Empowered Disabled Parenting Intervention
Facilitator's Guide

National Research Center for
Parents with Disabilities

Centro Nacional de Investigación para
Padres con Discapacidades

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Funding Statement

About This Guide

The intervention described in this guide was developed by Dr. Kara Ayers, PhD, Associate Professor of Pediatrics in the College of Medicine at the University of Cincinnati and Cincinnati Children's Hospital Medical Center and Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities.

How to Cite This Guide

National Research Center for Parents with Disabilities. (2026). *Empowered Disabled Parenting Intervention*. Brandeis University, Waltham, MA.

Empowered Disabled Parenting Intervention: Facilitator's Guide

Introduction to the Empowered Disabled Parenting Intervention: Notes to Facilitators

The Empowered Disabled Parenting Intervention (EDPI) is a novel intervention informed by Health Empowerment and Self-Determination Theories (Shearer, 2009; Ryan & Deci, 2000). Both theories focus on empowering the individual, particularly in healthcare settings. Both also acknowledge stigma as a frequently shared experience of people from marginalized groups, including people with disabilities. Many people with disabilities, particularly people considering parenthood, have likely felt disempowered in their past interactions with healthcare and other social-service providers when talking about parenting. To maintain the fidelity of this intervention, the intervention will repeatedly return to the question, "What Matters Most?" This question is meant to highlight what matters most *to the participant*, with the ultimate goal of developing an individualized EDPI plan for the participant to utilize in working towards a parenting goal they themselves have identified.

The EDPI intervention is unique because it provides the disabled parent the opportunity to work with a disabled peer facilitator who is also a parent and to talk about challenges in day-to-day life along with experiences of stigma and discrimination common to many parents with disabilities and hopes for the future. While the discussion of stigma and discrimination may come up as early as the first session, the intervention will address it in more detail as rapport is established with the participant. The intervention maintains a strengths-based approach throughout the engagement between peer facilitator and participant. As a parent's strengths emerge, they can identify how their strengths can best be applied to achieve the goals for parenting they have set.

Using the Facilitator's Guide

This Facilitator's Guide is *not* a semi-structured interview guide. This guide was written so that it may be administered by a trained disabled facilitator who has personal experience with parenting children age five and under.[1] The process of developing the participant's Empowered Disabled Parenting Intervention is meant to take place through a series of discussions between participant and facilitator, without the use of scripted questions. While each module has a discrete topic and objectives, the participant may identify other parenting concerns that they wish to discuss. If you have questions about this intervention or its intended use, please contact Dr. Kara Ayers.

Resources for Facilitation

Slides for facilitation[2]: These slides provide visual support to facilitate the sessions. They are *not* intended to guide the entire facilitation—the participant should not feel as if they are attending a lecture. Please consider turning the share-screen on and off to provide some visual cues with the slides before returning to a face-to-face discussion using the full screen.

A logistical note: There are slides embedded within this document to guide facilitation of this intervention. Many participants will likely use their smart phones, which minimizes the ability to see slides *and* faces at the same time. For this reason, it's advised to stop "screen share" after sharing a slide to build rapport with the participant as you talk through the material. After each session, complete the debriefing document, documenting any observations or lessons learned by the participant from the session.

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[1] Shearer, N. B. C. (2009). Health empowerment theory as a guide for practice. *Geriatric Nursing, 30*(2 Suppl), 4–10. https://doi.org/10.1016/j.gerinurse.2009.02.003; Ryan, R. M., & Deci, E. L. (2000). Self-Determination Theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68–78. https://doi.org/10.1037/0003-066X.55.1.68.

[2] To obtain the EDPI slides, please contact Dr. Ayers at kara.ayers@cchmc.org.

Module 1: Welcome and Getting to Know You

Module Objectives

- Describe the purpose and goals of the EDPI program.

- Discuss reasons for participating and explain how the participant, the participant's family, and the community can benefit from it.

- Get to know each other.

- Define stigma.

- Practice pride.

Module Agenda

1.1 Getting to know you

Greet participant and **welcome** them to the first module of the program. **Share introductions of program, participant, and facilitator.**

Enhancing Autonomy and Control: When introducing the program, emphasize the participant's role in shaping the course of the intervention. Make it clear that the participant's input and feedback will guide the direction of the sessions.

- Provide the following brief introduction about the goals and purpose of the EDPI.
    - "The Empowered Disabled Parenting Intervention is a new program we've developed to support disabled parents as they raise their families. We are part of the National Research Center for Parents with Disabilities. We know through research and our own lived experiences that people with disabilities can be parents. We know parenting is tough, and stigma or judgment from others makes it even more difficult. Through this program we hope to give you a chance to think about some of your strengths and challenges in ways you haven't before. We hope to support you to become an even more empowered

parent, that is, a parent who feels in control of your parenting decisions, and able to find the supports you need."

