

April 10, 2025

FEELS LIKE HOME

AGENDA

- 04:00 - 04:10 pm** **Welcome Remarks**
- 04:10 - 04:25 pm** **Pre-Screening**
Feels Like Home
- 04:25 - 04:40 pm** **Fireside Chat**
Learnings from the film team
- 4:40 - 05:30 pm** **Panel Discussion**
Why home accessibility matters
- 05:30 - 06:30 pm** **Reception at the Gallery**
An exhibition highlighting the systems and stories shaping home accessibility

A COLLABORATION BETWEEN



i D E A S
L A B

Planning Team

Faculty Leads

Rebecca Seltzer, Andre Nogueira

Dracopoulos-Bloomberg iDeas Lab, Johns Hopkins Berman Institute of Bioethics
Lauren Arora Hutchinson, Anna Oakes

Event Design

Anushka Jajodia, Akshay Pagar, Martin Thaler.

Gallery Installation

Andrea Bertino

Printing

Alpha Graphics, Baltimore

Tech & Facilities

Meredith Medina, Richard Robinson III, Marz Macahia

Event Photographer and Videographer

Daniel Martinez

Adaptive Equipment/Assistive Technology contributions to the exhibit:

MDTAP, Adaptive Design Association, TOM

RESILIENCE Center team

Debbie Gross, Janiece Taylor, Alicia Cooke, Brian Fitzek, Samantha Curriero, Kennedy McDaniel, Thomas Cudjoe, Advisory Board members

Land Acknowledgement

We respectfully acknowledge and give thanks to the Piscataway Tribe – the Indigenous people who are traditional stewards of the lands of the Chesapeake Bay region. We also acknowledge all Indigenous Peoples, the traditional stewards of the lands and waters of the United States of America.

Funding Acknowledgement

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Welcome,

Thank you for joining us today as we come together to explore the realities of life at home for families of children with disabilities and medical complexities. We will begin by sharing a powerful short film produced by the Dracopoulos-Bloomberg iDeas Lab that offers an intimate look into the joys, struggles, and everyday experiences these families face in their homes.

After the film, we will have a conversation with the production team followed by a panel discussion, where we will dive deeper into a discussion about the value of home modifications and the true cost of not making these changes. You'll also have the opportunity to experience a gallery exhibition that highlights the systems and stories shaping home accessibility.

This event is part of a broader initiative called Opening Doors to Home Accessibility: Designing Keys For Children With Disabilities To Thrive. This initiative aims to advance and accelerate actions that improve home accessibility for all children with disabilities in Maryland and beyond.

We hope today sparks new ideas, strengthens connections, and inspires action that will create lasting change for families who need accessible, functional, and supportive homes.

Thank you for being part of this event—we're excited to share this experience with you.

With thanks,

Rebecca Seltzer

Associate Professor of
Pediatrics
Johns Hopkins School
of Medicine

Andre Nogueira

Assistant Professor of
Design Knowledge
Johns Hopkins School
of Nursing

Lauren Arora Hutchinson

Director
Dracopoulos-Bloomberg iDeas
Lab, Johns Hopkins Berman
Institute of Bioethics

FEELS LIKE HOME

SHORT FILM

Feels Like Home is a short film developed by the Dracopoulos-Bloomberg iDeas Lab of the Berman Institute of Bioethics, in close partnership with Dr. Rebecca Seltzer. This film is one element of a larger interactive audiovisual experience highlighting how families of children with disabilities and medical complexity adapt their home environments to meet their child and family's needs.

For the past year, the iDeas Lab has developed relationships with families across the country, from Ohio to California to Maryland. The film draws entirely from footage sourced from these families, detailing moments throughout their homes – from physically navigating through the house, to birthday celebrations – to capture both the joys and challenges of daily life and families' ingenuity in adapting their homes.

By increasing visibility of the lived experience of these families, we seek to advocate for greater home modification support for these families. The Lab has collaborated closely throughout this process with Cara Coleman and Lora Batson, parents of children with medical complexity, as advisors and guides.

Production

iDeas Lab

Directed by

Mike Attie and Kat Poljak

Produced by

Anna Oakes

Executive Produced by

Lauren Arora Hutchinson

Funded by

Johns Hopkins Discovery Awards

In collaboration with

Rebecca Seltzer, Cara Coleman, Lora Batson, and the Johns Hopkins Disability Health Research Center

AUDIO INSTALATION

Sounds Like Home is an immersive audio installation developed by the iDeas Lab of the Berman Institute of Bioethics that brings audiences into the home space of families of children with disabilities and medical complexity. Using audio footage sourced directly from families, who themselves recorded the sounds of their homes, the installation imparts the joys, challenges, and everyday moments of life for children with medical complexity.

Production: Lauren Arora Hutchinson, Anna Oakes and Hannis Brown.

FIRESIDE CHAT

After the pre-screening, Andre Nogueira invites Lauren Arora Hutchinson and Anna Oakes to a fireside chat. Together, they reflect on their production processes and key learnings from Feels Like Home.



Lauren Arora Hutchinson

Director, Dracopoulos-Bloomberg iDeas Lab,
Assistant Research Professor Johns Hopkins
Berman Institute of Bioethics

Lauren Arora Hutchinson joined the Johns Hopkins Berman Institute of Bioethics in June 2022 as the inaugural director of the Dracopoulos-Bloomberg iDeas Lab, a creative studio and incubator for world class stories at the intersection of science, ethics, medicine and public health. She was previously a BBC journalist, award-winning audio storyteller, and academic who founded the immersive audio studio Sunday Blue as a way to further explore the intersection between sound, story and interactivity. Hutchinson holds a PhD in the History of Science with a focus on Oral History from the London School of Hygiene and Tropical Medicine, where she taught in the Masters for Global Public Health program for six years, and completed a Wellcome Trust Imperial Media Fellowship to develop skills in science communication.



Anna Oakesto

Journalist and Producer,
Dracopoulos-Bloomberg
iDeas Lab.

Anna Oakes is a journalist and podcast producer. She has worked at the iDeas Lab since 2023, helping produce English- and Spanish-language multimedia projects around data privacy, medical ethics, and public health. Prior to joining the Lab, she spent over two years as the producer and co-host of Bot Love, a series with Radiotopia that was first developed in collaboration with the iDeas Lab. She is currently pursuing an MS in Journalism at Columbia University.

