

**THE BEST KEPT SECRET:**  
**Programs and Policies**  
**Across States to Support**  
**Accessible Homes for**  
**Children with Disabilities**

*September 29, 2026*

# Speakers and Moderators



**Carolyn Foster, MD, MS**

Assistant Professor of Pediatrics  
Northwestern University



**Rebecca Seltzer, MD, MHS**

Associate Professor of Pediatrics  
Johns Hopkins University



**Callie Kaplan, MPH**

Senior Research Scientist  
Lurie Children's Hospital

# Panelists



**Lori Berrong,  
ATACP, MEd, MFA**

Executive Director  
Maryland Department of Disabilities  
Assistive Technology Program



**Molly Hofmann,  
APRN, DNP**

Director of Care Coordination, Systems  
Development and Education  
University of Illinois Chicago's Division  
of Specialized Care for Children



**Tami Allen**

Co-Executive Director  
Families Together Inc.

# Agenda

## Introduction

*Carolyn Foster*

## Overview of Research Findings

*Rebecca Seltzer*

## Panel Discussion

*Tami Allen, Lori Berrong, Molly Hofmann*

*Moderated by Callie Kaplan*

## Q+A

*All*

# Introduction

Carolyn Foster, MD, MS

# Welcome

**Instructions**

Q&A

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**Funding**

Lucile Packard Foundation for Children's Health

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**Acknowledgement**

Research Team Members, Parent Partners,  
Advisory Team Members

# Home Accessibility is a Right, Not a Luxury

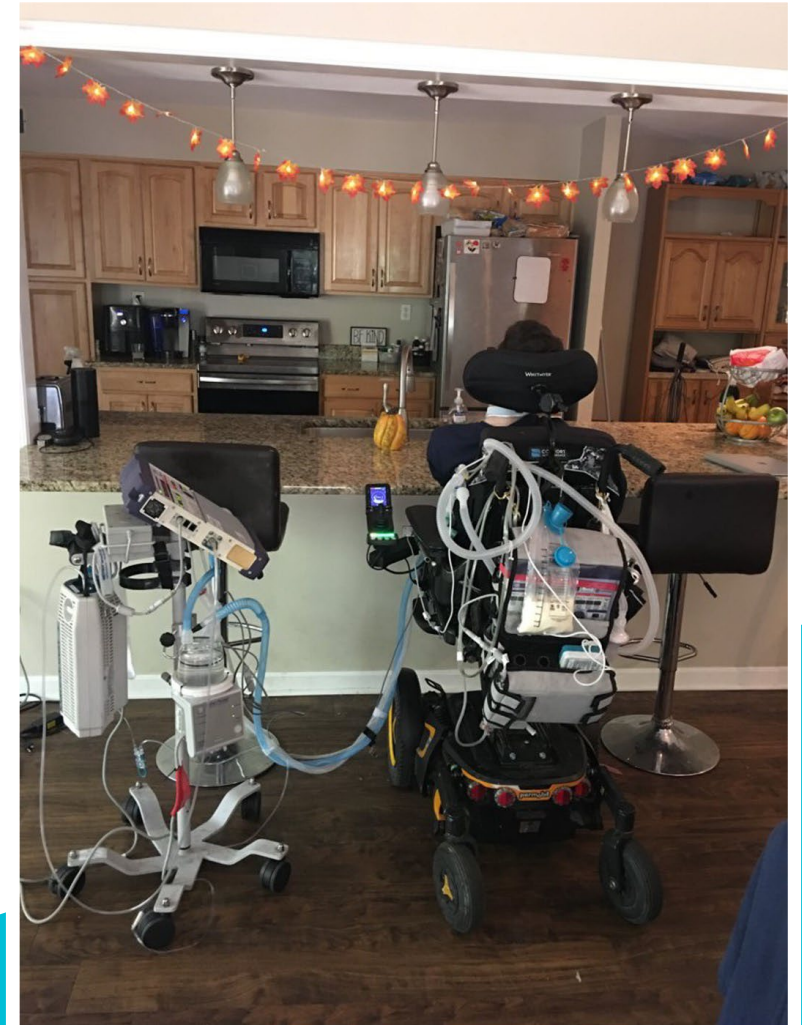
**Home modifications** are integral to ensuring integration in the home and community.