- o "This program will take place entirely over Zoom. We think it will take between 2 and 4 modules. If you ever have questions, you may always ask them during the module. And if you have questions between modules, I'm going to make sure you have the contact information of Dr. Kara Ayers, who can help you with those.

- Lead the participant in a "Getting to Know You" activity.
  - o Both participants and facilitators should engage in the activity.

  - o Use a virtual icebreaker to learn more about each other. A possible icebreaker option is below but *feel free to develop your own*.

    - What? When? Where? (find this below)

  - o Ask the participant to share about their family. The facilitator will then briefly share their own family dynamics.

- Transition into the first components of the program.

WHAT? WHERE? WHEN?

| | What was the last TV show you binge watched? | Where is your dream vacation? | What is your favorite meal? | When is your favorite time of day with your family? |

Add your notes here · **Add your notes here** · **Add your notes here**

Add your notes here · **Add your notes here** · **Add your notes here** · **Add your notes here** · **Add your notes here**

What? Where? When?
(See Appendix A for a printable version.)

1.2 What is stigma?

Define and **introduce** the concept of stigma as it relates to parents with disabilities:

> "One of the reasons we developed this intervention was to make sure parents with disabilities had a chance to talk about this stigma. What we mean by this is the way some people in our society believe that we can't or shouldn't be parents because we have disabilities. Does that word fit for you or would you like to use something else—like discrimination, doubt, or judgment?"

> "For some parents with disabilities, they've lost custody of their children for a period of time or forever because other people had these doubts and the child welfare system is not always fair to people with disabilities. We want more families to stay together."

Knowledge and Understanding: **Understand** the history of ableism in healthcare and the child welfare system.

> "Some parents with disabilities have encountered doubt and judgment from people who they thought were there to help them. Some of these people have been nurses, teachers, or case managers. Sometimes even other family members doubt our ability to parent."

Participatory Approach: **Encourage** participants to suggest alternative words for stigma if they feel other words better represent their experiences. This fosters a sense of ownership and engagement in the conversation.

Discuss how (if at all) the participant has already experienced or anticipates stigma.

> "Have you ever had people doubt your parenting because you have a disability or is it something that you worry about?"

Identify what coping mechanisms the participant uses in response to stigma, discrimination, and ableism.

> "What do you do when you have these worries or realize someone is doubting you?"

Emphasize Self-Efficacy: When discussing these experiences, the facilitator should focus on how participants have or are working to navigate these challenges successfully and how they can continue to do so in the future. This helps build confidence in their ability to handle these situations.

Facilitator Note: **Use an adaptive approach**. This module proposes an introduction to the program. Introduce ideas—like the history of ableism in the child welfare system—with basic information while paying attention to whether this is known or new information to the participant. This will guide how often and when to readdress these concerns in later modules. For participants who are already familiar and are concerned about potential overinvolvement or unfair involvement of child welfare workers in the lives of their family, this topic may be appropriate to discuss during each module. For participants unaware of

this concern for many parents with disabilities, it may be more appropriate to wait until later modules to discuss this issue further; this is so that these participants will have an opportunity to increase their locus of control and develop their plan before this concern of the threat of child welfare involvement is added into the discussion.

1.3 Pride practice

Conclude this module by asking the participant to reflect on what about their family makes them most proud. **Encourage** them to choose a point of pride about their family and, also a point of pride about themselves as a parent.

Community and Social Support; Self-Efficacy and Empowerment: **Guide** participants to recognize and articulate their strengths and achievements as parents. This reinforces a positive self-image and empowerment.

Module 2: What Matters Most for Your Family?

Module 2 of the Empowering Disabled Parents Intervention (EDPI) is focused on identifying personal values and building a support network, which are essential for empowering participants.

Module Objectives

At the end of this module, the participants will be able to:

- Identify what matters most for the participant's family;

- Know what is needed to support the accomplishment of goals related to what matters most;

- Demonstrate ways to communicate clearly to family, friends, and professionals about how they parent their child(ren).

Module Agenda

2.1 Recap and reconnect

Welcome the participant to Module 2 (or let the participant know that they are now moving into Module 2 of the program).

Review that the goal(s) of this program are to empower the participant in their parenting.

2.2 What matters most to your family?

Ask the participant what matters most to them as a parent. This emphasizes *autonomy* and *control*. **Explain** that thinking through this question will be repeated throughout, and that it is shown in research to help parents and families, especially those who may face stigma.

- What Matters Most is different for everyone. There are no right or wrong answers.

- Sometimes we feel pressured by others about What Matters Most to *them*. WMM should be the participant's choice.

- What Matters Most may or may not be in the participant's control.

Enter what matters most to the participant into this graphic. Download for review in later modules. **Do not add identifying information**.

What Matters Most?
(See Appendix B for a printable version.)

