

The background is a light blue gradient. In the center, there is a large, dark blue rounded rectangle containing white text. Behind this rectangle, there is a faint illustration of three people working together to build a large globe. One person is on a ladder on the left, another is sitting on top of the globe, and a third is kneeling on the right. A white circuit-like line with small circles at the ends runs horizontally across the middle of the image, passing behind the dark rectangle.

BUILDING CONNECTIONS: SUPPORTING FAMILIES WITH EDUCATION, SHARED DECISION MAKING, AND COLLABORATION

2025 WASHINGTON BEHAVIORAL HEALTH CONFERENCE

KAREN KELLY, KAREN SCHILDE, AND CAMMIE PERRETTA

JUNE 13, 2025

TODAY'S PRESENTERS



Karen Kelly



Karen Schilde



Cammie Perretta, LICSW



KAREN KELLY

- Karen Kelly is the Project Director for Washington State Community Connectors, a Parent Consultant on the Children's Long-Term Inpatient Program (CLIP) Steering Committee, and is certified in WISE, and a certified Peer Counselor. She comes into this work because of her lived experience in parenting a child with intense behavioral health care needs.



KAREN SCHILDE

- Karen Schilde serves on the boards for National Alliance for Mental Illness (NAMI) Sno-Isle and Everett Clubhouse (under Hero House Northwest), facilitates NAMI family support groups and trains state teachers for NAMI's Family-to-Family program. She volunteers with the UW SPIRIT Center as a Psychosis REACH Family Ambassador and currently with Family Bridger.



CAMMIE PERRETTA, LICSW

- Cammie Perretta has been engaged with Washington's Coordinated Specialty Care model for first episode psychosis, called New Journeys since 2016. She has served in various roles including; Individual Resiliency Training, Director/Family Education position, state subject matter expert, and now serves as a New Journeys trainer at the UW SPIRIT Center.



TODAY'S OBJECTIVES

- 1.Highlight collaborative work between state/system partners and family organizations
- 2.Share family stories about their experiences and what helped and what hurt in their journey
- 3.Q&A to bolster conversation to strengthen supporting families in wellness together





WHY ARE FAMILIES IMPORTANT?

Families and natural supports are integral to providing whole-person care and connecting to community.

Including families/naturally supports in care leads to:

- Better treatment outcomes (Glick, Stekoll, Hays, 2011)
- Fewer hospital admissions (Pitschel-Walz, Leucht, Baumi, Kissling & Engel, 2001)
- Shorter inpatient stays (Pfammater, Junghan & Brenner, 2006)
- Overall improvement in quality of life (Evert et al., 2003)
- Better work and role performance (Brekke & Mathiesen, 1995)
- Reduced substance use (Clark, 2001)
- Potentially reduced mortality (Revier et al., 2015)

QUESTIONS TO CONSIDER:

How do our families' experiences of caretaking someone with a mental illness compare to families you know?

How is caregiving for SMI different?

What resources could have helped for families like ours?

What communication strategies could you use in your role with the individual or the family?

What is the System of Care?

A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.

System of Care Values

- Family and Youth Driven
- Community Based
- Culturally and Linguistically Responsive



System of Care Principles

1. Comprehensive Array of Services and Supports
2. Individualized, Strengths-Based Services and Supports
3. Evidence-Based Practices and Practice-Based Evidence
4. Trauma-Informed
5. Least Restrictive Natural Environment

System of Care Principles

- 6. Partnerships with Families and Youth
- 7. Interagency Collaboration
- 8. Care Coordination
- 9. Health-Mental Health Integration
- 10. Developmentally Appropriate Services and Supports

System of Care Principles

- 11. Public Health Approach
- 12. Mental Health Equity
- 13. Data Driven and Accountability
- 14. Rights Protection and Advocacy

HOW ARE CAREGIVERS IMPACTED?

Families are the front line workers when caring for loved ones with mental health challenges



Families experience direct and indirect costs (financially, work impairment, emotional toll)²

- Yearly out of pocket expenses cost of caregiving: \$7,200

<https://www.aarp.org/caregiving/financial-legal/info-2021/high-out-of-pocket-costs.html>



Families can spend half of a full-time work week providing care to their loved one⁶

¹GBD 2016 Disease and Injury incidence and Prevalence Collaboration, 2017; ²Schizophrenia Commission, 2021; ³Gupta et al, 2015; ⁴Hayes et al., (2015), ⁵Angemeyer et al., (2006), ⁶Hayes et al., (2015); ⁷Flyckt et al., 2013

HOW ARE CAREGIVERS IMPACTED?