WHY HOME ACCESSIBILITY MATTERS

The evening continues with a panel discussion moderated by Cara Coleman focused on the costs of not doing and the value of doing home modifications for families with children with disabilities and medical complexity.



Cara Coleman

Principal at Bluebird Consulting/ Director of the Bluebird Way Foundation

Cara Coleman is Principal at Bluebird Consulting and Director of the Bluebird Way Foundation- a 501(c)3 committed to using the arts, humanities, storytelling and narrative medicine to humanize health care and health profession education. The foundation is in honor of and carries on the work of her daughter, Justice Hope, who had disabilities and was medically complex. In 2012, Justice and Cara began reading the children's book Cara wrote, *I am Justice, Hear me Roar*, to medical students and residents. Cara is also an Instructor of Medical Education at University of Virginia Medicine INOVA Campus and Associate Editor for Family Partnerships, Pediatrics Executive Editorial Board.



Carolyn Foster

Assistant Professor of Pediatrics at Northwestern University Feinberg School of Medicine

Dr. Carolyn Foster is a tenure track Assistant Professor of Pediatrics at Northwestern University Feinberg School of Medicine and an attending physician at Ann & Robert H. Lurie Children's Hospital of Chicago in primary and complex care. As a primary investigator of the Foster Health Lab, she holds NIH, AHRQ, and Lucile Packard Foundation for Children's Health funding to improve the health of children with disabling chronic conditions, while reducing health-care related stress for their families, through innovative healthcare design, research, and policy change. She directs Lurie Children's Stanley Manne Research Institute's Health@Home Initiative to catalyze innovation in pediatric healthcare delivered outside hospital walls by designing, developing, and evaluating novel digital tools and devices for care at home and in the community where children and families live their everyday lives.



Tamara Morgan

Community Partnerships
Coordinator, Adaptive
Design Association, Inc.

Tamara holds a Master’s degree in Creative Art Therapy from New York University and has four years of experience in preventive support services for families and youth. At Adaptive Design, she is dedicated to supporting children with disabilities and their families through advocacy, public speaking, development, and community outreach. She oversees all community-building initiatives, including school programs, corporate workshops, volunteer engagements, and internship programs, ensuring they run efficiently and effectively. In addition to her work at Adaptive Design, Tamara serves on the boards of three organizations: Philanthropy Leaders, the Museum, Arts & Culture Access Consortium (MAC), and the Southern California University of Health Sciences. Her leadership across these sectors reflects her deep commitment to inclusive education, accessibility, and community-driven impact.



Dominique Sessa

Chairwoman of the
Maryland Technology
Assistive Loan Program
Board

Dominique Sessa serves as the Chairwoman of the Maryland Technology Assistive Loan Program Board and a former Commissioner on the Maryland Commission on Disabilities. Her contributions and dedication to the disability community have led to her being recognized at both the local and state level. She even has had the immense privilege of being a voice for Marylanders at the federal level and at nationwide organizations. At 17, she created a digital platform called The Girl in The Pink Wheelchair to help create a community and advocacy platform for young women and women with disabilities. She was Ms. Wheelchair Maryland 2024, which allowed her to promote her platform of “Disability Shouldn’t Have a Price Tag.” At the Ms. Wheelchair America competition, she was the recipient of the Nicki Ard Achievement. She now serves as the State Coordinator, along with her mother, for the Ms. Wheelchair Maryland program.



