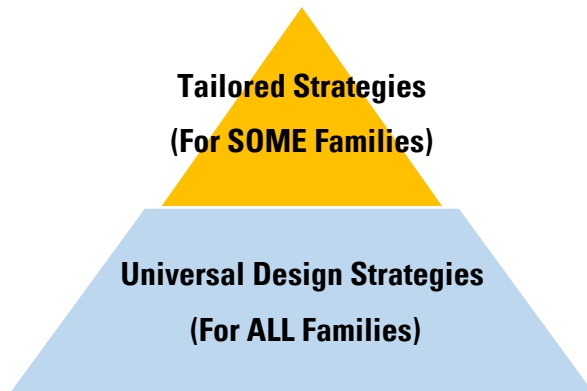
Figure 3. Universal vs. tailored strategies

The Conceptual Model suggests the need for stakeholders to consider both **universal design strategies** and **tailored strategies** (Figure 3). *Universal design* refers to ways of designing environments and instructional strategies and materials "to be *usable by all people*, to the greatest extent possible, *without the need for adaptation or specialized design.*"[13] Because home visiting is a platform for parenting *education* and support, universal design ensures *equitable* learning environments and enables *access* to parenting information and supports for caregivers with *all* abilities. Home visiting models, programs and staff must consider the structures, processes, and supports that are needed to effectively integrate universal design strategies. There are nine guiding principles of universal design. Table 1 describes the five guiding principles that are particularly relevant to home visiting: *equitable use, flexibility in use, simple and intuitive use, perceptible information*, and *tolerance for error.*

Table 1. Universal Design: Five Key Principles[14]

Principle	Description and Example
Equitable use	Handouts and other materials may need to be redesigned in ways that increase accessibility for caregivers with varied learning needs and levels of literacy.
Flexibility in use	Parenting education techniques must accommodate a wide range of caregivers' preferences and abilities. This is often accomplished by providing *choices* in learning activities.
Simple and intuitive use	Content must be presented in ways that are straightforward and consider caregivers' background *knowledge, language skills,* and *concentration levels.*
Perceptible information	Curriculum content must be presented and practiced in varied ways, including the use of illustrations, tactile experiences, and visible contrasts of essential content.
Tolerance for error	Instruction anticipates variation in individual student learning pace and prerequisite skills.

In contrast to universally designed strategies**, tailored strategies** refer to specific strategies and accommodations to support participation, engagement, learning, and service coordination for families in which a caregiver has been *identified* as having a learning difference. Home visiting staff tailor strategies when they have a good understanding of the caregiver's unique needs and preferences.

Figure 4, below, presents an overview of the conceptual model. The Conceptual model is represented as a logic model with three essential "buckets" of factors hypothesized to influence outcomes: *Federal, Tribal, State & Community Supports*, *Service Model & Local Implementing Agency Supports,* and *Direct Service Supports.*

- *Federal, Tribal, State, & Community Supports* include expectations and supports provided by federal, state, local funders, and national models related to recruitment, enrollment, direct services, and coordination specific to caregivers with learning differences. This level also considers the extent to which resources are available and accessible within the local community.
- *Service Model & Local Implementing Agency Supports* refer to administrative and programmatic supports such as clear expectations, guidelines for caseload sizes, staff training, supervision and coaching, and tailored curricula.
- *Direct Service Supports* refer to specific activities and behaviors used by home visiting staff to support caregivers with learning differences, such as use of universal design principles, identification of caregiver learning needs and preferences, use of inclusive and adaptable materials and strategies, opportunities for mutual support, and recognition of family achievements.

The Model is intended to be read from left to right, with the understanding that the quality of services families receive is influenced by factors at multiple levels, and that front line staff cannot be expected to provide high quality services without higher level supports. The Model also specifies anticipated **outcomes** for programs, staff, and caregivers with learning differences. It is worth noting that some concepts in the Model are applicable to all families (e.g., develop a family-centered goal plan), whereas others are specific to caregivers with learning differences. **Appendix B** provides more detailed information about the Model, including definitions and examples.

Figure 4. Conceptual Model for Supporting the Needs of Caregivers with Learning Differences in Home Visiting (Revised August 2022)

Federal, Tribal, State & Community Supports

- o Implement universal design
- o Develop a culture of continuous learning and flexibility
- o Ensure available and accessible community supports

Service Model & Local Implementing Agency Supports

- o Implement universal design
- o Establish workforce competencies
- o Establish clear and realistic expectations and guidance for all staff and points of interaction
- o Identify, adapt, or develop curricula and materials
- o Provide specialized curricula and materials
- o Provide specialized training
- o Ensure high quality supervision
- o Ensure coaching or consultation
- o Establish guidelines for collaboration with community providers
- o Establish a Community of Practice

Direct Service Supports

- o Implement universal design
- o Assess caregiver strengths and needs
- o Identify learning needs and preferences
- o Develop a family-centered goal plan
- o Tailor approach and provide accommodations
- o Locate supportive services
- o Establish relationships with supportive services
- o Offer referrals to services
- o Facilitate linkages to services
- o Monitor, follow-up and respond to change
- o Promote access to financial resources
- o Support self-determination, advocacy and agency
- o Provide opportunities for mutual support
- o Provide opportunities to honor families

Anticipated Outcomes

Program and Staff Outcomes
- o Improved role clarity
- o Increased knowledge of learning differences
- o Increased confidence when working with families with learning differences
- o Increased awareness of community services for parents with learning differences
- o Increased job satisfaction

Short-Term Outcomes for Families with Learning Differences
- o Services aligned with needs and preferences
- o Families receive and access referrals
- o Increased satisfaction in home visiting
- o Increased participation in home visiting
- o Improved retention in home visiting

Intermediate Outcomes for Families with Learning Differences
- o Improved caregiving knowledge and skills
- o Improved confidence
- o Increased feelings of empowerment

Long-Term Outcomes for Families with Learning Differences
- o Reduced risk for child injury, maltreatment and removal
- o Improved child and family health and wellbeing
- o Equity in health and wellbeing over the life-course

Appendix A. How the Conceptual Model was Developed

The project team used multiple methods and drew from theory, research, and practice to inform the Conceptual Model. The Model identifies multilevel factors and strategies to support family engagement and positive outcomes for families headed by caregivers with learning differences. Evaluators developed the Model using data from four sources: **stakeholder and consultant feedback, literature reviews, key informant interviews, and home visitor focus groups**. The Conceptual Model incorporates findings from all activities.

Stakeholder and Consultant Feedback. The project team established a stakeholder advisory group (SAG) comprised of home visitors, supervisors, program managers, state agency representatives, home visiting model representatives, and parents with learning differences. The SAG met seven times over the course of the project and helped define the scope and goals of the work and gave feedback on all project activities. We also engaged three consultants with expertise in caregivers with learning difficulties.

Literature Reviews. The project team reviewed literature on a) factors that contribute to disparities in health outcomes among families headed by a caregiver with learning differences, b) conceptual models related to parenting with disabilities, c) research on parenting interventions for caregivers with learning differences, and d) models and theories of program implementation.

- The literature highlights **multi-level factors that contribute to disparities in service use and health outcomes**. This research shows that risk for adverse outcomes may be less directly related to disability status than to the myriad confounding health, economic, and psychosocial challenges that caregivers with learning differences often experience.[6] For example, caregivers with intellectual disabilities tend to be younger, are less likely to be married, have poor formal and informal supports, and experience higher rates of poverty, physical and behavioral health challenges, trauma, stress, social isolation, and are overrepresented in child welfare systems compared to caregivers without ID.[4,5,7,8,15–18] Discrimination is pervasive,[19,20] and stigma and fears of discrimination may impact caregivers' trust in systems of care and willingness to seek help when needed, thereby increasing risk for poor outcomes. This literature points to the need for a comprehensive assessment of family strengths and needs, and for an approach that is sensitive to parent's concerns and prior negative experiences with service providers.
- Our search located **conceptual models** that have been used to explain parenting and effective ways to measure and teach parenting skills to caregivers with intellectual and developmental disabilities and other learning differences. Examples include Wade and colleagues' *Adapted Family Stress Model*[21] and Aunos and Feldman's *Parenting Interactional Model*.[22] These models are grounded in ecological frameworks, self-determination theory, stress theory, and principles of behavior analysis. They highlight dynamic interactions between caregivers with disabilities and environmental supports and stressors and emphasize the need for approaches to parenting education that are flexible and tailored to caregivers' unique needs.
- We also reviewed studies of **home-based parenting interventions for caregivers with intellectual disabilities** led by investigators such as Feldman et al,[22,23] Gaskin,[24] Glazemakers,[25] Hodes,[26] Knowles,[27] Llewellyn,[28] Monsen,[29] and Tymchuk.[30] Overall, there is limited research on the effectiveness of parenting interventions for

caregivers with intellectual disabilities and other learning differences. This finding was further supported by two systematic reviews on this topic.[31,32] Some interventions focus on caregiver skills training and do not address broader ecological factors that contribute to poor outcomes.[33] We identified only one study involving a MIECHV-eligible home visiting model, which was an adaptation of the SafeCare model for caregivers with intellectual disabilities.[24]

- Finally, we drew from **implementation research**[34] and from a **framework for service coordination**[35] to develop a start list of domains and indicators for the conceptual model. Implementation research highlights the important role that policies and procedures, staff training, supervision and coaching, and other factors play in supporting and strengthening home visiting services for caregivers with learning differences. This literature emphasizes the need to select strategies that are feasible, acceptable, and useful from the perspectives of end-users, including funders, national HV models, HV program staff, and families.[36]

Key Informant Interviews. Key informant interviews helped the team understand the broader context of services for caregivers with learning differences in Maryland. As a group, key informants had extensive experience working with adults or caregivers with intellectual and developmental disabilities and other learning differences. Overall, data from interviews were consistent with the literature and showed that caregivers with learning differences often have complex and confounding needs, such as lack of formal and informal supports and limited access to reliable transportation. Families' case management needs were described as "intense" and time consuming. Key informants described challenges providers face when serving caregivers with learning differences, such as:

- Ways in which stigma influences identification of learning differences, help-seeking behavior, and ability to communicate successfully
- Lack of reliable and valid screening tools to identify caregivers who may have learning differences.
- Varying service availability by location, and limited access to services due to eligibility restrictions based on the caregiver's age or residence
- Poor referral and service coordination across systems that serve caregivers with learning differences (e.g., disability services, child welfare, early intervention)
- Lack of services specifically for *caregivers* with learning differences
- Lack of funding

Home Visitor Focus Groups. Focus groups helped the team understand current practices and experiences of home visitors who provide services to caregivers with learning differences. Home visitors described varied experiences, challenges, and supports related to working with caregivers with learning differences. All home visitors reported that they have caregivers with learning differences on their current caseload. Home visitors described challenges and needs when providing high quality services to this population, such as the need for more time and flexibility, the need for curricula materials that to better suit caregivers' pace and learning needs, and the need for training. Almost all home visitors reported that they adapt materials on their own to meet families' needs. Home visitors appreciated the supports they received from supervisors, colleagues, consultants, and community resources.

Appendix B. Detailed Conceptual Model for Supporting Caregivers with Learning Differences in Home Visiting

The table below integrates qualitative data from home visitor focus groups (HV FG) conducted in FY18 with qualitative data from general caregiver interviews (CI) and interviews with staff and clients from the screening tool pilot study (ST pilot) conducted in FY21.

> Strength = data reinforces what home visiting already doing
> Opportunity = data suggests opportunities / areas for improvement
> Note. In some instances, extra words have been removed from quotes for brevity and clarity (e.g., "Um," "like,").