Families also experience:

Significantly higher rates
of common mental
health challenges and
psychological distress³

Burnout at similar rates
to those in paid
psychiatric settings⁴

Social isolation

¹GBD 2016 Disease and Injury incidence and Prevalence Collaboration, 2017; ²Schizophrenia Commission, 2021; ³Gupta et al, 2015; ⁴Hayes et al., (2015),
⁵Angemeyer et al., (2006), ⁶Hayes et al., (2015); ⁷Flyckt et al., 2013

HOW ARE CAREGIVERS IMPACTED?

Multidimensional Caregiver
Strain Index (MCSI) :

The Caregiver Strain Index,
Erica Goss reflects on the
experience of caring for
her son within a
dysfunctional mental health
system.

<https://www.oregonhumanities.org/rll/beyond-the-margins/the-caregiver-strain-index/>



APA 2015 STUDY MENTAL AND PHYSICAL HEALTH EFFECTS OF CAREGIVING IN FAMILIES NOT SMI


- A recent survey by the National Opinion Research Center (2014) found that 83 percent of caregivers viewed it as being a positive experience.
 - 33 percent of caregivers reported “no strain”
 - 50 percent reported “some strain”
 - 17 percent reported “a lot of strain”

“ON PINS AND NEEDLES”
RESEARCH ON
CAREGIVERS OF ADULTS
WITH MENTAL ILLNESS

ON PINS AND NEEDLES

[HTTPS://WWW.CAREGIVING.ORG/
G/MENTALHEALTH/](https://www.caregiving.org/mentalhealth/)





FROM 2016 RESEARCH ON 1,700 FAMILY CAREGIVERS FOR SMI

Most are moms aged
45 to 64

Recipients of
caregiving are mostly
adult children 18-39

Half are financially
dependent on
caregivers

Employed 36 hrs
weekly, but provide
additional 32 hours of
care

Provide \$7K in
support while 10% are
forced to quit their
jobs

62% find caregiving
worsens emotional
and physical health

Half report despair
and isolation due to
high levels of stress

Greatest needs: policy
support to facilitate
education, care
access, navigation
and parity

Nearly 12 years
before getting a
diagnosis

How do we show up?

18

Are you
Mind Full or
Mindful?



Mind Full, or Mindful?

SHARING OUR LIVED EXPERIENCES

◦As you listen to our stories we want you to think about:

- What problems were there in navigating to care?
- What might have been a solution with today's resources?



Who are the Kellys?



Our Family – Finally Complete



A Family in Crisis?

What Hurt?

- Lack of Knowledge
- Silos (Isolated Services)
- Age of Consent
- Hidden Doors
- Slow Movement



What Helped?



- Opportunities to Learn
- Collaboration
- Power of My Voice
- Accountability
- Supports

What's Changed?

small changes
can have
a big
impact

<http://daily-ink.davidfruss.com/small-changes>

- Laws
- Understanding
- Culture
- Peer Support

SHARING OUR STORIES- KAREN SCHILDE



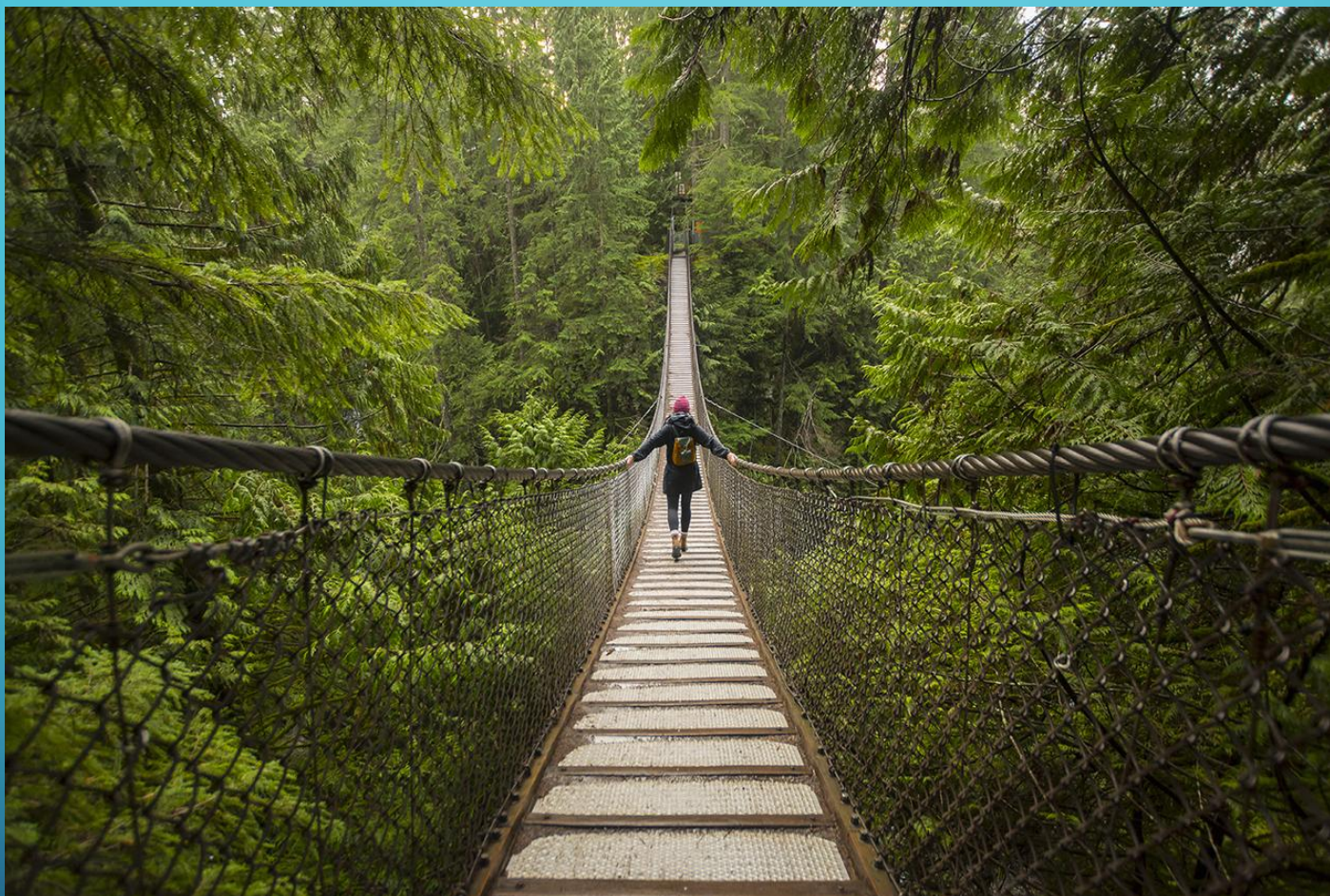
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[Faint handwritten notes on lined paper, mostly illegible due to blurriness.]