**Living in the home and community setting is a:**

- Legal right (Civil right)
- Human right

**As codified by:**

- Americans with Disabilities Act - 1990
- Olmstead vs LC Supreme Court Case - 1999
- UN Convention on the Rights of Persons with Disabilities - 2006





# OPTIMIZING THE HOME ENVIRONMENT FOR CHILDREN WITH DISABILITIES: UNDERSTANDING CURRENT POLICIES AND PLANNING FOR THE FUTURE

**Funder: Lucile Packard Foundation for Children's Health**

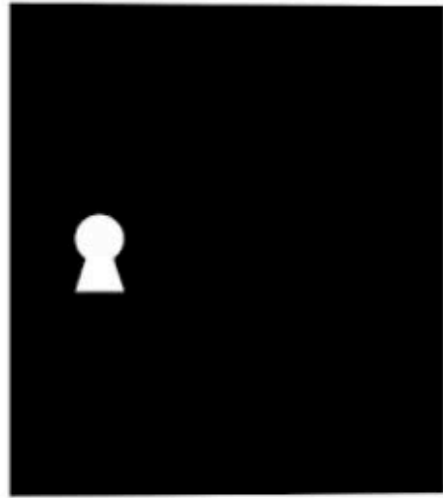
# Project Overview

- BACKGROUND:** Prior research in Maryland and Illinois shows insufficient resources and information to ensure accessibility for safe, independent, and developmentally appropriate life at home for children with disabilities (CWD).
- OVERALL GOAL:** Inform and galvanize more effective, equitable home accessibility programs and policies for CWD nationally.
- ACTIVITIES:** Analysis of key informant interviews from 10 states (n=62) to understand and communicate about the current national landscape of programs and policies that promote home accessibility for CWD and their families.



