

# **NAMICon 2020**

A Virtual Event • July 13-14

**Together Toward Tomorrow**

RESEARCH  
UPDATE

# CBT for Psychosis-Informed Caregiving: Bringing Evidence-Based Strategies to Family and Caregivers

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*Recovery by Enabling Adult Carers at Home*



# Agenda for this Research Update

- ❑ Describe the **Psychosis REACH** (Recovery by Enabling Adult Carers at Home) model and its rationale.
- ❑ Share Psychosis REACH pilot data from Washington State.
- ❑ Present a sneak peak of what's next for **Psychosis REACH**.



*Recovery by Enabling Adult Carers at Home*



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# With Tremendous Gratitude to the UW Psychosis REACH Implementation Team



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# And our trainers and intervention co-developers!



**Douglas Turkington, MD**



**Kate Hardy, Clin.Psy.D.**



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# Recovery from psychosis is the default. Expect recovery.



<sup>1</sup> Bellack, A. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schizophr Bull*, 32:432–442

# Schizophrenia and Psychosis Treatment Guidelines



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# Implementation of Practice Guidelines in 2020

- **Fewer than half of all Americans with a SMI have access to care<sup>1</sup>**
- **2% are offered evidence-based therapeutic approach<sup>2</sup>**
- **Poor access to care and social factors are driving poor outcomes<sup>3</sup>**



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1 Folsom et al. (2005)

2 ISMICC (2019)

3 Cloutier et al. (2016)



What if we  
treated  
psychosis the  
way we treat  
other chronic  
health  
conditions?

## Help for Families Newly Diagnosed with Type 1 Diabetes



Finding out your child has type 1 diabetes can be scary. Most people will have many questions and concerns. It's only natural. We're here to help guide you, to care for your child and help you and your entire family move forward with confidence.

### Type 1: You've got this

A type 1 diabetes diagnosis can be challenging because it requires constant attention and care. But, so does childhood! You have a bond with your child that drives your natural instincts, so with a little help and knowledge, you, your child and your entire family can thrive and live well with diabetes.

### Coping with a Type 1 Diabetes Diagnosis Video

Finding out your child has type 1 diabetes can be scary. Many people have had similar feelings after the diagnosis. See how 6 families coped with the diagnosis and learned to manage their kids' diabetes.



Source: <https://www.chop.edu/pages/help-families-newly-diagnosed-diabetes>

# Caregivers have a positive impact on recovery

- ❑ **Better treatment outcomes** (Glick, Stekoll, Hays, 2011)
- ❑ **Fewer hospital admissions** (Pitschel-Walz, Leucht, Bauml, Kissling & Engel, 2001)
- ❑ **Shorter inpatient stays** (Pfammatter, 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)



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# Need to Buck the Status Quo

- ❑ Collaboration between supports & mental health providers is uncommon.
- ❑ Most mental health providers (psychiatrists, psychologists, and social workers) reported no contact with the families of their patients.<sup>1</sup>
- ❑ Carers can spend the equivalent of a full-time job in caregiving activities and provide high levels of unpaid care.<sup>2</sup>



# Caregivers are impacted by caregiving

- Caregivers experience overall work impairment and indirect costs<sup>1</sup>
- Clinical levels of depression identified in caregivers<sup>2</sup>
- Burnout and emotional exhaustion, at equivalent levels to those reported by paid psychiatric staff<sup>3</sup>



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1 Schizophrenia Commission (2012)

2 Lowenstein et al. (2010)

3 Angermeyer, Bull, Bernert, Dietrich, & Kopf (2006)

# Research to Practice Gap

## ❑ Empirically-Supported Family Interventions for psychosis:

- ❑ Psychoeducational Family Approach (Anderson, Hogarty, & Reiss, 1986)
- ❑ Psychoeducational Multi-Family Group (MacFarlane, 1994)
- ❑ Family Support Service (Somerset Partnership NHS and Social Care Trust; Burbach & Stanbridge, 1998)
- ❑ NAMI Family to Family (Dixon, 2001)
- ❑ Recovery-Oriented Decisions for Relative's support (REORDER; Cohen et al., 2013)
- ❑ Online (Glynn et al., 2010; Duckworth & Halpern, 2014)

## ❑ Poor uptake by providers (Kavanagh et al, 1993; Burbach & Stanbridge, 2006)



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# Incorporating Families within Psychotherapeutic Interventions

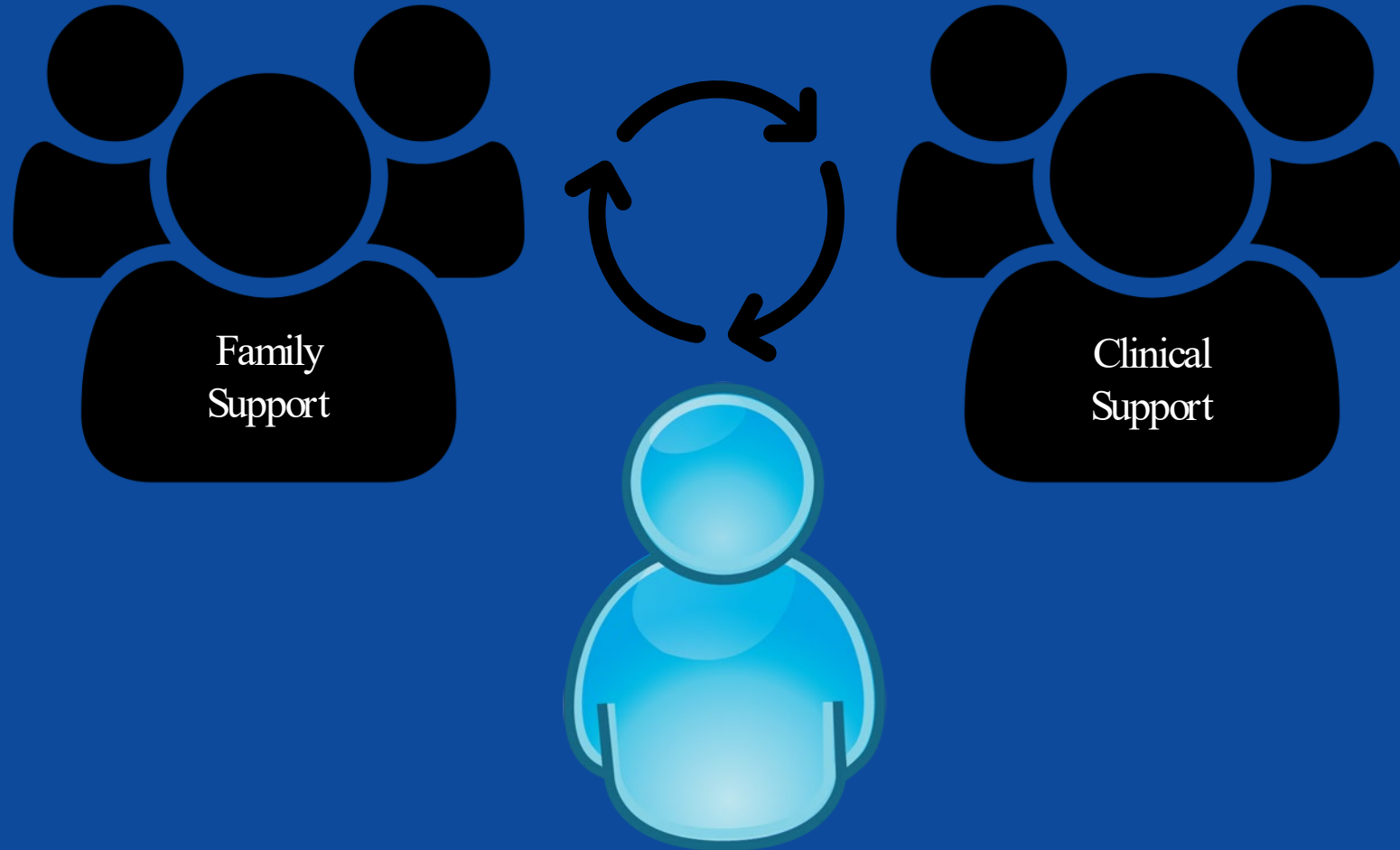
- ❑ Within the context of individual treatment
  - ❑ Guided by clinical formulation and client comfort
- ❑ As a separate cognitive behavioral family intervention
- ❑ As a supplement to CBTp treatment, families learn CBTp-informed skills
- ❑ Families whose loved ones will not engage with treatment can learn CBTp-informed skills