2.3 What accommodations and supports would be most helpful for your parenting? Do you have supports that are helpful now?

Brainstorm and **identify** accommodations, supports, and strategies to help the participant in parenting.

- **Discuss** what has already been helpful. Remember informal AND formal supports are meaningful.

- **Identify** what supports are missing and/or what accommodations are needed.

- **Encourage** the participant to use their imagination about what kind of resources, services, and supports would benefit them.

Knowledge and Understanding: **Discuss** examples of both typical and unique accommodations that other disabled parents have found helpful. This should stimulate or continue the participant's brainstorming.
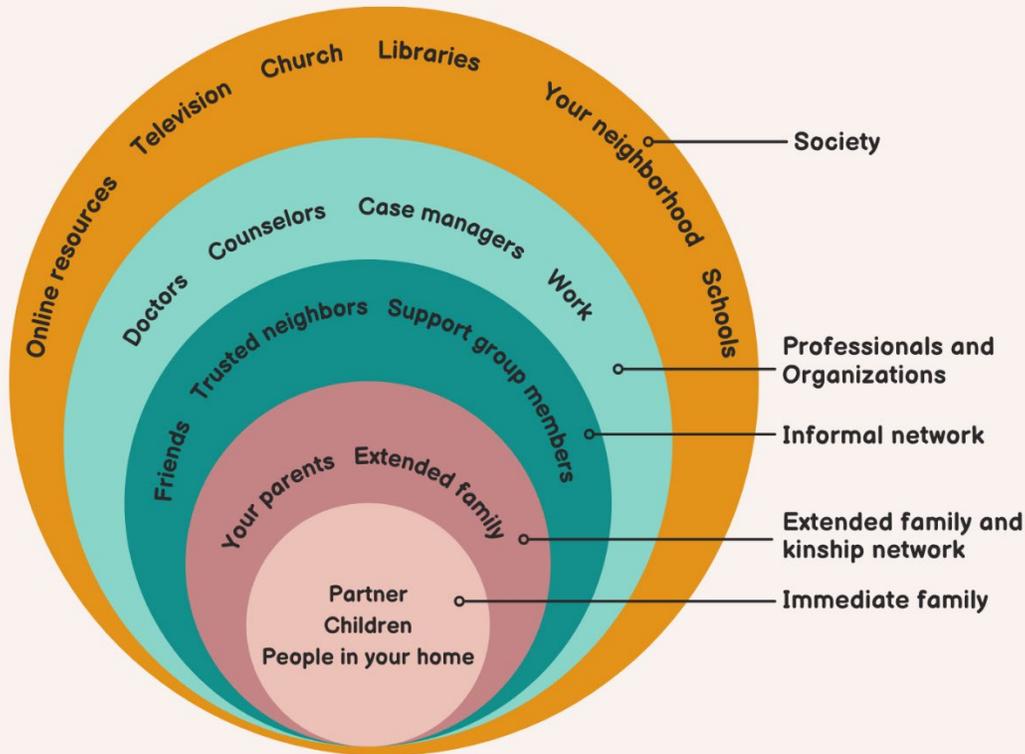
2.4 Who are members of your team?

Discuss who is supportive of the participant. **Encourage** the participant to think both broadly and specifically.

- **Identify** people and roles who will support the participant at various stages through parenting.

- **Discuss** strategies the participant uses to communicate with members of their team.

- **Discuss** sources of information about parenting. Credibility of sources can vary. A lot of sources may not include the experience of disability.

Identify layers of resources and support through discussion of the EDPI Mapping Resources slide ("Mapping Family Supports," found below in this guide and in [Appendix C](#)). **Encourage** the participant to think specifically about who and what places, organizations, etc. feel both close and further away in terms of support.

Mapping Family Supports

Society — Online resources, Television, Church, Libraries, Your neighborhood, Schools

Professionals and Organizations — Doctors, Counselors, Case managers, Work

Informal network — Friends, Trusted neighbors, Support group members

Extended family and kinship network — Your parents, Extended family

Immediate family — Partner, Children, People in your home

Adapted from Enabling & Empowering Families, by Dunst, Trivette, and Deal (1988)

Mapping Family Supports
(See Appendix C for a printable version.)

Community and Social Support: **Discuss** the role of the community and social networks in providing information support, emphasizing the value of these often overlooked resources.

Homework: Empowerment through Exploration. Ask the participant to spend some time between Module 2 and Module 3 exploring their community resources to consider what else might be available and what else they'd like to access to support their parenting. In other words, they should think about what is available and what they wish were available. Give examples for internet search terms and websites to look at, if needed. The Mapping Family Supports illustration provided in this guide may help in this.

Facilitator Note: While it is possible to complete Modules 1 and 2 together, the homework between Modules 2 and 3 requires a break.

Module 3: What Resources are Available to You and Your Family?