# **“Best Kept Secret”:** *Overview of Research Findings and Resources*

**Rebecca Seltzer, MD, MHS**



**Opening  
doors** to home  
accessibility

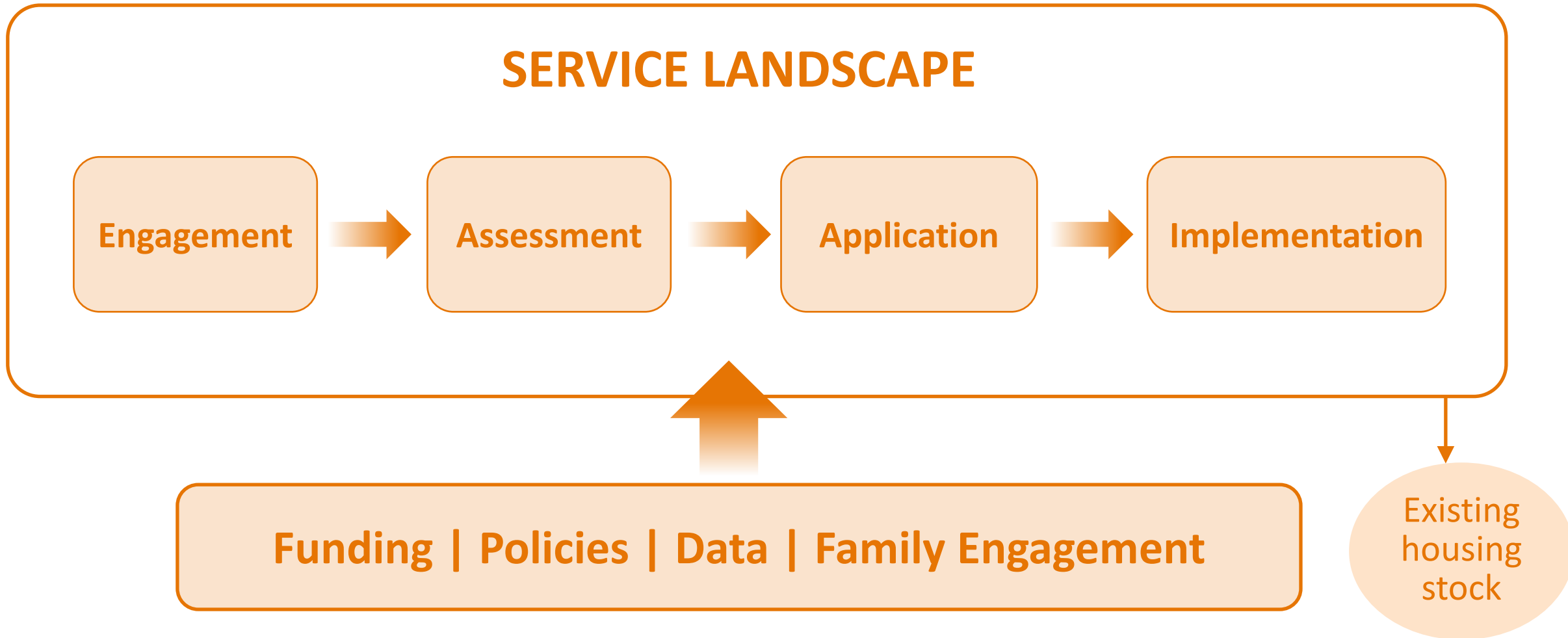


[www.openingdoors.design](http://www.openingdoors.design)