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# Psychosis REACH

A Cognitive Behavioral Therapy-Informed Training for Families and Caregivers







# Psychosis REACH Training

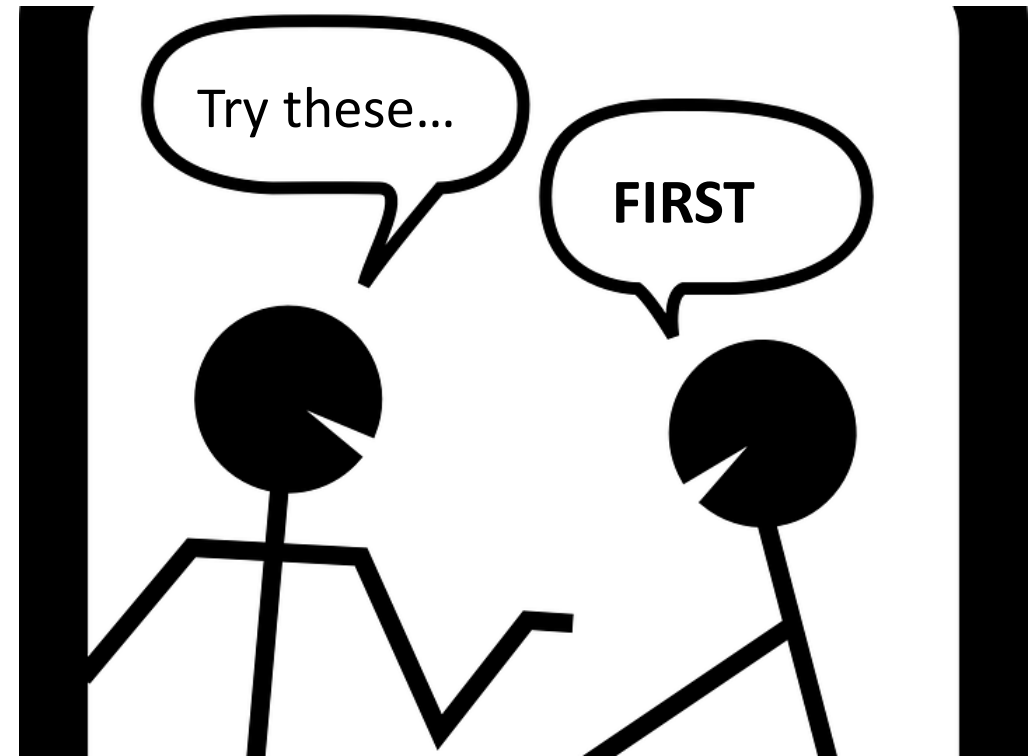
1. Recovery-oriented psychoeducation
2. Applicability of cognitive behavioral theory and therapy to psychosis and caregiver experience
3. Coaching in CBT for psychosis-informed skills and concepts (FIRST skills)



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# The FIRST Skills: An Overview

- Fall back on your relationship
- Inquire Curiously
- Review the information and put it together
- Skill development
- Try out the skill and get feedback



# The FIRST Skills: An Overview

- **F**all back on your relationship
  - Highlight strengths/shared interests
  - Develop shared goals
  - Normalize experiences



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# The FIRST Skills: An Overview

- **Inquire Curiously**
  - Asking questions about their experiences & symptoms
  - Dropping assumptions



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# The FIRST Skills: An Overview

- **R**eview the information and put it together
  - Orient to role of stress & stress management strategies
  - Make sense of experiences through shared understanding
  - Orient to cognitive triangle & maintenance formulation



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# The FIRST Skills: An Overview

- **S**kill Development
  - Cognitive skills
  - Behavioral skills
  - Problem-solving



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# The FIRST Skills: An Overview

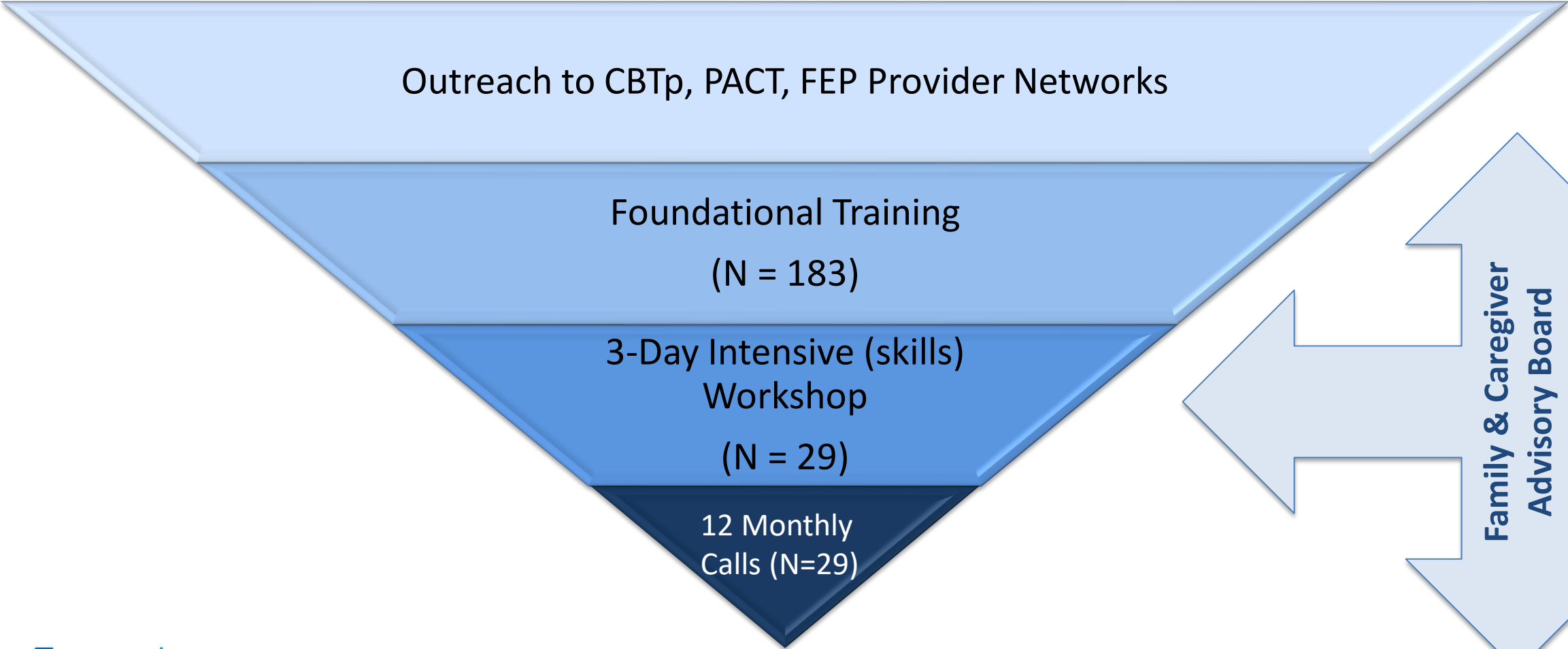
## Try out the skill and get feedback

- Encourage the individual to practice the skill independently and provide feedback on how it worked



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# p-REACH Implementation Model