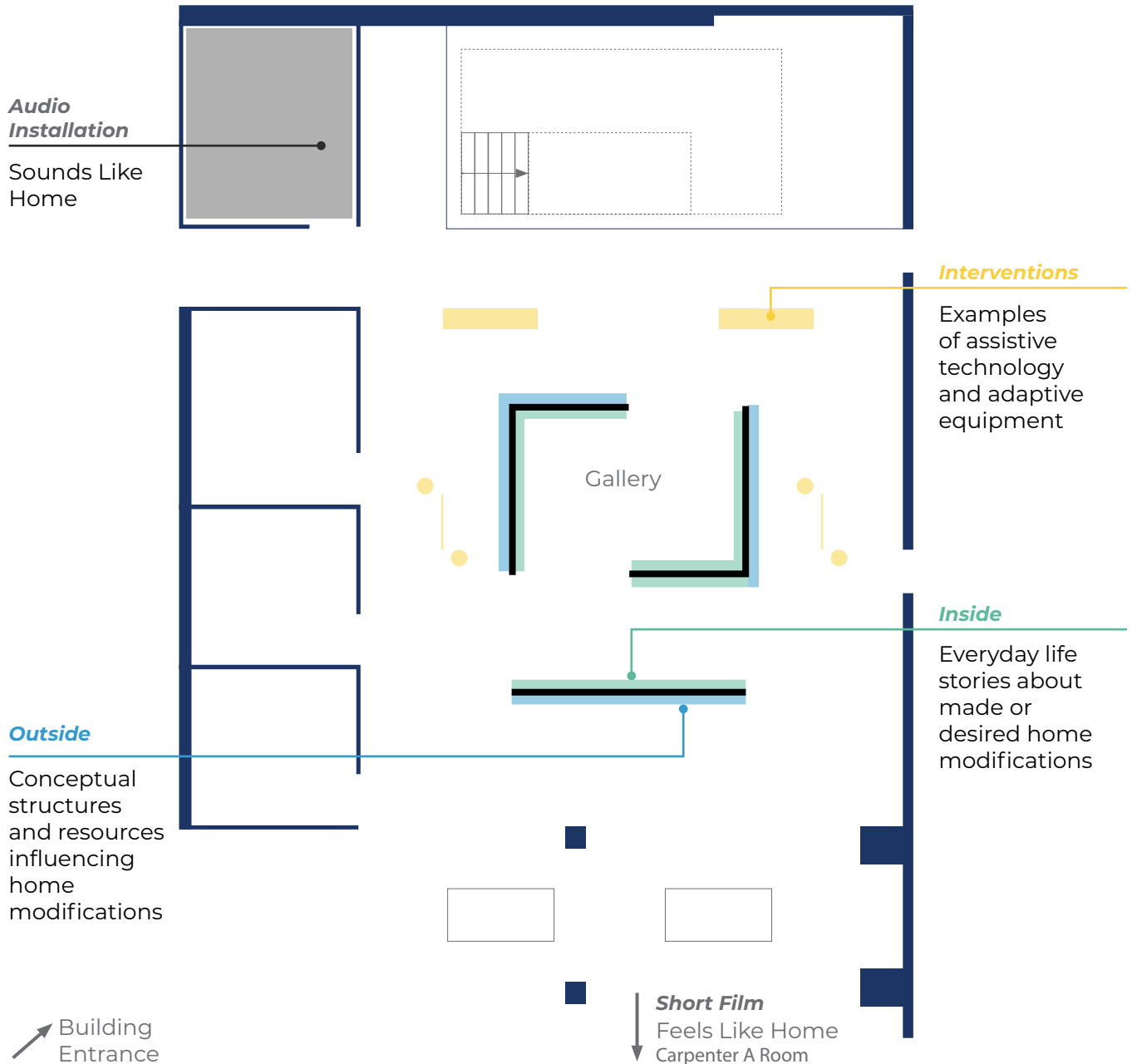
Stacy Taylor

Deputy Director, Office of
Children and Youth with
Specific Health Care Needs
Maryland Department of Health.

Stacy Taylor lives in Baltimore County with her husband, children and 2 cats. She is the mother of 4 youth and young adults with various disabilities. Her two youngest - ages 16 and nearly 18 - have complex medical conditions that include physical disabilities. Stacy is the Deputy Director of the Office of Children and Youth with Specific Health Care Needs at the Maryland Department of Health.

SYSTEMS AND STORIES THAT SHAPE HOME ACCESSIBILITY

A reception at an installation containing information about the conceptual structures and existing resources influencing home accessibility, examples of modifications, and stories of everyday life that reflect the lived experiences of families at home.



FACULTY LEAD



Rebecca Seltzer

Associate Professor of Pediatrics
Johns Hopkins School of Medicine

Rebecca Seltzer MD, MHS is an Associate Professor of Pediatrics at the Johns Hopkins School of Medicine in the Division of General Pediatrics, with joint faculty appointments at the Johns Hopkins School of Nursing, Berman Institute of Bioethics, and Bloomberg School of Public Health. Her academic work, which intersects research, clinical care, advocacy, and medical education, focuses on optimizing the care and well-being of children with medical complexity and disabilities.

Her research aims to inform interventions, practice, and policy that strengthen and support families to care for children with medical complexity in their own home, as opposed to in a hospital or foster care setting. Clinically, she is a general pediatrician at the Harriet Lane Primary Care clinic, where she teaches pediatric residents and medical students.



Andre Nogueira

Assistant Professor of Design Knowledge
Johns Hopkins School of Nursing

André Nogueira, Ph.D., holds the first-of-its-kind position as an Assistant Professor of Design Knowledge at the Johns Hopkins School of Nursing and a member of the Bloomberg Distinguished Professorships Cluster, Knowledge to Action and the Business of Health. Through his work, he intersects design knowledge with other disciplines to drive systems-level transformations. His solution-oriented research explores how design can help improve the well-being of people and the ecosystems within which they live.

Over the last two decades, André has helped institutions in his home country, Brazil, and in the US build design laboratories that bridge theory and practice through cross-sector partnerships, influencing public policy. His work, funded by public, private, and social sector organizations has earned him the 40 Under 40 Public Health Catalyst Award. Before moving to the U.S., André worked on business development, sustainability strategies, and urban and architectural design in Brazil and Mexico.

THE RESEARCH BEHIND THE EVENT

This initiative leverages design approaches for catalyzing systems change developed by Andre Nogueira and colleagues, to bring to life several years of research led by Dr. Rebecca Seltzer and colleagues to better understand life at home for families of children with disabilities and medical complexity.

Since 2020, the team has conducted surveys and interviews with Maryland families, utilized photovoice methodology to capture the home environment from the family's perspective, piloted an adapted intervention (CAPABLE Kids) to implement low-cost home modifications, and interviewed policymakers, advocates, and community-based programs to assess existing policies and support systems for home modifications.

These research projects are described next and represent a collaborative effort among researchers, clinicians, trainees, and parents of children with disabilities and medical complexity, whose lived experiences are integral to this work.

Housing and Household Expenses Survey and Interviews

- Conducted surveys (n=137) and interviews (n=31) with parents/guardians of children and youth (under 26 years old) with special healthcare needs between July and December 2020. The study included a diverse sample of families across Maryland.
- Parents/guardians completed a survey covering demographics, child medical care needs, household expenses, financial supports, and housing-related factors such as structure, adequacy, and stability concerning their child's care needs.
- A subset of parents participated in in-depth, semi-structured interviews about their housing experiences.
- Recruitment was conducted in partnership with Parents' Place of Maryland and The Coordinating Center.
- Research Team: Pamela Donohue (PI), Rebecca Seltzer, Renee Boss, Brandon Smith, Danielle Gaskin, Breanna Watson, Karen Fratantoni, Kate Detweiler
- Funder: Thomas Wilson Foundation

Through the Family's Lens: Photovoice Study

- Parents/guardians of children with medical complexity (n=13) took photos of their home environments to highlight barriers or facilitators affecting their child's function, independence, and quality of life. Participants uploaded up to 10 photos and discussed them in a semi-structured interview.
- Recruitment was conducted in partnership with Parents' Place of Maryland and The Coordinating Center.
- Research Team: Rebecca Seltzer (PI), Pamela Donohue, Brandon Smith, Mona-Esmat Jarrah, Lora Batson, Caitlin Nalda
- Funder: Thomas Wilson Foundation

CAPABLE Kids: Pilot Intervention (In Progress)

