

# 2024 LEND Lived Experience Summit

Monday, March 4 & 5, 2024

3:00 PM-6:00 PM Eastern Time



INTERDISCIPLINARY TECHNICAL ASSISTANCE CENTER  
ON AUTISM AND DEVELOPMENTAL DISABILITIES



# **LEND Lived Experience Summit**

## **Day 2**

### **Tuesday, March 5**



# Zoom Housekeeping

- Ensure your name is displayed correctly in the participant list. You may also include the program name and state and preferred pronouns.
  - Example: Jeanette Cordova, AUCD, she/her
  - Hover over your name in the “Participants” box and select “More” → “Rename”
- Feel free to introduce yourself in the chat box!
  - Name, Role, Program
- Please remain muted
- Please type your questions in the chat or use the raise hand icon.
- Captioning is available via the CC icon.

# **Workshop D**

## **Bringing Lived Experience to LEND Programs: How New Hampshire-Maine LEND is Developing an Accessible Program for ALL**

**Presented by:**

**Amy Frechette and Stacy Driscoll**

**NH-ME LEND**



**NH-ME LEND**

# **Bringing Lived Experience to LEND Programs: How New Hampshire-Maine LEND is developing an Accessible Program for ALL**

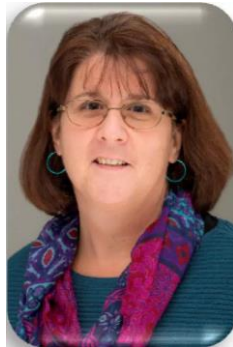
Amy H. Frechette, B.A., Stacy Driscoll, M.Ed. & Susan Zimmermann, Ph.D.



*NH-ME LEND is supported by a grant (#T73MC33246) from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services and administered by the Association of University Centers on Disabilities*

# Who We Are

- Amy H. Frechette, B.A. Program Support Asst/Advocate
- Stacy Driscoll, M.Ed. Training Director
- Susan Zimmermann, Ph.D. Family Faculty
- Kathy Bates, B.A. Advocate Faculty
- Marnie Morneault, M.Ed. Family Faculty
- Susan Russell, MS Co-Training Director
- Betsy P. Humphreys, Ph.D. Program Director



# History: HRSA Timeline -2021

Health Resource and Services Administration (HRSA) required all LEND programs:

- to recruit and hire self-advocate faculty members.
- to recruit a minimum of one self-advocate long-term trainee each year, beginning in 2024.
- to establish a new “Self-Advocacy Discipline” in LEND.



# History: HRSA Timeline -2024

- HRSA lifts educational minimum for applicants.
- Applicants without a BA must demonstrate experience as a leader, a readiness to further advance their leadership skills, and a willingness to share their lived experiences with others in the cohort.
- Doors are opened for wider recruitment of self advocates, including those with intellectual disabilities.





# History: NH-ME LEND Timeline: 2014

- In 2012, the Family Discipline was established in LEND programs across the country.
- In 2014, Kathy Bates became the first self-advocate graduate in the NH-ME LEND program.



# History: NH-ME LEND Timeline: Spring 2022

Spring 2022, NH-ME LEND formed a Self-Advocacy Discipline work group.

- How can we best prepare for recruiting and supporting self-advocates in our program?
- What will this new discipline will look like?
- How can we best support a broader range of learners and educators in our program?



# History: NH-ME LEND Timeline: Summer 2022

- Improving access to the curriculum for *all* trainees.
- Using a Universal Design for Learning (UDL) Lens.



# History: NH-ME LEND Timeline: 2023-2024

- Under the HRSA guidelines, our program Supported a Self-Advocate trainee during the 2022-2023 academic year.
- A second trainee is being supported this academic year.



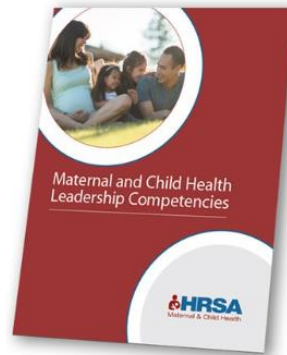
# Activities Within Our Group

- Formed a Self-Advocacy Discipline workgroup consisting of faculty and staff, including those with lived experience.



# Activities Within Our Group 2

- Reviewed the recently drafted AUCD LEND Self-Advocacy Discipline Network (LSDN) competencies. Cross-referenced the Self Advocacy Discipline competencies with the Maternal and Child Healthcare (MCH) competencies to consider gaps in our current curriculum.



# An Example of our Crosswalk:

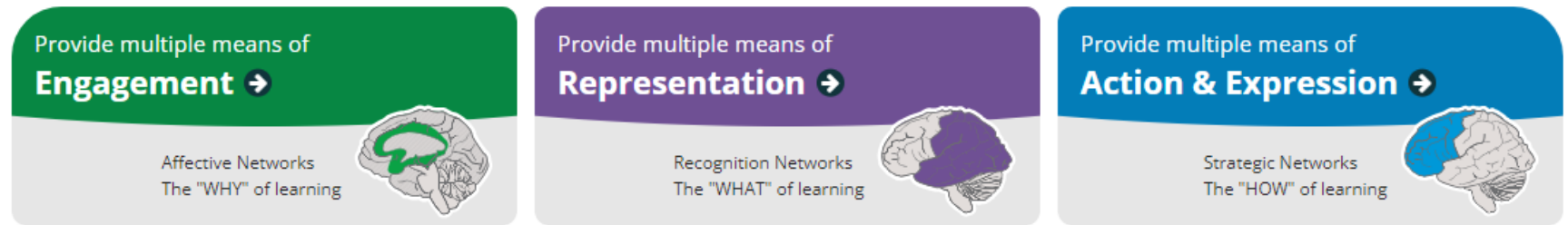
<b>LSDN Competency</b>	<b>Objective</b>	<b>Current curriculum Alignment- Where is this covered?</b>	<b>Link to MCH Competency?</b>
Demonstrate an understanding of the history of the disability rights movement in the United States	1.1 Identify 5 important events in the history of the Maternal Child Health Bureau (MCHB)	Module 3-Leadership Intensive •History of Disability	1 MCH Knowledge Base and Context •Individuals and populations •The role of federal, state and local government in ensuring equitable healthcare for women, children, youth, families and children and youth with special health care needs.



# Activities Within Our Group: UDL

- Researched Universal Design for Learning (UDL) as a guiding framework.

## Universal Design for Learning Guidelines





# Activities Within Our Group Continued...

- Revised and updated recruitment materials, including our application and interview questions; course materials including syllabus and handbooks; and assignments to make them more accessible and written in plain language.



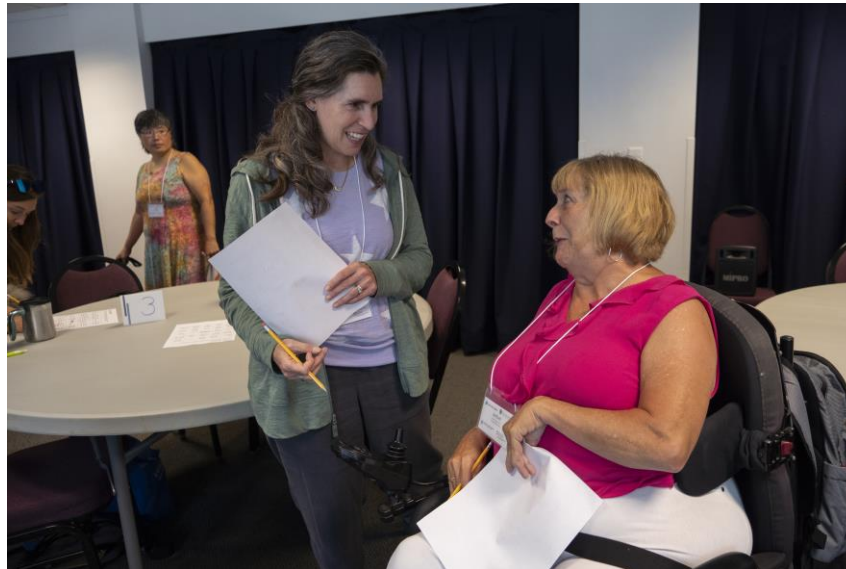
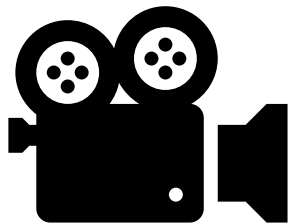
# Example of Plain Language Recruitment Materials

- The NH-ME LEND Program looks for applicants with a variety of experiences, backgrounds, and perspectives. With this in mind, tell us a bit about yourself.
  - What has been your experience with disability or chronic health conditions?
  - What interests you about the LEND program?