## Psychosis REACH Project Timeline

**Registration: February – May 2019**

**Event: May 14<sup>th</sup> – 17<sup>th</sup>, 2019**

**Data Collection: May - September 2019**

298 registered for Psychosis REACH

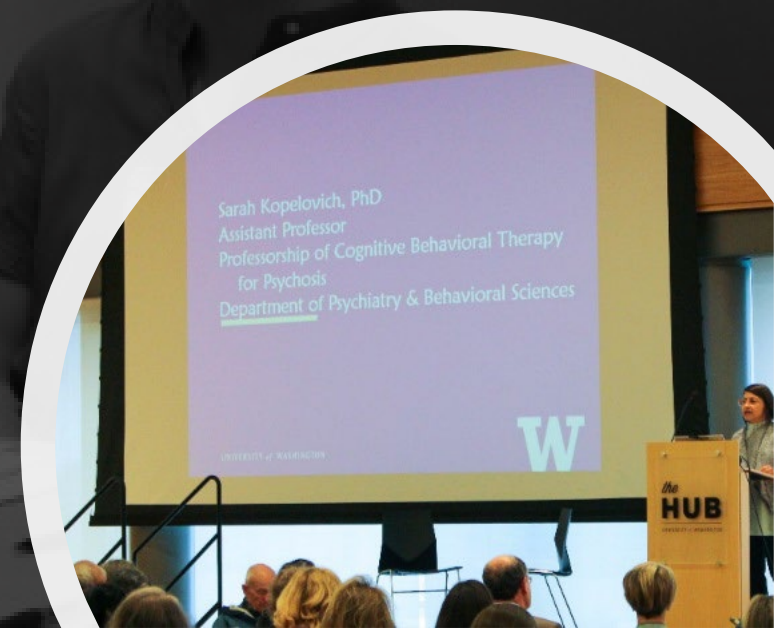
183 family & caregivers enrolled

170 consented to surveys

168 completed pre-training survey

134 completed post-training surveys

121 completed follow-up surveys

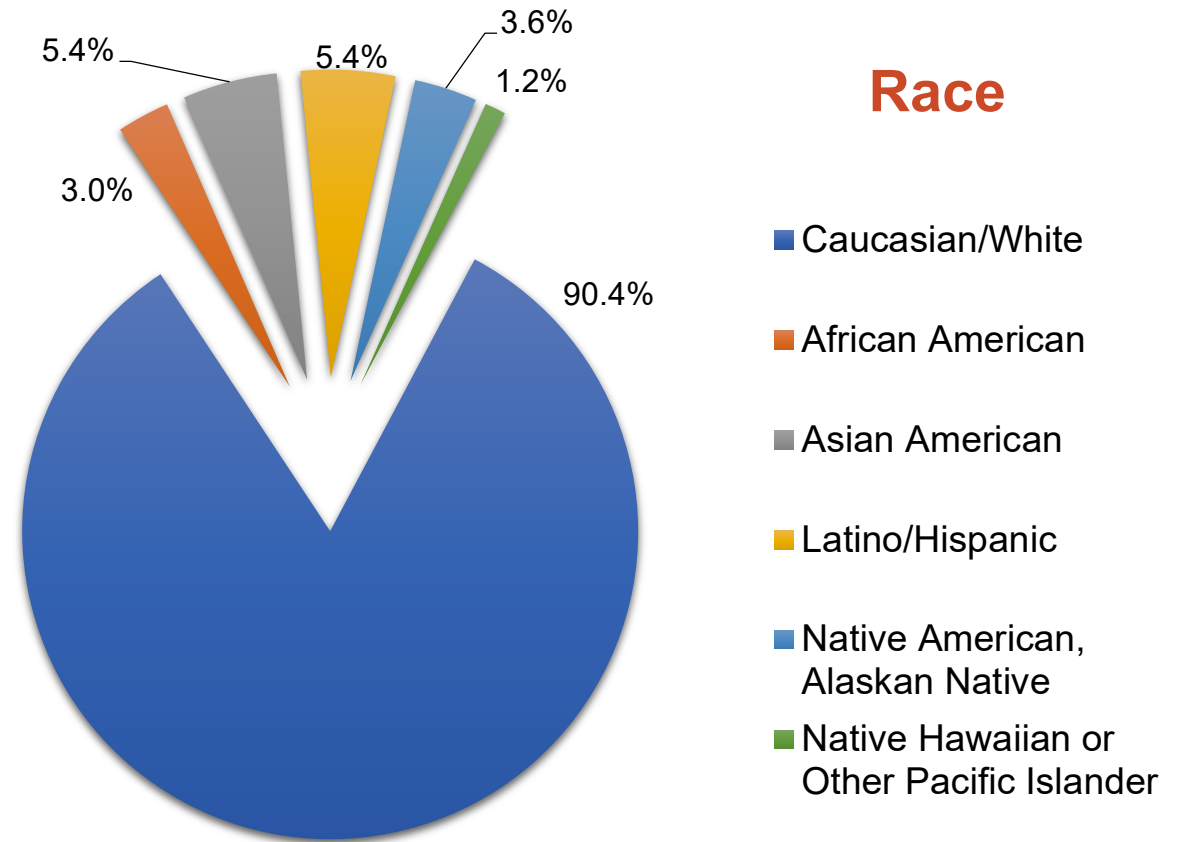


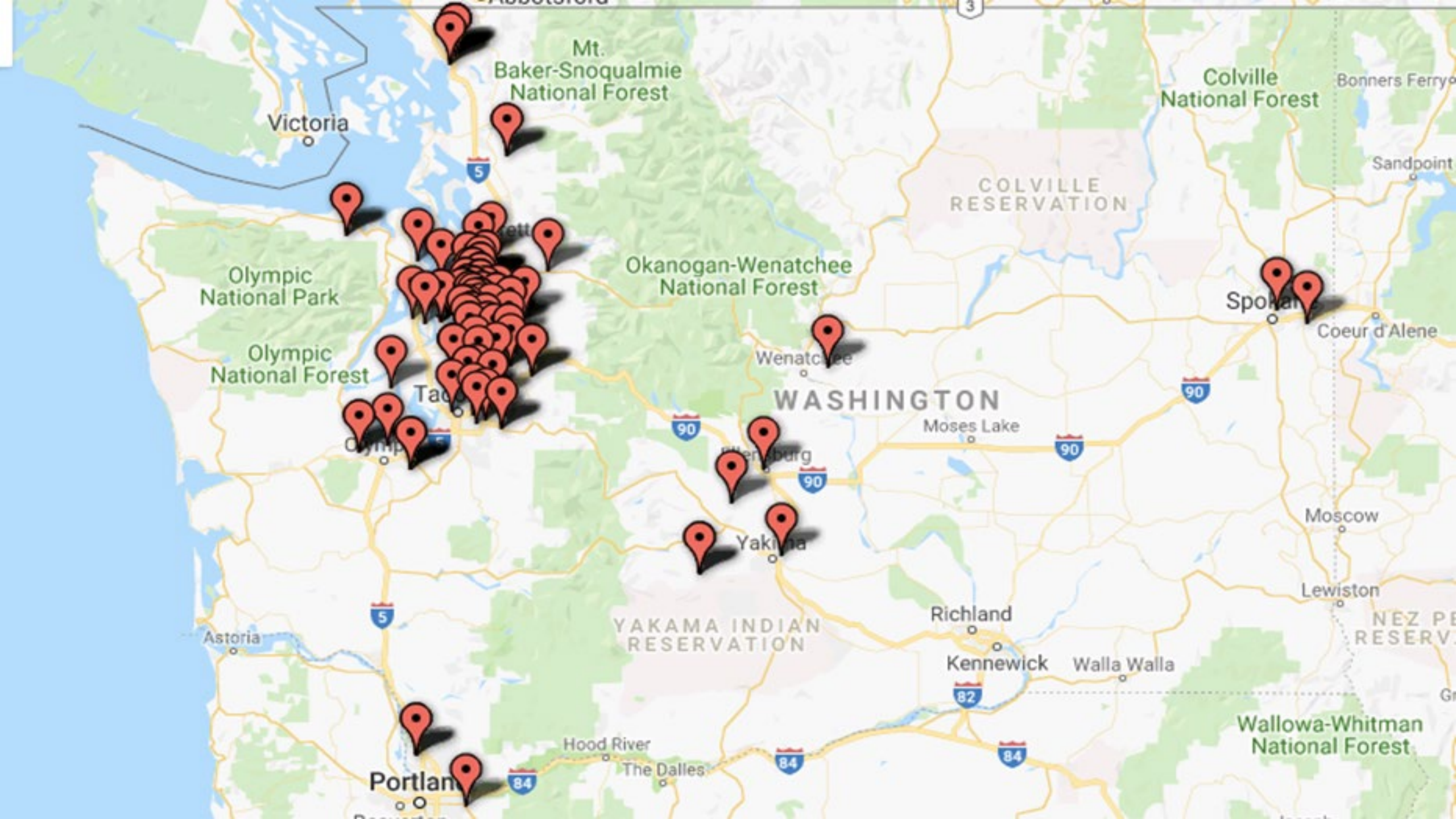


**What did we find?**

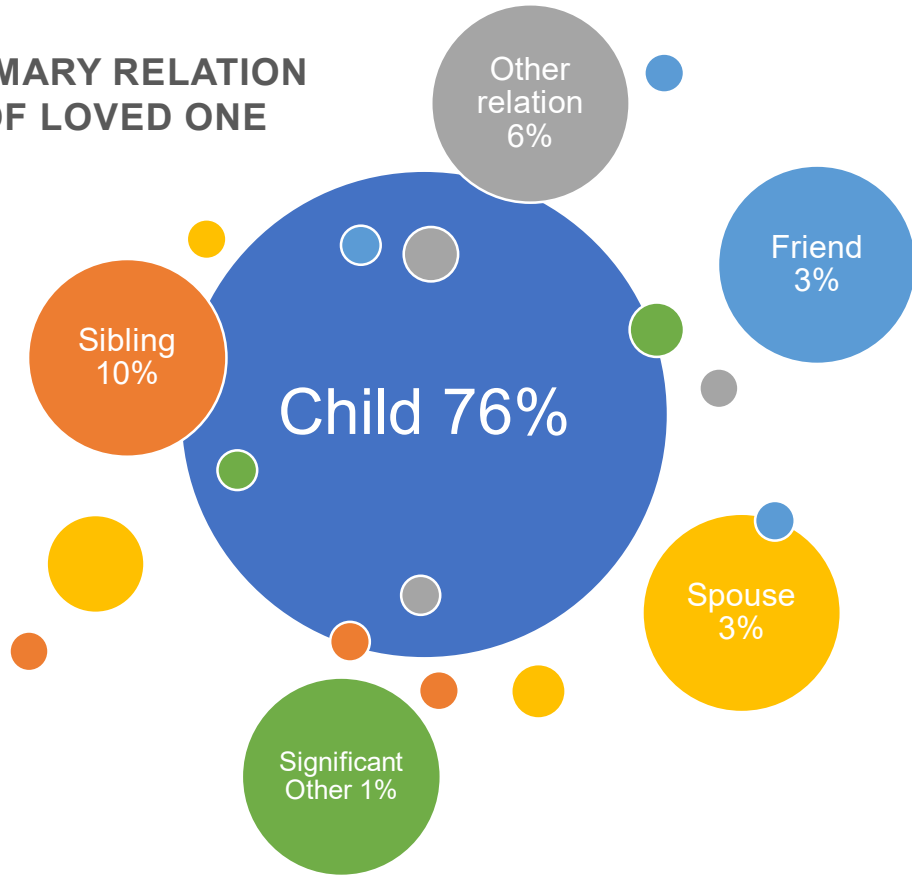
# Psychosis REACH Trainee Demographics

Family & Caregiver Demographics	REACH N = 168	Intensive Trainees N = 29
Age	56.2 (14.7)	57.9 (11.9)
Gender		
<b>Female</b>	<b>123 (73.2)</b>	<b>23 (82.1)</b>
Male	42 (25.0)	5 (17.9)
Non-binary or Transgender	2 (1.8)	-
Education Level		
Some high school/HS graduate or GED	4 (2.4)	1 (3.4)
Business or tech training, incl. military	6 (3.6)	-
Some college	14 (8.3)	-
Associates degree	11 (6.5)	2 (6.9)
Bachelors degree	65 (38.7)	<b>13 (44.8)</b>
<b>Some graduate or Masters/Doctoral degree</b>	<b>68 (40.4)</b>	<b>13 (44.8)</b>
Marital Status		
Single	26 (15.5)	4 (13.8)
<b>Married</b>	<b>105 (62.5)</b>	<b>19 (65.5)</b>
Separated	2 (1.2)	-
Divorced	25 (14.9)	4 (13.8)