- Community Aging in Place - Advancing Better Living for Elders (CAPABLE) is an innovative, evidence-based, person-centered intervention that provides low-cost home modifications to older adults with chronic medical conditions and disabilities. This adaptation supports children with medical complexity and their families.
- The pilot study includes 20 families with children (ages 5-17) who have complex medical needs in Baltimore City and Baltimore County.
- Research/Clinician Team: Rebecca Seltzer (PI), Shelbie Atkins, Eliana Perrin, Sarah Szanton, Ally Evelyn-Gustave, Susan Huff, Patricia Romond, Francesca Gill, Angela Bellan, Samantha Tobon, Rebecca Singer Cohen, Sharon Gifford, Elizabeth Szymanski, Laura Pritchett
- Parent Partners: Crystal Thomas, Darcel Jackson
- Home Modifications by: Civic Works
- Funders: National Institute on Disability, Independent Living, and Rehabilitation Research; Johns Hopkins Children's Center Innovation Grant

Optimizing the Home Environment for Children with Disabilities: Understanding Current Policies and Planning for The Future (in progress)

- This study aims to assess existing programs and policies that promote housing accessibility and home modifications for children with disabilities across 10 states within the Health Resources and Services Administration regions
- In partnership with the Lucile Packard Foundation for Children's Health and guided by an advisory board—including parent partners, housing and disability policy researchers, legal and disability advocacy experts, and key government agencies—this project will develop a proposal for a national convening to shape a policy agenda focused on optimizing home environments for children with disabilities.
- Research Team: Rebecca Seltzer (Co-PI), Carolyn Foster (Co-PI), Callie Kaplan, Merone Eshetu, Irete Obaitan
- Parent Partners: Cara Coleman, Kate Detweiler, Darcel Jackson, Crystal Thomas
- Funder: Lucile Packard Foundation for Children's Health

Home Modifications Resource Project

- Project team: Prayernal Uppal (lead), Rebecca Seltzer, Pamela Donohue
- Partners: FindHelp.org, Hopkins Community Connections

Recommended Papers

Home Modifications for Children With Medical Complexity: Untapped Potential for Improving Care (2022)

The Home-Built Environment of Children With Medical Complexity (2024)



A BOLD INITIATIVE

This event is part of *Opening Doors to Home Accessibility*, a bold initiative dedicated to ensuring that children with disabilities and their families have homes that support their unique needs and aspirations.

Led by Rebecca Seltzer and Andre Nogueira, the goal of this initiative is to activate and mobilize cross-sector partnerships and investments to improve access to essential home modifications for families across Maryland.

To create meaningful change, we must rethink the foundational systems and supports that shape home accessibility for children with disabilities and their families.

A Systems Approach to Home Accessibility

In this first phase, we will explore ways that different parts of Maryland's ecosystem can collaborate to develop new institutional frameworks, support systems, and equitable pathways to home accessibility. Most importantly, all interventions must be rooted in the lived experiences of families with children with disabilities and the goals they seek to achieve.

While this initiative focuses broadly on children with disabilities, much of our research has centered on families of children with medical complexity. Their photographs and stories, featured throughout this exhibition, provide a window into their experiences.

Breaking Silos, Building Solutions

Collaboration across sectors is essential to making progress in home accessibility. While it is challenging for a single organization to drive change alone, the complexity increases across sectors, where diverse—and sometimes competing—priorities exist. Yet ensuring that children with disabilities and their families have access to home modifications is a systemic challenge that no single organization can address in isolation.

This initiative aims to bridge these gaps by bringing together key stakeholders from often-disconnected sectors to shape policies and solutions that empower families to create home environments that truly meet their needs.

If we envision a world where all children thrive at home and in their communities, we must ask:

What systems must we design to ensure children with disabilities and their families are fully included and supported?

April 11, 2025

Opening doors to home accessibility



Designing keys for children
with disabilities to thrive

A convening bringing
together persons
with lived experience,
advocates, program
leaders, policymakers,
and field experts to
expand and accelerate
actions that improve
home accessibility.



JOHNS HOPKINS
SCHOOL of MEDICINE



JOHNS HOPKINS
SCHOOL of NURSING

Planning Team

Faculty Leads

Rebecca Seltzer, Andre Nogueira

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Welcome,

We are so grateful to have you here!

Our goal is to advance and accelerate actions that improve home accessibility for all children with disabilities in Maryland. Today, we are here to learn from each other and share experiences. We will explore the value of home accessibility, the cost of not addressing these needs, and the resources currently available to families in Maryland.

Throughout the day, we will also identify gaps and opportunities in current systems, barriers families may face navigating resources, and explore ways through which different sectors can work together to better support families. Your insights and expertise are vital as we join toward a future where every family has the resources they need, and where all children have a home that supports their needs and allows them to thrive.

Thank you for being part of this important movement.