SHARING OUR STORIES- MY BIG BROTHER





GROUNDING EXERCISE



My Family Path

August 2012 – Hollie Joins the Family

2013-2016 – Attempting to
get treatment

~~Informed Choices~~ ~~Skills/Knowledge~~
~~Treatment Access~~ ~~Cross Systems~~
~~Infrastructure~~ ~~Supports~~

Youth can decline services at 13. Parents are not able to be informed about what is happening.

Unique skills are needed to parent youth with intensive BH needs.

Not qualified for certain services or programs. Assessments not completed by youth

Workforce shortage. Programs are not functioning as designed. No programs available.

There are little formal supports and no education on informal or natural supports.

Systems are working siloed and are unaware of available resources.

An Alternate Path

What could it have looked like?

2013-2016 – Getting Treatment

Informed Choices Skills/Knowledge
Treatment Access Cross Systems
Infrastructure Supports

Family-Initiated Treatment provides more access to information and potential treatment.

Work is being done to design a system that has no closed doors.

Workforce shortage.
Programs are not functioning as designed. No programs available.

There is now a WA Statewide Family Network, Youth Network, COPE Project, and more.

Opportunities for skill-building are more available than ever before.

Intentional work is being done to educate and hold the system accountable for SoC values

Family and Peer Based Supports

Family Youth
System Partner
Round Table
(FYSPRT)

COPE Project

WSCC

Family, Youth, System Partner Roundtables (FYSPRTs)

- Equal Voice
- Shared Community
- Authority to Initiate Change



WHAT IS A FYSPRT?

Family Youth System Partner Round Tables (FYSPRTs) bring together families, youth, system partners, and community members to work on improving behavioral health services and supports for children, youth, and their families. They embrace the idea that youth and families can and should have an active role in how behavioral health systems serve them and focus on building lasting, family and youth-driven solutions.

All FYSPRT meetings are led by Tri-leads that include a Family Tri-lead, a Youth Tri-lead and a System Partner Tri-lead who share leadership in organizing and facilitating FYSPRT meetings and action items.

There are 10 Regional FYSPRTs and one Statewide FYSPRT in Washington.

* From the HealthCare Authority Website

WHAT DO FYSPRTS DO?

Regional FYSPRTs bring youth, families, and youth serving system and community partners together to identify recurring behavioral health service gaps or needs in their regions, and work to address those needs. The goal of this collaboration is to create behavioral health services and supports that work for youth and families, including but not limited to Wraparound with Intensive Services (WISe). Regional FYSPRTs are also part of the Child, Youth and Family Behavioral Health Governance Structure, which connects recurring needs identified and unresolved by the community to legislative groups to help address those needs.