Widowed	2 (1.2)	-
Other	8 (4.8)	2 (6.9)





### PRIMARY RELATION OF LOVED ONE



Average # of hospitalizations

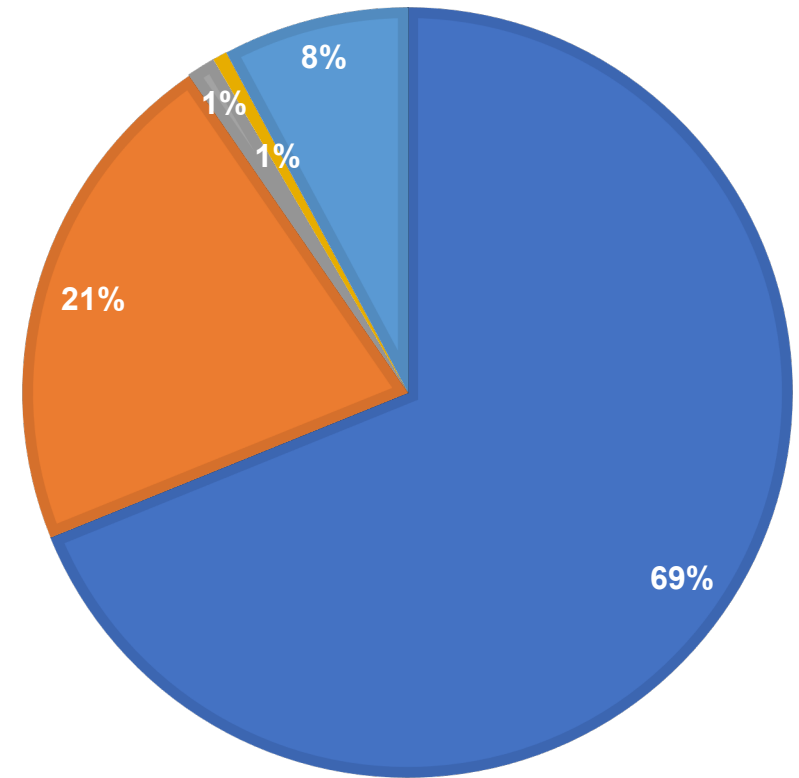
4.67

Average # years since first diagnosis

5

### PRIMARY DIAGNOSIS

- Schizophrenia spectrum disorder
- Mood disorder with psychotic features
- Neurodevelopmental disorder
- Personality disorder
- Unknown

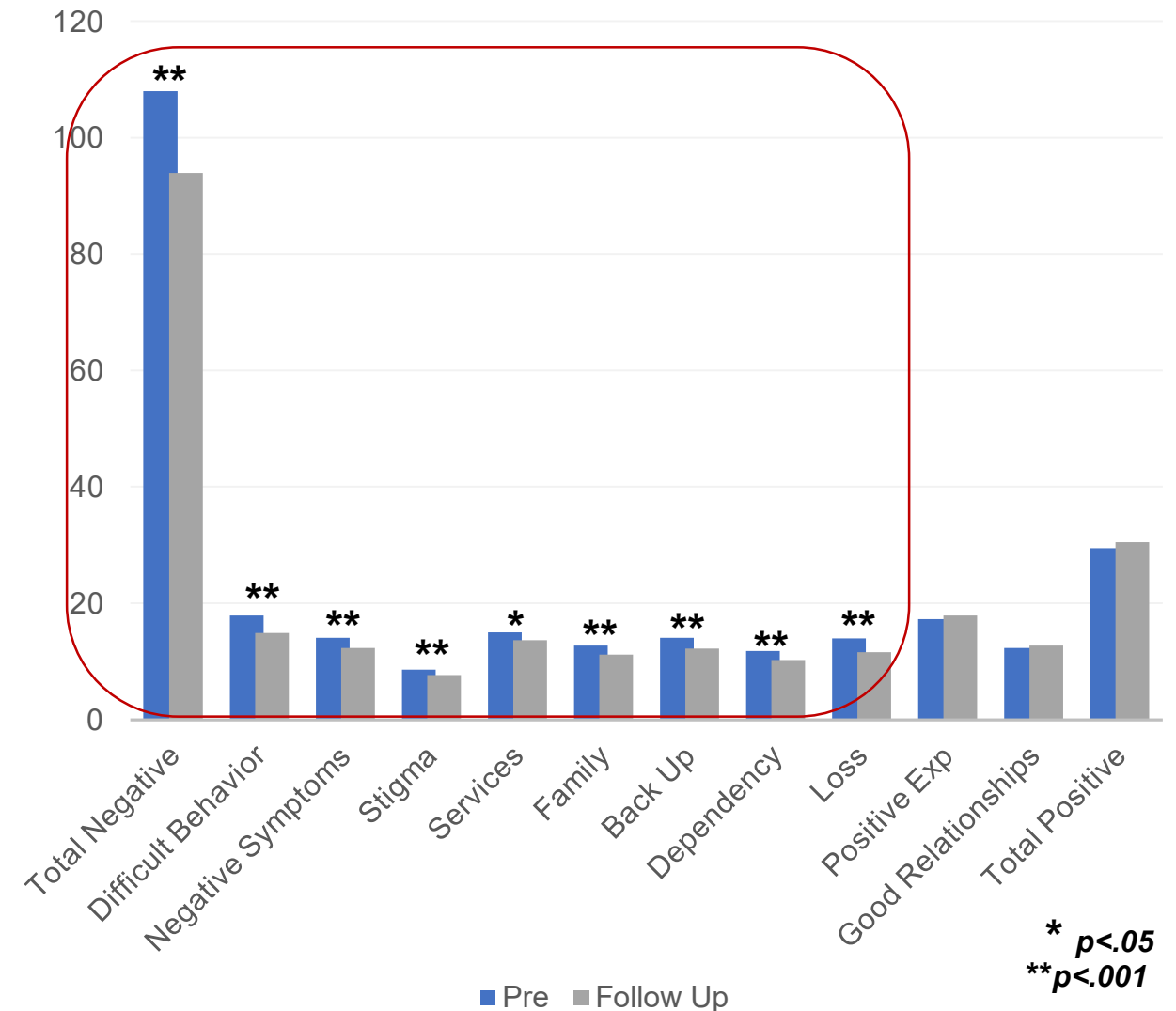


# Caregivers' Experiences

## Experience of Caregiving Inventory (Szmukler et al., 1996)

N = 122	Range	Pre Score (Mean [SD])	F/u Score (Mean [SD])	T-score	P-value
Difficult Behaviors	0-32	17.93 (6.91)	15.01 (6.72)	5.68	p<.001
Negative Symptoms	0-24	14.01 (5.42)	12.36 (5.26)	3.99	p<.001
Stigma	0-20	8.46 (4.42)	7.58 (3.90)	3.29	p<.001
Services	0-32	15.06 (7.12)	13.64 (6.49)	2.56	p<.05
Family	0-28	12.84 (5.40)	11.25 (5.17)	4.14	p<.001
Backup	0-24	14.15 (4.45)	12.25 (4.26)	5.54	p<.001
Dependency	0-20	11.81 (3.98)	10.26 (4.00)	5.61	p<.001
Loss	0-28	13.96 (4.59)	11.56 (4.70)	7.67	p<.001
<b>TOTAL NEGATIVE SCORE</b>	0-208	108.28 (30.19)	93.92 (30.53)	7.25	p<.001
Good aspects of relationship	0-24	12.21 (4.10)	12.71 (3.89)	-1.73	p=.11
Positive personal experiences	0-32	17.27 (4.81)	17.85 (4.46)	-1.60	p=.08
<b>TOTAL POSITIVE SCORE</b>	0-56	29.45 (7.42)	30.46 (6.78)	-1.89	p=.06