With thanks,

Rebecca Seltzer

Associate Professor of Pediatrics
Johns Hopkins School of Medicine

Andre Nogueira

Assistant Professor of Design Knowledge
Johns Hopkins School of Nursing

A BOLD INITIATIVE

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Faculty Leads



Rebecca Seltzer

Associate Professor of Pediatrics
Johns Hopkins School of Medicine

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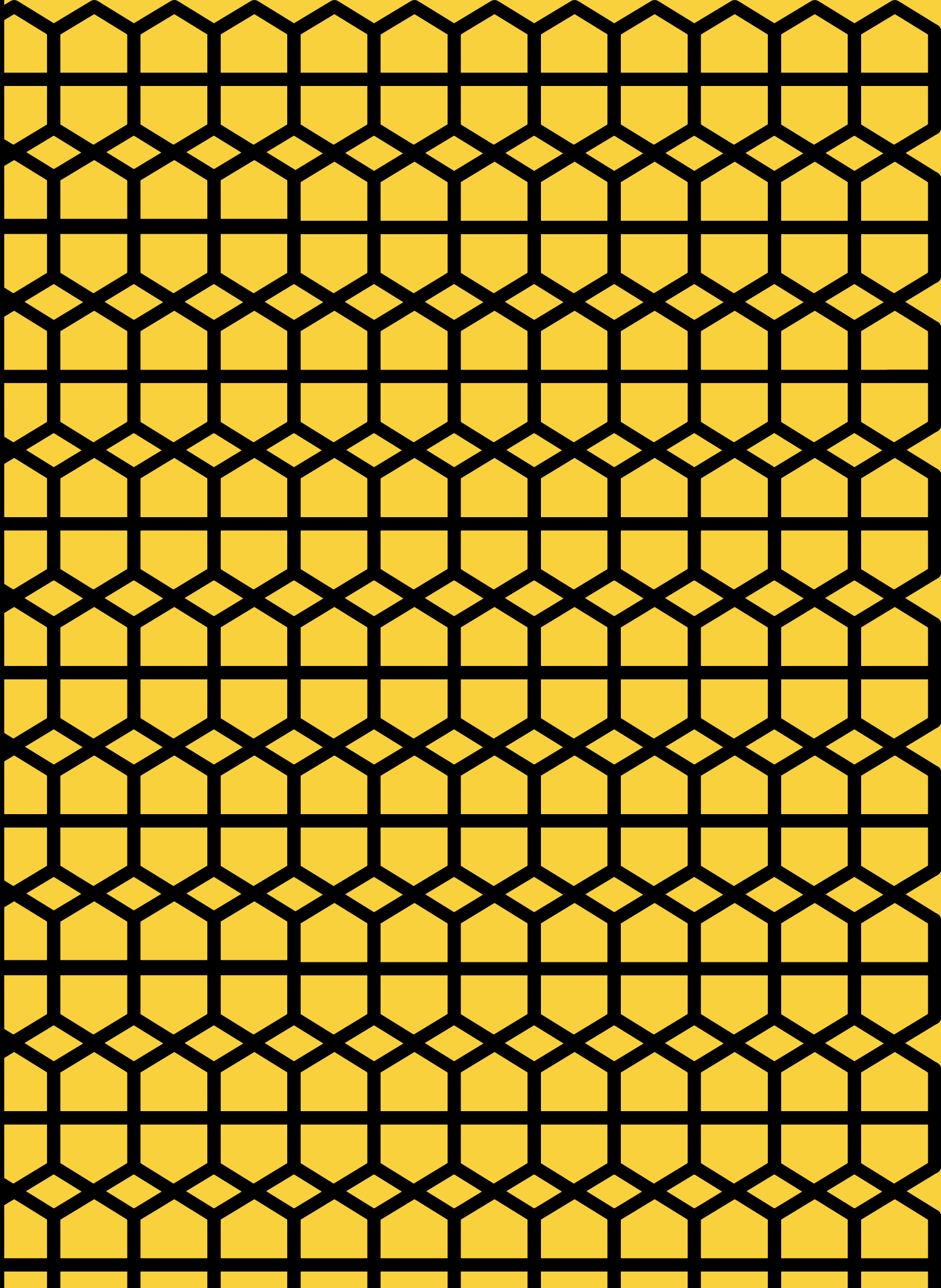


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AGENDA



09:00 - 09:30 am **Check-in and Breakfast**

09:30 - 09:45 am **Opening Remarks** Welcome

09:45 - 10:15 am **Overview** Why Are We Here & What Do We Know

10:15 - 11:30 am **Gallery Exploration** Systems and Stories

11:30 - 12:15 pm **Co-Design** Connecting With Purpose

12:15 - 01:30 pm **Lunch & Learn Panel**

Barriers & Opportunities To Home Modifications

01:30 - 03:00 pm **Co-Design** Pathways To Home Accessibility

03:00 - 04:00 pm **Collective Reflections**

Share Out, Discussion, and Closing Remarks

Opening Remarks
09:30 - 09:45 am

OPENING REMARKS

The day starts with opening remarks from Rebecca Seltzer and the artist and health care and disability rights advocate, Rob Stone.



Rob Stone

Artist & Health care and disability rights advocate

Rob Stone is a 2018 Walt Whitman High School graduate. After leaving high school, Rob wanted to be a health care and disability rights advocate, so he began advocating with Little Lobbyists in 2019. Rob has been part of Capitol Hill press conferences and met with U.S. Senate and House congresspersons and staff.

He also works with the Self-Directed Advocacy Network and other groups on state issues, and has testified before the Maryland General Assembly. He is a 2020 graduate of The Arc's Partners in Policymaking program. Rob enjoys writing poetry, composing music, and making art. He lives in Bethesda, Maryland.

WHY ARE WE HERE & WHAT DO WE KNOW

Opening Doors

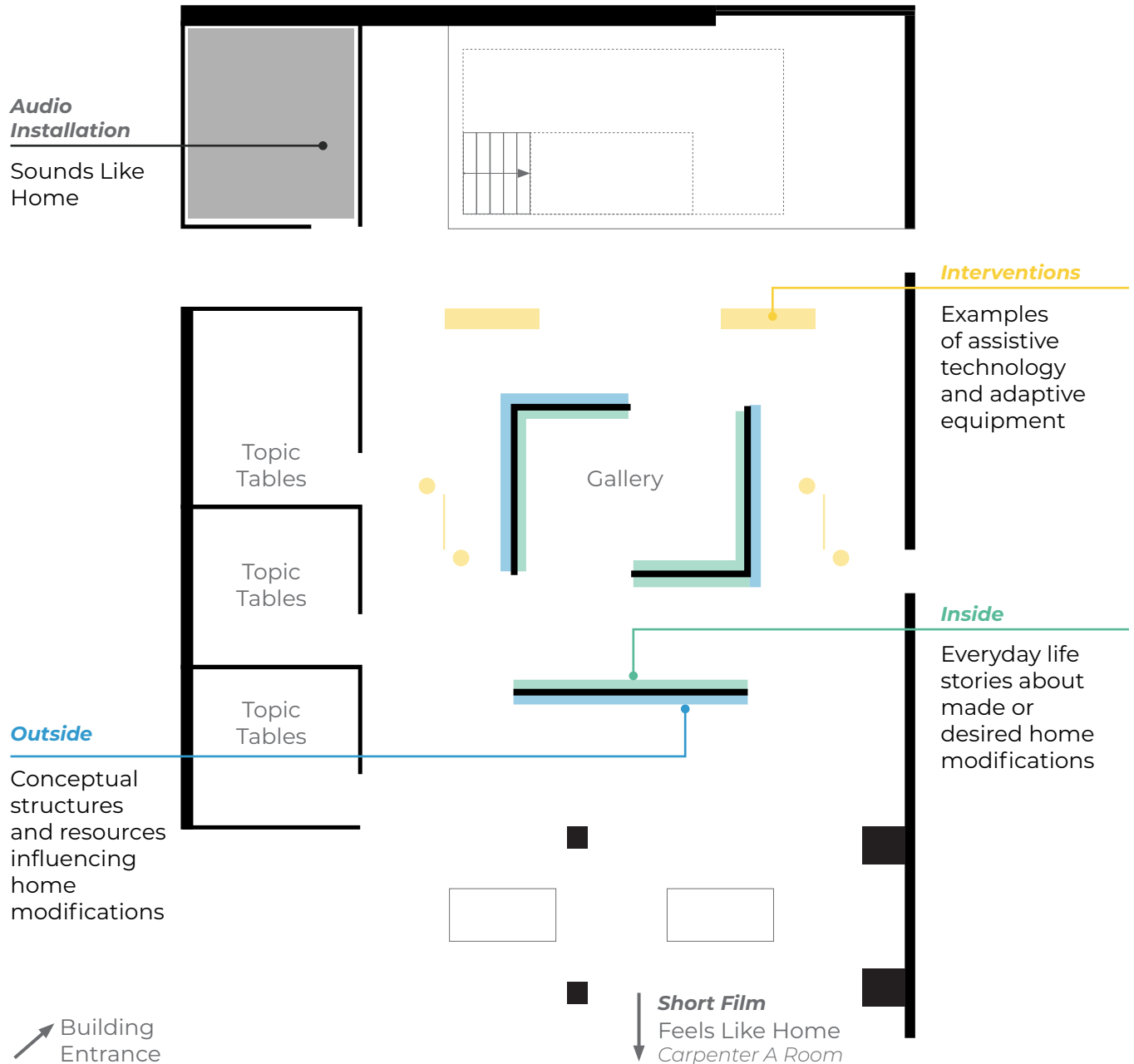
Dr. Seltzer provides an overview of why this work is important for families of children with disabilities and medical complexity and why it matters for all.

