

Toolkit to Support Home Visiting Services for Caregivers with Learning Differences

Conceptual Model and Resource Compendium



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Table Of Contents

Acknowledgements	3
Toolkit Overview	4
<u>Part A: Background and Conceptual Model</u>	
Introduction	5
What do we mean by “learning differences”?	5
Background	6
Overview of the Conceptual Model	8
Conceptual Model for Supporting the Needs of Caregivers with Learning Differences in Home Visiting	11
Appendix A. How the Conceptual Model was Developed	12
Appendix B. Detailed Conceptual Model for Supporting Parents with Learning Differences in Home Visiting	15
References	19
<u>Part B: Resource Compendium</u>	
Introduction to Resource Compendium	21
<u>Skim</u>	
Quick Reference Guide: ABCs	22
<u>Swim</u>	
ABC: “What to Do” - Tips for communicating with caregivers with learning differences	23
RESPECT: “How to Be” - How to approach working with caregivers with learning differences	24
Quick Start Guide – Easy-to-read resources for working with caregivers with learning differences	25
Resources to review with caregivers with learning differences	26
<u>Dive</u>	
Full Resource Compendium	28

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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)

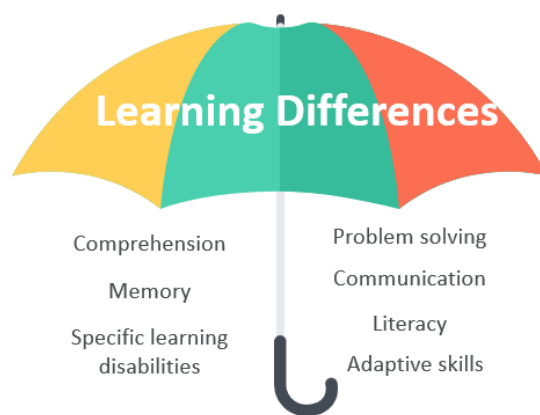


Figure 1. Examples of learning differences

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.

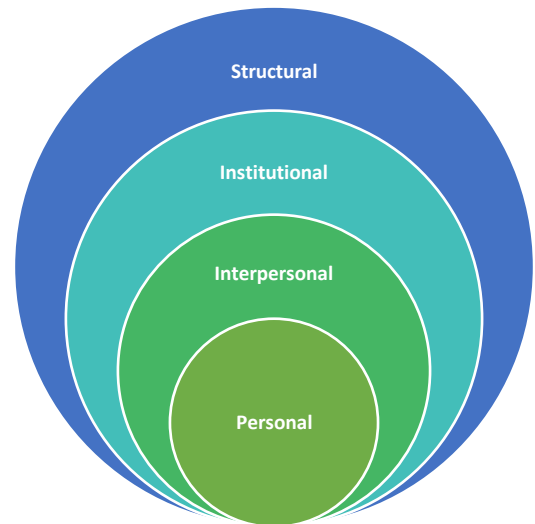


Figure 2. Levels of change

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)

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.

to leverage funding opportunities, increase efficiency, reduce gaps in services, and ensure coordinated service delivery.

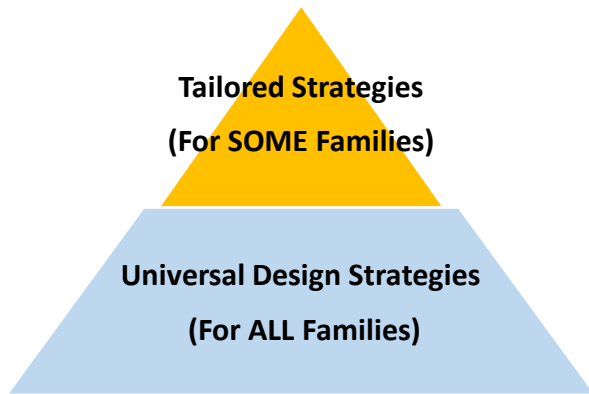


Figure 3. Universal vs. tailored strategies

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 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 Principles¹⁴

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 <i>choices</i> in learning activities.
Simple and intuitive use	Content must be presented in ways that are straightforward and consider caregivers' background <i>knowledge</i> , <i>language skills</i> , and <i>concentration levels</i> .
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.