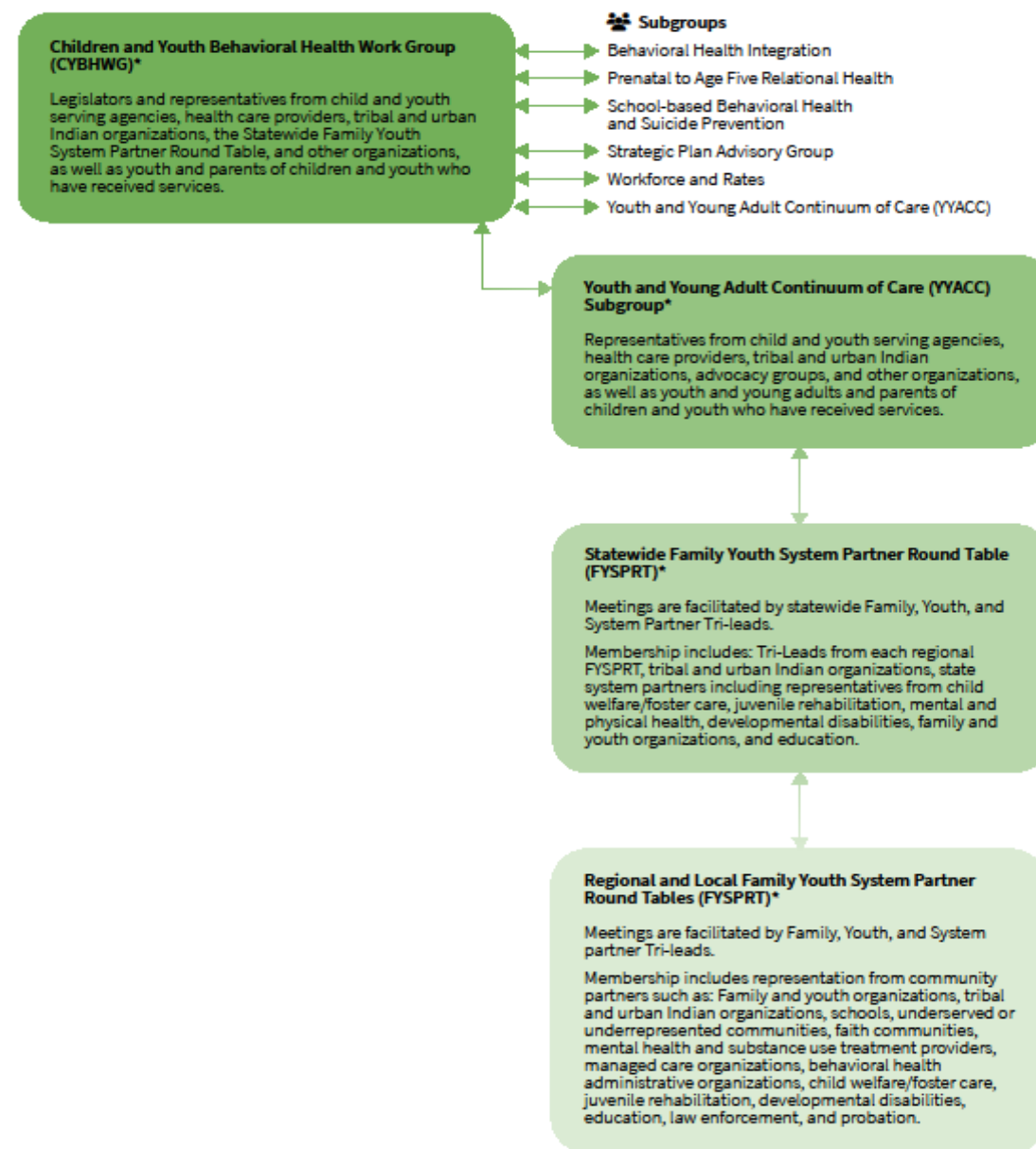
* From the HealthCare Authority Website

Children and Youth Behavioral Health Governance Structure

<https://www.hca.wa.gov/about-hca/programs-and-initiatives/behavioral-health-and-recovery/family-youth-system-partner-round-table-fysprt>

Child, youth, and family behavioral health governance structure

*Meetings are open to the public.



COPE Project

(Center of Parent Excellence)

The Center of Parent Excellence (C.O.P.E.) offers support, across the state of Washington, to parents and caregivers who are raising children and youth (ages 2-22) experiencing behavioral and mental health challenges in the home, school, and community.



WA State Community Connectors

- Family-Led Organization
- Training and Resource Sharing
- WA Statewide Family Network
 - Committees and Workgroups
 - Connections
 - Trainings
 - Events
 - Pathways to Change

An aerial photograph of a large, rectangular hedge maze made of green box hedges on a light-colored stone path. The maze is complex, with many dead ends and loops. In the center of the image, there is a dark, semi-transparent rectangular box containing white text. On the left and right sides of this box, there are light blue circuit-like lines with small circles at the ends, resembling a stylized path or data flow. The background shows parts of a building with a red roof and some trees.