## Activities Within Our Group Continued...

- Work with our faculty to develop alternative course materials including podcasts and videos as alternatives to written materials.



# Example of Course Materials

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Fall Session: **Cultural Competence and Health Equity**

Prep materials included:

The Health Disparities Podcast:



# Activities Within Our Group Continued...

- Offer alternative ways for trainees to express what they know when completing assignments other than written work, such as self-recorded audios or videos.



# Example of UDL Assignment

Leadership Reflection Assignment:

*You may present your reflection in one of the formats below:*

- 1. Write a one-page reflection, at least two paragraphs and single-spaced.*
- 2. Create a video or audio recording of your reflection (no more than 2-3 minutes).*



## Successes

- As we made accommodations to support self-advocates by improving access to the curriculum, we are also creating an *inclusive program* for ALL NH-ME LEND trainees so they may reach their full potential as leaders.



# Challenges

Our Q and A today will address some challenges we faced.





# AUCD Annual Meeting Poster Session November 2023



## Q & A



- How can LEND programs maintain graduate-level rigor while ensuring that the curriculum is fully accessible to all?
- What strategies for building the capacity of LEND faculty should be used?
- Could a UDL curriculum improve the accessibility of the program and the ability of trainees to model principles of UDL in their lives after LEND?



## Q & A Continued.

- How can LEND programs integrate concepts of accessibility and presuming competence into all aspects of planning and teaching?
- Is there a need for separate competencies or tracks for self-advocates if we apply the principles of UDL?



## Contact us:

- Amy Frechette: [Amy.Frechette@unh.edu](mailto:Amy.Frechette@unh.edu)
- Stacy Driscoll: [Stacy.Driscoll@unh.edu](mailto:Stacy.Driscoll@unh.edu)
- Susan Zimmermann: [Susan.Zimmermann@unh.edu](mailto:Susan.Zimmermann@unh.edu)



# Authors of Presentation

- Frechette, A. H., Driscoll, S., Morneault, M., Bates, K., Zimmermann, S., Russell, S. & Humphreys, E. (2024, March 4). *Bringing Lived Experience to LEND Programs: How New Hampshire-Maine LEND is developing an Accessible Program for ALL* [Virtual Presentation]. LEND Lived-Experience Summit, Association on University Centers on Excellence in Disability, Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities.
- NH-ME LEND WebSite Link: <https://iod.unh.edu/nh-me-lend>



# Poster Session 1

## **Caregiver Panel: “What Providers Need to Know” a Care Perspective Collaboration from UW LEND, UW PPD, Family Voices, CHLA**

**Presented by:**

**Susan Adelman, Shawnda Hicks, and Lianne Caster  
Washington LEND**

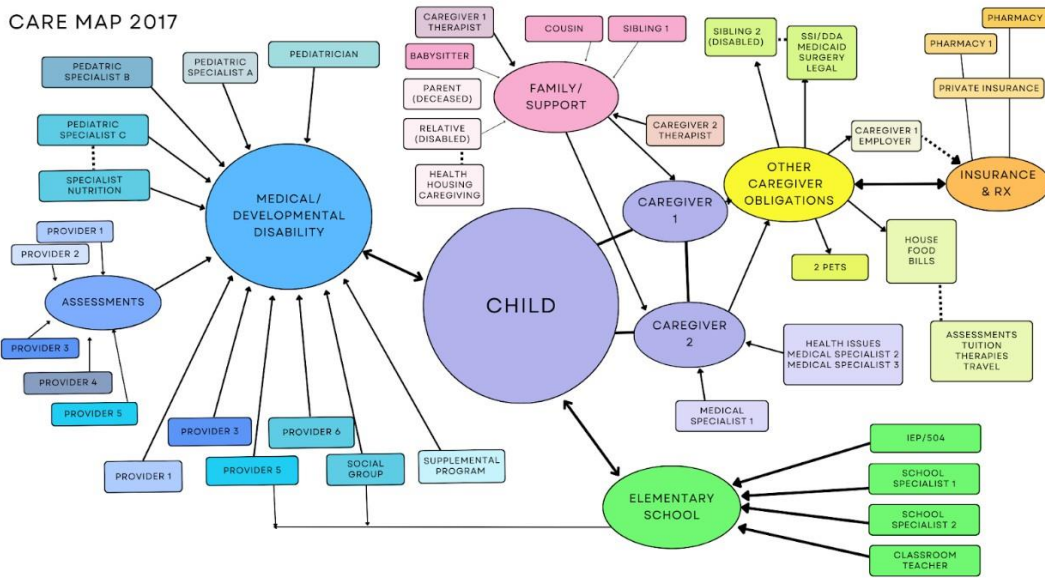
### FOUNDATION:

UW PPC and UW LEND Family Faculty collaborate on family leadership, interdisciplinary training and projects. We identified the need to build a bridge between the programs to work on common issues facing caregivers of children and youth with special healthcare needs (CYSHCN) and children/youth with neurodevelopmental and related disabilities

### METHOD:

In 2023, the UW PPC and UW LEND created a caregiver panel presentation: "Caregiver Panel: What Providers Need to Know" that explores caregiver burden of care issues to facilitate partnerships with providers. The Caregiver Panel represents a wide range of diagnoses, geography, ethnic and racial diversity to enable the presentation to be used in a variety of educational and training purposes

CARE MAP 2017



This Care Map exemplifies the complexity of caregiving as described in the panel

### OBJECTIVES OF THE CAREGIVER PANEL:

- Promote training in family leadership and cross project collaboration between faculty and trainees in both PPC and LEND programs
- Enable faculty, trainees and providers to gain deeper understanding of the intersection of issues when providing care to families served by both PPC and LEND programs
- Deepen provider understanding of the experiences of caregivers.

### RESULTS:

The Caregiver Panel was recorded in 2023 and included caregiving families from across the country who shared their powerful personal stories. Caregivers discussed the physical and mental health of caregivers and the impact that provider-caregiver partnerships have on positive outcomes for patients and families.

### FUTURE USE:

The Caregiver Panel is widespread, including:

- Incorporating it into the national PPC curriculum
- Developing it to train medical residents and students
- Housing it on the LEND National Family Discipline Networks library for other LEND programs to access,
- Integrating it locally into the UW LEND curriculum to enhance trainee understanding of family centered care.

### ACKNOWLEDGMENT:

This project was supported in partnership with:  
 University of Washington Pediatric Pulmonary Center (PPC)  
 University of Washington Leadership Education in Neurodevelopmental and Related Disabilities (LEND)  
 Childrens Hospital of Los Angeles (CHLA) Leadership training programs at the University of Washington funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA).



PAVE Specialized Care Roadmap

Personal Overview:

Fillable, Personalized Specialized Care Roadmap

# Poster Session 2

## **Pathways to Leadership: Connecting the NM LEND Self-Advocacy Discipline to Community Leaders and Leadership Programs**

Presented by:

**Daniel Ekman, New Mexico LEND**



# Pathways to Leadership: Connecting the NM LEND Self-Advocacy Discipline to Community Leaders and Leadership Programs

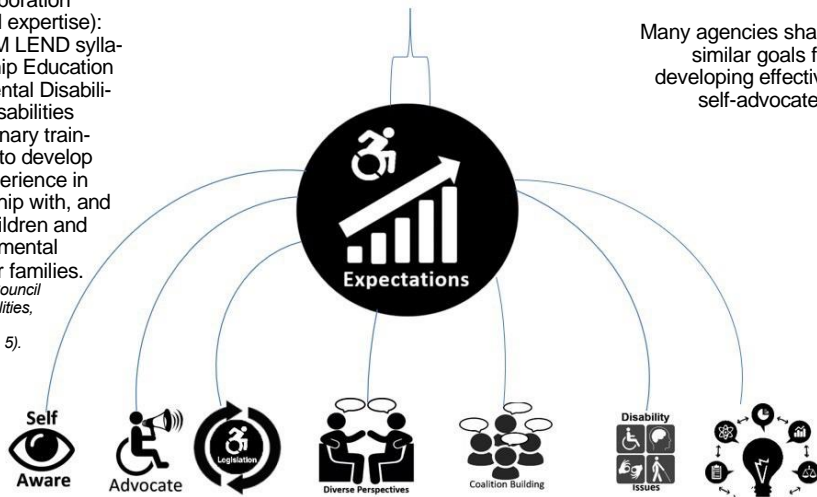
*Daniel Ekman, MA, NM LEND Faculty & Program Manager, Center for Self Advocacy, NM DDC*

Summary: In order to create truly effective self-advocacy leadership competencies and pathways within LEND, we simply need to collaborate and utilize our organizations, programs, and expertise that we already have.