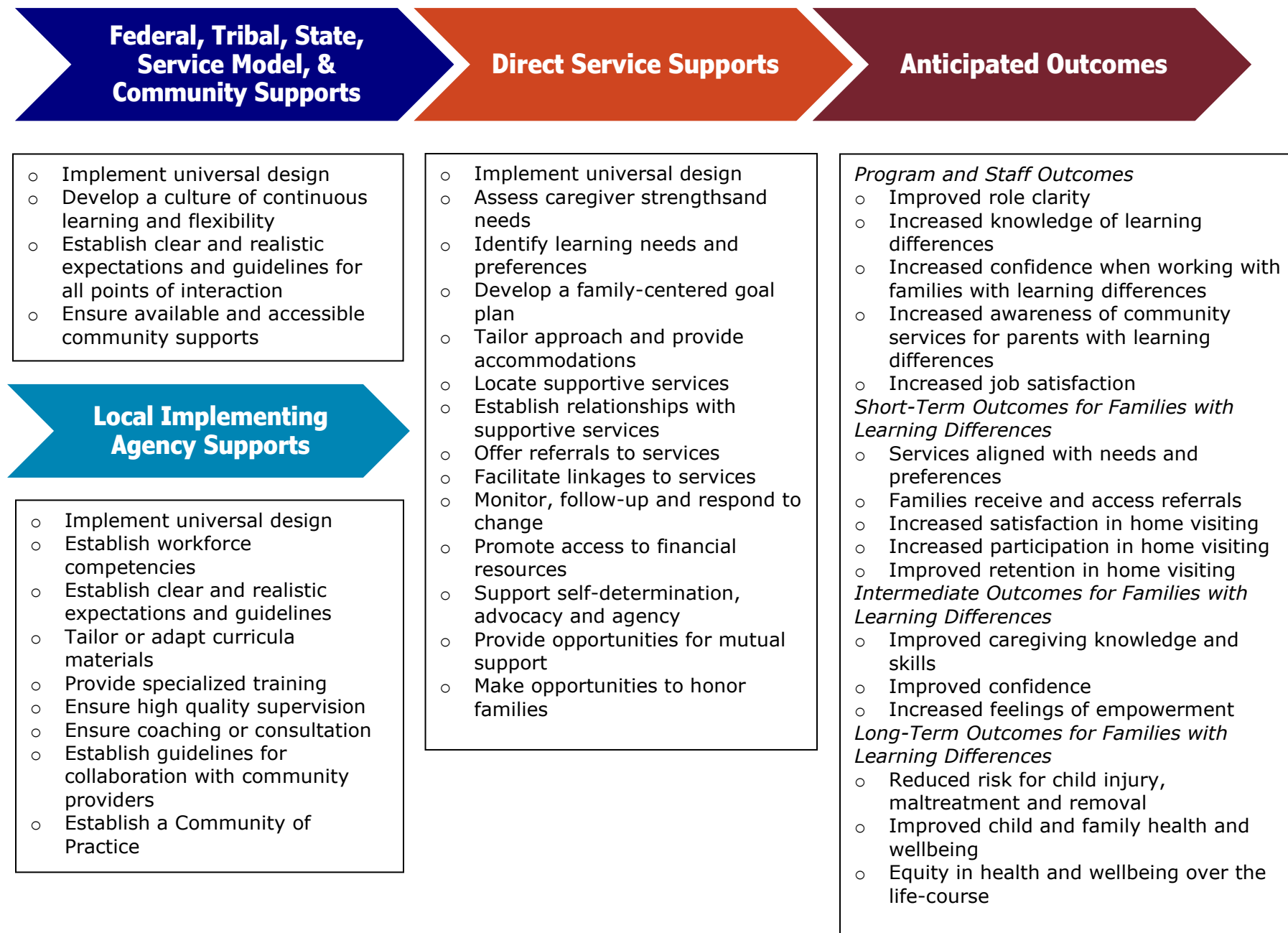
Figure 4 presents an overview of the conceptual model. The Conceptual model is represented as a logic model with three essential “buckets” of factors hypothesized to

influence outcomes: *Federal, Tribal, State, Service Model, & Community Supports, Local Implementing Agency Supports, and Direct Service Supports.*