Level of Support: Federal, Tribal, State, & Community Supports for Home Visiting Programs and Staff Working with Caregivers with Learning Differences		
Support/Indicator	Detailed Definition	Example Quotes
Implement universal design principles	Relevant entities design policies, guidelines, standards, procedures, and materials to ensure that HV services are usable by ALL people, to the greatest extent possible, without the need for adaptation or specialized design.	**HV FG** - Another HV suggested that more visual materials would be helpful for all families: "Whether you're kinesthetic or visual, or any type of learner, that's not classified by whether you have a learning difficulty or not. I definitely think that could be helpful for anybody" (PAT-J). OPPORTUNITY
Develop a culture of continuous learning and flexibility	Relevant entities regularly reflect on the extent to which policies, guidelines, standards, procedures, and materials are accessible and relevant for ALL families, regularly update these as needed, and continually attempt to embed new knowledge, skills, and innovations.	Did not assess.
Ensure available and accessible community supports	Community organizations collaborate to develop and sustain a system of care in which services and resources needed to support caregivers with learning differences are both *available* and *accessible*. Examples include transportation, housing, health care, assistance with basic needs, and employment.	**HV FG** - Many home visitors reported difficulties coordinating with other providers on behalf of caregivers with learning differences. One stated, "it's frustrating for me to go through the process to get a hold of some of these places, [and] I still can't get a living, breathing human being. You put a family that is already at a disadvantage to go through this, they give up" (PAT-B). OPPORTUNITY **HV FG** – This problem may be confounded with caregivers' needs for extra assistance, such as help with required paperwork, "A lot of times I'm helping to fill out paperwork", said another, "but if I can't go at that specific time, then the family gets deterred" (EHS-A). OPPORTUNITY

Level of Support: Service Model & Local Implementing Agency Supports for Home Visiting Staff Working with Caregivers with Learning Differences		
Support/Indicator	Detailed Definition	Example Quotes
Implement universal design principles	HV models and LIAs implement policies, guidelines, standards, procedures, and materials to ensure that HV services are usable by ALL people, to the greatest extent possible, without the need for adaptation or specialized design.	See above.
Establish workforce competencies specific to working with caregivers with learning differences	HV models and LIAs agree on knowledge, attitudes, and skills that are necessary to provide services effectively to caregivers with learning differences and that are realistic given other job demands.	**CI** – Caregivers' comments suggested that important competencies include strong communication skills that help build rapport and strong relatohships with families. "I would want them to know that even though it's time-consuming, it's worth it. It's rewarding. Having the help and the guidance and the reassurance, it's great. There's nothing you could ask for or nothing else you could ask for than that" (HFA-C7). STRENGTH
Establish clear and realistic expectations and guidance for all staff and points of interaction	HV models and LIAs provide clear expectations and guidance for all points of interaction with caregivers with learning differences, including recruitment, enrollment, direct services, and service coordination. Guidance should be clear, aligned with workforce competences, and reasonable given other job demands. Examples include guidance for caseload size and frequency and length of visits that take into account additional time often needed to support caregivers with learning differences, flexible timelines for achieving benchmarks and flexibility in selecting and using curricula/curricula supports. *See also organizational supports.*	**HV FG** - Half of the HVs mentioned devoting more time to visits with caregivers with learning differences than with other families. Several HVs remarked that the additional time needed is often not considered when caseloads are assigned, and suggested that higher weights be assigned to caregivers with learning differences.÷ "I'm spending an extra thirty minutes to an hour on that specific mom and she's at a lower case weight than a mom that doesn't have a learning disability. It really doesn't make sense" (HFA-D). OPPORTUNITY

HV FG - Data also showed the need for ALL staff to have realistic expectations: "When we do intake…sometimes our parents need more support, and the person who does intake isn't always so willing to work with the family" (EHS-A). OPPORTUNITY

HV FG - A few HVs emphasized that caregivers with learning differences often need help with basic adult life skills, which takes time. "You're not meeting the milestones that you're supposed to be meeting with the child because you're more focused on the parent. Because you need to build their skills, so they can help their own child" (EHS-A). OPPORTUNITY

HV FG - Some home visitors described having more flexibility in how they approach their work with families with learning differences. One stated, "We have deadlines that we do have to meet, but there's not like an end date to a topic that we're talking about, or an activity that has to be completed by [a given date]. Even though we do have deadlines for some home visits, I work with all my families at the pace that they're able to work at" (EHS-E). "Our benchmarks and reporting are based on our evaluations and screenings. By working with our supervisors, we can schedule those individually. (…) As long as [the caregiver] is making small steps, there's nothing really competing with our deadlines" (HFA-D). STRENGTH |

		CI – Caregivers consistently emphasized the need for time and flexibility. "[The HV should] be more patient and just to take their time, be patient with [the caregiver] and understand that they are different and … all things that they learn differently, and they just need somebody that they can take their time with them" (EHS-C6). STRENGTH AND OPPORTUNITY
Identify, adapt, or develop curricula and materials	HV models and LIAs tailor or adapt evidence-based curriculum and materials to meet the learning needs of caregivers with learning differences. The curriculum protocol includes accommodations such as extra time, varied instructional formats, and optional lesson plans (e.g., basic adult life skills).	**HV FG** - Some HVs felt their curriculum reading level was too high. "As of now," said one, "the PAT curriculum reads at a 10th or 11th grade level. Some of those families can't even read on a third-grade level" (PAT-B). One EHS HV commented on the curriculum she uses as "not very HV friendly, so it's not very parent friendly. The verbiage is very professor-like written [sic]. So, I do not like it" (EHS-A). OPPORTUNITY
		HV FG - Three home visitors mentioned that they found it helpful to use older handouts, which were more accessible than the current ones. "Old-school PAT curriculums (…) They used to have handouts, and then like very simplified handouts. I do kind of miss those, for those that could read a little bit. I thought they were helpful, but they don't have those anymore" (PAT-I). STRENGTH AND OPPORTUNITY
		HV FG - More than half of the home visitors described using the internet (mostly Google and Pinterest) to identify activities, pictures, videos, and learning tools to work more effectively with caregivers for whom they felt the existing curriculum and hand-outs were out of reach. "Pinterest has a lot of activities that I can work into our curriculum. If we're talking about physical and brain development, then I can find something that's easier than what might be offered in the GGK curriculum" (HFA-D).
		HV FG - For a caregiver with low literacy, another home visitor described creating custom materials and tools that would be useful for both the caregiver and the child: "I would sit down and create a visual tool that would help her remember things…not singling her out, because it's things that she can apply to her children as well. If she needs to put pictures to label things around the house, that would help her, too, as well as understanding, or routine charts…it's an overall learning experience for both, without singling out one or the other" (PAT-J). OPPORTUNITY
		HV FG - A few home visitors described making adaptations that may have contradicted their models' expectations. One home visitor described her approach, stating, "We had to get rid of a lot of it. [The model] want[s] you to give hand-outs to the families for every visit and there are families where they don't read on that kind of level. So, forget that" (PAT-B). OPPORTUNITY
		HV FG - HV perspectives varied on whether and how curricula could be adapted. One shared, "The GGK is very adaptive. We can break those modules [and] sections up, so that some moms can go through them in one visit, and I've had moms that [take] three or four visits to go through a module." (HFA-D). Yet, another HV using the same curriculum disagreed, stating, "they really want you to sit there and read word-for-word from the book, and I don't think that's really going to be helpful to those parents. (…) I don't think that GGK will work well with families, [with a] disability" (HFA-G). OPPORTUNITY

Provide specialized curricula and materials	HV models and LIAs offer (and train staff to use) evidence-based curriculum and materials that were *developed* or *adapted* to meet the learning needs of caregivers with learning differences.	**HV FG** - Most HVs expressed the need for a simple, visual curriculum, yet they disagreed on whether curricula should be universal or targeted to families with learning differences. [no quote] OPPORTUNITY
Provide specialized training to strengthen workforce competencies	HV models and LIAs provide opportunities for staff to receive ongoing evidence-based training to ensure workforce competencies based on best practices to support caregivers with learning differences. Examples include communication skills and how to tailor approach or use of materials.	**HV FG** - None of the home visitors reported receiving specific guidelines for working with caregivers with learning differences. [no quote] OPPORTUNITY **HV FG** - Almost half of the participants stated a need for training relevant to their work with caregivers with learning differences, and two felt that such trainings should be mandatory. Four HVs indicated a need for training in how to teach adult life skills to caregivers with learning differences. [no quote] OPPORTUNITY **HV FG** - HV also reported missed opportunities and lack of accessible trainings, "Communication as far as what other trainings and events for this targeted audience would be helpful … if we needed to travel, we're willing to, we just need to know that these opportunities are available" (HFA-D). OPPORTUNITY **ST pilot** – One HV noted the importance of empathy and communications skills training. She said, "… the family resource specialists are already trained (…) to be able to ask questions that some parents might feel uneasy about answering … everyone can't be a family resource specialist (…) some people don't like (…) asking difficult questions (…) good communication skills (…) I think all those is a skill that not everybody has" (STS-5). STRENGTH AND OPPORTUNITY
Ensure high quality supervision	HV models and LIAs provide regular reflective supervision to support staff, ensure realistic workforce expectations, and build competencies for working with caregivers with learning differences.	**HV FG** - Several home visitors shared that they had discussed with their supervisors how to adapt their curriculum and service delivery strategies to the meet the needs of the family. "Sometimes I talk to supervisors about how to do it," one said. "But it's more of, wherever we get to, that's where we leave off. And if we need to stop and explain it, or work through something, that's what we do" (HFA-D). STRENGTH
Ensure availability of coaching or consultation	HV models and LIAs have experts on staff or on call who can support HV staff working with caregivers with learning differences, as needed.	**HV FG** - A few home visitors described support they received from other specialists, such as mental health professionals. [no quote] STRENGTH
Establish guidelines for effective collaboration with relevant community providers	HV models and LIAs are intentional in their approach to establish and maintain relationships and workflows to support referral and coordination with community providers that serve adults with learning differences.	**CI** - One caregiver described how the collaboration between the home visiting program and other community services was very helpful for her. "With Family Partnership, they have a GED program that has a daycare in the same building. She was able to go to school with me and actually interact with kids her age while I was in school" (PAT-C2). STRENGTH
Establish and support a Community of Practice	HV models and LIAs engage in a process of collective learning that includes discussions, joint activities, and mutual problem solving around	**HV FG** - Two PAT home visitors commented on the importance of peer support. One said, "We do a lot of peer one-on-one things, so we bounce ideas off of each other. Because if something's not working, then somebody might've had a similar situation

	supporting caregivers with learning differences.	that worked. Something they did worked for them, so we just create our own toolbox of things" (PAT-J). STRENGTH

Level of Support: Direct Service Supports for Home Visiting Staff Working with Caregivers with Learning Differences		
Support/Indicator	Detailed Definition	Example Quotes
Implement universal design principles	HV programs use or design spaces, assessments, curricula, procedures, and materials that are usable by ALL people, to the greatest extent possible, withough the need for adaptation or specialized design.	See above.
Assess caregiver strengths and needs	HV programs conduct a comprehensive assessment of families' biopsychosocial strengths and needs using validated tools.	No data.
Identify unique learning needs and preferences	HV programs identify caregivers' unique learning needs and preferences using validated tools.	**HV FG** - All HVs reported that they have caregivers with learning differences on their current caseload; however, none reported having a systematic way to identify learning differences. Reactions were mixed when asked "would an assessment tool be helpful? [no quote] OPPORTUNITY **HV FG** - Several home visitors suggested that acceptability of a screening tool would depend on the nature of the question. One said, "Depends on how they were worded, for sure. If it feels more like a medical diagnosis, they probably aren't going to want to answer. So, I think if it was more friendly, that would be beneficial" (EHS-A). Another said, "It probably depends on what the questions are (…) you won't want to offend anyone because you want to come back again for another visit" (HFA-G). STRENGTH AND OPPORTUNITY **ST pilot** – Some staff discussed how using the screening tool increased their awareness of caregivers' individual differences and needs. Some staff indicated that the tool filled a gap in existing assessments, noting that they do not get information about how caregivers learn from other routine screenign questions. [no quote] STRENGTH AND OPPORTUNITY **ST pilot** - Staff described how they used screening tools results: "You learn a lot about your parents. You learn a lot about their learning style. You learn a lot about what their challenges may be, or if there even are any challenges. You learn how fast or slow you may be able to give this parent information. If this parent needs an application or something, can you just send them the link to the application, and they can just do it on their own and ask you questions? Or do you have to sit with them and work on it with them, depending on what the screening says" (STS-4). Another said, "[It is] helpful to know the parent's learning style to adjust as needed - take more time, make sure they are grasping (…) [the screening tool] made me more aware of how I asked her questions…rearrange words, break them down a bit to where she understood" (STS-6). STRENGTH AND OPPORTUNITY