Module 3 of the Empowering Disabled Parents Intervention (EDPI) focuses on *resource identification* and *overcoming barriers*, which are crucial for empowering participants in their parenting journey.

Module Objectives

At the end of this module, the participants will be able to:

- Identify what kinds of resources exist in their community.

- Discuss how, if at all, they access those resources.

- Brainstorm what kinds of resources they wish existed or might keep looking for in other places.

Module Agenda

**Recap** and **Reconnect: Welcome** the participant to Module 3.

Discuss the results of homework assignment, *Empowerment through Exploration*. The participant will **share** about what resources they find helpful in their community. The facilitator will ensure this exchange is relaxed and no pressure is applied if the participant reports they didn't reflect on community resources. During this module, you'll talk more about these resources together.

3.1 Mapping community resources

Discuss what resources are available in the participant's community using the **Community Resources Map.**

- It's important to note that the participant may or may not have used these resources before. For now, we're going to try to think of as many resources as possible that are available.

- **Resource Mapping: Use** the support resources map above, starting from the participant's home, and move through the illustrated community below and in Appendix D as brainstorming points to thinking about resources in those areas of the participant's community.
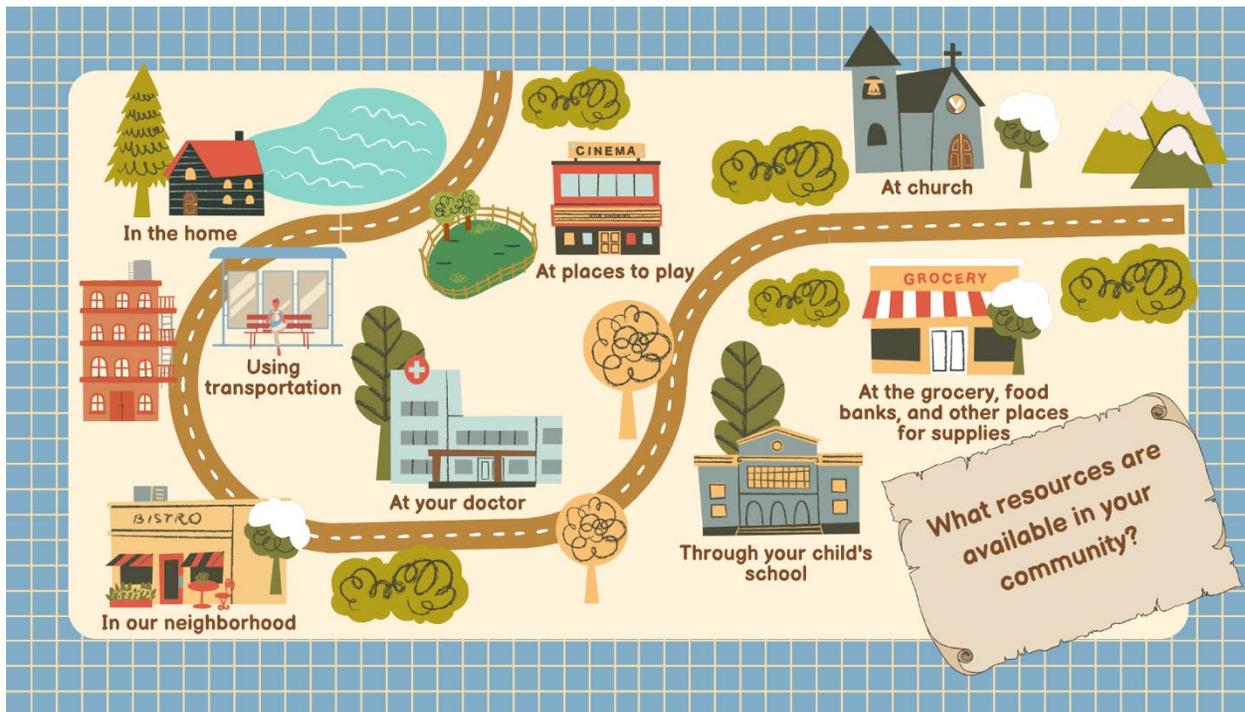
Community Resources Map
(See Appendix D for a printable version.)

3.2 What are the barriers to accessing current resources?

Identify what gets in the way of the participant accessing more supports and resources than they do right now with a **Problem-Solving Approach**.

- If the participant has difficulty or is hesitant to identify barriers, **consider** the following common barriers experienced by parents with disabilities:

    o Transportation

    o Financial resources

    o Trust in systems and people

    o Family and friends not in close proximity

- o Accessibility

- o Changing health needs

- **Respond** with *empathy* and *understanding* to acknowledge that facing barriers can be frustrating. **Encourage** sharing of experiences and feelings to foster a supportive environment.

- **Use** a *future-focused discussion* to shift the focus from current limitations to future possibilities. This might be called "Thinking About What's Next."