- *Federal, Tribal, State, Service Model, & 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.
- *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., create 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



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 Input. 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

SUPPORT	DETAILED DEFINITION
Level of Support: Federal, Tribal, State, Service Model, & Community Supports for Home Visiting Programs and Staff Working with Caregivers with Learning Differences	
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.
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.
Establish clear and realistic expectations and guidance for all points of interaction	Relevant entities provide clear expectations and guidance for all points of interaction with caregivers with learning differences, including recruitment, enrollment, direct services, and service coordination. Examples include guidance around flexible timelines for achieving benchmarks and flexibility in selecting and using curricula/curricula supports. <i>*See also organizational supports.</i>
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 <i>available</i> and <i>accessible</i> . Examples include transportation, housing, health care, assistance with basic needs, and employment.
Level of Support: Local Implementing Agency Supports for Home Visiting Staff Working with Caregivers with Learning Differences	
Implement universal design principles	HV programs 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.
Establish workforce competencies specific to working with caregivers with learning differences	HV programs 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.
Establish clear and realistic expectations for HV staff	HV programs establish expectations and guidelines for program managers, supervisors, and home visitors that are clear, aligned with workforce competences, and reasonable given other

	job demands. This includes guidelines for caseload size and frequency and length of visits that take into account additional time often needed to support caregivers with learning differences.
Tailor or adapt curriculum to meet the needs of caregivers with learning differences	HV models and programs 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).
Provide specialized training for HV staff on curriculum	HV programs train staff in the use of an evidence-based curriculum and materials that were <i>developed</i> or <i>adapted</i> to meet the learning needs of caregivers with learning differences.
Ensure ongoing training to strengthen workforce competencies	HV programs provide opportunities for staff to receive evidence-based training to ensure workforce competencies based on best practices to support caregivers with learning differences.
Ensure high quality supervision	HV programs provide regular reflective supervision to support staff, ensure realistic workforce expectations, and build competencies for working with caregivers with learning differences.
Ensure availability of coaching or consultation	HV programs have experts on staff or on call who can support HV staff working with caregivers with learning differences, as needed.
Establish guidelines for effective collaboration with relevant community providers	HV programs 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.
Establish and support a community of practice	HV programs engage in a process of collective learning that includes discussions, joint activities, and mutual problem solving around supporting caregivers with learning differences.
Level of Support: Direct Service Supports for Home Visiting Staff Working with Caregivers with Learning Differences	
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.
Assess caregiver strengths and needs	HV programs conduct a comprehensive assessment of families' biopsychosocial strengths and needs using validated tools.
Identify unique learning needs and preferences	HV programs identify caregivers' unique learning needs and preferences using validated tools.
Create a family-centered goal plan	HV programs collaborate with parents to develop a goal plan that incorporates families' strengths, needs, and preferences.

Tailor approach and provide accomodations	HV programs use inclusive and adaptable materials and strategies that accommodate the unique learning needs of each caregiver (e.g., extra time, accessible handouts).
Locate supportive services	HV programs establish and maintain a comprehensive list of community services that can support parents with learning differences.
Establish relationships with supportive services	HV programs establish relationships with a comprehensive array of community services that can support parents with learning differences.
Offer referrals to supportive services	HV programs offer referrals to families to relevant community services that can 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."
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.
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.
Support self-determination, self-advocacy and personal agency	HV programs help caregivers build capacity to set and achieve personal goals.
Provide opportunities for mutual social support	HV programs provide or identify opportunities for group social support for caregivers with learning differences.
Provide opportunities to honor families	HV programs recognize and acknowledge the achievements and contributions that families have made on a regular basis.

Anticipated Outcomes for Programs, Staff and Families Headed by Caregivers with Learning Differences

Program and Staff Outcomes

Improved role clarity	HV staff have clear understandings of their roles when working with caregivers with learning differences.
Increased knowledge of learning differences	HV staff understand how to assess caregivers' unique learning needs, and how to respond to those needs effectively.
Increased confidence when working with families with learning differences	HV staff are confident in their ability to serve caregivers with unique learning needs effectively.