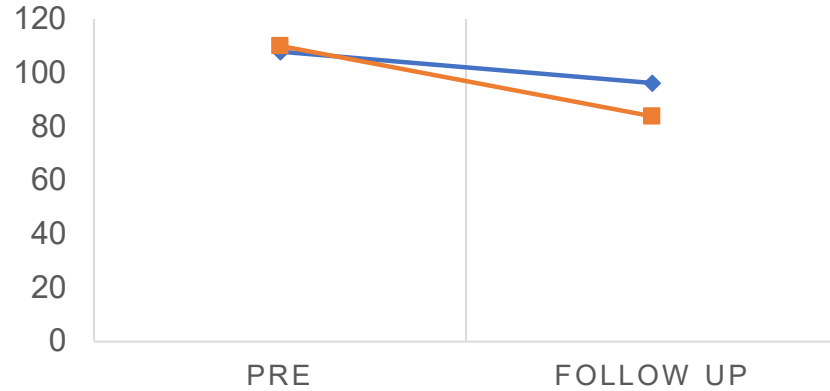
## ECI SUBSCALES & TOTALS



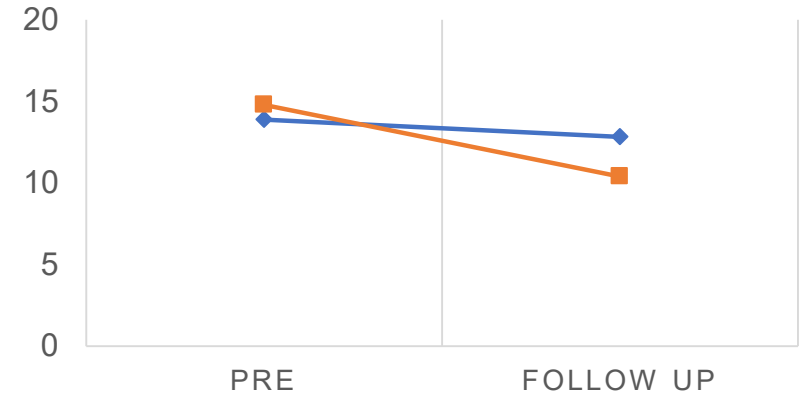
# Caregivers' Experiences

- One-Day Only
- Intensive Training

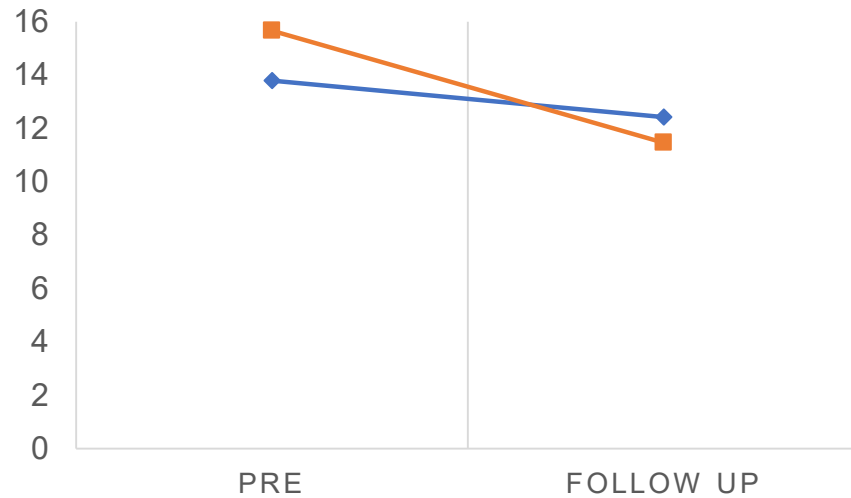
### ECI TOTAL NEGATIVE SCORE



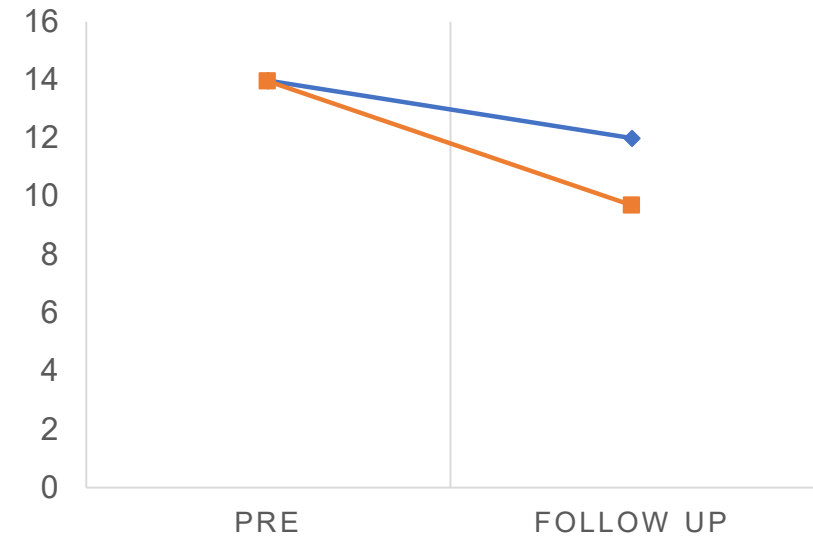
### ECI NEGATIVE SYMPTOMS SCALE



### ECI NEED FOR BACK UP SCALE



### ECI LOSS SCALE



# Attitudes Towards Psychosis

## Psychosis Attitude Scale (Sivec et al., 2020)

- Evaluated on 1 (Strongly Disagree) to 7 (Strongly Agree) scale

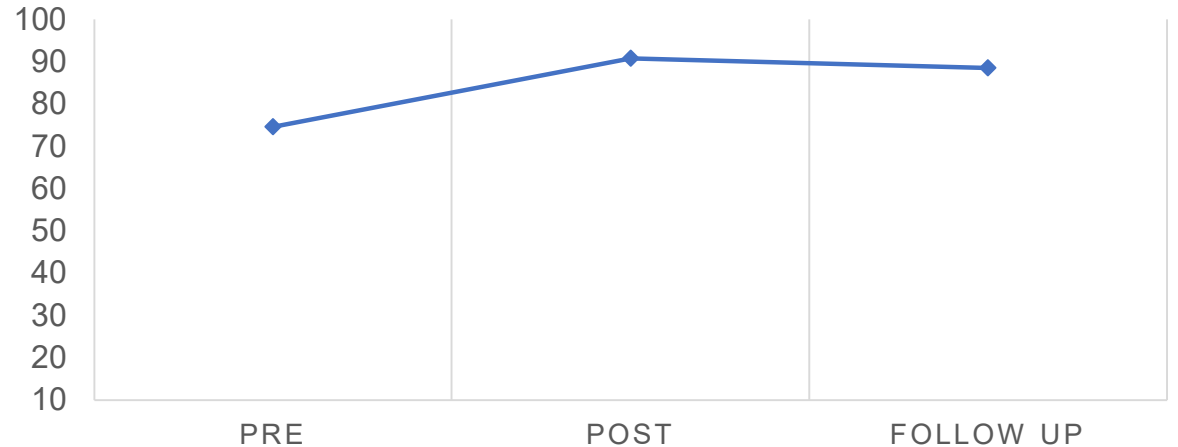
**PAS Total:** Statistically significant changes over time [ $F(1.852, 201.832) = 118.660, p < .0001, \text{partial } \eta^2 = 0.521$ ]

- Pre -> Post: +16.07 pts ( $p < .0001$ )
- Post -> F/u: -2.25 pts ( $p < .05$ )
- Pre -> F/u: +13.81 pts ( $p < .0001$ )