- **Discuss** how the participant currently tries to get around these barriers. In using the metaphor and imagery of the community map, *"Are there alternative roads to take or places to go to get to What Matters Most?"*

3.3 What resources are missing?

Identify what accommodations and supports are needed by the family or in the community at large.

- Some of these missing resources may have been discussed as barriers. **Differentiate** these for clarity based on which supports and resources are available but haven't been accessed and which are not available at the present time.

- **Discuss** how the participant stays up-to-date about new supports and resources. Where can they get more information?

Module 4: How Can You Stay Empowered by Remembering What Matters Most?

Welcome the participant to Module 4 (or inform the participant you are now beginning Module 4 materials). This is the last module before the participant and facilitator reconnect for a follow-up after the conclusion of the intervention.

Module Objectives

At the end of this module, the participants will be able to:

- Summarize and communicate with others about what matters most to them as a parent.

- Identify what supports and resources they already access.

- Plan to address barriers and find additional supports and resources.

- Experience empowerment in discussing and responding to stigma and discrimination faced as parents with disabilities.

Module Agenda

Recap and Reconnect

Review what matters most. **Ask** the participant if they'd like to make any additions and/or changes to what they've identified as what matters most to their family.

To do this, you'll need to pull up this participant's **What Matters Most notepad** graphic (see [Appendix B](#)). This review encourages *reflection* and *growth*. If the participant doesn't have access to a printer and wants a hard copy, the facilitator should document their address to mail a copy of the resources from the EDPI.

4.1 What is your family's story now?

Discuss what parents might add to their story now that they've spent time thinking about supports and resources they access, what barriers they face, and how (if at all) stigma impacts their lives. This is helpful for *narrative building*, which is a key to forming a positive self-identity.

- Participant and facilitator will again briefly **share** about their family.

- **Identify** what information is still needed and where/how the participant can find it.

Stress the importance of *empowerment through communication*. Effectively communicating needs and values to others is an important part of empowerment.

4.2 How will you stay empowered in the face of stigma and discrimination?

Experiencing stigma, stereotypes, and discrimination is not uncommon for parents with disabilities. **Discuss** ways the participant will build and/or maintain confidence and belief in their abilities to be "good parents" despite some negative interactions with others.

Share knowledge and experiences of myths, stereotypes, and discrimination faced by parents with disabilities using the "Microaggression Table" below. While researchers call these experiences microaggressions, **pay attention** to how your participant describes these experiences.

- **Discuss** how parents with disabilities may face discrimination in different forms. This builds *Resilience* and *Advocacy*. **Show** the graphic about microaggressions faced by parents with disabilities. **Ask** the participant if they have experienced any of these microaggressions. **Validate** their experiences.

MICROAGGRESSIONS EXPERIENCED BY DISABLED PARENTS

Type	Description	Example
Invasion of privacy	People may invade personal space and ask personal questions because you have a disability.	"What happened to you?" "Oh here let me pick her up for you." (Picking up child without asking.)
Helplessness	People may frantically try to help and treat you like a child.	"Oh let me do that for you!" Running to open doors.
Patronization	People praising you for almost anything and finding it surprising you do ordinary things.	"It is so good to see you out and about!"
Denial of disability	Disability is ignored-or claimed to be ignored.	"I don't even think of you as having a disability"
Questioning our children	People may ask children personal questions about their parents or how their family works.	"You are so kind to help your parents." "Who takes out the trash in your house?"

Adapted from Disability Affirmative Therapy by Rhoda Olkin (2017)

Microaggressions Experienced by Disabled Parents
(See Appendix E for a printable version.)

4.3 How will you continue working towards what matters most?

Summarize the participant's reflections and plans identified throughout the EDPI.

- **Review** strategy for communication and implementation of action towards addressing barriers to accessing supports and resources the parent needs or wants. *Action Planning* provides a clear and actionable plan for moving forward. *Information Sourcing* is a skill that helps people find additional information when they need it.

  - **Complete** the "What Matters Most worksheet," below and in Appendix F to summarize EDPI with the participant. *Do not add identifying information.*