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.
Increased job satisfaction	HV staff report high levels of job satisfaction related to working with families with learning differences.
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.
Families receive needed referrals	Families receive timely referral information for needed services.
Increased satisfaction with home visiting	Families report satisfaction with home visiting services.
Increased participation in home visiting	Families receive expected home visits within a specific time frame.
Improved retention in home visiting	Families remain enrolled in home visiting for the recommended time period.
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.
Improved confidence	Caregivers report confidence in their ability to promote child health, safety, and development.
Increased feelings of empowerment	Caregivers feel empowered to advocate for themselves and their children to improve their health and wellbeing.
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.
Improved child and family health and wellbeing	Caregivers and their children demonstrate improvements in intended program outcomes.
Equity in health, well-being, and life-course	Caregivers with learning differences and their children no longer experience systematic disparities in health and wellbeing over the life-course trajectory.

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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.

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

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 needs¹.

ABCs² 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 language³ 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 information⁴.



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.

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/getting-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

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. Don't 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 bad.



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**](#)

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

RESPECT¹ 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.

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. TASP
-

	<h2>Resources to review with caregivers with learning differences</h2> <p>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.</p>
<h3>Resources</h3>	
	<h3><u>Advice and facts for mothers and expecting mothers with intellectual disabilities</u></h3> <ul style="list-style-type: none"> • 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.
	<h3><u>Being Good Parents – A Guide for Parents with Intellectual Disabilities</u></h3> <ul style="list-style-type: none"> • This is a list of facts about parents with intellectual disabilities. • It describes some common supports that parents with learning differences can use. • <i>It was written to help parents who may be scared to get help from services</i> • It uses a format that is very easy to read.
<h3>Websites</h3>	
	<h3><u>Baby Center</u></h3> <ul style="list-style-type: none"> • 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 <i>Pregnancy Tracker – BabyCenter</i>.
	<h3><u>TASP: The Association for Successful Parenting – A chance to parent</u></h3> <ul style="list-style-type: none"> • TASP helps communities and families support parents with learning difficulties. • TASP helps parents advocate for themselves and get the supports they need.

	<ul style="list-style-type: none"> • 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.
	<p><u>Best Beginnings</u></p> <ul style="list-style-type: none"> • This is a website from the UK with information about pregnancy, childbirth and childcare. • The website has a section about parents with learning differences. <ul style="list-style-type: none"> ○ 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 <i>Baby Buddy</i> app can help parents with learning difference.



Full Resource Compendium

This resource compendium 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 three essential levels of support to consider when working with caregivers with learning differences. These levels include:

1. Supports offered by federal, tribal, state, home visiting service model, and community-based agencies and organizations.
2. Supports offered by the local implementing home visiting agency or organization.
3. 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 for Home Visiting Services for Parents with Learning Differences* in an earlier section of the Toolkit. Individual resources also have icons that indicate their type.

Government report:



Research paper or article:



Book:



Book chapter:



Practice brief or white paper:



Training manual:




Website:




Video/Webinar:




Level of Support: Federal, Tribal, State, Service Model, & Community


Name of Resource	Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities / Manual	
Author / Year / Country	Baum. S., Gray, G. & Stevens, S. / 2011 / UK	
Description	<p>This document is aimed at providing guidance and direction specifically for clinical psychologists when assessing parents with intellectual disabilities. However, Section 1 is a very good review of literature (up 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. Sections end with 'Key Point's which are concise summaries. Figure 1 (pg 22) 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 (pg 32-34), stating that 'a person's ability to care for a child can be affected by a number of different factors other than, or in addition to, learning difficulties'. The factors include: childhood experience (of the parent), physical and psychological factors, co-parenting partner, number and characteristics of child(ren), informal support network, formal support network, ability of parent(s) to work with professionals, and previous experience of children being removed.</p>	
Link		


Name of Resource	Navigating the System: Addressing the Overrepresentation of Parents with Disabilities in CPS / Online learning module	
Author / Year / Country	Center for Advanced Studies on Child Welfare (CASCW) / 2021 / US	
Description	<p>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 are recorded talking directly about ways to best serve parents with disabilities, including addressing biases, training gaps, engagement strategies, etc. Sections topics include Addressing</p>	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