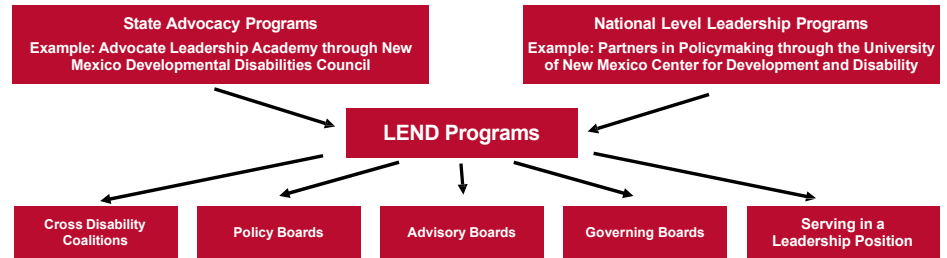


Example 1 for collaboration (Organizations): The DD Act was created to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.”

Example 3 for collaboration (Competencies and expertise): According to the NM LEND syllabus, “The Leadership Education in Neurodevelopmental Disabilities and Related Disabilities (LEND) interdisciplinary traineeship is designed to develop knowledge and experience in working in partnership with, and advocating with, children and adults with developmental disabilities and their families. (Minnesota Governor’s Council on Developmental Disabilities, Partners in Policymaking Coordinator’s Handbook, 5).



Many agencies share similar goals for developing effective self-advocates.



Example 2 for collaboration (Programs and People): According to the Minnesota Governor’s Council on Developmental Disabilities: Partners is an innovative, competency-based leadership training program for adults with disabilities and parents of young children with developmental disabilities. The purpose of the program is two-fold: to teach best practices and to teach the competencies needed to influence public policy. State-of-the-art information gives Partners participants the big picture, allows them to dream big, and provides strategies to turn dreams into reality. The collective impact of Partners participants dreaming the big dream and working to achieve it will affect people far beyond the graduates and their families—the face of disability issues will change! (Minnesota Governor’s Council on Developmental Disabilities, *Coordinator’s Handbook*, 5).

Program	Disability Advocacy in Public Policy	Leadership and Effective Collaboration	Best Practices (related to disability)	Disability Knowledge, Self-advocacy
Advocate Leadership Academy—NM DDC	X	X		X
Self-Advocacy Competencies - NM DDC	X	X	X	X
Partners in Policymaking (Minnesota Developmental Disabilities Council)	X	X	X	X
NM LEND Program Core Competencies	X	X	X	X

Coffee break...

10:00



# **Workshop E**

## **Navigating Dynamics Between Self-Advocates and Non-Disabled Family Members: Research and Curricular Innovation**

**Presented by:**

**Andy Arias and Maya Coleman**

**Georgetown LEND**

**2024 LEND Lived Experience Summit**  
**Navigating Dynamics Between Self-Advocates and**  
**Non-Disabled Family Members:**  
**Research and Curricular Innovation**

**Tuesday March 5, 2024**  
**4:25-5:05 PM Eastern US Time**

**Andy Lopez Arias, , Maya B. Coleman,**  
**Libbie S. Rifkin, & Pamala A. Trivedi**  
**and collaborating faculty: Lydia X. Z. Brown**



**University Center for Excellence  
in Developmental Disabilities**

GEORGETOWN UNIVERSITY CENTER FOR CHILD AND HUMAN DEVELOPMENT



# Welcome!

Thank you so much for joining us today! We really appreciate the time and attention you are taking to be with us for the next 40 minutes.

We will be sharing some PowerPoint slides with you, and these will be available to you after this presentation.

We have set aside 10 minutes at the end of our time for discussion.

We have enabled captioning, and you can display captions by clicking on the "show captions" button at the bottom of your screen.

Please feel free to send a message in the chat if you would like us to adjust sound/visuals.

Thank you again for being here!





# Presenting Team

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Andy Lopez Arias



Lydia X. Z. Brown



Maya B. Coleman, PhD



Libbie S. Rifkin



Pamala Trivedi, PhD, NCSP



# Our GULEND Community

Disciplines represented by the 2023-4 cohort
Speech-language Pathology; Advocate with lived experience of disability
Early Care & Education
Rehabilitation Technologies; Advocate with lived experience of disability
Family Advocate; Policy
Family Advocate; Policy & Systems Building
Law; Public Policy & Advocate with lived experience of disability
Family Advocate & Community Organizing
Clinical Psychology; Neuroscience & Advocate with lived experience of disability
Social Work & Family Advocate
Psychology & Early Intervention

## Dynamics & Current Context

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As LEND programs work through content on early childhood, school years, and adult services, tensions between family members positioned as nondisabled, and disabled self/community advocates, can surface, disrupting the learning process and affecting members' psychological safety.

LEND cohorts provide unique laboratories for engaging with difficult real-world issues like this one in an intentionally-designed space that supports the psychological safety of the group.





# Community Building & Norms

- Intentional, research-informed structure for learning that anticipates and is responsive to the potential conflicts between members of our community
- Informed by a systemic understanding of differential effects of ableism
- Committed to disability justice principles of intersectionality and “leadership of those most impacted.”
- Incorporates wisdom from neurodivergent community practices
- Employs multiple self-reflective practice tools: “Listening Exchanges\*” “River of Life” & Leadership Modules

\*developed by Hand in Hand Parenting (also known as Listening Partnerships).



# Our Research Project

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## Components:

- Review of scholarly research across a variety of domains
- Review of best practices (interviewing other LEND programs)
- Information gathering from Georgetown University LEND participants

## Goals:

- Understand context and current dynamics between disabled self/community advocates and nondisabled family members through an anti-ableist framework
- Develop a curricular component/unit to share with larger LEND community
- Advance disability equity through collective and aligned action in policy, education, and culture



# Historical & Current Context

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- Interactions between self/community advocates and family members - generative & challenging
- Parent and self/community advocacy organizations frequently pursue opposed agendas
- Families may feel compelled by ableist and sexist systems to compete for perceived scarce resources in order to maximize capacity to be “independent,” “normal,” and “productive”
- Parents and their organizations may be motivated by the curative calendar\*; may embrace therapeutic approaches regarded by self/community advocates as abusive
- Self/community advocates may align with principles of Disability Justice

\*(concept put forth by disability studies scholar Alison Kafer)



# GULEND Learning Objectives & Approaches



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Embedding Cultural & Linguistic competence in work

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## Advancing Equity & Inclusion

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Learning how to lead from where you are in our local systems of care for persons with disabilities and their families

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Strengthening comprehensive services and supports across the lifespan

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Increasing capacities to function on interdisciplinary teams that meet the interests and complex needs of persons with autism and related disabilities, their families & providers who care for them

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Promoting Person-, family-centered & trauma-informed care

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Understanding how to build the foundation for self determination and supported decision-making from the earliest years

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Meaningfully incorporating lived experiences of disabilities

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Building & sustaining a vibrant learning community grounded in psychological safety

# GULEND Key Components

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Classroom Experiences & Materials

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Experiential Learning

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Opportunities to Build Reflective Practice

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Advising

---

Applied Research/Capstone Project

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Mentorship for Equity

---

Partnership with other LENDs

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Interdisciplinary Teaming Experiences in the Community

# Reflective Practice Opportunity

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## Listening Exchanges



- 1) Split time equally, use a timer
- 2) Take turns listening and being listened to
- 3) Simply listen and communicate warmth mostly non-verbally
- 4) Avoid interrupting, asking questions, giving advice, sharing own thoughts, reflecting
- 5) Can talk about anything; encouraged to notice/have/express emotions
- 6) Everything shared is confidential and not referred to, even to the person who shared



# Reflective Practice Progression

## Progression of "Topics"

- 1) Access Practice – diverse communication channels; equal time
- 2) Trauma-Informed Practice
- 3) Self-Reflective Practice
- 4) Equity Practice – within/across affinity groups; heal from the impact of systemic oppression
- 5) Leadership Practice - telling your story

### Reflection: A Definition (1)

*'Reflection is an important human activity in which people recapture their experience, think about it, mull over & evaluate it. It is this working with experience that is important in learning'.*

Boud, D., Keogh, R. & Walker, D. (1985) p 43 *Reflection: Turning Experience into Learning*. London: Kogan Page.





# Reflective Practice Opportunity

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*River of Life*  
Exercise in the  
context of  
GULEND  
Leadership for  
Cultural and  
Linguistic  
Competence





# Feedback from Our Community

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- Privileged Voices & 'Airtime'
- Make it explicit what 'lived experience' are we centering at each moment
- Intersectionality
- Self-Care & Community Care
- Psychological Safety
- Feedback from Site Visitors About G
- Ivymount Practicum
- River of Life



## Discussion – 10 min

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What questions and comments do you have for us?

Feel free to...