		ST pilot - One HV staff described how the screening tool can initiate conversations that are useful regardless of whether caregivers have learning differences: "If they are a reader, like, 'Oh, I like to read or I think I learn more if I read,' I will send like more reading articles (…) or if a parent says like, 'I'm a visual learner so I like pictures,' it helps me determine how to provide information or materials to them" (STS-3). STRENGTH AND OPPORTUNITY
		CI – Caregivers varied in their perspectives of whether and how HV staff should ask about learning differences: "I think they should find out the comfortability of that person first before they jump into that subject. Like I said, a lot of people don't like sharing or they're learning disabilities because they may be embarrassed, or feel ashamed, or anything"; STRENGTH AND OPPORTUNITY
Develop a family-centered goal plan	HV programs collaborate with parents to develop a goal plan that incorporates families' strengths, needs, and preferences.	CI – One caregiver described goal planning as useful "…yesterday I did a goal thing where … teacher was typing up a goal for me and I basically was just answering … we're doing steps on what I can do as far as getting my car and stuff for driving school and doing my license … She wrote down my goals so it can make it easier for me to complete them. (…) it's an easy way for me to know for sure that I'm going to be able to fulfill my goals as far as what I want to do and stuff. It's not something that I got to think about. If I could just go back and look at that paper and look at the goals that I set … [and] what steps it was that I wanted to take in order to get to those goals that I set for myself" (HFA-C1). STRENGTH
Tailor approach and provide accomodations	HV programs use inclusive and adaptable strategies that accommodate the unique learning needs of each caregiver (e.g., extra time, accessible handouts).	HV FG - Half of the home visitors mentioned devoting more time to visits with caregivers with learning differences than with other families. Some described increasing the number of contacts with families between visits. "I might send a text message and say, 'Hey, don't forget that they had that class today'; "Were you able to make that phone call?'; 'Did the baby have a well-child visit scheduled?' So, it seems like I'm just checking in a lot more with those families" (HFA-G). A few HVs also mentioned taking time to help caregivers with organizational skills and scheduling. STRENGTH
		HV FG - For most home visitors, insufficient time was the main challenge when working with caregivers with learning differences. Most home visitors mentioned the additional time needed to complete forms and assessments as the primary difficulty, particularly when working with caregivers who struggle to understand, process, and answer questions. One HV stated, "I do have a couple of families where I know our assessments are going to take two visits. So, I need to strike them earlier, so that they're done by a deadline. And trying to work that in with everything else we have to do and talk about can be difficult" (EHS-E). Another HV said, "families have trouble comprehending" (the Healthy Families Parenting Inventory), so completing it "is really, really difficult, and we have three or four visits just for that one form" (HFA-G). Time required for caregiver education and referrals was also a concern. One HV described "having to repeat or reword directions or referrals or just having to kind of pull double duty" due to "the lack of memory or maybe even lack of understanding" by the caregiver (PAT-I). OPPORTUNITY
		HV FG - When asked about strategies they use to work with caregivers with learning differences, many HVs described being creative and making adaptations

		that were not part of their formal training. Regarding one of the caregivers in her current caseload, one related, "As I'm trying to explain things at a second or third grade level, she didn't quite understand or grasp the concepts, so I had to come up with creative ways of trying to explain things to her in an even lower level, without making her feel inadequate or dumb" (PAT-J). STRENGTH AND OPPORTUNITY
		HV FG - Most home visitors also tailored their mode of communication to match the preferences or abilities of caregivers with learning differences. For some this meant connecting via phone calls instead of texts or doing in-person check-ins rather than phone calls. One remarked, "I have currently one Hispanic client who doesn't read or write, so that becomes a little problematic, but we try and see if they're visual learners or if repetition works with them, so whatever way they can learn is the path we're going to go down with them" (HFA-H). OPPORTUNITY
		ST Pilot - Some staff discussed how screening tool results could deepen understanding of the caregiver and inform accommodations: "[The mom] is talking about a particular issue that she's having, maybe filling out an application or something she may be doing for a job or anything like that. Before [using the screening tool] I would say, 'you should just do this' or maybe 'you should try that,' but now by me doing this screening with her, I understand why she may have difficulty doing particular things. I could definitely be a little more supportive in that aspect. With this program, we try to help them with being independent and work toward self-sufficiency, but I understand some people may just need a little extra help with things. It helped me with that" (STS-4). STRENGTH AND OPPORTUNITY
		CI – Caregivers described many ways in which HVs tailored services or made helpful accommodations. "Yes, she was very, very, very helpful. She was like, "Oh, it's okay. You can ask me (…) Let me explain it to you … She'll just like, explain it with different words … I don't want to say dumb it down … but like dumb it down, if that makes sense" (HIPPY-C5). STRENGTH
Locate supportive services	HV programs establish and maintain a comprehensive list of community services that can support parents with learning differences.	**CI** - "… she [home visitor] helped me out a lot with getting a lot of resources that [child] needed, that I didn't even know that she could even have at her age. That's what home visiting helped me out tremendously with about because I wouldn't have been able to get her evaluated because of the ride situation. I wouldn't have found out the resources that I needed to get her into John Hopkins, get her evaluated for her speech, impediment her" (PAT-C2). STRENGTH
		CI - "You can talk about exactly what … you could do for your daughter or in your case, which you could do for yourself too, because they even give out help if yourself you need help on any aspect … It's just, they like to help. They just give out any resources they possibly can, and I love that…" (PAT-C2). STRENGTH
Establish relationships with supportive services	HV programs establish relationships with a comprehensive array of community services that can support parents with learning differences.	Not assessed.
Offer referrals to supportive services	HV programs offer referrals to families to relevant community services that can	See below.

	support caregivers with learning differences.	
Facilitate linkages with community services	HV programs help link families with community services that can support caregivers with learning differences, such as by providing a "warm hand-off."	**CI** – "She even tries contacting them when I'm not with them, to try to get them on the phone and explain, 'Look, this is the situation, this is what we need. Is there any way you can help?' She'll even take me out. Like I had to change something on my food stamps, she took me straight out to DHS and got everything switched over and what I needed to be done. She even helped fill it out because my handwriting sucks. … [and] I felt like they've put more of a priority (…). It just feels like when they [HV] help, it's just a faster process" (PAT-C2). STRENGTH AND OPPORTUNITY **CI** - " … [home visitor] would take me to some appointments if I was not able to get a ride. They're really helpful in that, especially if they're not busy. [Child] had, I think her one-year checkup or something when I was in the program, and [home visitor] was able to take me. There were a couple of times that we had to take [child] to the doctor and she took me. Even for doctor's appointments for me, they take you. It's not just for your kid. They also help you tremendously." (PAT-C2). STRENGTH
Monitor, follow-up and respond to change	HV programs follow-up with families to learn if they accessed the service, and to discuss next steps.	No data.
Promote access to financial resources	HV programs promote equitable access to available financial resources to help families meet basic needs and access needed services in the community.	No data.
Support self-determination, self-advocacy and personal agency	HV programs help caregivers build capacity to set and achieve personal goals.	No data.
Provide opportunities for mutual support	HV programs provide or identify opportunities for group social support for caregivers with learning differences.	**CI** – "I had this parent group where it was five parents. It lasted for two weeks, and it was more based on how to stay with children and parenting … they call it The Circle … In that Circle, how a child may have independence, she will run, do her thing, play, and then she'll come back to the parents for comfort or whatever she may need, to go back out and then do her one little thing (…) stuff like that" (EHS-C6). STRENGTH
Provide opportunities to honor families	HV programs recognize and acknowledge the achievements and contributions that families have made on a regular basis.	No data.

Anticipated Outcomes for Home Visiting Programs and Staff, and Families Headed by Caregivers with Learning Differences		
Support/Indicator	Detailed Definition	Example Quotes
Program and Staff Outcomes		
Improved role clarity	HV staff have clear understandings of their roles when working with caregivers with learning differences.	Not assessed.
Increased knowledge of learning differences	HV staff understand how to assess caregivers' unique learning needs, and how to respond to those needs effectively.	Not assessed.
Increased confidence when working with families with learning differences	HV staff are confident in their ability to serve caregivers with unique learning needs effectively.	Not assessed.
Increased awareness of community services for caregivers with learning differences	HV staff are knowledgeable of specific community resources available to support caregivers with learning differences.	Not assessed.
Increased job satisfaction	HV staff report high levels of job satisfaction related to working with families with learning differences.	Not assessed.
Short-term Family Outcomes		
Services align with family needs and preferences	Families receive services that have been selected based on results from assessments and family-centered goal plans.	No data.
Families receive needed referrals	Families receive timely referral information for needed services.	No data.
Increased satisfaction with home visiting	Families report satisfaction with home visiting services.	CI - "When you don't really have a support system at your house, they're your support system, and it's amazing to have. Because unfortunately, I don't really have much of a support system at my house. Having [home visitor] is my basic support system, it's helpful" (PAT-C2). STRENGTH CI - "[I like] all of it, really. I like my home visitor. She's super awesome. I like having help, learning, getting tips on how to address things that make me worry. I like, seriously, all of it, the games and stuff" (HFA-C7). STRENGTH
Increased participation in home visiting	Families receive expected home visits within a specific time frame.	Not assessed.

Improved retention in home visiting	Families remain enrolled in home visiting for the recommended time period.	Not assessed.
Intermediate Family Outcomes		
Improved caregiving knowledge and skills	Caregivers demonstrate an understanding of implementation, generalization, and maintenance of caregiving skills to promote child health, safety, and development.	**CI** - "She taught me how to distract him when he is really mad and throwing a huge fit and kicking and screaming or throwing himself on the floor … give him something else to focus on, and play games with him, be super attentive. She also taught me to teach him how to put things in buckets and that he keeps doing" and "She would explain the milestones and when he's supposed to meet them and then she would give me tips on how to help him develop in order to meet them on time. She was so good at it that I excelled with him, and he excelled my little baby genius, and he actually hit almost all of his milestones within months before he was supposed to." (HFA-C7). STRENGTH **CI** - "[Home visitor] helps me with a lot … she helps me with when [child] crawls, the stages that she goes through. She helps me with a lot of it. She helps me develop as a parent because she teaches me what I can do better as a parent next time" (PAT-C3). STRENGTH
Improved confidence	Caregivers report confidence in their ability to promote child health, safety, and development.	**CI** – *Interviewer*: "… how does it feel to talk about your learning difference?"; *Caregiver*: It's good because she's very empowering. She tends to lift me up and make me realize that I'm not as bad as I think I am. She reminds me that there are people way worse off than I am as far as learning goes. That makes me feel better. I guess having that empowerment also makes me try a little bit harder instead of just giving up immediately and getting frustrated." (HFA-C7). STRENGTH
Increased feelings of empowerment	Caregivers feel empowered to advocate for themselves and their children to improve their health and wellbeing.	**CI** - "What part of that is the most helpful for you? *Caregiver*: The encouragement … When I hear things like, "You did a good job," or "I'm proud of you. I had set a goal with her and I accomplished it. I told her that I feel proud of myself because I set a goal with her and I was able to accomplish one of my goals and that was to move. I feel good about it." (HFA-C1). STRENGTH
Long-term Family Outcomes		
Reduced risk for child injury, maltreatment and removal	Caregivers demonstrate reductions in emergency department visits, child abuse potential and reports, and out-of-home placements.	Not assessed.
Improved child and family health and wellbeing	Caregivers and their children demonstrate improvements in intended program outcomes.	Not assessed.
Equity in health and well-beingover the life-course	Caregivers with learning differences and their children no longer experience systematic disparities in health and wellbeing over the life-course trajectory.	Not assessed.