- o **Save and download** the graphic to be emailed or mailed to the participant.
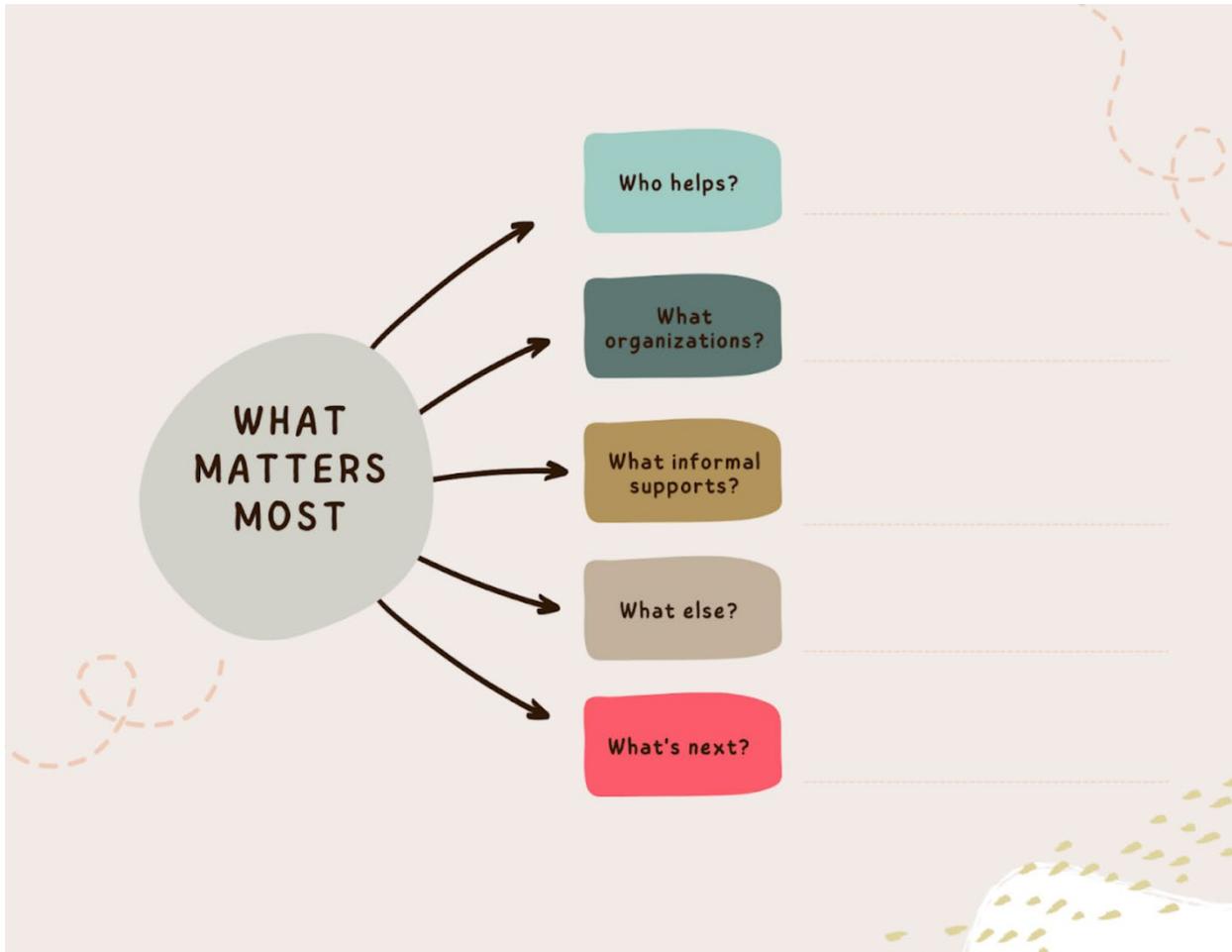
What Matters Most worksheet
(Please see Appendix F for a printable version.)

Conclusion

This will be the final meeting of the Empowered Disabled Parenting Intervention. The facilitator should **confirm** participant's contact information to follow up in 4 to 6 weeks.

Module 5: Follow-Up

Reconnect with the participant in this final, follow-up module. In this module, they'll discuss their experiences with parenting since completing the Empowered Disabled Parenting Intervention. This is a dynamic evaluation.

5.1 Has What Matters Most changed?

Review and **reconsider** what the participant identified as What Matters Most and **discuss** if anything has changed and why.

- **Encourage** the participant to consider their own strengths and self-direction for setting goals for their families.

5.2 What has gone as planned and what hasn't related to What Matters Most for you and your family?

Reflect on how the participant's experience matched or did not match what they expected. This is *Reflective Learning* and measures *Adjusting Strategies*.

- **Discuss** facilitators and barriers to accessing supports and resources.

- **Identify** what informal and formal supports have been newly helpful.

- **Consider** how support needs and dynamics have changed over time and through this experience.

5.3 What are sources of support for the next phases of parenting?

Identify what sources of information, support, and services exist for parents with disabilities.

- *Network Expansion:* **Consider** further connections with parents with disabilities to address questions and seek information about parenting with a disability.

- *Resource Exploration:* **Discuss** what services are needed and what might be available in the participant's communities.

- **Reflect** on what accommodations and types of support were most helpful and what might remain or change in the future.

Conclude with expressions of appreciation for the participant's willingness to engage in this process. **Reflect** on the benefits of empowerment as outlined throughout the program (i.e., identifying needs, planning for the future, and connecting to peers). Refer the parents to the National Research Center for Parents with Disabilities as one source of information about parenting with a disability.