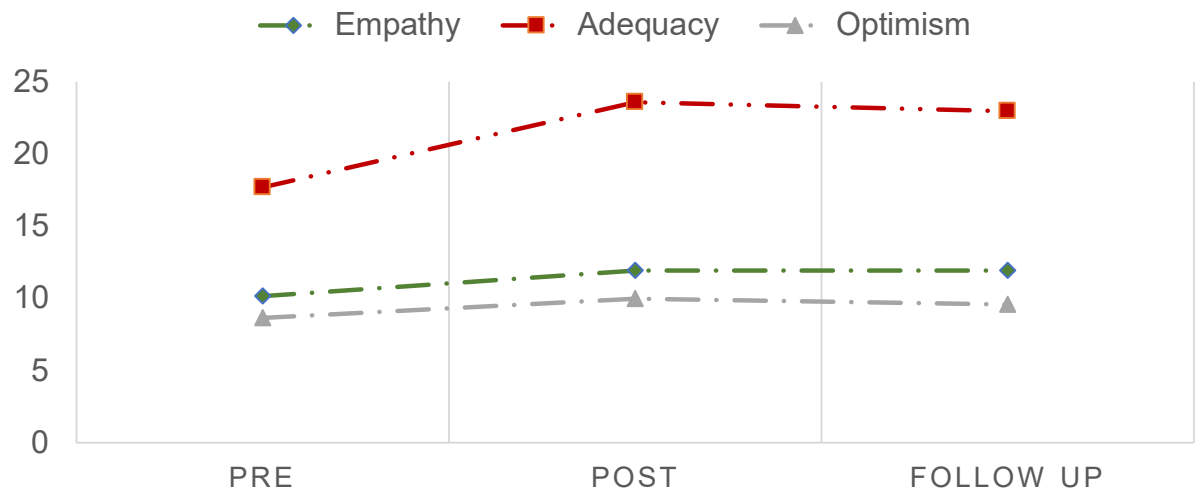
**Subscales:** All demonstrated statistically significant changes over time, with the following observations:

- **Empathy & Adequacy:**
  - Statistically significant increase from Pre->Post
  - No statistically significant change observed from Post->Follow-up
  - Relationship of Pre->F/u is a statistically significant increase
- **Optimism:**
  - Yielded statistically significant increase from Pre-Post
  - *Statistically significant decrease Post->F/u*
  - Relationship of Pre->F/u is a statistically significant increase