References

1. Michalopoulos, C., Faucetta, K., Hill, C.J., Portilla, X., A., Burrell, L., Lee, H., Duggan, A., and Knox, V. (2019). Impacts on Family Outcomes of Evidence-Based Early Childhood Home Visiting: Results from the Mother and Infant Home Visiting Program Evaluation. OPRE Report 2019-07. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

2. Akobirshoev E I, Parish, SL, Mitra, M, Rosenthal. Birth outcomes among US women with intellectual and developmental disabilities. *Disability and Health Journal*. 2017;10(3):406-412. doi:10.1016/j.dhjo.2017.02.010

3. Mitra M, Parish, SL, Clements, KM, Cui, X, Diop, H. Pregnancy Outcomes Among Women with Intellectual and Developmental Disabilities. *American Journal of Preventive Medicine*. 2015;48(3):300-308. doi:10.1016/j.amepre.2014.09.032

4. Hindmarsh G, Llewellyn G, Emerson E. Mothers with intellectual impairment and their 9-month-old infants. *Journal of Intellectual Disability Research*. 2015;59(6):541-550. doi:10.1111/jir.12159

5. Emerson E, Brigham P. The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities*. 2014;35(4):917-921. doi:10.1016/j.ridd.2014.01.006

6. Powell RM, Parish SL, Akobirshoev I. The Health and Economic Well-Being of US Mothers with Intellectual Impairments. *Journal of Applied Research in Intellectual Disabilities*. 2017;30(3):456-468. doi:10.1111/jar.12308

7. LaLiberte T, Piescher K, Mickelson N, Lee MH. Child protection services and parents with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2017;30(3):521-532. doi:10.1111/jar.12323

8. Slayter EM, Jensen J. Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*. 2019;98:297-304. doi:10.1016/j.childyouth.2019.01.013

9. Duggan A, Portilla XA, Filene JH, et al. *Implementation of Evidence-Based Early Childhood Home Visiting: Results from the Mother and Infant Home Visiting Program Evaluation*. Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services; 2018.

10. Emerson E. Health status and health risks of the "hidden majority" of adults with intellectual disability. Intellectual and developmental disabilities. 2011 Jun;49(3):155-65.

11. Campinha-Bacot et al*.* Transforming the face of health professions through cultural and linguistic competence education: The role of HRSA centers of excellence (n.d.). HRSA. *https://www.hrsa.gov/sites/default/files/culturalcompetence/cultcompedu.pdf*

12. National Equity Project. The lens of systemic oppression. Accessed November 14, 2021. https://static1.squarespace.com/static/5e32157bff63c7446f3f1529/t/5f1739965f252b1d45f0c d4f/1595357599748/Lens-of-Systemic-Oppression.pdf

13. Burgstahler S. Universal Design of Instruction (UDI): Definition, Principles, Guidelines, and Examples. 2020. doi:https://www.washington.edu/doit/sites/default/files/atoms/files/ UD_Instruction_06_15_20.pdf

14. King-Sears M. Universal Design for Learning: Technology and Pedagogy. *Learning Disability Quarterly*. 2009;32(4):199-201. doi:10.2307/27740372

15. DeZelar S, Lightfoot E. Parents with Disabilities: A Case Study Exploration of Support Needs and the Potential of a Supportive Intervention. *Families in Society*. 2019;100(3):293-304. doi:10.1177/1044389419841172

16. Collings S, Llewellyn G. Children of parents with intellectual disability: Facing poor outcomes or faring okay? *Journal of Intellectual and Developmental Disability*. 2012;37(1):65-82. doi:10.3109/13668250.2011.648610

17. Feldman M, McConnell D, Aunos M. Parental Cognitive Impairment, Mental Health, and Child Outcomes in a Child Protection Population. *Journal of Mental Health Research in Intellectual Disabilities*. 2012;5(1):66-90. doi:10.1080/19315864.2011.587632

18. Llewellyn G, Hindmarsh G. Parents with Intellectual Disability in a Population Context. *Current Developmental Disorders Reports*. 2015;2(2):119-126. doi:10.1007/s40474-015-0042-x

19. Parish SL, Mitra M, Son E, Bonardi A, Swoboda PT, Igdalsky L. Pregnancy Outcomes Among U.S. Women With Intellectual and Developmental Disabilities. *American Journal on Intellectual and Developmental Disabilities*. 2015;120(5):433-443. doi:10.1352/1944-7558-120.5.433

20. National Council on Disability. Rocking the Cradle: Ensuring the rights of Parents with Disabilities and their Children. Published online 2012. https://www.ncd.gov/publications/2012/Sep272012

21. Wade C, Llewellyn G, Matthews J. Parent mental health as a mediator of contextual effects on parents with intellectual disabilities and their children. *Clinical Psychologist*. 2015;19(1):28-38. doi:10.1111/cp.12055

22. Aunos M, Feldman MA. Attitudes towards Sexuality, Sterilization and Parenting Rights of Persons with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*. Published online 2002:12.

23. Feldman MA, Case L. Teaching child-care and safety skills to parents with intellectual disabilities through self-learning. *Journal of Intellectual & Developmental Disability*. 1999;24(1):27-44. doi:10.1080/13668259900033861

24. Gaskin EH, Lutzker JR, Crimmins DB, Robinson L. Using a Digital Frame and Pictorial Information to Enhance the SafeCare. *Journal of mental health research in intellectual disabilities*. 2012;5(2):187.

25. Glazemakers I, Deboutte D. Modifying the 'Positive Parenting Program' for parents with intellectual disabilities. *Journal of Intellectual Disability Research*. 2013;57(7):616-626. doi:10.1111/j.1365-2788.2012.01566.x

26. Hodes MW, Meppelder M, Moor M de, Kef S, Schuengel C. Alleviating Parenting Stress in Parents with Intellectual Disabilities: A Randomized Controlled Trial of a Video-feedback Intervention to Promote Positive Parenting. *Journal of Applied Research in Intellectual Disabilities*. 2017;30(3):423-432. doi:10.1111/jar.12302

27. Knowles C, Machalicek W, Norman RV. Parent education for adults with intellectual disability: a review and suggestions for future research. *Developmental neurorehabilitation*. 2015;18(5):336-348. doi:10.3109/17518423.2013.832432

28. Llewellyn G, McConnell D, Honey A, Mayes R, Russo D. Promoting health and home safety for children of parents with intellectual disability: a randomized controlled trial. *Research in Developmental Disabilities*. 2003;24(6):405-431. doi:10.1016/j.ridd.2003.06.001

29. Monsen K, Sanders A, Yu F, Radosevich D, Geppert J. Family home visiting outcomes for mothers with and without intellectual disabilities. *Journal of Intellectual Disability Research*. 2011;55(5):484-499. doi:10.1111/j.1365-2788.2011.01402.x

30. Tymchuk A, Groen A, Dolyniuk C. Health, Safety, and Well-Being Reading Recognition Abilities of Young Parents with Functional Disabilities: Construction and Preliminary Validation of a Prescriptive Assessment Instrument. *Journal of Developmental and Physical Disabilities*. 2000;12(4):349-366. doi:1009484114146

31. Coren E, Ramsbotham K, Gschwandtner M. Parent training interventions for parents with intellectual disability. *Cochrane Database of Systematic Reviews*. 2018;(7). doi:10.1002/14651858.CD007987.pub3

32. Wade C, Llewellyn G, Matthews J. Review of Parent Training Interventions for Parents with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*. 2008;21(4):351-366. doi:10.1111/j.1468-3148.2008.00449.x

33. Lightfoot E, DeZelar S. Parent centered planning: A new model for working with parents with intellectual and developmental disabilities. *Children and Youth Services Review*. 2020;114:105047. doi:10.1016/j.childyouth.2020.105047

34. Fixsen DL, Blase KA, Naoom SF, Wallace F. Core implementation components. *Research on Social Work Practice*. 2009;19(5):531-540. doi:10.1177/1049731509335549

35. West A, Duggan AK, Gruss K, Minkovitz CS. Creating a measurement framework for service coordination in maternal and early childhood home visiting: An evidence-informed, expert process. *Children and Youth Services Review*. 2018;89:289-297. doi:10.1016/j.childyouth.2018.04.037

36. Proctor E, Silmere H, Raghavan R, et al. Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health and Mental Health Services Research*. 2011;38(2):65-76. doi:10.1007/s10488-010-0319-7

Part B: Resource Compendium

This Compendium contains resources for anyone in home visiting who is seeking information about how to provide services for caregivers with learning differences. Resources may be useful for national models, local home visiting programs, and individual home visiting staff. The resources come in a variety of formats, from research papers to websites, and cover a range of topics, from best practices on how to talk with someone with learning differences, to policy statements on services that should be offered. The list is limited to resources that we were able to determine are evidence-informed - meaning that they reference or are grounded in research.

❖ What is a learning difference?

For the purposes of this compendium, we use the term "learning difference" to describe any number of challenges that a caregiver may experience as a result of having an intellectual or developmental disability, learning disability, brain injury, or other similar impairment. Knowing the specific challenge is less important than understanding that *a caregiver's learning difference may impact how they are able to use and benefit from* home visiting services.

❖ How is the Resource Compendium organized?

The compendium is organized into three sections. Following this introduction, readers are invited to "skim," "swim," or "dive"[1] into the content depending on their needs.

➢ Section 1: *Skim* is a 1-page "Quick Reference Guide" with the accepted position on parents with intellectual disabilities and 3 easy to remember tips for working with caregivers with learning differences.

➢ Section 2: *Swim* contains:

✓ A tip sheet for adapting communications for caregivers with learning differences

✓ A one-page summary of best approaches for working with caregivers with learning differences

✓ A list of easy-to-read resources focused on communication and support strategies

➢ Section 3: *Dive* is the full curated list of resources.

❖ Suggestions for how to use the Resources

The resources can be used in several ways. Here are some suggestions:

✓ Take time at a staff meeting to introduce a resource

✓ Use the Facts and Fallacies statements in a game, as a fun way to spark interest and learning

✓ Use the ABCs and RESPECT statements to start a conversation with HV staff about how they can use these principles with their families. Ask for examples.

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[1] Clifton-Ross, J., Dale, A., & Hodson, J. (2019, May). Academic Research Curation - Best Practices Guide. Changing the Conversation. https://www.changingtheconversation.ca/research-curation-best-practices
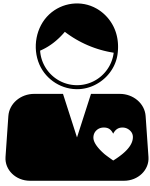
ABC: Quick Reference Guide

Skim

When working with caregivers with learning differences, remember that the presence of an intellectual disability or other learning difference does not mean a person cannot be a great parent. The right to be a parent cannot be denied just because a caregiver has a learning difference. Caregivers with learning differences should have access to the supports that they need to be great parents, just as they receive supports for other needs[1].

ABCs[2] are a brief set of core inclusive best practice points that home visiting programs can apply to their work with caregivers with learning differences. They include:

A – Allow time

Allow for and schedule extra time for all activities, from asking and answering questions, to going over handouts, scheduling appointments and teaching skills.

B – Break into smaller steps

Break all information and instructions down into smaller pieces and steps. Use simple, direct sentences and concrete, specific language[3] in both written and verbal communication.
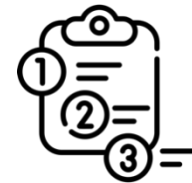
C – Check understanding

Frequently check the caregiver's understanding of information or instructions. Provide frequent opportunities for caregivers to ask questions. Ask the caregiver if they would like more information, or if they would like you to repeat any information. Invite the caregiver to restate the information back to you at each step. Seek opportunities for the caregiver to demonstrate what they have learned. Be prepared to repeat the instructions or information[4].