- Physically raise your hand on the video
- Press the "raise hand" react button on your screen
- Type your thoughts and questions into the chat



# Modifications/Improvements

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- Give more time for development of Community Norms
- Move unit to orientation month
- Build in more processing time/listening exchanges each week
- Emphasize that sharing can be done verbally, non-verbally, through chat comments, working on artwork, etc.
- Share our Community Norms document with invited guests prior to their visits
- Personal follow up with invited guests after their visit
- Presenting River of Life virtually with additional support after those sessions



# Thank You!

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Thank you so much for joining us today, and for your engagement, attention, thoughts, questions and feedback!

We would love to continue these conversations with you, so please don't hesitate to reach out anytime.



Andy Lopez Arias [aa2853@georgetown.edu](mailto:aa2853@georgetown.edu)  
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Maya B. Coleman [mbc121@georgetown.edu](mailto:mbc121@georgetown.edu)  
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Pamala A. Trivedi [pat33@georgetown.edu](mailto:pat33@georgetown.edu)



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in Developmental Disabilities

# Workshop F

## **HOPE AND LEND: Increasing Positive Experiences for Families Members and Children with Disabilities**

Presented by:  
LaTysa Flowers, CA LEND

# Spreading HOPE

Increasing access to the Building Blocks of HOPE of families with disabilities



# TODAY'S FACILITATORS

**LaTysa Flowers**

**Family Support Discipline Director**

**CA-LEND**

**SD-LEND Affiliate FS Discipline Faculty**

**Association Director DEIB**

**YMCA San Diego County**

**Tufts H.O.P.E. Champion & Advanced  
Trainer**





# SHARED LEARNING AGREEMENTS

## Creating Safety

Today's topic may be upsetting. Please care for yourself & engage in a ways that feel safe to you.

## Choice & Control

Know that you have choice in how you participate & we encourage you to lean into the process for learning & growing.

## Regulation

We encourage you to notice what your body & emotions are telling you as cues for practicing regulation as you need.

## Relationships

Us connecting & sharing with one another fosters our learning & transferring ideas.

## Reflection

We encourage reflecting on the content & ideas of others to foster self-awareness.

# CROSS OUT BINGO

**Grab a  
blank  
piece of  
paper..**

Fold it in 3 (like a brochure)

Fold it in 3 again! (you'll have a small  
square)

When you unfold it you'll have 9 boxes


**Building Blocks**

Realms of ACEs

Civic Engagement

Relationships

Emotional Growth

Dads With Fairy Wings

Two non-parent adults

Safety

Dr. Sege

Implicit Bias

**Building Blocks**

Wisconsin

Rainbows and unicorns

Climate Change

Resilience

**Impact**

Sense of Belonging



# Introduction to HOPE





**Think about a positive experience that stands out to you from your childhood. Hold that in your mind as we talk.**





**HOPE**

HEALTHY OUTCOMES  
FROM POSITIVE EXPERIENCES

## Why HOPE Exists

Positive experiences help children grow into more resilient, healthier adults. HOPE aims to better understand and support these key experiences.





# Core assumption

from the Science of the Positive:

The **positive** exists, it is real and worth growing.

Positive experiences:

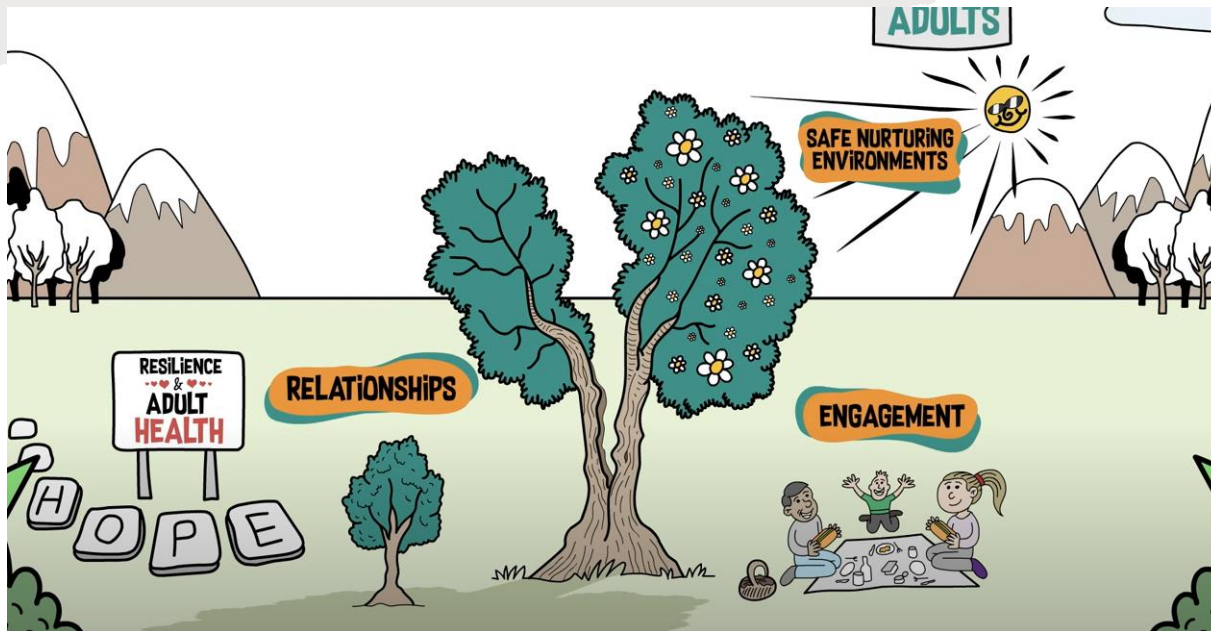
- Promote children's **health and well-being**
- Allow children to form strong **relationships** and connections
- Cultivate positive self-image and **self-worth**
- Provide a sense of **belonging**
- Build skills that promote **resilience**

Linkenbach, J. (2007, 2018). The Science of the Positive: The Seven Core Principles Workbook: A Publication of The Montana Institute, LLC.



# HOPE

HEALTHY OUTCOMES  
FROM POSITIVE EXPERIENCES



<https://www.youtube.com/watch?v=bypJUDxfZTU>





## Many systems focus on the negative

Screening tools, many of which perpetuate implicit bias, create a presumption of deficit

**HOPE** shifts the narrative: people are defined by their strengths as well as their challenges.

**HOPE** creates a presumption of strength



Remember this cartoon, what was easier to see?



**HOPE**

HEALTHY OUTCOMES  
FROM POSITIVE EXPERIENCES

© Devereux, adapted with permission



## Type 1 vs. Type 2 thinking

### Type 1 thinking

- ✓ Fast, intuitive, unconscious thought
- ✓ Effortless
- ✓ Everyday activities
- ✓ Training and experience
- ✓ **Implicit bias**



### Type 2 thinking

- ✓ Slow, calculating, conscious
- ✓ Takes more effort!
- ✓ Problem solving
- ✓ Something novel
- ✓ **Perspective taking**