AN ALTERNATIVE PATH- KAREN S.

NAMI EDUCATION AND SUPPORT GROUPS

- **Family-to-Family** 8 weeks, 2.5 hours each week=20 hours
- **Basics** for families of school aged children. 6 weeks=15 hours Also online independent study module
- **Family & Friends** 4 hour webinars with e-manuals in 11 languages
- **Peer-to-Peer** 6 week=15 hours for adults living with a mental health condition

Family-to-Family is a free, 12-week course for families, partners of individuals with serious mental illness taught by 3,500 trained NAMI members and caregivers of individuals living with mental illness. The course dwells on the emotional responses families have to the trauma of mental illness. Many family members describe their experience in the program as life-changing. Also available in Spanish in selected areas.

NAMI Family Support Group is a free, local meeting of caregivers of individuals with a mental illness where family members can talk frankly about challenges and help one another through their learned wisdom. These groups are facilitated by trained NAMI members in NAMI Affiliates across the country. Participants are encouraged to share actively in the work of the group.

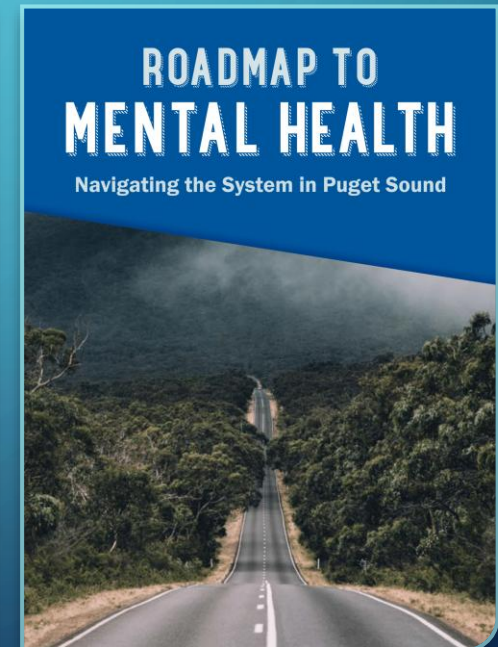
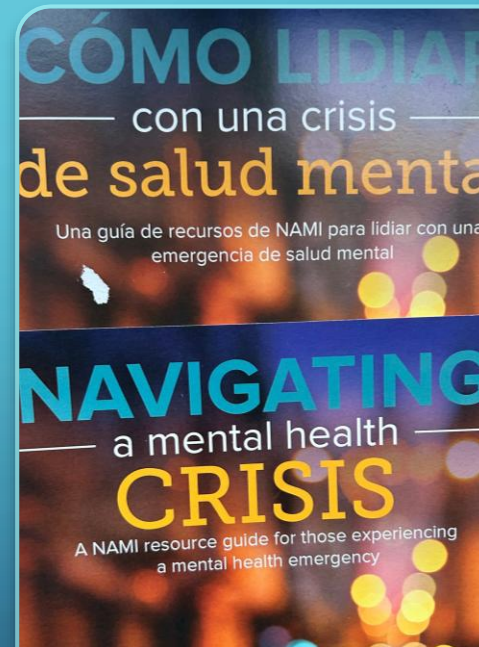
NAMI Basics is a free, six-week peer-directed education program designed specifically for parents and other caregivers of children and adolescents who either have been diagnosed with a serious mental illness/serious emotional problem or who are experiencing symptoms but have not yet been diagnosed.

Peer-to-Peer is a free, 10-week, peer-led, recovery education course for any person with a serious mental illness. Peer-to-Peer emphasizes recovery from mental illness as a feasible, supportable goal and challenges the stigma wrongly associated with mental illness.

NAMI Connection is a free, weekly, 90-minute, recovery support group for people living with mental illness in which people learn from each other's experiences, share coping strategies and offer each other encouragement and understanding.

NAMI NATIONAL RESOURCES IN ENGLISH AND SPANISH

- For local Puget Sound resources, see NAMI Seattle's Road Map to Mental Health



FAMILY AND FRIENDS

- A 4 hour condensed version of the 20 hour Family-to-Family course
 - E-manuals available in 11 different languages