She introduces what is known from prior and ongoing research in Maryland and shares her views around where we might go from here.

The goal is to provide an overview of the context, highlighting existing resources, families' experiences in accessing them, and the remaining unmet home accessibility needs for families with children with disabilities.

SYSTEMS AND STORIES THAT SHAPE HOME ACCESSIBILITY

An opportunity to explore an installation and topic tables containing information about the conceptual structures and existing resources influencing home accessibility, examples of modifications, and stories of everyday life that reflect the lived experiences of families at home.



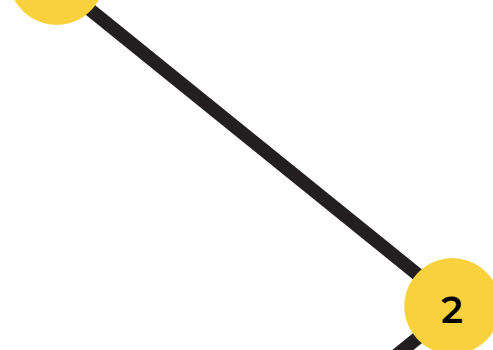
CENTERING ON PURPOSE

After the gallery exploration, participants move into pre-arranged team tables. Facilitated by Andre Nogueira, this activity involves individual reflection, pair conversations, and team introduction and discussion, supporting participants to meet and learn from each other in the context of our shared purpose.

5'

Individual Reflection

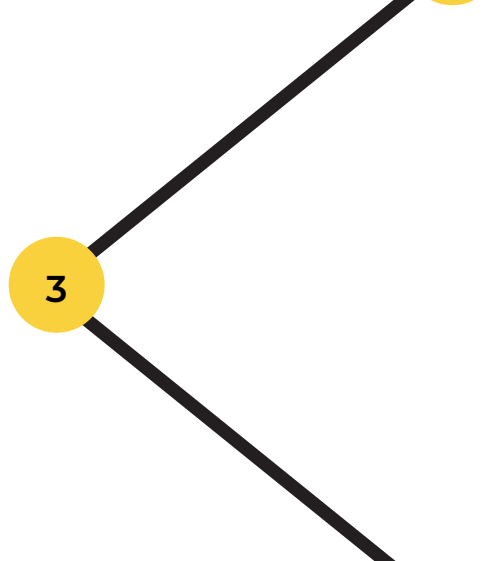
Participants reflect on why they came to the event and a story related to a successful change they were involved in.



15'

Pair Conversation

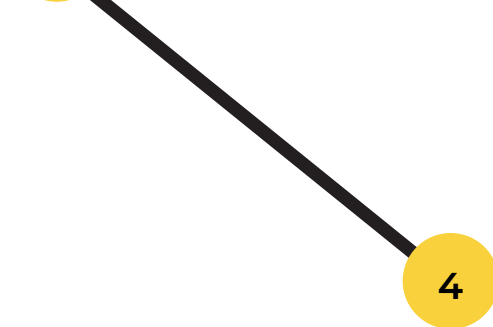
In pairs, participants share their reasons and story with one another through a guided protocol.



15'

Team Introduction

Participants share their colleague's reasons and story with the rest of the table.



10'

Team Reflection

Team discussion around their shared purpose and the next activity.

Lunch and Learn
12:15 - 01:30 pm

BARRIERS & OPPORTUNITIES

The day continues with a panel discussion moderated by Rebecca Seltzer focused on barriers and opportunities to home modifications for children with disabilities in Maryland.



Rosie Rivera Lily

Director of Engagement,
Parents' Place of Maryland

Rosa Rivera-Lily serves as the Director of Engagement at The Parents' Place of Maryland, where she works to ensure that underserved and underrepresented families—particularly those whose first language is not English—are informed, included, and empowered across the state of Maryland. Prior to joining The Parents' Place of Maryland, she spent over 15 years as an Operations Manager for a large medical laboratory. Her professional path shifted after the birth of her medically complex daughter, igniting her passion for advocacy and support for families navigating similar journeys. Rosa is the proud mother of a young daughter with congenital heart disease, Epilepsy, bilateral hearing loss, and Cortical Vision Impairment, who attends the Maryland School for the Blind. She is an active member of both the school community and the broader Baltimore City Latino community. Fluent in English and Spanish, Rosa is dedicated to building bridges and creating inclusive spaces for families throughout Maryland.