## Type 1 vs. Type 2 thinking

Implicit biases are imbedded in Type 1 thinking



Unconscious, immediate reactions to difference

Type 2 thinking can help us notice and navigate our biases



Slow, conscious strategies to mitigate bias



# Adverse Childhood Experiences (ACEs)

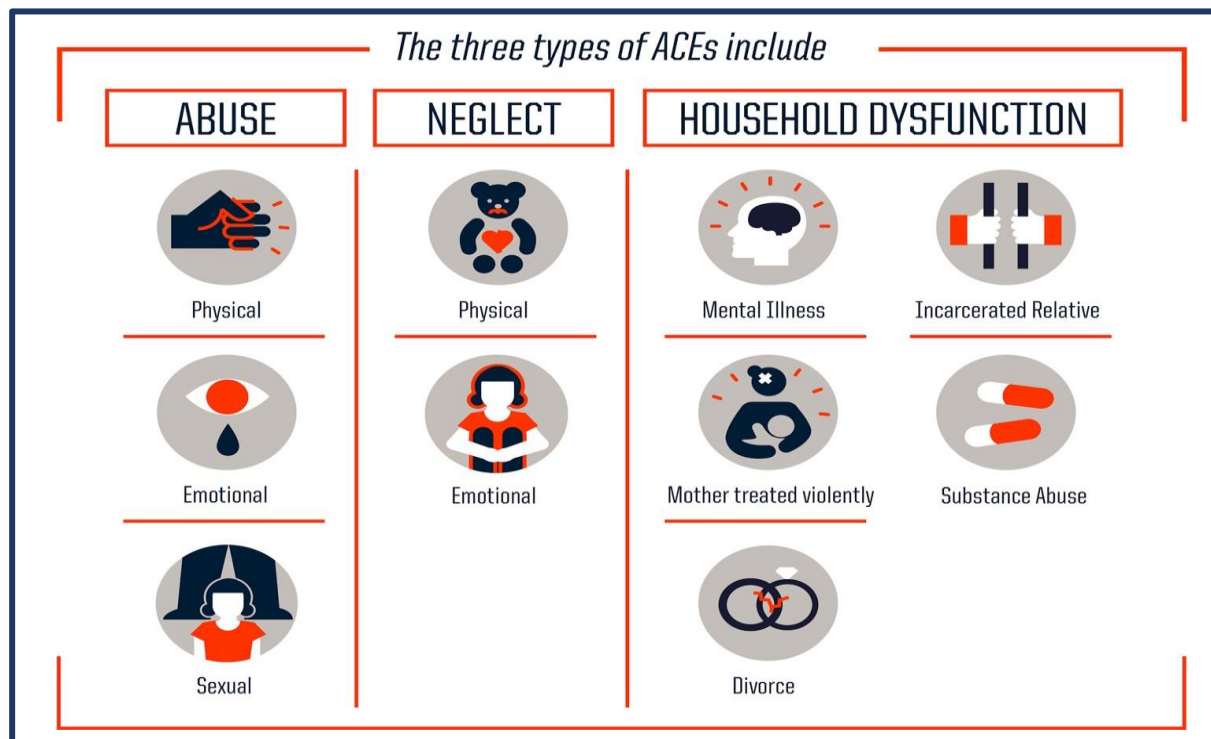


Image courtesy of RWJF





# Adverse Community Environments are the root causes of ACEs





## Reflective Work

Think about someone you know, personally or professionally, who has a disability, or is a caregiver to someone with a special healthcare need or challenging childhood but is fairly successful today.

In pairs, take 5 minutes to share adjectives you would use to describe that person.





## How much do you know about Positive Childhood Experiences (PCEs)?

1. Nothing – what are PCEs?
2. A little – I have heard the term before.
3. More than a little but probably still have a lot to learn.
4. I am well versed in PCEs and their effects on health.
5. I am a PCEs expert!





## ACEs and PCEs

### ACEs

- 1998 study of employed people in Southern California
- Patients answered questions about their childhood
- Correlated with mental and physical health

### PCEs

**NEW**

- 2015 population study in Wisconsin
- Part of the Behavioral Risk Factor Surveillance Survey
- Asked about ACEs
- Asked about Positive Childhood experiences
- Correlated with mental health



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2015 population study in Wisconsin

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Part of the BRFSS

---

Asked about ACEs

---

Asked about Positive Childhood experiences

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Correlated with mental health

## Developing the Positive Childhood Experiences (PCEs) score





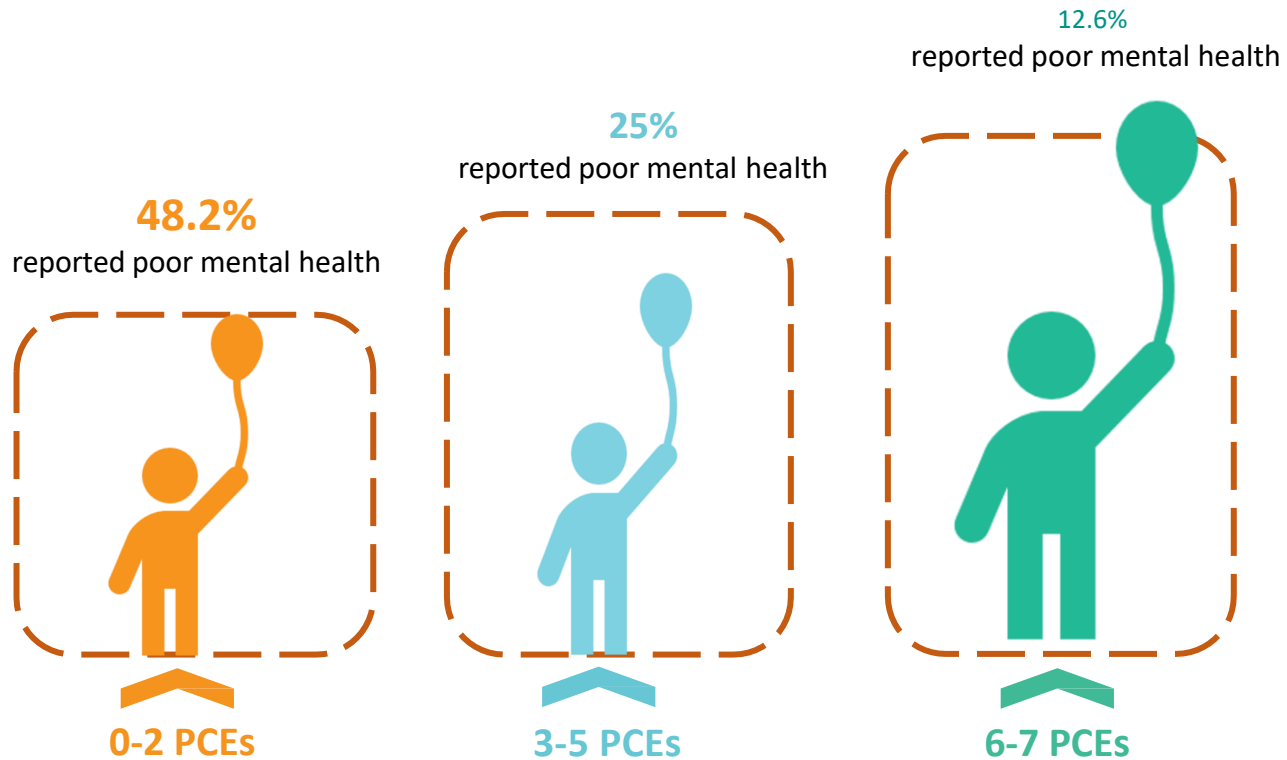
# Positive Childhood Experiences scale questions

*As a child, how often did you ...*

1. Feel able to talk to your family about feelings
2. Feel your family stood by you during difficult times
3. Enjoy participating in community traditions
4. Feel a sense of belonging in high school
5. Feel supported by friends
6. Have at least two non-parent adults who took genuine interest in you
7. Feel safe and protected by an adult in your home

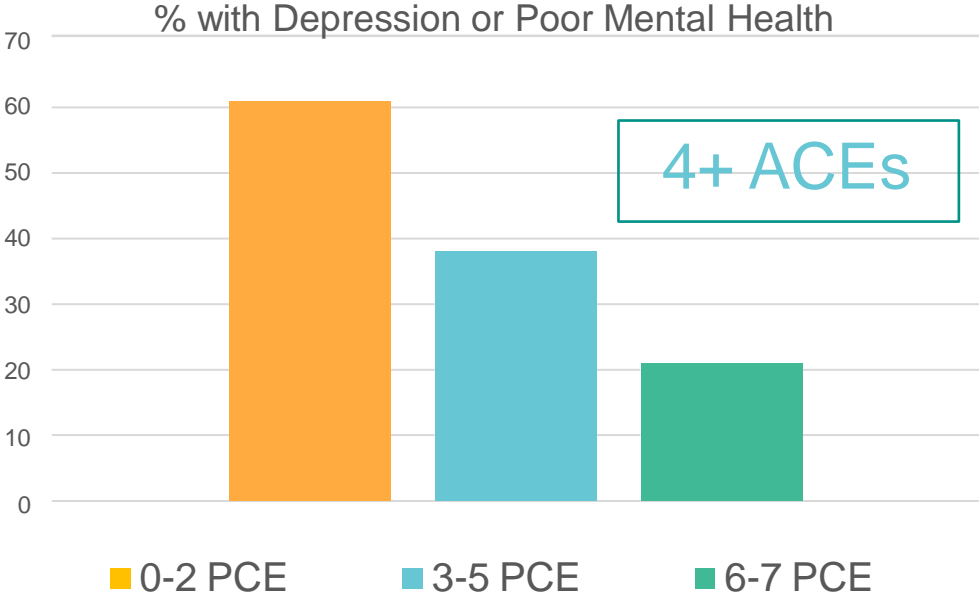


## Positive Childhood Experiences (PCEs) Protect Adult Mental Health



Bethell C, Jones J, Gombojav N, Linkenbach J, Sege R. Positive Childhood Experiences and Adult Mental and Relational Health in a Statewide Sample: Associations Across Adverse Childhood Experiences Levels. *JAMA Pediatr.* 2019 Sep 9; e193007

# Positive Childhood Experiences Mitigate ACEs Effects



Bethell C, Jones J, Gombojav N, Linkenbach J, Sege R. Positive Childhood Experiences and Adult Mental and Relational Health in a Statewide Sample: Associations Across Adverse Childhood Experiences Levels. *JAMA Pediatr.* 2019 Sep 9; e193007