	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 / Online learning module	
Author / Year / Country	Center for Advanced Studies in Child Welfare / 2020 / US	
Description	<p>This brief discusses the parent-centered planning model to help parents with disabilities plan for parenting. The brief is written for Child Welfare arena, but the model is applicable to all services that assist parents and parents with disabilities. The parent-centered planning model 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. Model also makes the parent the 'expert' by allowing them to take a lead role in planning. Parent-centered planning model implemented with each parent(s) by a trained facilitator to create the parenting plan.</p>	
Link		


Name of Resource	Disability and Child Welfare Episode 1: Parent-Centered Planning for Parents with Disabilities / Brief	
Author / Year / Country	Center for Advanced Studies in Child Welfare (CASCW) - CASCW Core Series Podcasts / 2021 / US	
Description	<p>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.</p>	
Link		

Name of Resource	Practice Notes: Promising Practices to Support Parents with Intellectual Disabilities / Brief	
Author / Year / Country	Center for Advanced Studies in Child Welfare / 2019 / US	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Description	<p>This brief discusses two main types of interventions to help support parents with intellectual disabilities that have shown positive outcomes, interventions aimed at parenting skill development and interventions aimed at increasing parental social connections and supports. The brief is from the Child Welfare arena, 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. Of the interventions aimed at increasing parental social connections and supports, the most studied is the structured support group. While there is less research and program development in this area, there are promising practices. The practice brief provides 8 strategies for supporting parents with intellectual disabilities. Some strategies require implementation, but many can be used by direct service practitioners.</p>
Link	

Name of Resource	CW360 - a comprehensive look at a prevalent child welfare issue: The Intersection of Child Welfare and Disability: Focus on Parents / Journal	
Author / Year / Country	Center for Advanced Studies on Child Welfare (CASCW) - Articles #4, #5, #10, #11 / 2013 / US	
Description	<p>The entire 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:</p> <ul style="list-style-type: none"> a) "Needs of Parents with Intellectual Disabilities: An Ecological Perspective", Bernard & O'Hara (pg10); b) "Understanding and Supporting Parents with Cognitive Limitations", Aunos & Pacheco (pg 12); c) "Change Attitudes, Change Practice", Spencer (pg 13); d) "Working with Parents Who Have Cognitive Limitations: The Parent Support Project", Fier (pg 17); e) "Adapting Assessment, Diagnosis, and Communication for Individuals with Dual Diagnosis", Sweetland (pg 18); and f) "Interventions for Parents with Disabilities", Feldman (pg20). 	
Link		


Name of Resource	Supporting disabled adults in their parenting role / Summary - findings	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

Author / Year / Country	Morris, J / 2003 / UK	
Description	<p>Summary '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. The 'findings' summarizes the full report. 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. Specifically, the findings review the following: access to information, disabling attitudes, lack of focus on disabled parent support needs, more focus on parental 'incapacity' rather than on supports that could help with child care, lack of coordination between child and disabled parent support services, role of poverty and need for additional monies, 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 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.</p>	
Link		


Name of Resource	Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children / Report	
Author / Year / Country	National Council on Disability / 2012 / US	
Description	<p>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 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.</p>	
Link		


HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Chapter 12: The Impact of Disability on Parenting and Chapter 13: Supporting Parents with Disabilities and Their Families in the Community / Report chapters	
Author / Year / Country	National Council on Disability / 2012 / US	
Description	<p>Chapter 12 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.'</p> <p>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.</p>	
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 / Summary - Executive	
Author / Year / Country	Tarleton, B., Ward, L., & Howarth. J. / 2006 / UK	
Description	<p>The purpose of the larger study was to map out the issues confronting parents and professionals around supporting parents with ID, and their children, along with strategies for positive practice in providing parents with ID with supports. This executive summary pulls out key findings and strategies and recommendations gathered from the study. Key findings cover: the wide range of agencies and providers engaging with parents with learning difficulties (ID), the range of barriers to providing appropriate supports - including negative attitudes, the idea that effective support involves a wide range of strategies and supports throughout parenting that are flexible and coordinated, the need for easy to understand information; the idea that professionals working with parents with LD need 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.</p>	
Link		