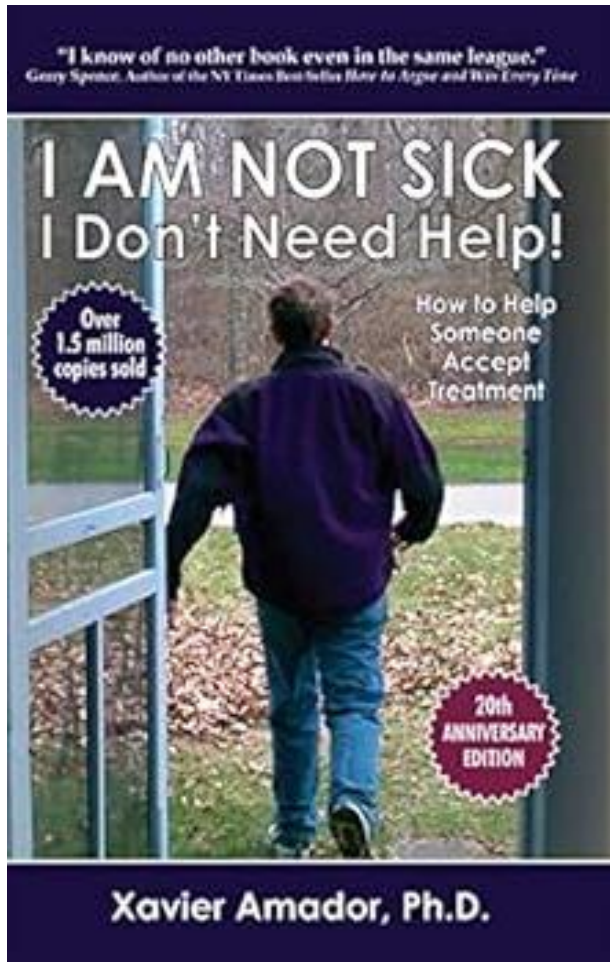


NAMI Family & Friends **Helping Those We Love**

An informative seminar for
people who have a loved one
with a mental health condition



LEAP (LISTEN, EMPATHIZE, AGREE, PARTNER)



- Dr. Xavier Amador
- Anosognosia (neurological lack of awareness or understanding of illness)



Treatment
Advocacy
Center

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**Fighting for the lives of people with severe mental illness in
a system stacked against them**

[Who We Are](#)

TAC.ORG

Treatment Advocacy Center

PAD AND WRAP



Psychiatric Advance Directive



Wellness Recovery Action Plan

OFFICE OF BEHAVIORAL
HEALTH ADVOCACY
(FORMERLY OMBUDS)

1 King County Region
kingcountyregion@obha.org
1 Pierce County Region
piercecountyregion@obha.org
1 Thurston County Region
thurstoncountyregion@obha.org
1 Clark County Region
clarkcountyregion@obha.org
1 Yakima County Region
yakimacountyregion@obha.org
1 Snohomish County Region
snohomishcountyregion@obha.org

1 Eastern Columbia Region
easterncolumbiaregion@obha.org
1 Yakima Region
yakimaregion@obha.org
1 South Central Region
southcentralregion@obha.org
1 South Sound Region
southsoundregion@obha.org
1 South Region
southregion@obha.org

1 Annapolis Care Service Region
annapolisregion@obha.org

Call us at 1 (800) 366-3123

Office of Behavioral Health Advocacy
(OBHA) has replaced the former
behavioral health ombuds.

OBHA provides behavioral health
advocacy services to individuals needing
access to and consistent experience of
behavioral health services in Washington
state. OBHA is focused on ensuring that
the rights of recipients of behavioral
health services are respected, and that
services are responsive to individuals' needs. OBHA provides recommendations
to local, regional, and statewide
community and governmental entities to
bring about changes in laws, rules,
regulations, policies, and procedures that
will improve the quality of behavioral
health services for Washington's residents.



OBHA
OFFICE OF BEHAVIORAL HEALTH ADVOCACY



CONTACT US

obhaadvocacy.org
info@obhaadvocacy.org
Toll-free 1 (800) 366-3123
OBHA (366) 292-5038

FAMILY AND PEER BASED SUPPORTS

- Release of Information- what if your loved one hasn't signed one?
- Treatment Advocacy Center (TAC)
- "Supported Decision Making," now an alternative to guardianship/conservatorship





PSYCHOSIS REACH

Recovery by Enabling Adult
Carers at Home

UW Medicine
DEPARTMENT OF PSYCHIATRY
AND BEHAVIORAL SCIENCES





What We Do ▾ | Who We Are | Support for Psychosis ▾ | Research | Implementation | Training | Events | News | Give | Contact Us 

A wide-angle photograph of a mountain range under a cloudy sky. The mountains are rugged and rocky, with some snow patches. In the foreground, there is a dense forest of evergreen trees. The text "Cognitive Behavioral Therapy for Psychosis (CBTp)" is overlaid in white on the lower half of the image.