## TOTAL SCORE



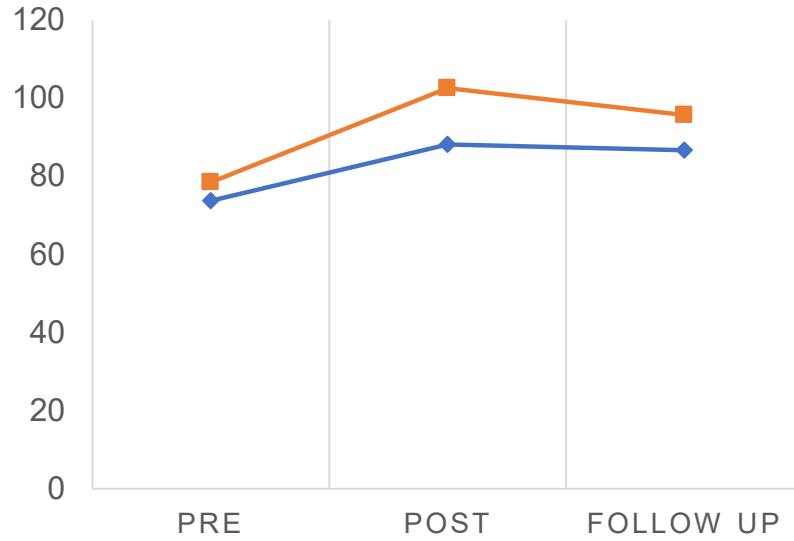
## SUBSCALE SCORES



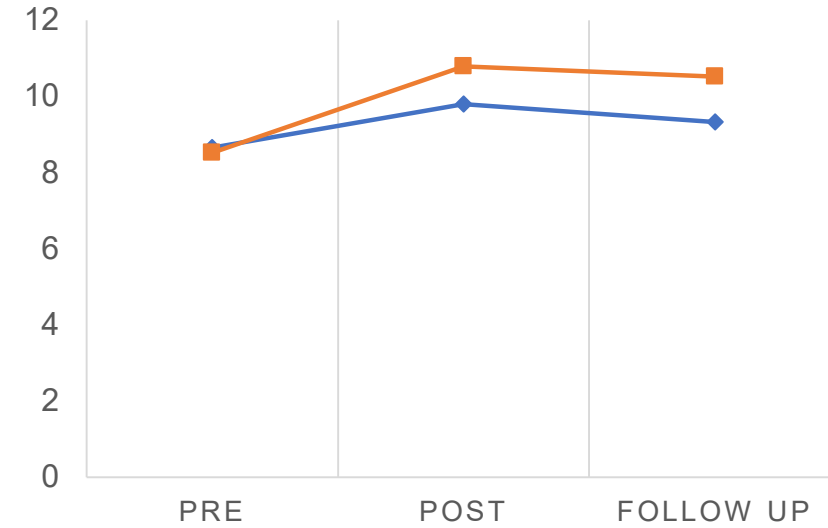


# Attitudes Towards Psychosis

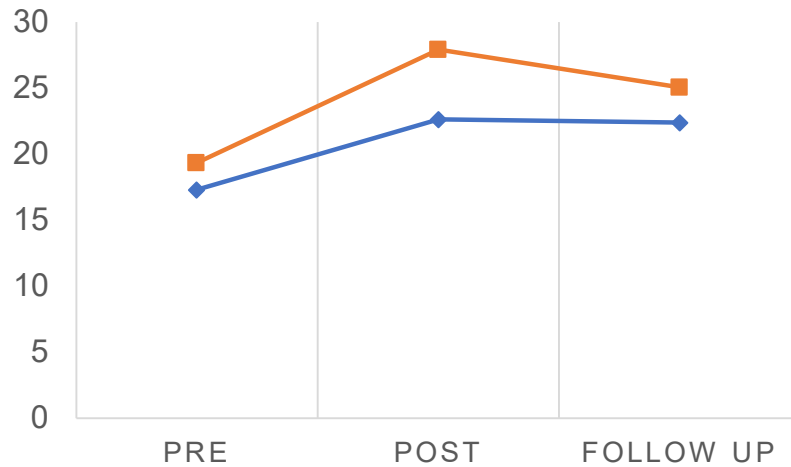
## PAS TOTAL SCORE



## OPTIMISM SUBSCALE



## ADEQUACY SUBSCALE

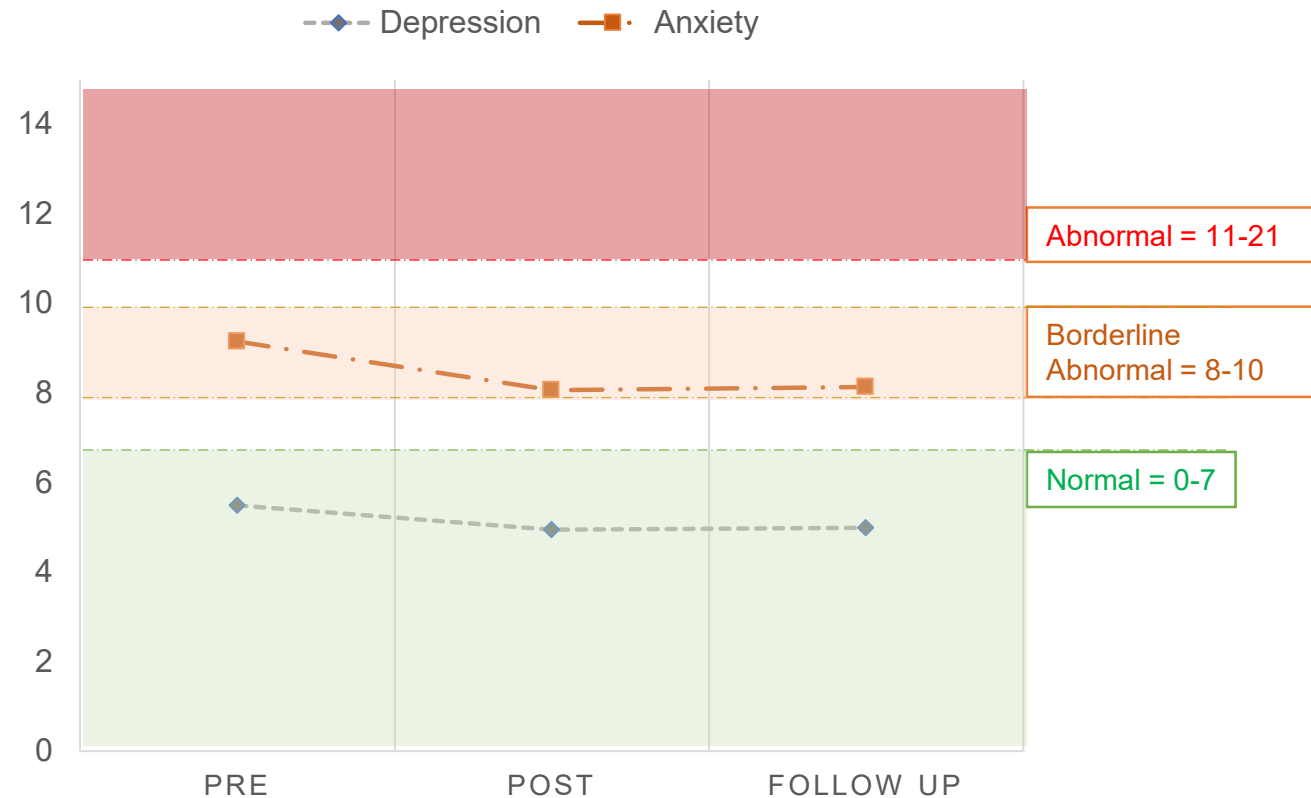


# Caregiver Depression & Anxiety

## Hospital Anxiety & Depression Scale (HADS)

- **Anxiety**
  - Statistically significant reduction between Pre->Post (-1.09 score) which persisted through F/u (-1.10 score;  $p = .002$ )
  - No statistically significant change between Post->F/u ( $p = .792$ )
  - No difference between groups
- **Depression**
  - Statistically significant reduction between Pre->Post (-0.52 score,  $p = .007$ ) and Pre->F/u (-0.61 score;  $p = .04$ )
  - No statistically significant change between Post->F/u ( $p = .882$ )
  - No difference between groups

## DEPRESSION & ANXIETY SCORES

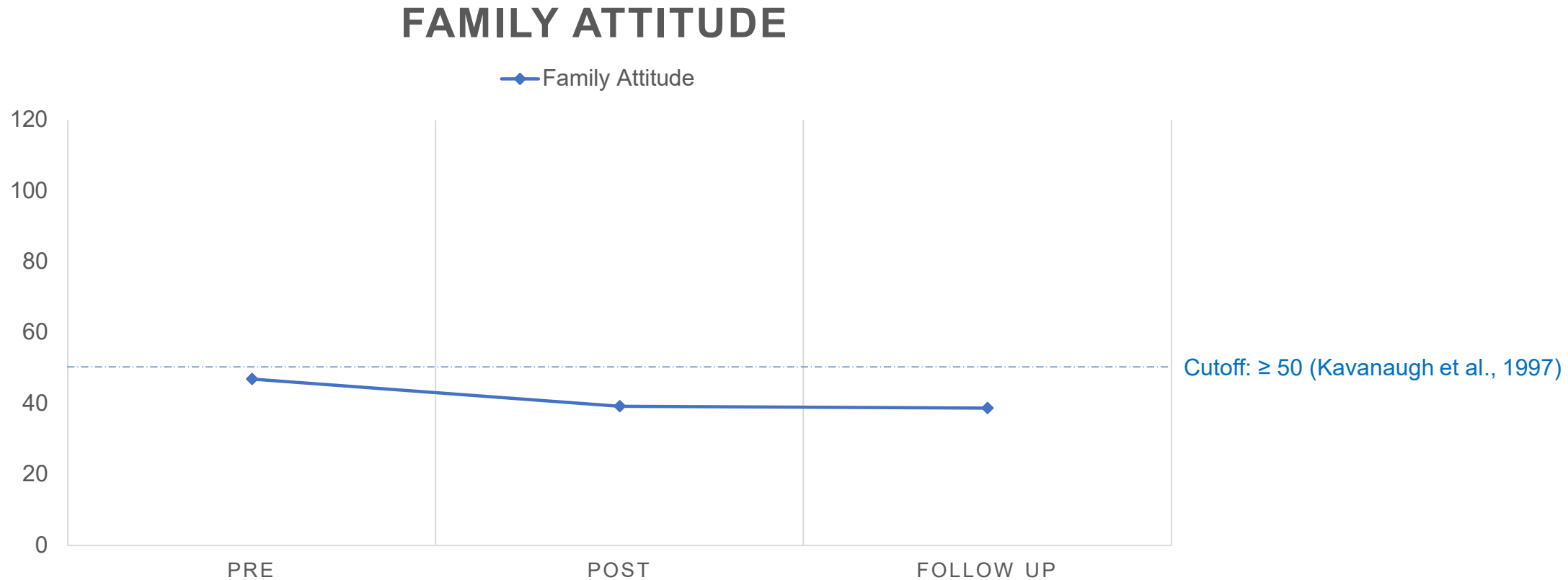


# Family Attitude Scale

## Family Attitude Scale

- On a scale of “Every Day” (4) to “Never” (0)
- Scores range from 0-120; higher scores indicate higher levels of burden or criticism
- Statistically significant change in scores over time [ $F(2, 214) = 32.969, p < .0001, \text{partial } \eta^2 = 0.236$ ]

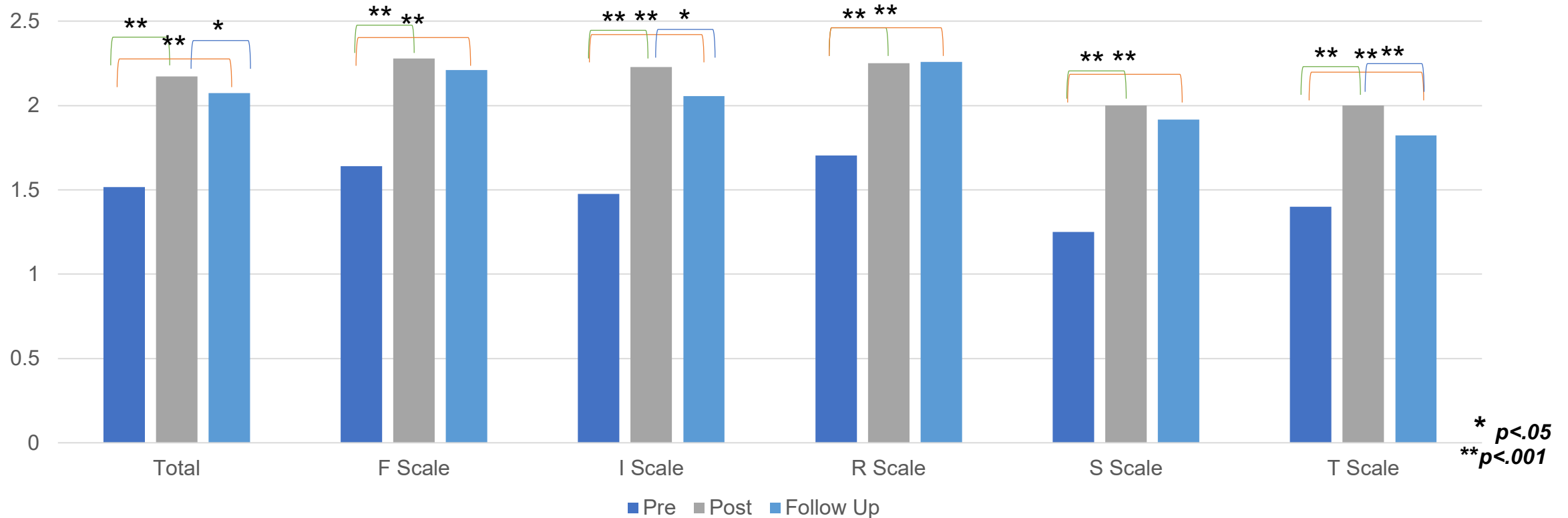
- Statistically significant Pre->Post (-7.21 points,  $p = .0001$ ) and Pre->F/u (-7.99 points,  $p = .0001$ )
- No statistically significant change in points between Post->F/u ( $p = .664$ )
- No differences between groups