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Using Medicaid to Support Parents with Disabilities / Brief	
Author / Year / Country	Powell, R. / 2020 / US	
Description	<p>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 (PCA) services, but because parenting is not considered an activity of daily living (ADL) 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, with recommendations for Centers for Medicare and Medicaid Services (CMS) and States.</p>	
Link		


Name of Resource	The ARC Position Statement / Position statement	
Author / Year / Country	The ARC / 2019 / US	
Description	<p>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.</p>	
Link		

Name of Resource	Lurie Institute / Website	
Author / Year / Country	2021 / US	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Description	<p>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.</p>
Link	


Name of Resource	The Arc / Website	
Author / Year / Country	2021 / US	
Description	<p>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. With hundreds of state and local chapters across the country, The Arc's chapter network is on the frontlines from first breath to last 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.</p>	
Link		


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

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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) / Website	
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 / Website	
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	DO-IT (Disabilities, Opportunities, Internetworking and Technology) / Website	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


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 / Website	
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) / Website	
Author / Year / Country	2021 / US	
Description	CAST created the Universal Design for Learning (UDL) framework, from the UD 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		

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Disabled Parenting Project / Website	
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) / Website	
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 / Website	
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,	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


	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 / Website	
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: Local Implementing Agency

Name of Resource	Equal Access: Universal Design of Instruction / Brief	
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		


HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Universal Design of Instruction (UDI): Definition, Principles, Guidelines, and Examples / Brief	
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 (Disabilities, Opportunities, Internetnetworking and Technology) center.	
Link		


Name of Resource	Parenting Capacity Assessments: Some Guiding Principles / Brief	
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	
Description	10 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 / Website	
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		


HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Best Practice in Family Support / Brief	
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? / Brief	
Author / Year / Country	Healthy Start - Parenting Research Centre / 2018 / AU	
Description	What is an intellectual disability anyway' explanation 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 / Article	
Author / Year / Country	Irwin, B. / 2010 / US	
Description	<p>The article is a helpful review of 4 task force reports around the paradigm shift in attitudes and policies towards parenting by people with intellectual disabilities, to a 'right to parent'. It also provides the recommendations from the task force reports.</p> <p>The President's Committee for People with Intellectual Disabilities 1999, American Association on Intellectual and Developmental Disabilities 2010, United Nations 2007 , and The Association for Successful Parenting 2009</p>	
Link		

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

Name of Resource	Strategies for Successfully Including People with Disabilities / Report	
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, helpful for description 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 / Brief	
Author / Year / Country	North Carolina Division of Social Services and Family & Children's Resources Program / 2004 / US	
Description	Information for child welfare workers who work with parents with cognitive limitations; 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; provides basic information about people with cognitive limitations, presents a tool for identifying parents with cognitive limitations.	
Link		


Name of Resource	The Principles of Universal Design / Manual	
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	The Parenting Young Children training program - part of PRC / Training - website	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Author / Year / Country	Parenting Reseach Centre / 2021 / AU	
Description	<p>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.</p>	
Link		


Name of Resource	Healthy & Safe training program / Training - website	
Author / Year / Country	Parenting Reseach Centre / 2021 / AU	
Description	<p>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.</p>	
Link		


Name of Resource	Supported Parenting - Refreshed Scottish Good Practice Guidelines for Supporting Parents with a Learning Disability / Report	
Author / Year / Country	Scottish Consortium for Learning Disability / 2015 /UK	
Description	<p>Scottish Good Practice Guidelines - to help services improve their support for parents with learning disabilities (ID) and their children. It is a government report, but very readable and applicable to other countries and systems. Uses the 'Supported Parenting' approach - recognizing the human rights of parents and children within a family that needs supports, that parents have abilites as well as needs and that support should be tailored to parent capacity as well as deficits. Introduction and Executive Summary as a good background and summary of current situation of parents with learning disabilities (ID). 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 - What do we mean by people with learning disabilities - good explanation.</p>	


HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

[Link](#)