Any type of learning difference might impact a caregiver's ability to understand, learn, remember, and apply information provided in a home visit. Caregivers with learning differences may need accommodations such as those described above to benefit fully from home visiting services.

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[1] The Arc. (2021). *Parents with Disabilities Position Statement*. The Arc. https://thearc.org/position-statements/parents-with-intellectual-developmental-disabilities/

[2] McConnell, D., & West, A. Personal Communication. 14 July 2021.

[3] Smeltzer, S., Mariani, B., & Meakim, C. (2017) *Communicating with People with Disabilities*. Villanova University College of Nursing. http://www.nln.org/docs/default-source/professional-development-programs/ace-series/gettting-started-communication-with-pwd.pdf?sfvrsn=8

[4] Strike, R., & McConnell. (2002). Look at Me, Listen to Me, I have Something Important to Say. *Sexuality & Disability*, 20(1), 53-63

"What To Do"
Tips for communicating with caregivers with learning differences

Swim

Caregivers with learning differences face extra challenges in getting the information they need. Changing the way you present information — **verbally, visually, and in writing** — can make it easier for everyone to understand. **Making information more accessible is likely to benefit ALL families.**[1]

❖ Know your audience

Think about the caregivers on your caseload and their individual abilities and needs. Are there a couple of small changes or adaptations that you could make in how you communicate that would benefit many caregivers? If possible, involve caregivers in the process by asking them for their advice and ideas.

❖ Relevant information

Provide only the most relevant information. Cut out any confusing or unnecessary detail, and make sure that the essential information is very clear.

❖ Use plain language

Present information in a logical order. Use simple sentences with only one main idea in each sentence. Break up long, compound sentences. Do not use jargon or abbreviations. Use the same words and phrases for each concept consistently. For numbers, use the number (2) not the word (two).

❖ Remember that you are communicating with adults

While many caregivers with learning differences will benefit from using simpler language and pictures, using pictures that are too childish may make caregivers feel badly.

❖ Use images

Using visuals to support plain text is one of the best ways to make writing easier to understand as well as more attractive. Aim to make the subject of your material clear at a glance, even to a non-reader.

❖ Use a variety of formats

Provide information in multiple formats, such as in writing or using audio or video recordings. Take time to find the words, pictures or photos that best support and explain your message. Be prepared to 'do whatever it takes'.

For an example of a plain text resource with images, refer to:
Being Good Parents – A Guide for Parents with Intellectual Disabilities

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[1] Adapted from: MENCAP. (2002). Am I Making Myself Clear? MENCAP's guideline for accessible writing. *MENCAP Understanding Learning Disability.* http://www.accessibleinfo.co.uk/pdfs/Making-Myself-Clear.pdf

RESPECT: "How to Be"
Best practices for working with caregivers with learning differences

Swim

RESPECT[1] is an acronym for the inclusive best practices that describe how to approach working with caregivers with learning differences.

R – Recognition
Recognize that caregivers with learning differences are capable of learning and growth. Acknowledge both personal and parenting strengths while not minimizing challenges and concerns.

E – Engagement
Engage caregivers with learning differences by addressing *their* felt needs and priorities *first*. Many caregivers with learning differences have had negative experiences with service providers in the past. Take time to develop rapport. Explain your role, ask the caregiver about their expectations and needs, and work together to set goals and priorities.

S – "Step-by-step"
Break skills down into small steps. Teach skills step-by-step. *Show,* don't 'tell'. Allow opportunities for practice.
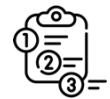
P – Praise
Use praise generously to recognize caregivers' strength and resilience, reinforce their learning, and build the caregiver's confidence in their ability to succeed. Tie the praise statements to specific accomplishments.

E – Environment
Address environmental stressors that hinder learning and challenge parenting.

C – Connectedness
Connect the caregiver with other caregivers (if they are interested), such as through group activities, to reduce isolation and support learning and growth.

T – Time
Allow for extra time. Move at the caregiver's pace.

Any type of learning difference might impact a caregiver's ability to understand, learn, remember, and apply information provided in a home visit. Caregivers with learning differences may need accommodations such as those described above to fully benefit from home visiting services.

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[1] McConnell, D., & West, A. Personal Communication. 14 July 2021.

Quick Start Guide
Easy-to-read resources for working with caregivers with learning differences

Listed below are easy-to-read resources for busy home visiting staff who are interested in learning more about how to improve direct services for families with learning differences. The resources contain information on intellectual disabilities (1,2), best practices and tips for communicating with people with disabilities (3,4), strategies for working with caregivers with intellectual disabilities (5), and ways to support caregivers with learning differences (6,7,8).

❖ **Facts and Fallacies:** List of false beliefs about caregivers and children with intellectual disabilities, and the facts behind them.

❖ **Stigma and Stereotypes Facing Mothers with Disabilities:** Compilation of two Twitter chats with mothers with disabilities, discussing the stigma they have been subject to because of the numerous stereotypes and harmful misconceptions that exist about their ability to raise children.

❖ **Communicating with Parents with Learning Difficulties:** From a father with intellectual disabilities; 7 statements about how to communicate with caregivers with learning difficulties and reminders to check the caregivers' understanding of your conversation.

❖ **Communicating Effectively with People who have a Disability:** Provides guidance in 5 areas: 'people first language', communicating with people with all types of disabilities, '10 Commandments' of good communication; attitudinal barriers towards people with disabilities; and 'Friendly Strategies' for organizational workplaces.

❖ **Advice for Professionals Working with Parents with Intellectual Disabilities:** General summary of research findings about needs of parents with ID and the environment they face; followed by 7 broad 'advice' tips for providers working with parents with ID.

❖ **16 Tips for supporting a parent who has a learning challenge - How to have successful In-Home visits:** Reviews Worker's goals, how to approach communication, tips about how and why people with IDD may respond, and how to assist parents with IDD.

❖ **Promising Practices to Support Parents with Intellectual Disabilities:** Provides a brief review of types of interventions available for parents with intellectual disabilities, including skill development and improved social connections / supports to show that parents with ID are capable and lists 8 broad strategies to consider when working with parents with ID.

❖ **Effective Support Strategies for Parents with Cognitive Difficulties:** Provides a list of challenges faced by parents with cognitive difficulties, a review of effective support strategies and how to approach attempts to provide support, and reviews three service models that providers can use to assist and support parents with cognitive difficulties.

Resources to review with caregivers with learning differences

Swim

This list of resources and websites may be helpful for caregivers with learning differences. Note that we suggest reviewing the resources *with* caregivers, as there are very few resources created specifically for caregivers with learning differences.

Resources

Advice and facts for mothers and expecting mothers with intellectual disabilities

- This is a list of helpful facts about being a parent with an intellectual disability.
- It includes advice for parents about being an advocate and asking for help.
- It was written to help parents with intellectual disabilities feel strong in their abilities.

Being Good Parents – A Guide for Parents with Intellectual Disabilities

- This is a list of facts about parents with intellectual disabilities.
- It describes some common supports that parents with learning differences can use.
- *It was written to help parents who may be scared to get help from services*
- It uses a format that is very easy to read.

Websites

Baby Center

- This website has a lot of helpful information and videos about pregnancy and early childhood.
- It includes pictures of what a baby looks like at each week of pregnancy.

- There is a Spanish version of the website at https://espanol.babycenter.com

- Baby Center also offers an app called *Pregnancy Tracker – BabyCenter*.

TASP: The Association for Successful Parenting – A chance to parent

- TASP helps communities and families support parents with learning difficulties.

- TASP helps parents advocate for themselves and get the supports they need.

- A good resource is called 'Parenting Tips: by Parents, For Parents'. This is a monthly set of 3 tips written by a parent with learning differences.

Best Beginnings

- This is a website from the UK with information about pregnancy, childbirth and childcare.

- The website has a section about parents with learning differences.

  ➢ It provides information about parents with learning differences and pregnancy, childbirth, and childcare.

  ➢ It also lists other organizations and resources.

  ➢ The website also describes how the *Baby Buddy* app can help parents with learning difference.

Full Resource Compendium

Dive

This is a collection of resources gathered for the Home Visiting Services for Parents with Learning Differences Project. Our goal was to include resources that are current, relevant, and useful for early home visiting programs in the US. We curated the list of research-related resources to include only those that are evidence-informed, meaning that they reference or are grounded in research.

The list is organized in sections that align with the three essential levels of support to consider when working with caregivers with learning differences. These levels include:

➢ Supports offered by federal, tribal, state, home visiting service model, and community-based agencies and organizations.
➢ Supports offered by the local implementing home visiting agency or organization.
➢ Supports offered by home visiting staff directly to families they serve.

You can learn more about each level of support by reviewing the Conceptual Model in an earlier section of this Toolkit.

➢ When reading through the Resources, note that in England and the United Kingdom the term 'learning disability' has the same meaning as the US term 'intellectual disability'.

Each resource in the list has an icon shows what kind of resource it is, as shown below:

App	⊡
Government report	▤
Podcast	🎧
Practice brief or White paper	🗒
Research paper or Article	⚲
Training manual	✎
Video or Webinar	▦
Website	💻

Level of Support: Federal, Tribal, State and Community

Name of Resource	Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities	
Author / Year / Country	Baum. S., Gray, G. & Stevens, S. / 2011 / UK	
Description	This document provides guidance and direction specifically for clinical psychologists when assessing parent with learning disabilities (intellectual disabilities). However, Section 1 is a very good review of literature (to 2010) on parents and parenting with learning disabilities: experiences of parents with learning disabilities and factors that influence parenting abilities, effects on children of having parents with learning disabilities, parent training and interventions, services for families, rewards of parenthood, and removal of children. All sections end with "Key Point's" which are concise summaries. In addition, Figure 1, pg22, is McGaw's Parenting Skills Model (PSM), which describes the predictors of parenting skill and how these interact. Finally, authors summarize factors that may affect parenting outside of the parent's learning disabilities (pg32-34), including childhood experience (of the parent), physical and psychological factors, co-parenting partner, number and characteristics of child(ren), informal support network (extended family, peers), formal support network, ability of parent(s) to work with professionals, and previous experience of children being removed.	
LINK		

Name of Resource	Navigating the System: Addressing the Overrepresentation of Parents with Disabilities in CPS	
Author / Year / Country	Center for Advanced Studies on Child Welfare (CASCW) / 2021 / US	
Description	A learning module created for child welfare professionals. The first part covers background, parent experiences, statistics and current research on the overrepresentation of parents with different types of disabilities at various points in the child welfare system. However, in the "Voices from the Field" sections (min 22:52) practitioners and researchers talk directly about ways to best serve parents with disabilities, touching on addressing biases, training gaps, engagement strategies, etc. Sections topics include addressing bias and discrimination, screening and identification of disability, policy and systemic barriers, successful service provision, and workforce training.	
LINK		

Name of Resource	Practice Notes: Parent-Centered Planning for Parents with Disabilities	
Author / Year / Country	Center for Advanced Studies in Child Welfare / 2020 / US	

Description	This brief discusses the parent-centered planning model to help parents with disabilities plan for parenting. The brief is written for Child Welfare, but the model is applicable to all services that assist parents and parents with disabilities. The parent-centered planning model makes the parent the 'expert' by allowing them to take a lead role in planning and puts the parents' desires and goals as the focus of planning and decision-making, shifting focus away from parents' weaknesses and needs. Parents supporters (family members, friends, neighbors, clergy, coworkers, and others) are invited to participate.
	LINK