Cognitive Behavioral Therapy for Psychosis (CBTp)

<https://uwspiritcenter.org/coognitive>

Open Dialogue



ADAI Symposium

Cannabis, Schizophrenia, and Other Psychotic Disorders:

*Moving Away from Reefer Madness
Toward Science*



- <https://adai.uw.edu/cerp/symposium-2024/>

FAMILY BRIDGER ROLE DEVELOPMENT

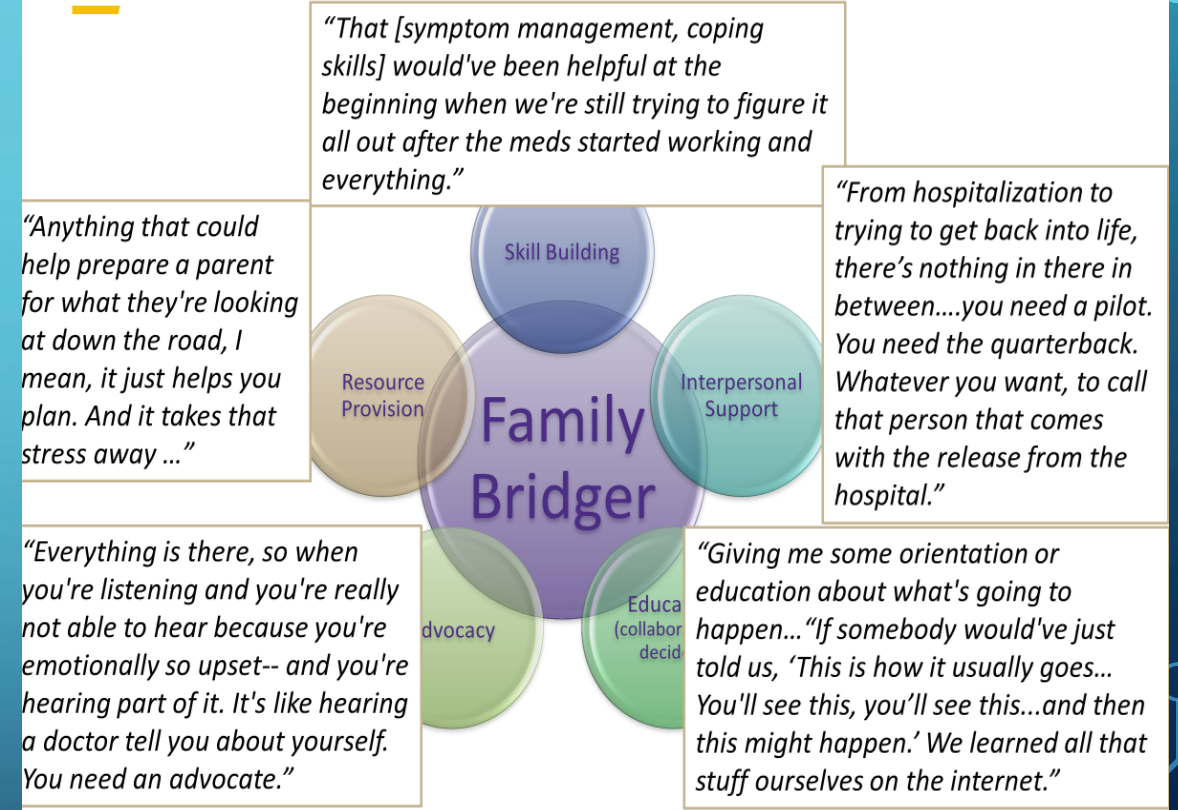
- Our team asked families what they would have liked to receive when their loved ones were hospitalized
- We conducted 9 focus groups in 6 WA locations

Family Focus Group Locations & Participants (N=58)

- 1) Harborview (N=14)*
- 2) Seattle Children's (N=9)*
- 3) Mount Vernon (N=9)
- 4) Vancouver (N=4)
- 5) Yakima (N=14; English=9, Spanish=5)
- 6) Spokane (N=3)
- X) Online (N=5)

*Two focus groups at site

Functions of Family Bridger





Support for families of people living with psychosis

Wish you could talk to someone who
understands?

Connect with a Family Bridger - they have
experience caring for a loved one with psychosis
and have been trained to provide **FREE** support and
resources to people like you.

The Family Bridger Program is a **research study** to improve this program
including compensation up to \$130 for completion of all surveys and interviews

Want to Learn More?



Reach out in any of these ways:

Scan the QR Code

Email

FAMILYBRIDGER@UW.EDU

Call

[206-677-4029](tel:206-677-4029)