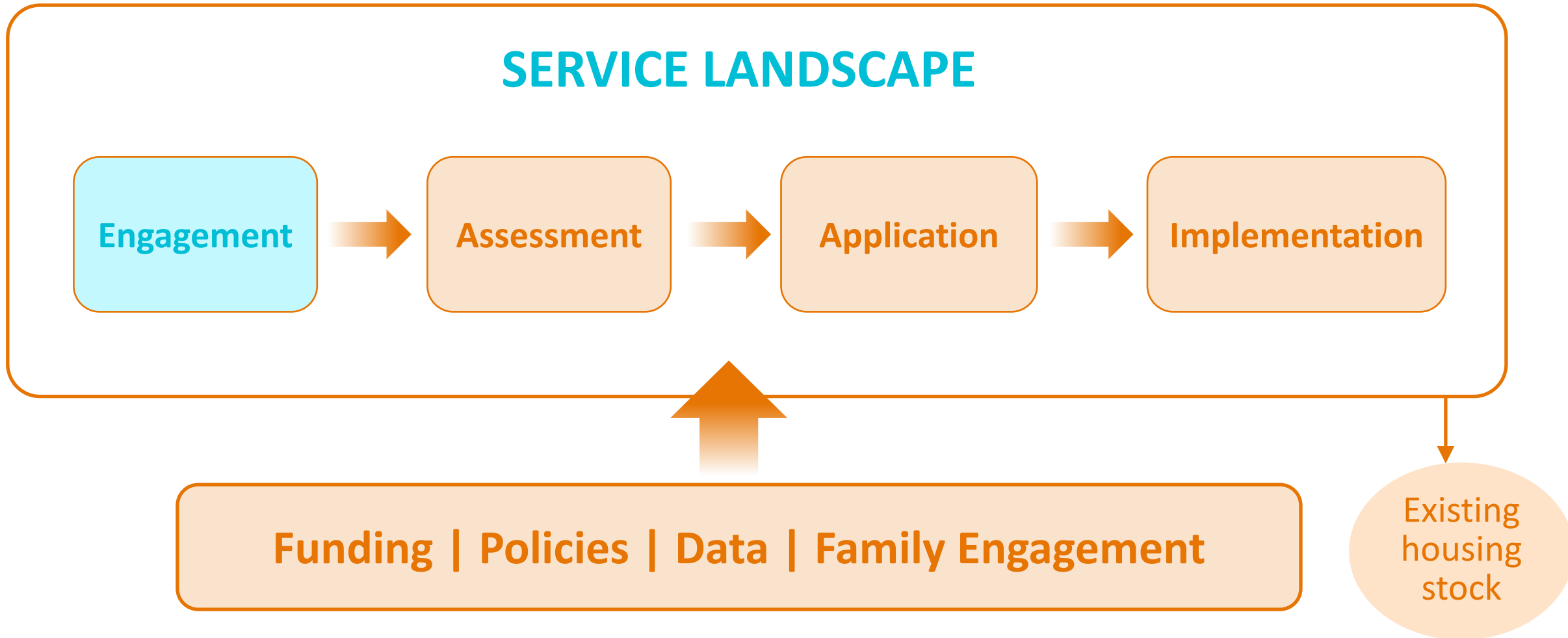


# Understanding the Landscape of Resources

# Key Informant Interview Domains



# Key Informant Interview Domains



# What Resources Exist?

# Start with the Family's Question



**“We are not sure where to start.”**

**Family-to-Family Health Information Center (F2F), Family Voices, Parent Training and Information Center**

Family-led navigation, program information, and application support.



**“We need help paying and getting the work done.”**

**Medicaid/HCBS waivers, state agencies, community organizations, non-profits**

Funding, assessment, and/or implementation of home accessibility adaptations.



**“We need equipment or technology.”**

**State Assistive Technology Program**

Device demonstrations, short-term loans, reuse programs, low-interest financing, and local referrals.



**“We need help understanding our rights.”**

**State Protection and Advocacy organization, family and disability advocacy organizations**

Help with disability rights, denials, appeals, access, and housing concerns.



## Find help in your community

43

Family Voices Affiliate Organizations  
(FVAOs)

What are FVAOs?

 [F2Fs and FVAOs: What's the difference?](#)

59

Family-to-Family Health Information  
Centers (F2Fs)

What are F2Fs?

 [Family-to-Family Health Information Centers](#)

# Home Modification Resource Directory

Home Modification Information Network



Home > **National Resource Directory**

## National Directory of Home Modification and Repair Resources

Before searching the directory or jumping to a State Resource Page, skill up on the basics below! Then, continue on to the State Resource Pages by clicking any of the state options above the map. We hope you find this information useful!



**Before you begin...**

**What is Home Modification?**

**How to Modify the Home**

**Home Modification Tips**

# Disability Services Locator

Home



Disability Information  
& Access Locator

Speak with trained staff  
Monday - Friday from 8am to 9pm ET

Find help in your community by entering a location.



Home / Resources

A listing of resources available in your community is below. To learn more about each type of agency, hover over the  icon located next to each service type.

# Potential funding pathways

*Programs may have different eligibility rules, approval processes, and waitlists.*

## STARTING POINTS

- 1 Medicaid state plan and EPSDT
- 2 Home- and community-based services waivers
- 3 State disability agencies
- 4 Other state agencies: Title V / CYSHCN, Housing, Education/Early Intervention, Aging, or Vocational rehabilitation programs
- 5 Low-interest loan programs
- 6 Local nonprofits and state-specific programs



Tikkun Olam Makers



# Connect families to assessment, technology, and local expertise

## 1 State Assistive Technology (AT) Programs

### Try before choosing

- Device demos and loans
- Equipment reuse
- Alternative financing
- Connections to AT specialists

[www.at3center.net/state-at-programs](http://www.at3center.net/state-at-programs)

## 2 Centers for Independent Living (CIL)

### Disability-led local support

- Navigation and advocacy
- Independent-living expertise
- Local program knowledge
- Some limited funding

[www.ilru.org/cil-directory](http://www.ilru.org/cil-directory)

## 3 University Centers of Excellence in Developmental Disabilities (UCEDD)

### Disability expertise and systems connections

- Assessment or AT expertise (varies)
- Training and technical assistance
- Connections to local disability services

[www.aucd.org/urc/ucedd](http://www.aucd.org/urc/ucedd)

# Rights and advocacy resources matter when families encounter barriers

## Protection and Advocacy

Every state and territory has a federally mandated disability rights organization.