Name of Resource	Disability and Child Welfare Episode 1: Parent-Centered Planning for Parents with Disabilities
Author / Year / Country	Center for Advanced Studies in Child Welfare (CASCW) - CASCW Core Series Podcasts / 2021 / US
Description	In this episode Dr. Liz Lightfoot, interviews Dr. Sharyn DeZelar about the parent-centered planning model and its benefit to parents with disabilities involved in child welfare.
	LINK

Name of Resource	Practice Notes: Promising Practices to Support Parents with Intellectual Disabilities
Author / Year / Country	Center for Advanced Studies in Child Welfare / 2019 / US
Description	This brief discusses two interventions to help support parents with intellectual disabilities that have shown positive outcomes, 1) interventions aimed at parenting skill development and 2) interventions aimed at increasing parental social connections and supports. The brief is written for Child Welfare, but the information and practical considerations are applicable to all services that assist parents and parents with disabilities. Overall, interventions aimed at parenting skill development show that parents with intellectual disabilities can acquire skills to improve their parenting ability. Interventions aimed at increasing parental social connections and supports are less studied, but there are promising practices. The practice brief provides 8 strategies for supporting parents with intellectual disabilities.
	LINK

Name of Resource	CW360 - a comprehensive look at a prevalent child welfare issue: The Intersection of Child Welfare and Disability: Focus on Parents
Author / Year / Country	Center for Advanced Studies on Child Welfare (CASCW) / 2013 / US

Description	The entire journal issue focuses on the experiences of parents with disabilities and mental illness (MI) in the child welfare system. While many of the articles are informative, we recommend the following as relevant to serving parents with learning differences in home visiting: a- "Needs of Parents with Intellectual Disabilities: An Ecological Perspective", Bernard and O'Hara (pg10); b- "Understanding and Supporting Parents with Cognitive Limitations", Aunos & Pacheco (pg12); c- "Change Attitudes, Change Practice", Spencer (pg13); d- "Working with Parents Who Have Cognitive Limitations: The Parent Support Project", Fier (pg17); e- "Adapting Assessment, Diagnosis, and Communication for Individuals with Dual Diagnosis", Sweetland (pg18); and f- "Interventions for Parents with Disabilities", Feldman (pg20).
	LINK

Name of Resource	Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review
Author / Year / Country	Chinn, D. & Homeyard, C. / 2016 / UK
Description	Literature review of 42 papers which described the design and evaluation of written information adapted for adults with intellectual disabilities. Authors reviewed and synthesized evidence from their resulting groupings of these studies. Authors note that they were unable to 'find clear evidence that introducing accessible materials impacts outcomes'. Authors note that adapted health information that was more impactful was tailored to individuals, rather than for general public information.
	LINK

Name of Resource	What Works for Parents with Learning Disabilities? – Summary
Author / Year / Country	McGaw, S. / 2000 / UK
Description	This summary of findings reviews what is known to work for parents with learning disabilities (intellectual disabilities). Six parts include: a general discussion of learning disability (ID) and parenting, why parents with learning disabilities are of concern to health and social care services, ways of assessing families, ways of intervening, what is known about effectiveness, and current service issues. Even though the work is UK-based, this summary is helpful for its review of interventions and services that work, implications for practice, effective interventions, and implications for current practice.
	LINK

Name of Resource	Findings - Supporting disabled adults in their parenting role
Author / Year / Country	Morris, J / 2003 / UK
Description	This is the summary of findings from *The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role* (Morris, 2003). The task force

collected evidence from parents, professionals and researchers on the common barriers experienced by parents with disabilities. In general, disabled parents indicated that the difficulties they face come mostly from negative attitudes and unequal access to support and are not primarily due to their disabilities or mental health needs. The findings review multiple areas including the following: access to information, disabling attitudes, lack of focus on support needs, more focus on parental 'incapacity', lack of coordination between child and disabled parent support services, role of poverty, inaccessible health care environments and lack of up-to-date health care information, inaccessible physical environments and lack of appropriate information at children's schools, and lack of research into what works for parents with disabilities and lack of parents with disabilities involvement in research. The work was done in the UK so some information directly relevant only to UK programs, but many findings apply to environment for parents with disabilities in the US.

LINK

Name of Resource	Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children
Author / Year / Country	National Council on Disability / 2012 / US
Description	This is the 2012 report from the National Council on Disabilities. The report provides "a comprehensive overview of the current state of knowledge, attitudes, and practices toward parents with disabilities and their children … and a comprehensive review of the barriers and facilitators people with diverse disabilities—including intellectual and developmental, psychiatric, sensory, and physical disabilities—experience when exercising their fundamental right to create and maintain families, as well as persistent, systemic, and pervasive discrimination against parents with disabilities". Chapter 12 (see entry below) reviews the Impact of Disability on Parenting and Chapter 13 discusses Supporting Parents with Disabilities and Their Families in the Community (see entry below). The report concludes with a list of 20 Findings and Recommendations, specifically see 13, 14 and 17.
LINK	

Name of Resource	Chapter 12: The Impact of Disability on Parenting and Chapter 13: Supporting Parents with Disabilities and Their Families in the Community
Author / Year / Country	National Council on Disability / 2012 / US
Description	Chapter 12 of the National Council on Disability report. It is a review of current thinking, knowledge and research on parenting with disabilities. Sections cover intellectual and developmental disabilities, as well as psychiatric illnesses and physical and sensory disabilities. The authors conclude with the following statement: 'Current research, limited though it is, demonstrates that disability does not necessarily have a negative effect on parenting. Certainly, much more research in this area is needed; specifically, research that does not pathologize parental disability in a negative way. Moreover, research should focus on the effect of supports for parents with disabilities.' Chapter 13 explores supports should be available for parents with disabilities, noting that not all are universally available. It also includes a section on Early Intervention and Prevention (pg. 214) which references the role Early Head Start potentially could play in supporting parents with disabilities.

LINK

Name of Resource	Executive Summary: Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children	
Author / Year / Country	Tarleton, B., Ward, L., & Howarth. J. / 2006 / UK	
Description	This executive summary pulls out key findings from the larger study, *Finding the Right Support?*. The larger study mapped out the issues confronting parents and professionals around supporting parents with ID, and their children, and strategies for positive practice in providing supports to parents with ID. The key findings cover: the wide range of agencies and providers that engage with parents with learning difficulties (ID), the range of barriers to providing appropriate supports (negative attitudes, the need for easy to understand information, and the idea that effective support involves a wide range of strategies and supports that are flexible and coordinated); the need for professionals working with parents with LD to have training in child protection issues; the knowledge that service agencies often have eligibility criteria that exclude parents with LD or do not allow for additional supports; and the idea that action needs to be taken at multiple levels. The executive summary ends with multiple recommendations in each of 4 areas.	
LINK		

Name of Resource	Using Medicaid to Support Parents with Disabilities	
Author / Year / Country	Powell, R. / 2020 / US	
Description	This brief proposes expanding existing Medicaid-funded services and supports, available to adults with disabilities, to include assistance to parents with disabilities for childrearing tasks. For example, adults with disabilities are eligible personal care attendant services, but because parenting is not considered an activity of daily living this service is generally not offered to parents with disabilities for childrearing tasks. The background information summarizes some of current issues, discusses costs and surveyed need for help with childrearing tasks and adaptive equipment for parents, and policy variability across states. The brief concludes with 5 policy solutions and recommendations for Centers for Medicare and Medicaid Services and states.	
LINK		

Name of Resource	The ARC Position Statement	
Author / Year / Country	The ARC / 2019 / US	

Description	Joint position statement from The Arc and the American Association on Intellectual and Developmental Disabilities (AAIDD) on the ability of people with intellectual and developmental (IDD) disabilities to parent, their rights as parents, and their rights to access to supports for parenting. The position statement describes the issue and then the position of the two organizations.
	LINK

Name of Resource	Lurie Institute	
Author / Year / Country	2021 / US	
Description	The Lurie Institute for Disability Policy conducts multidisciplinary research on the needs, experiences, and policy priorities of people with disabilities. Their work covers a wide range of topics, including the experiences of parents with disabilities; policies addressing long-term services and supports for people with disabilities; and health and healthcare outcomes. The National Research Center for Parents with Disabilities, which focuses on parents with disabilities, is part of the Lurie Center.	
	LINK	

Name of Resource	The Arc	
Author / Year / Country	2021 / US	
Description	The Arc is the "largest national community-based organization advocating for and with people with intellectual and developmental disabilities (I/DD), and serving them and their families. We work tirelessly to uphold our vision that every individual and family living with I/DD in the United States has access to the information, advocacy, and skills they need to support their full inclusion and participation in the community throughout their lifetimes … the Arc's chapter network is on the frontlines … to ensure that people with I/DD have the support and services they need to be fully engaged in their communities. Our chapters provide a wide variety of services, supports, and advocacy for people with I/DD and their families. This varies by chapter and includes but is not limited to individual and public policy advocacy; residential, educational, and vocational services; person-centered and financial planning; recreational activities; and other supports that meet the unique needs of the community".	
	LINK	

Name of Resource	Through the Looking Glass	
Author / Year / Country	2021 / US	

Description	Nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability or medical issue. Promotes national and local services available. Under Publications has list of 10+ free resources for parents and parenting with disabilities, including intellectual disabilities. Website copyright updated in 2021. Information on website not current.
LINK	

Name of Resource	Inclusive Research Network (IRN)
Author / Year / Country	2021 / Ireland
Description	Resources, policy briefs etc., through the IRN are helpful. IRN is part of the National Federation of Voluntary Service Providers Supporting People with Intellectual Disability. Most of NFVSP is specific to Ireland.
LINK	

Name of Resource	International Association for the Scientific Study of Intellectual and Developmental Disabilities
Author / Year / Country	2018 / International
Description	IASSIDD promotes the scientific study of intellectual disabilities and related developmental disabilities and of conditions of persons with these disabilities and their families; is the first and only world-wide group dedicated to the scientific study of intellectual disability; promotes worldwide research and exchange of information on intellectual disabilities; it's definition of ID widely accepted and used; website has position papers, policy statements, webinars, publications and other resources. Also see the IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities
LINK	

Name of Resource	University of Alberta
Author / Year / Country	2021 / CA
Description	The Family and Disability Studies Initiative (FDSI) is a multi-disciplinary collaboration of community organizations, researchers and practitioners that work in partnership with parents and families affected by lifelong disability. The purpose of the FDSI is to promote the participation, health, and well-being of people with disabilities and their families across all areas of life. Research and work have a specific focus on parents with intellectual disabilities.
LINK	

Name of Resource	DO-IT (Disabilities, Opportunities, Internetworking and Technology)
Author / Year / Country	2021 / US
Description	DO-IT is the University of Washington's site/office promoting awareness and accessibility in classroom and workspace to empower people with all types of disabilities. It actively promotes universal design principles, with a Center for Universal Design in Education. Lots of resources
LINK	

Name of Resource	The Center for Universal Design - Environments and Products for All People
Author / Year / Country	2008 / US
Description	One of the original developers of universal design, the NC State University, College of Design, Center for Universal Design is no longer active due to funding issues. However, the website still lists good resources, with live links. A good resource for universal design.
LINK	

Name of Resource	CAST (Center for Applied Special Technology)
Author / Year / Country	2021 / US
Description	CAST created the Universal Design for Learning (UDL) framework, from universal design principles. The UDL guidelines offer a set of concrete suggestions that can be applied to any discipline or domain to ensure that all learners can access and participate in meaningful, challenging learning opportunities. CAST is a nonprofit research and development organization that works to expand learning opportunities for all individuals through Universal Design for Learning. Founded in 1984, CAST has earned international recognition for its innovative contributions to educational products, classroom practices, and policies.
LINK	

Name of Resource	Disabled Parenting Project
Author / Year / Country	2021 / US

Description	For parents with all disabilities, including learning differences, but more about physical disabilities. Information and focus of the site on technology as a way to create opportunities for parents with disabilities. Is an online community with blog, library of resources, and marketplace around assistive technology. DPP also seeks to inform social policy and to promote social justice for disabled families. It is part of the National Research Center for Parents with Disabilities.
	LINK