# Self-Rated Mastery of CBT-Informed Skills

## FIRST Skills

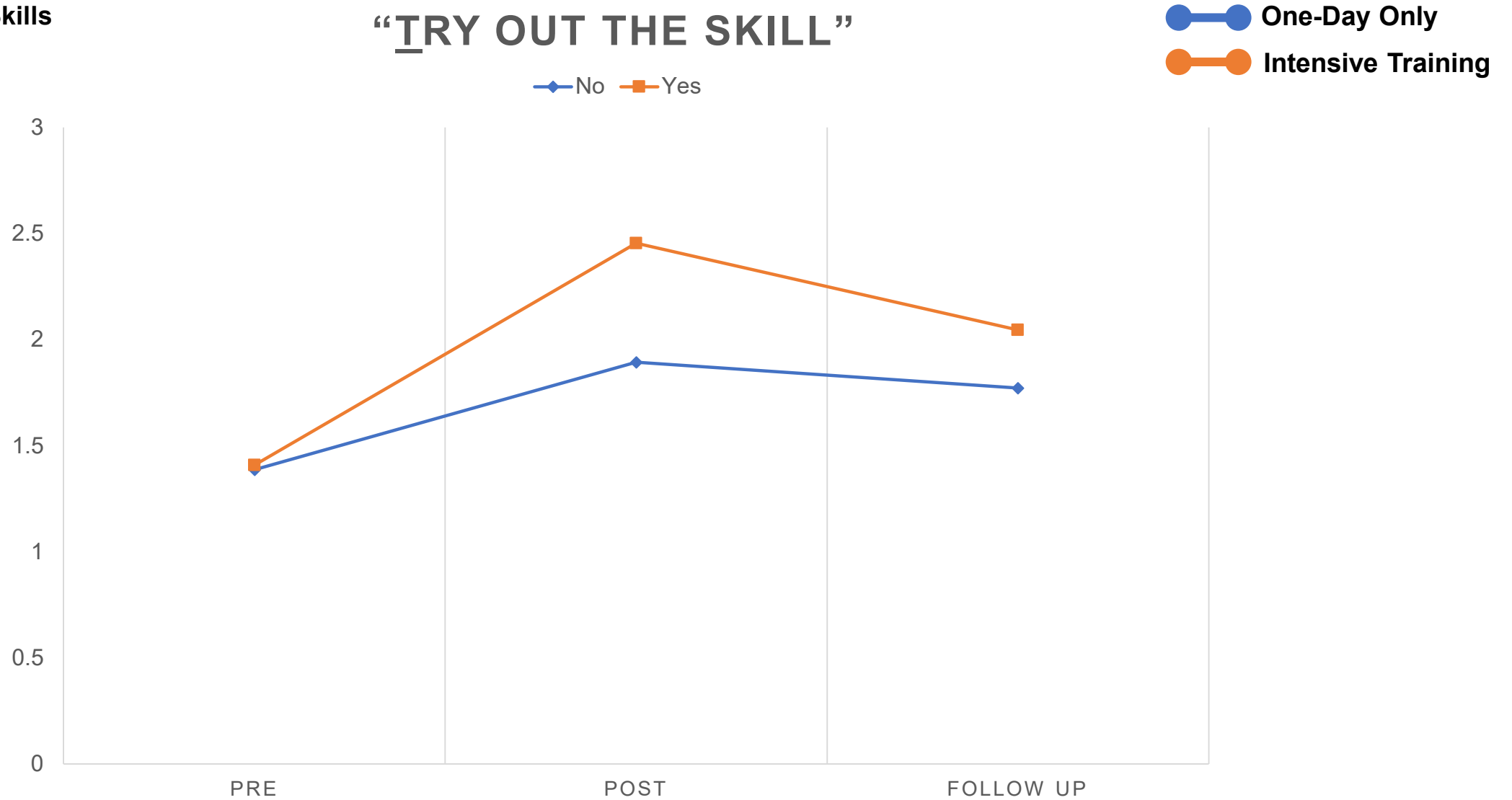
- Rated on a 1 (Minimal/Not Familiar) to 5 (Expert/Advanced) scale across five dimensions
  - Forming a Relationship
  - Inquire Curiously
  - Review the Information
  - Skill Build
  - Try Out the Skill
- Repeated Measures ANOVA conducted to determine differences across time



# Self-Rated Mastery of CBT-Informed Skills

- FIRST Skills

“TRY OUT THE SKILL”



Doug, Sarah, Maria, and Kate were the first to tell me there was hope with our son. After many different Social Workers, LMHC and Psychiatrists telling us that there is nothing you can do for schizophrenia (but over medicate) - we were given HOPE! I do not say this lightly - **This program saved our family!** Our life is so much calmer/peaceful now. Through education and CBTp Skills we have our son back. Through befriending and curiosity, as parents we are no longer the enemy. These are simple skills - not easy - but once incorporated peace is back in the house. And after sharing these skills I have learned with other parents I know I am not the only one that it helps. Many parents have said once they use the curiosity questioning their loved one in psychosis becomes calmer. Our gratitude for this program is overwhelming. Thank you does not begin to cover it. It works if you work it!



# Next Steps for Psychosis REACH



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# Expand Psychosis REACH



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# Next Psychosis REACH Foundational Training

- **Next p-REACH training is scheduled for October 15-16, 2020 in WA**
  - Bring together ~150 family members
  - 7 hours, including experiential and interactive exercises (+ networking time)
  - Broken into two days, 3-4 hours each
  - Includes supplemental materials
  - Leverage interactive app and webinars



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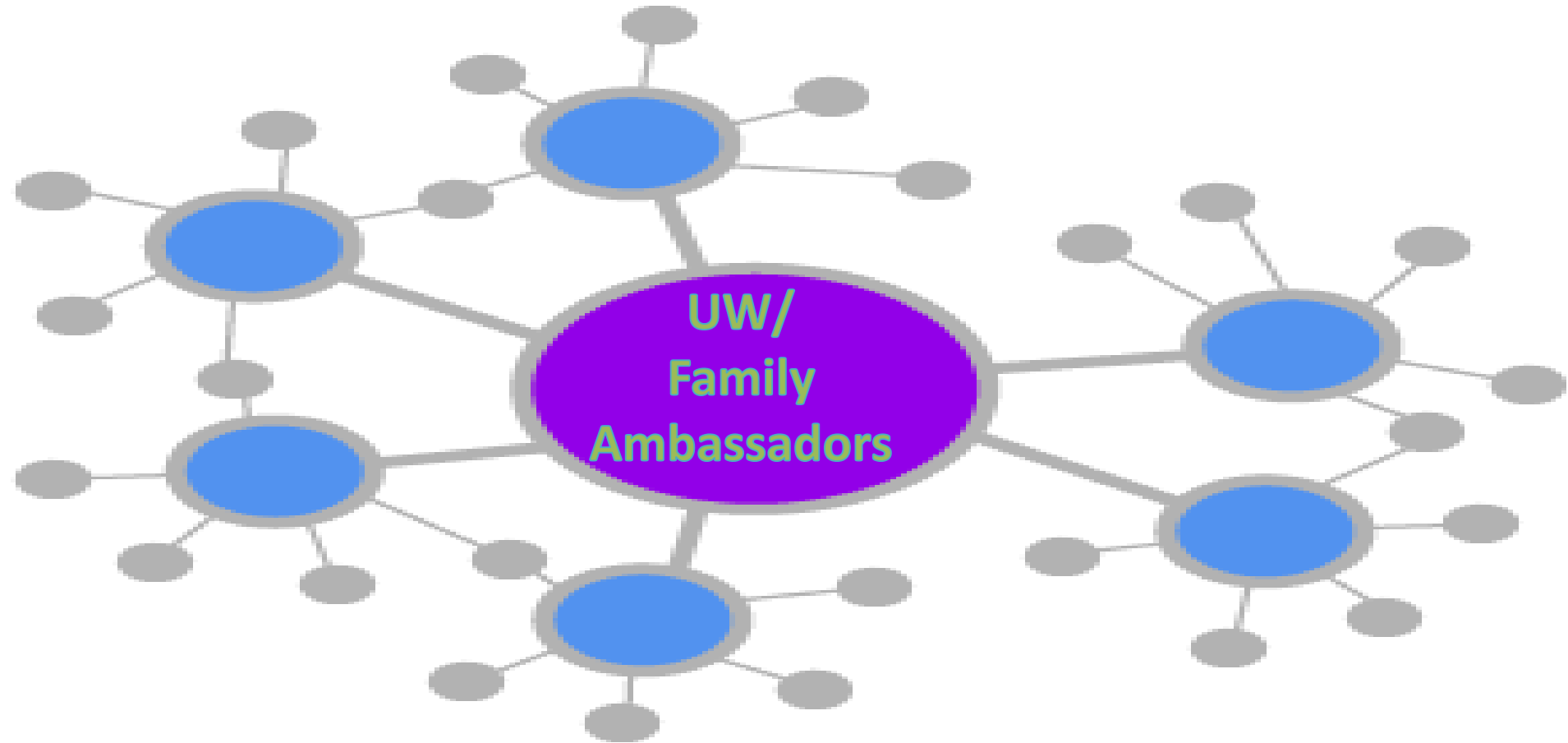
UW Medicine

# Psychosis REACH Family Ambassadors

- Attend training; serve as Ambassadors; Identify who they are on the app and where they're located
- Lend new families their *hope*
- After October training, start up monthly p-REACH Ambassador calls with UW training team, focused on helping new family members, developing comfort with training slides, connection to one another



# Psychosis REACH Hub & Spoke Model in WA State



# Psychosis REACH Nationally

- The virtual model is highly scalable.
- But, must be mindful of the limitations:
  - No CBTp Provider Network
  - No Family Ambassadors
  - Questionable capacity for follow-up skills training
- While we know that a 1-day training is helpful, more is better.



# Thank you!

Contact:

Sarah Kopelovich [skopelov@uw.edu](mailto:skopelov@uw.edu)



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