### Consider referral for:

- Denials or appeals
- Disability discrimination
- Housing access or accommodation concerns
- Questions about legal rights

## F2F, The Arc, CILs

Local family and disability-led advocacy organizations can help families understand systems, prepare questions, and advocate for community inclusion.

# Keep these national directories handy



**Family Voices / F2F**

[www.familyvoices.org/findhelp](http://www.familyvoices.org/findhelp)

Navigation and  
peer support



**Disability Services Directory**

<https://dial.acl.gov/home>

Disability  
information and  
access locator



**HCBS Waivers**

[www.kidswaivers.org](http://www.kidswaivers.org)

State waiver  
information



**State AT Programs**

<https://at3center.net/state-at-programs/>

Equipment, reuse,  
loans, financing



**CIL Directory**

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Local disability-led  
navigation



**UCEDD Network**

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Disability expertise  
and connections



**Protection & Advocacy**

[ndrn.org/about/ndrn-member-agencies](http://ndrn.org/about/ndrn-member-agencies)

Rights, denials,  
appeals, housing



**Home Modification Information Network**

<https://homemods.org/national-directory/>

*Programs and eligibility vary by state*

# How Do Families Engage with these Resources?

# Families find out about home modifications through a patchworked system.

## **Family-initiated searches:**

Google, internet sites, social media, word of mouth

## **Intentional outreach from state programs/agencies:**

Webinars, community events, resource guides

## **Families linked to resources through connectors:**

F2Fs, care coordinators, disability advocacy groups, medical providers, UCEDDs, early intervention/school providers

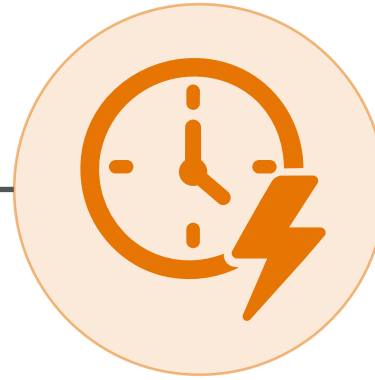
# What Prevents Families from Getting Started



**Not sure  
where to start**



**Lack of knowledge  
about home  
modifications and  
their value**



**Time  
and energy**



**Delaying  
until crisis**

*“A lot of times, families have no idea what resources are out there. There’s a panic level that hits for families. They're overwhelmed...sometimes us giving them a phone number just feels like one more thing they have to do, and they're just like, oh my god, I cannot make one more call. I don't have time.”*

*- Key Informant, State Agency, State A*

# The system makes it difficult for families to learn about home modifications.

## System Complexity

- No centralized resources; system siloed, fragmented
- Families get the "run around"
- Services/programs for children may be hidden in adult programs

## Inaccessible Information

- Too much information is overwhelming
- Information only in English and/or not plain language
- Most information requires technological/internet access
- Misinformation

“

*“It's a matter of being able to navigate this very tangled web that we have to live in in order to allow our children to have the most successful lives that they can have.”*