Chris Mason-Hale

Community Advocate,
Maryland Center for
Developmental Disabilities

Chris Mason-Hale is the Community Advocate at the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute. Mason-Hale is a former trainee of the Maternal and Child Health Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) program and a recent graduate of the University of Maryland, Baltimore County, where he received a bachelor's degree in social work. He also serves in Kennedy Krieger's Ethics Program as a member and identifies as a person with a disability.



Lori Berrong

Executive Director,
Assistive Technology
Program, Maryland
Department of Disabilities

Lori Berrong serves the Executive Director of the Maryland Department of Disabilities, Assistive Technology Program. As an AT Specialist working in the disability and AT field for over 20 years, Lori has a breadth of assistive technology knowledge and experience. She holds a BA and MFA from the University of Baltimore, post graduate certification in Assistive Technology Applications from California State University Northridge and is currently completing a Masters in Special Education Applied Behavior Analysis from Bowling Green State University. She's the mom of 3 children, one of whom has a learning disability and two of whom have ADHD.



Delegate Aaron Kaufman

Maryland House of
Delegates

Aaron Kaufman is the Senior Manager of Legislative Affairs at the Jewish Federations of North America's Washington DC. Aaron came from the Arc Maryland where he lobbied members of the Maryland General Assembly and the Maryland Congressional delegation on issues affecting Marylanders with intellectual and developmental disabilities and their families. He worked in the offices of then Congressman (now Senator) Chris Van Hollen and former Senator Evan Bayh as well as the Easter Seals Office of Public Affairs. In addition to working at JFNA, Aaron is a member of the Maryland House of Delegates where he serves on the Judiciary Committee. Having Cerebral Palsy, Aaron feels he brings a unique perspective to his work in the House of Delegates and JFNA's efforts on behalf of people with disabilities. Outside of advocacy, he was the instructor in Project SEARCH Montgomery, a job-training program for young adults with significant disabilities.

PATHWAYS TO HOME ACCESSIBILITY

This is a 90-minute exercise in the same teams. Starting with a scenario presented by the organizers, teams explore a future where the diverse families can succeed in modifying their homes. Then, they map the resources they need and the organizations they interact with throughout their journey.

20'

Intent Statement

Participants envision a future where families are able to succeed in making their home accessible.

1

25'

Future Scenario

Participants describe their future intention considering the journey that families will have to go through.

2

25'

Resource Mapping

Participants map available and desired resources against the journey they created.

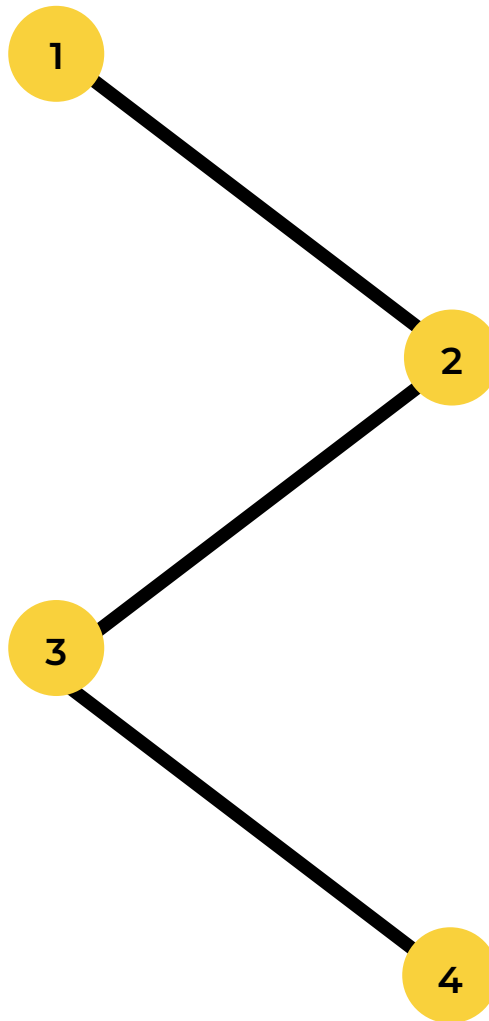
3

20'

Team Reflection

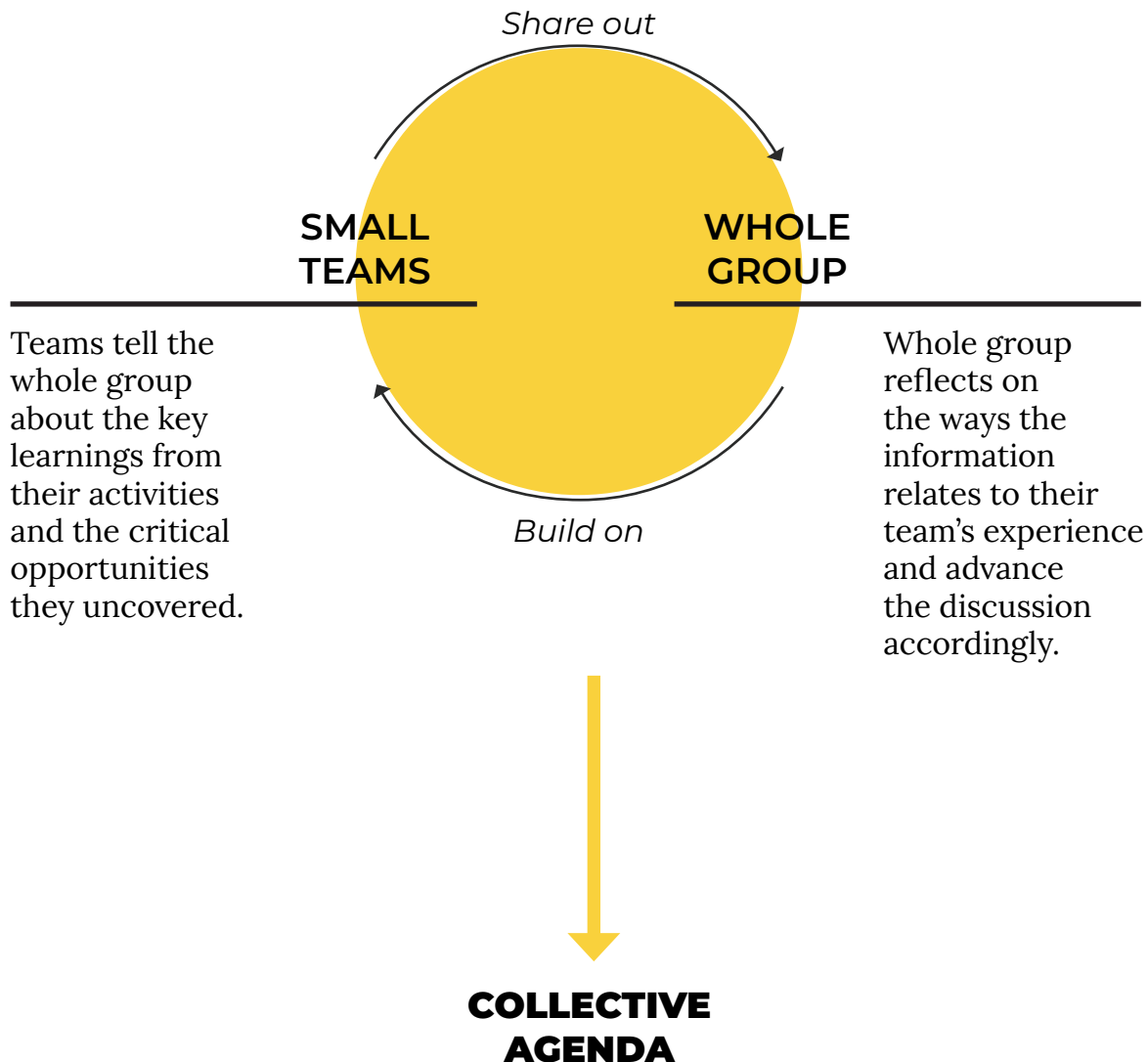
Teams discuss and prepare to share their learnings, new questions, and critical opportunities forward.