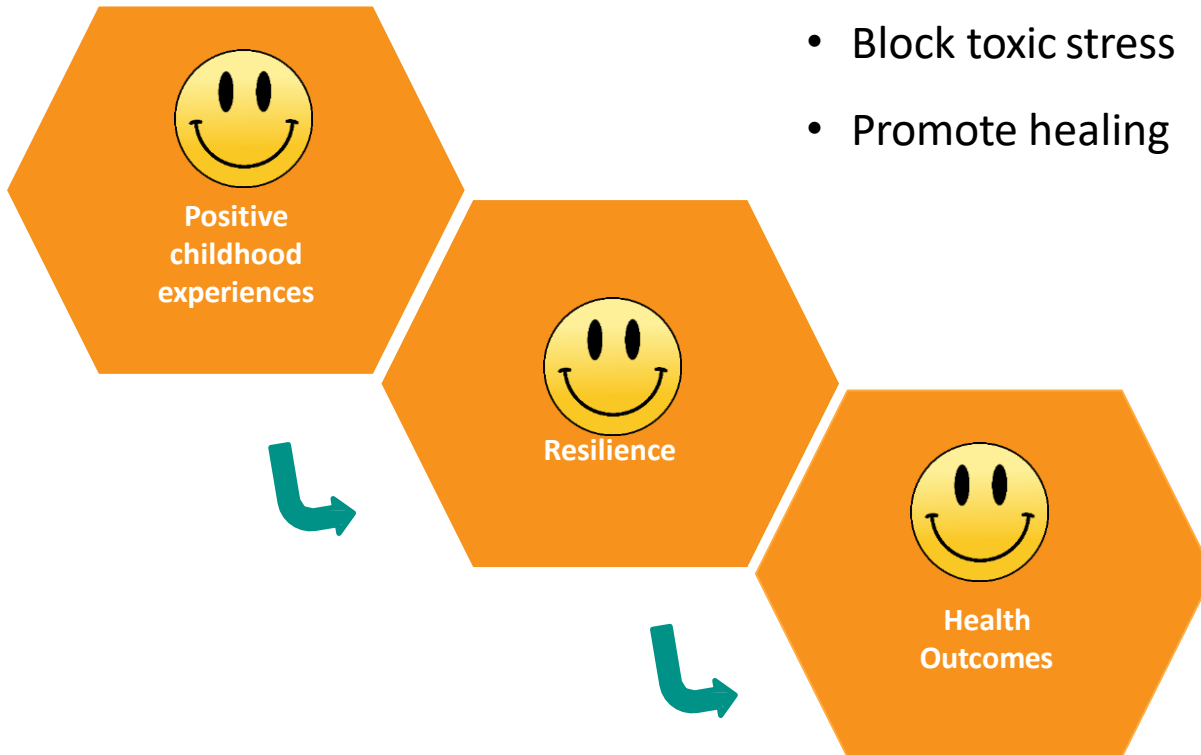
## Higher PCEs Associated with Other Outcomes

- Individuals with highest amount of PCEs were more likely to have a college degree, be employed, and earn a higher income.
- Individuals with highest amount of PCEs had a greatly reduced risk of cigarette smoking, alcohol and overall substance abuse.
- The individual PCEs with the greatest risk reductions:
  - Feeling safe and protected by an adult in the home
  - Feeling family stood by them during difficult times
  - Enjoying participating in community traditions





# Positive Childhood Experiences:



- Prevent ACEs
- Block toxic stress
- Promote healing

Photo by [Nathan Dumlao](#) on [Unsplash](#)





Research indicates that the

ABSENCE of PCEs

may be more damaging to long-term health

outcomes

than the presence of ACEs.

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HOPE



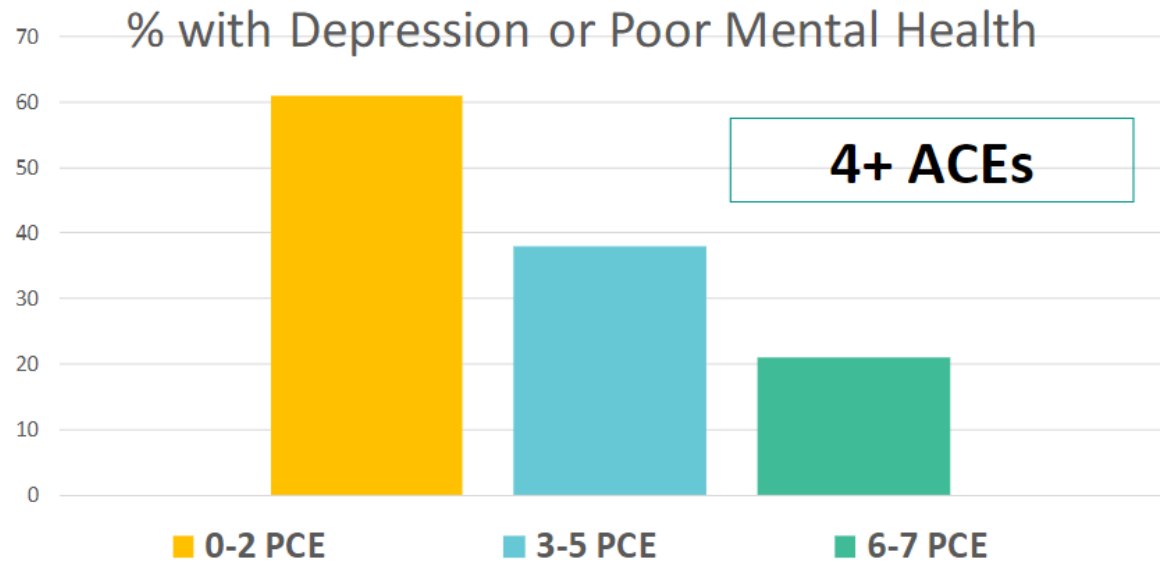


# Let that sink in.....

PCEs protect adult mental health...even in the face of ACEs.

# PCEs reduce the effects of ACEs

Bethell C, Jones J, Gombojav N, Linkenbach J, Sege R. Positive Childhood Experiences and Adult Mental and Relational Health in a Statewide Sample: Associations Across Adverse Childhood Experiences Levels. JAMA Pediatr. 2019 Sep 9; e193007





**Relationships** with other children and with other adults through interpersonal activities.

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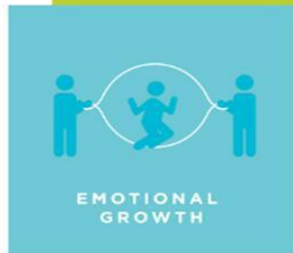
**Safe, equitable, stable environments** for living, playing, learning at home and in school.

---



**Social and civic engagement** to develop a sense of belonging and connectedness.

---



**Emotional growth** through playing and interacting with peers for self-awareness and self-regulation.

---



# The Four Building Blocks of HOPE





RELATIONSHIPS

**Relationships** with other children and with other adults through interpersonal activities.

---



ENVIRONMENT

**Safe, equitable, stable environments** for living, playing, learning at home and in school.

---



ENGAGEMENT

**Social and civic engagement** to develop a sense of belonging and connectedness.

---



EMOTIONAL GROWTH

**Emotional growth** through playing and interacting with peers for self-awareness and self-regulation.

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# The Four Building Blocks of HOPE





# Relationships

## The Four Building Blocks of HOPE

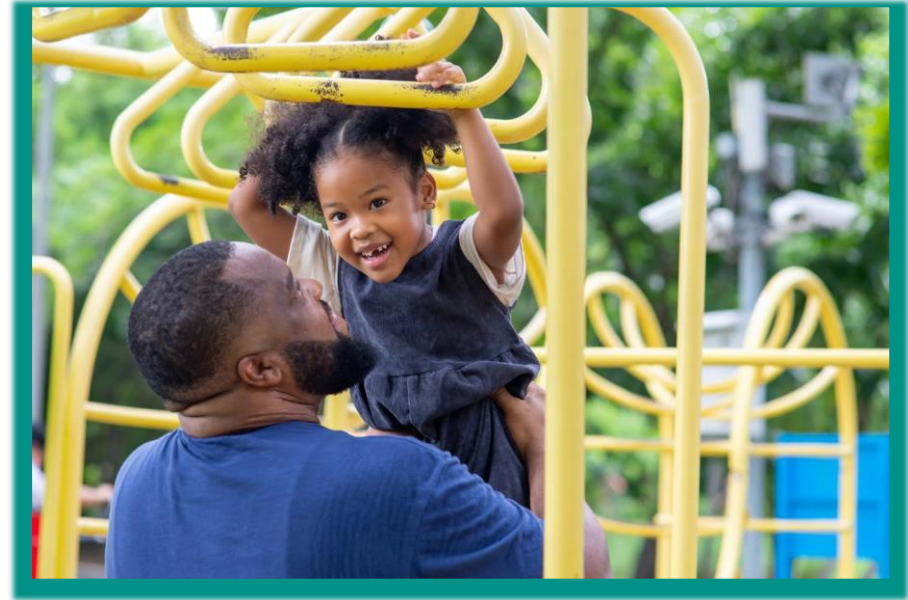


**Relationships** with other children and adults through interpersonal activities.



## What types of relationships are we talking about?

- Foundational relationships with parents and/or caregivers who respond to a child's needs and offer warm, responsive interactions
- Adults outside of the family who take a genuine interest in a child and support their growth and development
- Healthy, close and positive relationships with peers