Name of Resource	National Research Center for Parents with Disabilities (NRCPD)	🖥️
Author / Year / Country	2021 / US	
Description	The National Research Center for Parents with Disabilities conducts research and provides training and technical assistance to improve the lives of parents with disabilities and their families. The Center for Parents recognizes that parents with disabilities know what they need and is guided by the principle "nothing about us without us". NRCPD website has resource page with 'Parenting Tips and Strategies from Parents with Disabilities', under Information and Resources. The website also offers information sheets, research briefs, and other resources for parents with disabilities, legal professionals, social workers, and researchers. Applicable docs from the website regarding parents with intellectual disabilities are listed in the Swim and Dive resources sections.	
	LINK	

Name of Resource	Center for Advanced Studies in Child Welfare	🖥️
Author / Year / Country	2021 / US	
Description	CASCW provides a lot of resources around parents and parenting with disabilities; focused on intersection with child welfare, but many of the resources apply to other areas. Also produce 'Practice Points' and podcasts and videos and trainings with information. CASCW's Outreach activities connect child welfare stakeholders in Minnesota to dynamic, relevant, accessible, research-informed practice and policy resources and trainings. We produce a variety of training events and publications that bridge the worlds of research, policy, and practice, bringing the latest information to students, administrators, policymakers, and practitioners working directly with children and families.	
	LINK	

Name of Resource	TASP - The Association for Successful Parenting	🖥️
Author / Year / Country	2021 / US	

Description	TASP is 'committed to successfully supporting families when parents have learning difficulties'. Their work is centered around education, advocacy, direct support and resource sharing, for professionals and parents with learning differences, to build capacity of communities and families to support parents with learning difficulties. Education includes trainings for professionals, webinars, conferences and resources. Resources include 'Parenting Tips: by Parents, For Parents', monthly set of 3 tips written by a parent with learning differences.
	LINK

Level of Support: Service Model and Local Implementing Agency

Name of Resource	Equal Access: Universal Design of Instruction	📄
Author / Year / Country	Burgstahler, S. / 2020 / US	
Description	A 'checklist' of examples of Universal for Design of Instruction practices, and how to apply practices to each area of teaching. Specifically for classroom teaching, but many items in checklist apply to any kind of instruction. Also includes Communication tips. A good resource for understanding how to apply UDI principles.	
	LINK	

Name of Resource	Universal Design of Instruction (UDI): Definition, Principles, Guidelines, and Examples	📄
Author / Year / Country	Burgstahler, S. / 2020 / US	
Description	This brief review summarizes Universal Design of Instruction. It provides definitions of Universal Design, Universal Design for Instruction and Universal Design for Learning. It discusses the 7 principles and guidelines of UDI and gives examples of how to apply the principles to activities and resources. A good introduction to understanding universal design. From the Washington State DO-IT.	
	LINK	

Name of Resource	Parenting Capacity Assessments: Some Guiding Principles	📄
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	

Description	Ten guiding principles to think about before starting parenting capacity assessments with parents with intellectual disabilities; is a good review of how to approach working with parents with ID in general.
	LINK

Name of Resource	Step-by-Step Parenting Program	
Author / Year / Country	Feldman, M.A. / 2021 / CA	
Description	Step by Step Parenting Program is an evidence-based program that focuses on teaching skills to parents with learning differences (all types); it may also benefit 'inexperienced parents and caregivers, child-care workers, and babysitters'. The program can be implemented by range of professionals and workers. Some aspects of program are self-directed by the parent who can use the materials themselves and on their own. Website has links to Manuals (Step-by-Step Parenting program, The Family Game and Parenting Assessment) and Workshops to train professionals and workers. Step-by-Step has been reviewed by California Evidence-based Clearinghouse (CEBC). Manuals available with trainings enrollment.	
	LINK	

Name of Resource	Best Practice in Family Support	
Author / Year / Country	Healthy Start - Parenting Research Centre / 2018 / AU	
Description	Key facts', 'practice tips' and 'what we know' about how to think about and interact with parents with LD to best support them. From the Healthy Start initiative of the Parenting Research Centre which provide resources for those who work with parents with learning difficulties (intellectual disabilities).	
	LINK	

Name of Resource	What is intellectual disability anyway?	
Author / Year / Country	Healthy Start - Parenting Research Centre / 2018 / AU	
Description	This brief provides explanations of intellectual disability, negative societal assumptions (including social construction of disability) as relates to parenting ability, need for parenting assessment separate from IQ, and advise for support workers. From the Healthy Start initiative of the Parenting Research Centre which provide resources for those who work with parents with learning difficulties (intellectual disabilities).	
	LINK	

Name of Resource	New Ways of Thinking About Parents with Intellectual Disabilities	
Author / Year / Country	Irwin, B. / 2010 / US	
Description	This article is a helpful review of four task force reports around the paradigm shift in attitudes and policies towards parenting by people with intellectual disabilities, to their having a 'right to parent'. It also provides the recommendations from the task force reports.	
LINK		

Name of Resource	Social Work with Parents with Disabilities: Historical Interactions and Contemporary Innovations	
Author / Year / Country	Lightfoot, E. & DeZelar, S. / 2019 / US	
Description	This article provides an overview of the complicated history of social work practice with parents with disabilities, and then presents contemporary social work practice innovations, current concept of parental supports, and concept of parent-centered planning as an innovative intervention to provide supports for parents with disabilities.	
LINK		

Name of Resource	Parental Supports for Parents with Intellectual and Developmental Disabilities	
Author / Year / Country	Lightfoot, E. & LaLiberte, T. / 2011 / US	
Description	In this article the authors discuss the rise of the concept of parental supports for parents within child welfare legislation, define parental supports for parents with disabilities, and discuss the need for a normalization of the concept of parental supports in the field of intellectual and developmental disabilities.	
LINK		

Name of Resource	Enhancing the social connectedness of mothers with intellectual impairment	
Author / Year / Country	McConnell et al / 2014 / CA	

Description	This paper reports on the pilot trial of the Supported Learning Program (SLP) in Alberta, CA. The SLP is a group-based intervention designed to strengthen social connections and psychological well-being of mothers with intellectual impairment, with resulting benefits to their children. Overall, the SLP facilitators of the pilot program found it to be very worthwhile. Mothers who completed the program reported a high level of goal-achievement - including making new friends, strategies for handling difficult social situations and feeling more confident about participating in groups. They also reported feeling less alone and more understood and accepted.
	LINK

Name of Resource	Strategies for Successfully Including People with Disabilities	
Author / Year / Country	National Association of County & City Health Officials / 2014 / US	
Description	The report provides guidance on specific strategies and tools to help health departments include people with disabilities in health programming and planning. Page 3 has table of strategies by disability type, including Cognitive disabilities, and provides helpful descriptions of what disability might look like and how to adapt program materials.	
LINK		

Name of Resource	Practice Notes - Child Welfare Practice with Parents who have Cognitive Limitations	
Author / Year / Country	North Carolina Division of Social Services and Family & Children's Resources Program / 2004 / US	
Description	Practice Notes provide information for child welfare workers who work with parents with cognitive limitations. It has a good discussion of family-centered practice with parents with cognitive limitations, and role of worker and attitude and biases, and what parents want from services. It also provides basic information about people with cognitive limitations and presents a tool for identifying parents with cognitive limitations.	
LINK		

Name of Resource	The Principles of Universal Design	
Author / Year / Country	North Carolina State University, The Center for Universal Design / 2008 / US	
Description	This is the original statement of the Principles of Universal Design as developed and described by the founders of Universal Design at NC State.	
LINK		

Name of Resource	Communicating Effectively with People who have a Disability
Author / Year / Country	North Dakota Center for Persons with Disabilities / 2016 / US
Description	Provides guidance in 5 areas of communication: Using 'people first language'; general Respect and Courtesy tips for communicating with people with all types of disabilities; '10 Commandments' of good communication; Attitudinal barriers towards people with disabilities; and 'Friendly Strategies' for organizational workplaces. NDCPD states that while "a lot of progress has been made … actual communication and interaction with people with disabilities still needs attention. Many people are afraid of accidentally saying something that will offend a person with a disability, so they say nothing and avoid contact. In this publication you will find suggestions that will help educate people about communicating with people with disabilities".
LINK	

Name of Resource	The Parenting Young Children training program - part of PRC
Author / Year / Country	Parenting Research Centre / 2021 / AU
Description	Parenting Young Children is an evidence-based, comprehensive home-based parent training and support program that trains providers to help parents with learning difficulties develop positive interactions with their child and improve child-care skills. The PYC training is for professionals working in disability, health, child protection, welfare or family support who have the capacity to work individually with parents in their homes. Developed in 2003, it has been evaluated and widely disseminated across Australia as a part of the Australian national strategy 'Healthy Start'. Reviewed by CEBC in 2014. From the Healthy Start initiative of the Parenting Research Centre which provide resources for those who work with parents with learning difficulties (intellectual disabilities).
LINK	

Name of Resource	Healthy & Safe training program
Author / Year / Country	Parenting Research Centre / 2021 / AU
Description	Healthy & Safe is an evidence-based parent education program that trains providers to help parents with learning difficulties manage home dangers, accidents and childhood illness. The Healthy & Safe training is for professionals working in disability, health, child protection, welfare or family support who have the capacity to work individually with parents in their homes. Training includes 19 modules using evidence-based strategies. From the Healthy Start initiative of the Parenting Research Centre which provide resources for those who work with parents with learning difficulties (intellectual disabilities).
LINK	

Name of Resource	Supported Parenting - Refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability
Author / Year / Country	Scottish Consortium for Learning Disability / 2015 /UK
Description	The guidelines were developed to help services improve their support for parents with learning disabilities (intellectual disabilities) and their children. This is a government report, but very readable and applicable to other countries and systems. It uses the 'Supported Parenting' approach - recognizing the human rights of parents and children within a family that needs supports, that parents have abilities as well as needs and that support should be tailored to parent capacity as well as deficits. Introduction and Executive Summary are a good background and summary of current situation of parents with learning disabilities (intellectual disabilities). Section 1 - Key Features of Good Practice - has good information on accessible information and communication, coordination, support based on parents needs and strengths, long-term support, and access to advocacy. Appendix A is also a good explanation.
LINK	

Name of Resource	Communicating with People with Disabilities
Author / Year / Country	Smeltzer, S., Mariani, B., & Meakim, C. / 2017 / US
Description	Recommendations for health care providers, but applicable for all service providers on how to communicate effectively and appropriately with people with all types of disabilities. Has a section on general communication issues and strategies followed by issues and strategies specific to individuals with a variety of disabilities, including intellectual disabilities.
LINK	

Name of Resource	Effective Support Strategies for Parents with Cognitive Difficulties - A companion to the TASP webinar by Cathy Haarstad
Author / Year / Country	The Association for Successful Parenting / 2020 / US
Description	This brief provides a list of the challenges faced by parents with cognitive difficulties, then provides a review of effective support strategies and how to approach attempts to provide support, and then reviews three service models that providers can use to assist and support parents with cognitive difficulties.
LINK	

Name of Resource	Parenting Support Program
Author / Year / Country	2021 / US

Description	Home visiting program specifically for parents with intellectual disabilities. At Georgetown University in Washington, DC.
	LINK

Name of Resource	Health Care for Adults with Intellectual and Developmental Disabilities	
Author / Year / Country	2021 / CA	
Description	Toolkit for Primary Care Providers is a resource for PCPs providing care to Adults with IDD. Has a good list of resources on communication, consent, and 'Adaptive Functioning' which details how a person with IDD might come across and what skills a person might need help with.	
	LINK	

Name of Resource	Intellectual Disability and Health - University of Hertfordshire	
Author / Year / Country	2021 / UK	
Description	Center on Understanding Intellectual Disability and Health; educational resource for health and healthcare and social work practitioners; articles with evidence covering multiple aspects of ID and health; under Family is section on Parents with ID.	
	LINK	