HEALING

OUR PATH FROM
MENTAL ILLNESS TO
MENTAL HEALTH

THOMAS INSEL, MD









THREE RIVERS
THERAPY
PEER RESPITE

<https://3riverstherapy.com/>



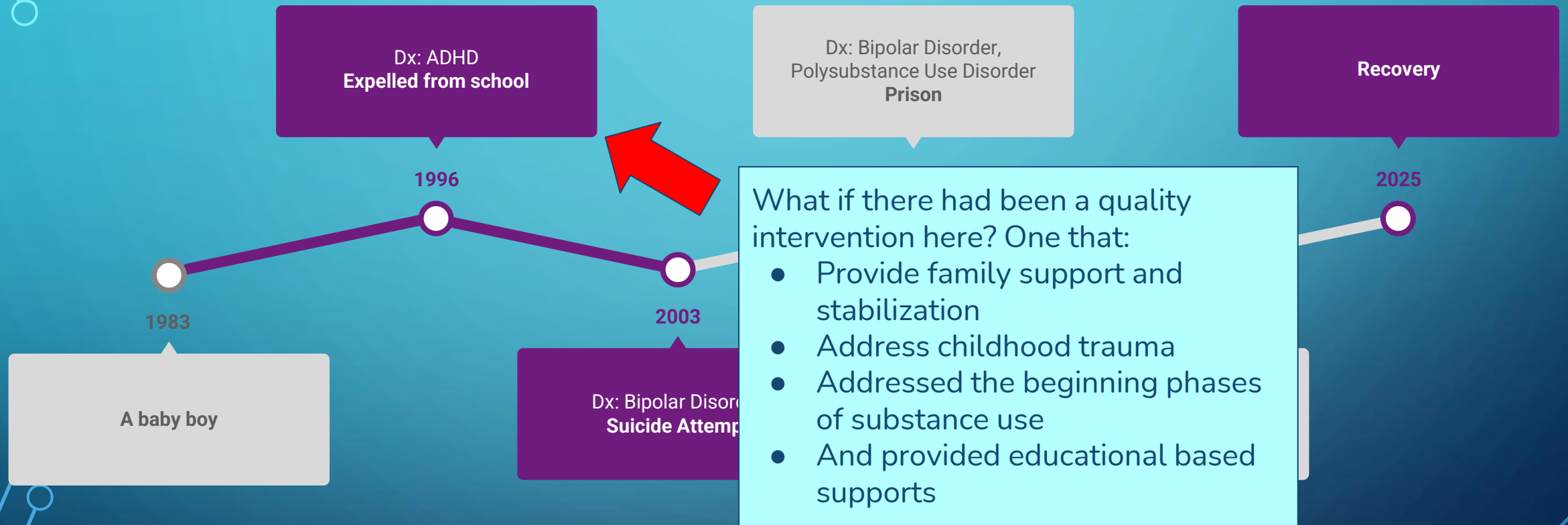
A Mother's Rest

THE NATION'S FIRST & ONLY
NON-PROFIT NETWORK OF YEAR-ROUND
PARENT & CAREGIVER WELLNESS INNS



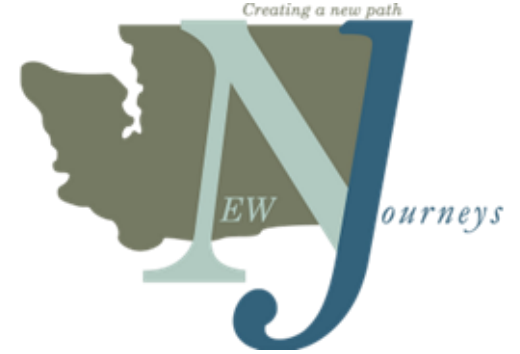
COMMUNITY OF CARE

AN ALTERNATIVE PATH- MY BIG BROTHER



FAMILY AND PEER BASED SUPPORTS

- Family Education / Intensive supports. Such as those from
 - New Journeys
 - WISe
- De-Stigmatization
 - Shared Decision Making
 - Pat Deegan's Recovery Library
 - Peer Support



FAMILY SUPPORT IN FIRST EPISODE PSYCHOSIS



NEW JOURNEYS: FAMILY EDUCATION



- Orients families to the New Journeys treatment model and rationale for family inclusion
- Provides families with culturally responsive and recovery-oriented information about psychosis and its treatment
- Helps the family develop coping skills and foster resiliency
- Supports the family in navigating the mental health system and developing advocacy skills
- Facilitates the development of a wellness (relapse prevention) plan
- Coaches family in communication and problem-solving skills

Highlight of WSCC Trainings

- Age of Consent ~ What it Means for Families
- SUD Family Navigator Training
- Who, What, Why of the Family, Youth, System Partner Round Table (FYSPRT)
- Levels of Listening and Conflict Management
- Personal Wellness
- Growing in Leadership
- Understanding... Series

GROUNDING EXERCISE

LOVING KINDNESS MEDITATION



*May I/you be filled with Loving
Kindness*

*May I/you be safe from inner + outer
dangers*

May I/you be well in body + mind

May I/you be at ease + happy

parentselfcare.com



GROUP DISCUSSION



THANK YOU!

Karen Kelly-
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Karen Schilde-
karens@nami-sno-isle.org

Cammie Perretta, LICSW –
cperre@uw.edu