## Environment

### The Four Building Blocks of HOPE



**Safe, equitable, stable**  
**environments** for living, playing,  
learning at home and in school.





## How can you promote access to safe, stable, equitable environments?

- **Make your spaces a safe space for all! Address bullying and teasing in the moment, and encourage the children in your programs to be upstanders instead of bystanders.**
- **Encourage self-advocacy with guided support when or if needed**
- **Diversify materials in your programs to make sure that children feel represented**
- **Know your community resources! Be the person who notices and connects students with support.**

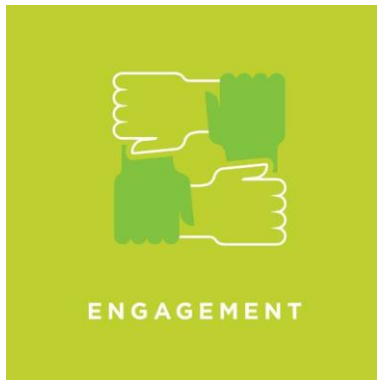






## Engagement

### The Four Building Blocks of HOPE



Social and civic engagement to develop a sense of belonging and connectedness.



## How can you promote access to social and civic engagement?

- Ask students about what they do outside of school , treatment or therapy
- Consider having children create projects with their peers about their favorite social activity
- Encourage civic engagement and volunteering

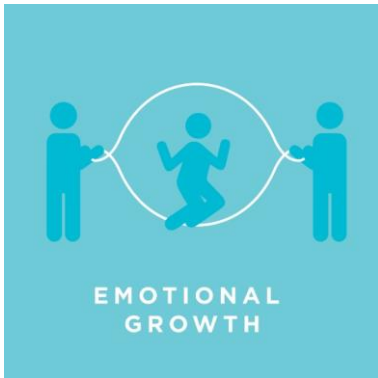


*Photo courtesy of Artists For Humanity*



## Emotional Growth

### The Four Building Blocks of HOPE



**Emotional growth** through playing and interacting with peers for self-awareness and self regulation.



## How can you support social and emotional growth?

- **Help children name their feelings as they arise and talk about what that feeling feels like in their body**
- **Normalize disagreements in peer groups and share information about how to disagree respectfully and productively**
- **Consider implementing a social and emotional (SEL) component in your clinic or as an IFSP, IEP or Independent Employment Plan goal**



## Adversity and the Building Blocks of HOPE

We know that adverse childhood experiences can disrupt access to positive childhood experiences.



### Child Abuse & Neglect...

Disrupts foundational  
*relationships*

Disrupts safe home  
*environments*

### Family Disruption...

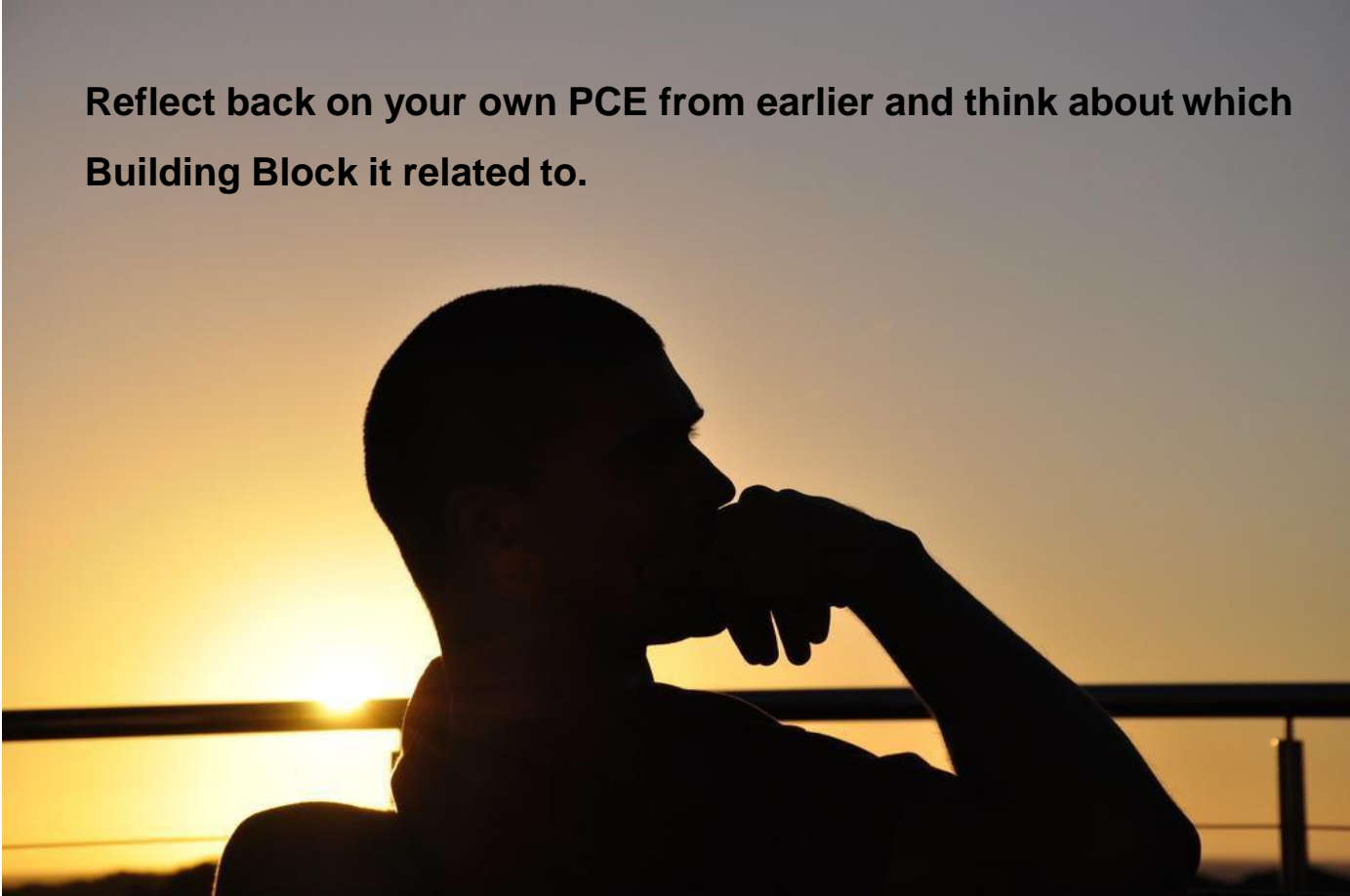
Disrupts safe  
*environments* (home and  
SDoH)

### Adverse Community Environments...

Reduce *engagement*  
Reduce opportunities for  
*emotional growth* (peer  
play)



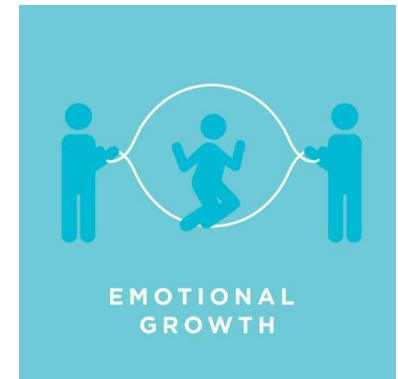
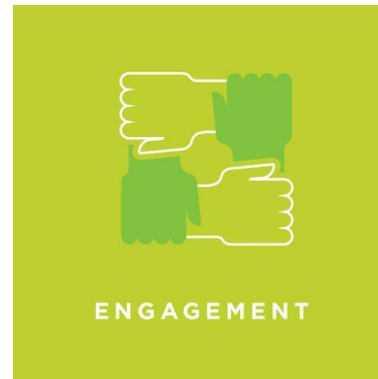
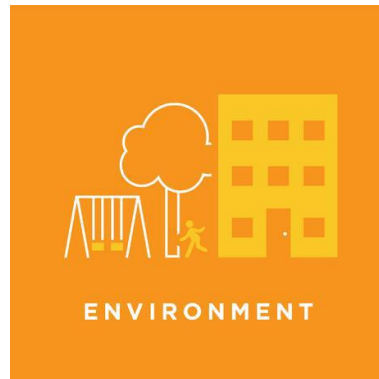
**Reflect back on your own PCE from earlier and think about which Building Block it related to.**



# Be the Change

How do you promote equitable access to one or more building blocks in your service, program clinic or as a caregiver?