Name of Resource	MENCAP	
Author / Year / Country	2021 / UK	
Description	MENCAP works to improve the lives of people with learning disabilities (intellectual disabilities in the US), their families and the professionals who work with them. Site has may resources, communication resources and guidelines for writing accessible materials , resources for people with ID around social issues, advice and support section.	
	LINK	

Name of Resource	Norah Fry Centre for Disability Studies	
Author / Year / Country	2021 / UK	

Description	Located within the University of Bristol, the Centre has resources and research on Parents with learning disabilities (intellectual disabilities in the US). It is also home to the Plain Facts briefs, and the Good Practice Guidance which describes how child and adult services 'can and should work together to improve services for a parent with a learning disability' - although in UK has good basic practices and policies.
	LINK

Name of Resource	Tools for Talking	
Author / Year / Country	UK	
Description	Resources to facilitate culturally sensitive, person-centered communication and understanding, service planning and delivery; specifically 5 short videos and 5 activities, developed for use in social support settings, to facilitate communication between people with ID/LD from minority communities and service providers; videos and activities result from ASC-LD study (Unwin ... Kroese et al 2016) which interviewed people with LD and from which 5 topics emerged as important: Culture, Good support, Independence, Relational networks and Activities.	
	LINK	

Name of Resource	Working Together with Parents Network - University of Bristol	
Author / Year / Country	2021 / UK	
Description	The WTPN supports professionals working with parents with learning difficulties and learning disabilities (intellectual disability) and their children. Promoting the welfare of children is paramount to all organizations and individuals within the network. Membership is free and accepted from outside the UK. Resources cover a range of topics from general information to positive practice to how to make information accessible. Also includes information for parents with ID, in varying formats (video and print), and the Plain Facts resources.	
	LINK	

Name of Resource	Connections for Families Society / Website	
Author / Year / Country	2021 / CA	
Description	Organization to support parents with cognitive challenges, provide parenting skills education and family support. In 'Learn More' menu have section for 'how to help parents with developmental disabilities', includes suggestions and downloadable resources. Resources for professionals and parents, some written by parents with ID.	
	LINK	

Name of Resource	Parenting Research Centre	
Author / Year / Country	2021 / AU	
Description	PRC is a national organization dedicated to helping children and families thrive by driving improved ways of supporting parenting. Healthy Start Healthy Start is program that specifically aims to improve health and well-being outcomes for children whose parents have learning difficulties. Located within the Parenting Research Center. Entire program designed to support professionals working with parents with LD. Many resources and trainings.	
LINK		

Level of Support: Direct Service

Name of Resource	16 Tips for supporting a parent who has a learning challenge How to have successful In-Home visits	
Author / Year / Country	Connections Counseling / 2021 / CA	
Description	This brief is a summary of best ways to support parents with IDD in home visits; reviews service workers' goals, how to approach communication, tips about how and why people with IDD may respond, and how to assist parents with IDD.	
LINK		

Name of Resource	7 Things You Should Know About Universal Design for Learning	
Author / Year / Country	Educause Learning Initiative (ELI) / 2015 / US	
Description	This brief reviews seven important things to know about universal design for learning. Mainly, that it is a framework for the design of materials and instructional methods, which supports many paths to learning, with equal access and accommodations for all learners. Useful in that it provides helpful to think about UD and UDL.	
LINK		

Name of Resource	Facts and Fallacies	
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	

Description	List of fallacies about parents with intellectual disabilities and the facts that dispute the fallacies.
	[LINK]

Name of Resource	Communicating with Parents with Learning Difficulties	
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	
Description	First-person statements from a father with intellectual disability about how to work with and approach parents with intellectual disabilities. Second page has tips for checking the understanding of parents with intellectual disabilities, to make sure they are understanding the information being provided.	
	[LINK]	

Name of Resource	Parenting Capacity Assessments: Some Guiding Principles	
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	
Description	Ten principles about how to approach parents with intellectual disabilities, how to view parenting capacity, importance of strengths and shortcomings, and how services provided should be realistic and feasible and appropriate.	
	[LINK]	

Name of Resource	Toolkit for Primary Care Providers	
Author / Year / Country	Health Care for Adults with Intellectual and Developmental Disabilities / 2021 / CA	
Description	This is a website with resources developed for primary care providers working with adults with intellectual and developmental disabilities. There are a lot of very good resources, covering a range of topics, including Communicating Effectively, and Adaptive Functioning and Different Levels of ID, and a Resources section and a Webinars section.	
	[LINK]	

Name of Resource	Your guide to Communicating with people with a learning disability / Training manual	
Author / Year / Country	MENCAP / 2021 / UK	
Description	Guide to communicating with people with learning disabilities (intellectual disabilities), describes problems faced by people with learning disabilities, and provides tips to help provider and person with disability communicate better.	
	[LINK]	

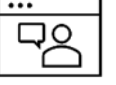|		
Name of Resource	Advice for Professionals Working with Parents with Intellectual Disabilities	
Author / Year / Country	National Research Center for Parents with Disabilities / 2021 / US	
Description	General summary of research findings about needs of parents with ID and the environment they face; followed by 7 broad 'advice' tips / strategies for providers working with parents with ID. NRCPD website has resource page with 'Advice for Professionals from Parents with Disabilities', under Information and Resources.	
	LINK	

Name of Resource	Advice and Facts for Mothers and Expecting Mothers with Intellectual Disabilities	
Author / Year / Country	National Research Center for Parents with Disabilities / 2021 / US	
Description	Information, facts, advice and suggestions for mothers and expecting mothers with intellectual disabilities. NRCPD website has resource page with 'Parenting Tips and Strategies from Parents with Disabilities', under Information and Resources.	
	LINK	

Name of Resource	Being Good Parents: A guide for parents with intellectual disabilities	
Author / Year / Country	National Research Center for Parents with Disabilities / 2022 / US	
Description	Being Good Parents is a guide *for* parents with intellectual disabilities, based on the "Plain Facts" brochures by the University of Bristol in the United Kingdom. It includes a list of facts about being a parent with an intellectual disability, and advice for parents about being your own advocate. It was written to help parents with intellectual disabilities who are often scared to get help from services. NRCPD website has resource page with 'Parenting Tips and Strategies from Parents with Disabilities', under Information and Resources.	
	LINK	

Name of Resource	Stigma and Stereotypes Facing Mothers with Disabilities	
Author / Year / Country	National Research Center for Parents with Disabilities / 2023 / US	
Description	The Disabled Parenting Project (DPP) hosted two Mother's Day Twitter Chats with mothers with disabilities. This brief is a compilation of the two Twitter chats. Mothers with disabilities discuss the stigma they have been subject to because of the numerous stereotypes and harmful misconceptions that exist about their ability to raise children.	

[LINK]	

Name of Resource	Recommendations for Communicating with Adults with Intellectual, Cognitive or Developmental Disabilities	
Author / Year / Country	National League for Nursing / 2021 / US	
Description	A short list of recommendations for communicating with adults with intellectual or developmental disabilities.	
[LINK]		

Name of Resource	I Can Parent Too! Engaging Virtually with Families who Learn Differently	
Author / Year / Country	Rapid Response - Virtual Home Visiting / 2020 / US	
Description	This webinar briefly reviews the importance of home visitor staff attitudes towards working with parents with cognitive delays, disabilities or who learn differently, and the barriers home visitors face when working with parents with learning issues. It also explores how to support a family virtually, and discusses training, resources and supports for home visitors. This webinar is a summary of the original 'I Can Parent, Too!' webinar, and slides from the original presentation are also available.	
[LINK]		

Name of Resource	Parents with intellectual disability Just the same, only different	
Author / Year / Country	Strike, J. & McConnell, D. / 2002 / AU	
Description	This article is co-written by Julie Strike, a mother with an intellectual disability and a self-advocate. It describes how *all* parents need supports, and that parents with ID simply want and need the same supports as other parents.	
[LINK]		

Name of Resource	Communicating with Parents with Learning Difficulties	
Author / Year / Country	Strike, R. & McConnell, D. / 2002 / CA	
Description	From a father with intellectual disabilities; 7 statements about how to communicate with caregivers with learning difficulties and reminders to check the caregivers' understanding of your conversation.	
[LINK]		

Name of Resource	Building Support Networks to Reduce the Risk of Isolation for Parents who have Intellectual and Developmental Disabilities - A companion to the TASP webinar by Tom Robinson	
Author / Year / Country	The Association for Successful Parenting / 2021 / US	
Description	This brief provides a review of factors that contribute to support networks, how those factors are impacted differently and sometimes negatively for people with intellectual and developmental disabilities, and how to assist people with IDD to grow their support networks.	
LINK		

Name of Resource	Beyond Words	
Author / Year / Country	2021 / UK	
Description	'Books Beyond Words' are award-winning wordless picture stories covering topics including physical and mental health, lifestyle and relationships, abuse and trauma, grief and bereavement, employment, and criminal justice. Each story is co-created with and for people who find pictures easier to understand than words. This includes people with learning disabilities and/or autism, people with cognitive or communication difficulties, people who have difficulty with reading, and people who do not use the language of the country where they are living. The stories have been used in multiple and varied settings. Beyond Words also publishes picture books in print and as e-books, in English and other languages, and offers DVDs and training workshops on how to use picture stories to improve communication. A PowerPoint presentation on how to use Books Beyond Words in clinical settings is available at: www. booksbeyondwords.co.uk/node/149	
LINK		

Name of Resource	CHANGE	
Author / Year / Country	2019 / UK	
Description	Human rights organization led by Disabled People, working to build an inclusive society where people with learning disabilities are treated equally'; 'Home of the Easy Read and Easy Write books and documents and Easy Read Doc Creator, other resources, and trainings for people with disabilities, including ID/LD.	
LINK		

Name of Resource	Rapid Response Virtual Home Visiting	
Author / Year / Country	2021 / US	

Description	Part of the Institute for the Advancement of Family Support Professionals , The Rapid Response-Virtual Home Visiting collaborative provides 'best practice principles and strategies to support all home visiting professionals in maintaining meaningful connection with families during this time of increased anxiety and need'. The collaborative seeks to provide immediate support to front-line HV staff and families. It is developing and distributing resources and webinars by leveraging the expertise and resources of existing home visiting organizations. The Institute for the Advancement of Family Support Professionals also provides learning modules for home visiting.
LINK	

Name of Resource	BabyCenter
Author / Year / Country	2021 / US
Description	Information for all parents, not specifically geared to parents with disabilities or learning differences. Spanish version of website available. Has helpful, practical information of wide range of topics from getting pregnant through baby's development to childhood. Site used good visuals and helpful icons. Popular for its 'what does my baby look like now' and 'Pregnancy Week by Week' timelines, which includes photographs of baby growing in the uterus and size comparisons for each week. Wide range of videos with information as well. Baby growth tracking personalization only available after joining/login.
LINK	

Name of Resource	Baby Center - Pregnancy Tracker - BabyCenter App
Author / Year / Country	2021 / US
Description	Additional app for tracking pregnancy and baby growth. Spanish version of App.
LINK	

Name of Resource	Best Beginnings
Author / Year / Country	2021 / UK
Description	UK website for parents and the professionals who work with them. Lots of information and resources on multiple topics. Has a page specifically for working with parents with LD, under 'Vulnerable Families': defines learning disability (ID in US), describes Baby Buddy app (only web version of app available in US currently), and summarizes information around issues in pregnancy, antenatal care, parenting and communication; with links to Key organizations and references.
LINK	

Name of Resource	Best Beginnings - Baby Buddy App	
Author / Year / Country	2022 / UK	
Description	This is an interactive pregnancy and parenting guide developed by Best Beginnings. It is evidence based, and includes resources and videos. It is written at a literacy age of 11yo so is easily accessible. Only the WEB app available in US currently.	
LINK		