4



COLLECTIVE REFLECTIONS

During our final hour, teams share their learnings, new questions, and future opportunities in a facilitated conversation.



THE RESEARCH BEHIND THE CONVENING

This initiative leverages design approaches for catalyzing systems change developed by Andre Nogueira and colleagues, to bring to life several years of research led by Dr. Rebecca Seltzer and colleagues to better understand life at home for families of children with disabilities and medical complexity.

Since 2020, the team has conducted surveys and interviews with Maryland families, utilized photovoice methodology to capture the home environment from the family's perspective, piloted an adapted intervention (CAPABLE Kids) to implement low-cost home modifications, and interviewed policymakers, advocates, and community-based programs to assess existing policies and support systems for home modifications.

These research projects are described next and represent a collaborative effort among researchers, clinicians, trainees, and parents of children with disabilities and medical complexity, whose lived experiences are integral to this work.

Housing and Household Expenses Survey and Interviews

- Conducted surveys (n=137) and interviews (n=31) with parents/guardians of children and youth (under 26 years old) with special healthcare needs between July and December 2020. The study included a diverse sample of families across Maryland.
- Parents/guardians completed a survey covering demographics, child medical care needs, household expenses, financial supports, and housing-related factors such as structure, adequacy, and stability concerning their child's care needs.
- A subset of parents participated in in-depth, semi-structured interviews about their housing experiences.
- Recruitment was conducted in partnership with Parents' Place of Maryland and The Coordinating Center.
- Research Team: Pamela Donohue (PI), Rebecca Seltzer, Renee Boss, Brandon Smith, Danielle Gaskin, Breanna Watson, Karen Fratantoni, Kate Detweiler
- Funder: Thomas Wilson Foundation

Through the Family's Lens: Photovoice Study

- Parents/guardians of children with medical complexity (n=13) took photos of their home environments to highlight barriers or facilitators affecting their child's function, independence, and quality of life. Participants uploaded up to 10 photos and discussed them in a semi-structured interview.
- Recruitment was conducted in partnership with Parents' Place of Maryland and The Coordinating Center.
- Research Team: Rebecca Seltzer (PI), Pamela Donohue, Brandon Smith, Mona-Esmat Jarrah, Lora Batson, Caitlin Nalda
- Funder: Thomas Wilson Foundation

CAPABLE Kids: Pilot Intervention (In Progress)

- Community Aging in Place - Advancing Better Living for Elders (CAPABLE) is an innovative, evidence-based, person-centered intervention that provides low-cost home modifications to older adults with chronic medical conditions and disabilities. This adaptation supports children with medical complexity and their families.
- The pilot study includes 20 families with children (ages 5–17) who have complex medical needs in Baltimore City and Baltimore County.
- Research/Clinician Team: Rebecca Seltzer (PI), Shelbie Atkins, Eliana Perrin, Sarah Szanton, Ally Evelyn-Gustave, Susan Huff, Patricia Romond, Francesca Gill, Angela Bellan, Samantha Tobon, Rebecca Singer Cohen, Sharon Gifford, Elizabeth Szymanski, Laura Pritchett
- Parent Partners: Crystal Thomas, Darcel Jackson
- Home Modifications by: Civic Works
- Funders: National Institute on Disability, Independent Living, and Rehabilitation Research; Johns Hopkins Children's Center Innovation Grant

Optimizing the Home Environment for Children with Disabilities: Understanding Current Policies and Planning for The Future (in progress)

- This study assesses programs and policies that promote housing accessibility and home modifications for children with disabilities across 10 states within the Health Resources and Services Administration regions.
- In partnership with the Lucile Packard Foundation for Children's Health and guided by an advisory board—including parent partners, housing and disability policy researchers, legal and disability advocacy experts, and key government agencies—this project proposes a national policy convening focused on optimizing home environments for children with disabilities.
- Research Team: Rebecca Seltzer (Co-PI), Carolyn Foster (Co-PI), Callie Kaplan, Merone Eshetu, Irete Obaitan
- Parent Partners: Cara Coleman, Kate Detweiler, Darcel Jackson, Crystal Thomas
- Funder: Lucile Packard Foundation for Children's Health

Home Modifications Resource Project

- Project team: Prayernal Uppal (lead), Rebecca Seltzer, Pamela Donohue
- Partners: FindHelp.org, Hopkins Community Connections

Recommended Papers

Home Modifications for Children With Medical Complexity: Untapped Potential for Improving Care (2022)

The Home-Built Environment of Children With Medical Complexity (2024)