- 1) What are you already doing well?
- 2) What could you do more of?
- 3) What resources you have in-house or can refer to that promote access to a Building Block?





## Moments of HOPE

The HOPE frameworks helps transform our work by actively promoting positive experiences that drive health and well-being for children, families, and communities







HEALTHY OUTCOMES  
FROM POSITIVE EXPERIENCES

Strengths-based,  
Child-centered,  
Family-led innovating  
around promoting  
access to the Four  
Building Blocks





Families are Resilient. HOPE celebrates their strengths.



HOPE



# Moments of HOPE

**Moments  
of HOPE  
can  
occur:**

In each encounter

During intake and assessments

When sharing referrals or community resources

When creating or revising policies

When designing programming

# Resources

## positiveexperience.org

### HOPE HEALTHY OUTCOMES FROM POSITIVE EXPERIENCES

#### as an Anti-Racism Framework in Action

The Four Building Blocks of HOPE—supportive relationships, safe, equitable, and stable environments, social and civic engagement, and emotional growth—can be incorporated into decision making at every level and in every sector to ensure that all children, including children of color, have what they need to thrive.

Access to the Four Building Blocks is often disrupted by systemic racism, historical trauma, and adverse childhood experiences. HOPE-informed agencies can partner with their communities, and together identify existing resources to promote HOPE and identify unmet needs. Working together, HOPE and our partners seek to ensure that every family and child can have those key experiences that promote resiliency.

**Racism is harmful to all of us.** Anti-racism frameworks intentionally upend racist policies and practice in an effort to combat White supremacy. As author and anti-racism activist Ibram X. Kendi describes it, a racist policy is “any measure that produces or sustains racial inequality.” This work requires tacit acknowledgement that systems, institutions, policies, practices and norms privilege White people, even when they do not explicitly mention race. While bias operates at the individual level, providers, practitioners, and educators are also operating within systems built on racist foundations. In this resource, we will be focusing specifically on systemic racism and unconscious bias.

This resource walks the reader through the process of thinking about policy and practice change from an anti-racist, HOPE-informed lens grounded in [Community Well-Being Resource Center’s document on Anti-racist Organizational Change](#). Let’s take a look at how a HOPE-informed organization might address two notable racial disparities in systems that serve children and families.

In each of the following scenarios, the same process will be followed:

- Start with Data:** What is the racial disparity you are trying to address, and how does it connect with access to a HOPE Building Block?
- Engage the Community:** How do those most affected by the disparity feel? What do they see as the problem? What would they like to see in the solution?
- Prioritize and Change Policy:** What change can you make to increase access to one or more of the HOPE Building Blocks?

### HOPE HEALTHY OUTCOMES FROM POSITIVE EXPERIENCES

#### Moments of HOPE



The HOPE framework helps transform our work by actively promoting positive experiences that drive health and well-being for children, families, and communities. HOPE begins with a shift in mindset that calls on each of us to identify, celebrate, and promote individual and family strengths in each moment.

Moments of HOPE can be integrated into existing models and layered into the work you’re already doing including:

- In each encounter**  
Start each encounter with a family or child with a moment of HOPE. What has gone well since the last time you saw each other? What is something they are proud of? Celebrate the successes with them, however big or small.
- During intake and assessments**  
Each of us has a unique mixture of strengths and challenges. Create a moment of HOPE by asking about strengths first. Consider asking open-ended questions about relationships, environments, engagement, and emotional growth. Please see the [training videos](#) that demonstrate HOPE-informed screening, and for a [description of four ways to assess for PCEs](#).
- When sharing referrals or community resources**  
Ensure that each connection you make for a family is individualized to their specific strengths, challenges, and culture. Offer a moment of HOPE to families by connecting referrals and community resources to the Building Block that it relates to. Infusing information about the protective nature of Positive Childhood Experiences into conversations about community resources reminds parents of the tremendous power they have to protect their children’s adult health!
- When creating or revising policies**  
Does your policy promote access to one of the Four Building Blocks? Does it block access? Does it intentionally recognize the positive? Are there certain groups of individuals who are disproportionately affected by your policy? Take a look at our [HOPE-informed Checklist for Decision Making](#) and [HOPE as an Anti-racist Framework in Action](#) to see how your everyday policies can promote equitable access to the Four Building Blocks.
- In your internal or organizational culture**  
Spreading HOPE goes beyond what happens with families and children: it starts with an internal culture of HOPE. Not sure where to begin? Start with our [HOPE-informed Supervision and Leadership document](#).  
Whether big or small, moments of HOPE can occur every day. We know they help us stay grounded and positive. We hope they do the same for you!


HOPE@tuftsmedicalcenter.org | positiveexperience.org

### HOPE HEALTHY OUTCOMES FROM POSITIVE EXPERIENCES

#### Four Ways to Assess Positive Childhood Experiences

Inquiring about strengths, learning proxy measures for resilience, and promoting access to positive childhood experiences are key components of the HOPE framework. While there is not a single, evidence-based approach providers can use to ask about positive childhood experiences, the following options represent research-informed methods currently being used in the field.

*The first two techniques are based on standardized, validated questions used with diverse scores. Higher scores are associated with stronger resilience. The questions can be included in any standard intake form, paired with an ACEs screen, or used as a stand-alone screening tool.*



- Positive Childhood Experiences scale** (Bethell et al, 2019)  
In a population survey conducted in a largely White sample in Wisconsin, this scale has been shown to protect adult mental health. A score is calculated based on the number of questions that were answered “always” or “almost always.”
  - Thinking back to your childhood, up to the age of 18, please indicate how often you
    - Felt able to talk to their family about feelings
    - Felt their family listened to them during difficult times
    - Enjoyed participating in community traditions
    - Felt a sense of belonging in high school
    - Felt supported by friends
    - Had at least two non-parent adults who took genuine interest in them
    - Felt safe and protected by an adult in their home
- Benevolent Childhood Experiences** (Sargan, Rivera, Bernstein, Harris & Lieberman, 2018)  
This instrument was developed for clinical use at the primary care clinic at the University of California, San Francisco. It has been validated in small studies conducted among high-risk populations. Similar to the Positive Childhood Experience scale above, a total score is generated by tallying the number of affirmative answers.
  - When you were growing up, during the first 18 years of life
    - Did you have at least one caregiver with whom you felt safe?
    - Did you have at least one good friend?
    - Did you have beliefs that gave you comfort?
    - Did you like school?
    - Did you have at least one teacher who cared about you?
    - Did you have good neighbors?
    - Was there an adult (non-parent/caregiver) who could provide you with support and advice?
    - Did you have opportunities to have a good “one”?
    - Did you like yourself or feel comfortable with yourself?
    - Did you have a predictable home routine, like regular meals and a regular bedtime?

### HOPE-Informed Checklist for Decision Making

This simple checklist will walk you through assessing if the decision you are making, policy you are creating, or tool you are considering is HOPE-informed. As you consider moving forward, ask yourself if your decision, policy, or tool does the following things.

- Identifies, celebrates and honors strengths and resilience
- Supports access to the 4 Building Blocks of HOPE (relationships, environments, engagement, and emotional growth)
- Reflects practice that promotes empathy, recognizes common goals, and understands that individuals are doing the best they can
- Incorporates community feedback into robust continuous quality improvement
- Has clear mechanisms to identify and address systems failures that result in inequities

Equally as important, you will want to screen your decision/policy/tool to ensure that it does NOT check any of the following boxes.

- Exclusive focus on identifying problems and referring to services
- Creates an “us” and “them” dynamic in association with services
- Inadvertently perpetuates labeling, stigma, or bias

If it checks all the boxes on the top of the page and none on the bottom, wonderful! You’re on your way towards more HOPE-informed practice. Otherwise, use this checklist as a guide for improvement. If you’re stuck, we’re here to help! Reach out to the HOPE National Resource Center team at [hope@tuftsmedicalcenter.org](mailto:hope@tuftsmedicalcenter.org).



# Thank You!

*Please share feedback on the two-day  
LEND Lived Experience Summit!*



[https://www.surveymonkey.com/r/DAY\\_2\\_LEND\\_LE\\_Summit](https://www.surveymonkey.com/r/DAY_2_LEND_LE_Summit)

**Full Team Email: [itac@aucd.org](mailto:itac@aucd.org)**