Name of Resource	Effective Support Strategies for Parents with Cognitive Difficulties - A companion to the TASP webinar by Cathy Haarstad / Brief	
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 / Website	
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 / Website	
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 / Website	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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 / Website	
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 / Website	
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); 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 / Website	
Author / Year / Country	UK	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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 / Website	
Author / Year / Country	2021 / UK	
Description	The WTPN supports professionals working with parents with learning difficulties and learning disabilities (ID in US) 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 information for parents with ID, in varying formats (video and print). Includes 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 / Website	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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 Reseach 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 / Brief	
Author / Year / Country	Connections Counseling / 2021 / CA	
Description	Summary of best ways to support parents with IDD 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.	
Link		


Name of Resource	7 Things You Should Know About Universal Design for Learning / Brief	
Author / Year / Country	Educause Learning Initiative (ELI) / 2015 / US	
Description	Review of 7 important things to know about universal design for learning. 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. Helpful to think about UD and UDL.	
Link		


Name of Resource	Facts and Fallacies / Brief	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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 / Brief	
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 / Brief	
Author / Year / Country	Family & Disability Studies Initiative / 2021 / CA	
Description	10 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 / Toolkit - website	
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; also a Resources section and a Webinars section.	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


[Link](#)

Name of Resource	Am I making myself clear? Mencap's guidelines for accessible writing / Brief	
Author / Year / Country	MENCAP / 2002 / UK	
Description	MENCAP works with people with learning disabilities (ID) to provide guidelines to make information more accessible. Has Key Points about making written materials easier to understand, using technology, getting feedback and tips, use a variety of formats, pay attention to layout, spacing and fonts, using symbols and pictures; and gives good and bad examples.	


[Link](#)

Name of Resource	Your guide to Communicating with people with a learning disability / 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 / Brief	
Author / Year / Country	National Research Center for Parents with Disabilities / 2021 / US	
Description	Strategies to help professionals when working with parents with intellectual disabilities. 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 / Brief	
Author / Year / Country	National Research Center for Parents with Disabilities / 2021 / US	

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

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 / Brief	
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	Recommendations for Communicating with Adults with Intellectual, Cognitive or Developmental Disabilities / Brief	
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 / Webinar	
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	


HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


	of the original 'I Can Parent, Too!' webinar, and slides from the original presentation are also available.
Link	


Name of Resource	Beyond Words / Website	
Author / Year / Country	2021 / UK	
Description	<p>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, such as Dementia, people who have difficulty with reading, including some Deaf people, and people who do not use the language of the country where they are living. Our stories are used in health care settings, schools and colleges, libraries, supported living settings, therapeutic services, and community organizations, amongst others. 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</p>	
Link		

Name of Resource	CHANGE / Website	
Author / Year / Country	2019 / UK	
Description	<p>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</p>	
Link		

HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES


Name of Resource	Rapid Response Virtual Home Visiting / Trainings	
Author / Year / Country	2021 / US	
Description	<p>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.</p>	
Link		


Name of Resource	BabyCenter / Website	
Author / Year / Country	2021 / US	
Description	<p>"Information for all parents, not specifically geared to parents with disabilities or learning differences. Spanish version of website. 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 in. Site has this statement: ""BabyCenter is committed to providing the most helpful and trustworthy pregnancy and parenting information in the world. Our content is doctor approved and evidence based, and our community is moderated, lively, and welcoming. With thousands of award-winning articles and community groups, you can track your pregnancy and baby's growth, get answers to your toughest questions, and connect with moms, dads, and expectant parents just like you". (used by Georgetown HV program)</p>	
Link		

Name of Resource	Pregnancy Tracker - BabyCenter App	
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HOME VISITING SERVICES FOR CAREGIVERS WITH LEARNING DIFFERENCES

Author / Year / Country	2021 / US	
Description	Additional app for tracking pregnancy and baby growth. Spanish version of App.	
Link		

Name of Resource	Best Beginnings / Website	
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	Baby Buddy App	
Author / Year / Country	UK	
Description	Interactive pregnancy and parenting guide developed by Best Beginnings, evidence based, includes resources, videos; at literacy age of 11yo so easily accessible; only WEB app available in US currently	
Link		