Appendices

Appendix A. What? Where? When? worksheet

Appendix B. What Matters Most notepad

Appendix C. Mapping Family Supports

Appendix D. Community Resources Map

Appendix E. Microaggressions Experienced by Disabled Parents

Appendix F. What Matters Most worksheet

WHAT? WHERE? WHEN?
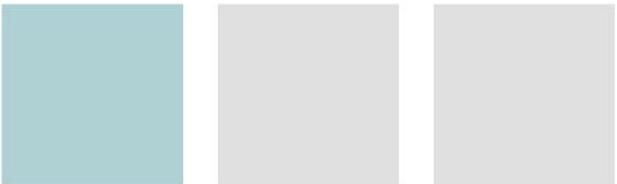
Add your notes on the colored squares outside the columns.

What was the last TV show you binge watched?

Where is your dream vacation?

What is your favorite meal?

When is your favorite time of day with your family?

What Matters Most

Mapping Family Supports

Society

Professionals and Organizations

Informal network

Extended family and kinship network

Immediate family

- Online resources
- Television
- Church
- Libraries
- Your neighborhood
- Schools
- Doctors
- Counselors
- Case managers
- Work
- Friends
- Trusted neighbors
- Support group members
- Your parents
- Extended family

Partner
Children
People in your home
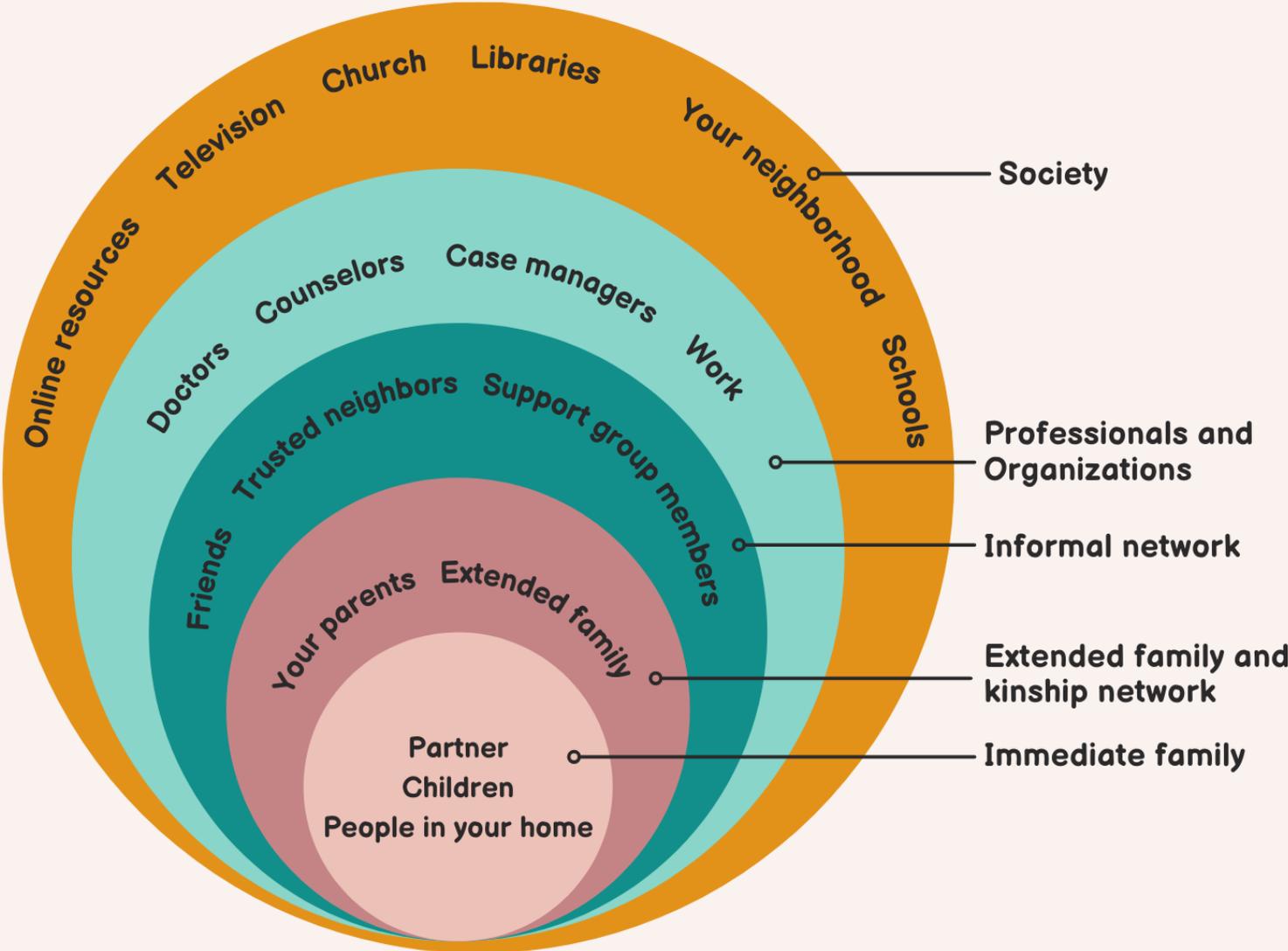
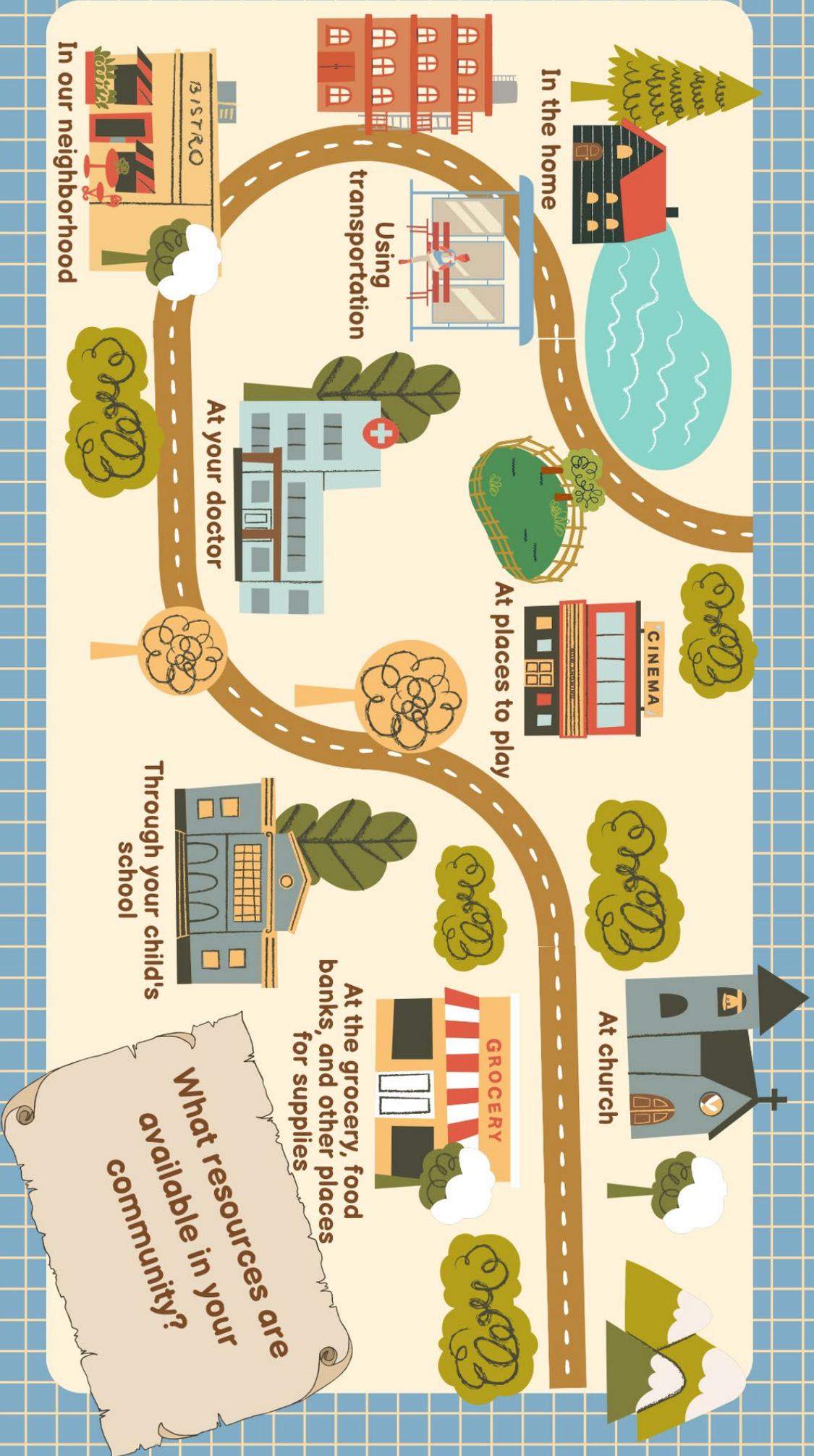Adapted from Enabling & Empowering Families, by Dunst, Trivette, and Deal (1988)

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What resources are available in your community?

In the home

In our neighborhood

Using transportation

At your doctor

At places to play

Through your child's school

At the grocery, food banks, and other places for supplies

At church

BISTRO

CINEMA

GROCERY

MICROAGGRESSIONS EXPERIENCED BY DISABLED PARENTS

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WHAT MATTERS MOST

What's next?

What else?

What informal supports?

What organizations?

Who helps?