*– Key informant, Family Advocate, State A*

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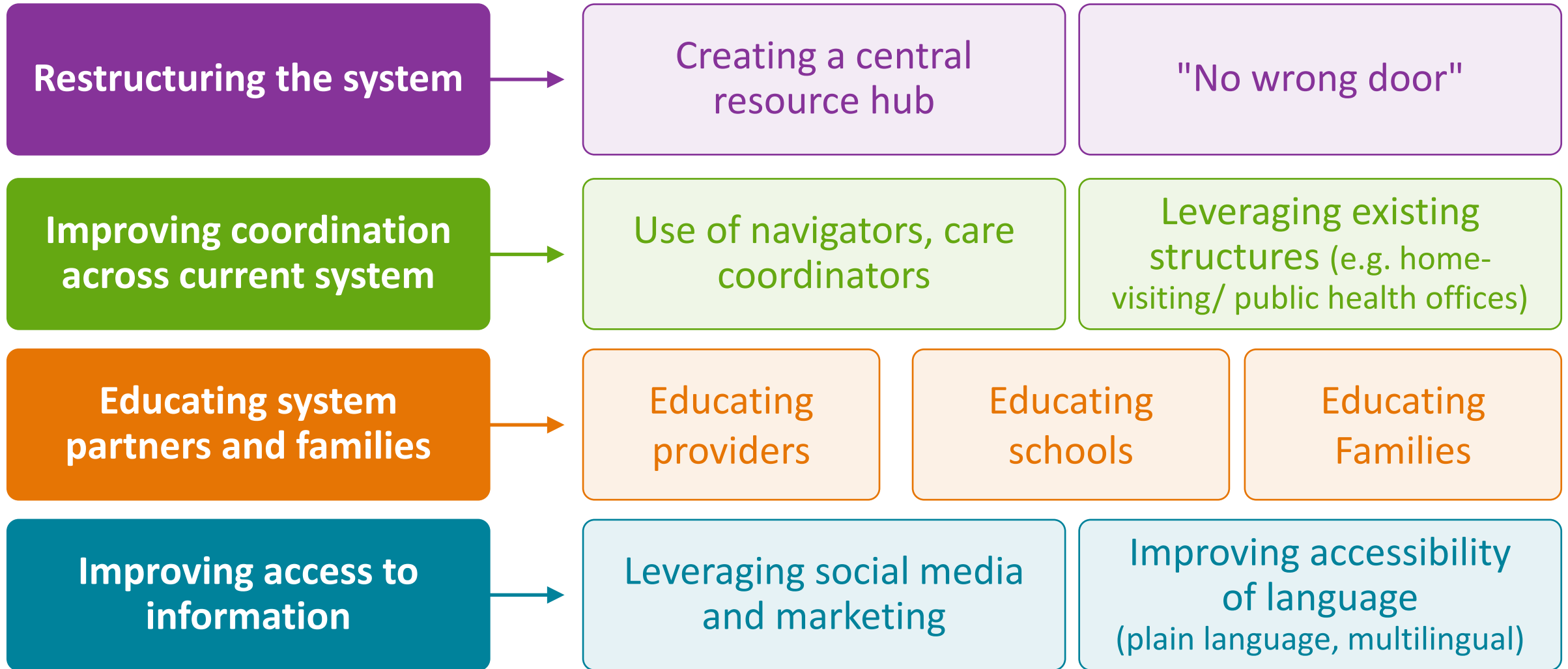
## Limited Staffing/Funding

- Limited staffing/turnover across programs
- Outreach limited, especially to rural areas
- Programs remain intentionally hidden in order to balance with demand

“So we have to find that sweet spot where it's just enough demand, but not enough to overwhelm us, right? Cuz once you get there and you have to put people on a waiting list, then we're in a bad light with the community.”

– Key informant,  
Program Staff, State D

# We can increase awareness of home modification resources among families by:



“

*Having a website that would say here's a diagnosis, and then here is how you get connected to the home modification...It could be so much easier for everybody, and I mean, this is where technology could really be good for us if we would just figure it out.*

*– Key informant, Family advocate, State B*

”

# Panel Discussion

- Tami Allen
- Lori Berrong
- Molly Hofmann

*Moderator: Callie Kaplan*

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# Opening doors to home accessibility



**More to come!**  
**Keep an eye out for our**  
**upcoming informational**  
**handouts and resource guide**