





### Crisis Contacts in START

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### Goal

- To characterize the timing, nature, type, and predictors of crisis contacts in START
- N=1188 children and youth from 8 states

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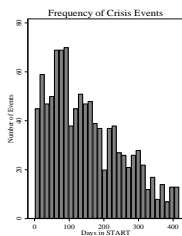
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### Timing

- Overall, 31% experienced a crisis
- Increase in crises 90 days after enrollment
- Steep drop off thereafter
- Half of crises happened after 6 months
- 25% occurred after 9 months
- Very few after 1 year.

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### START Model Guiding Principles



- Positive Psychology & Strengths Based Practice
- Person & Family-Centered
- Cultural and Linguistic Competence
- Trauma-Informed
- Bio-Psycho-Social
- Wellness Based

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### Evaluation and Evidence Informed Decision Making

- START Information Reporting System
- Clinical assessment
- Program evaluation
- Applied research in IDD/MH

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### Current START Programs & Projects



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### Funding Acknowledgments

This project is funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EA #15364)

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### Leadership Team (In order of appearance!)



Jessica Kramer,  
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Florida



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National Center  
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Georgetown  
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Micah Peace,  
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Center for  
Accessible  
Living



Destiny Watkins,  
DoTerra Wellness  
Advocate



Joan B. Beasley,  
UNH IOD &  
Center for  
START Services

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### What is Truth and Reconciliation?

- Truth and Reconciliation in an important concept in societies that have experienced deep inequities and injustices and where the communal trauma of these injustices has seldom been acknowledged.

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### What is Truth and Reconciliation?

Truth and Reconciliation is a process that has been used in international and domestic conflicts across the world and has been recently applied to human service systems in the United States, including the field of medicine.

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### What is Truth and Reconciliation?

#### U.S. Examples

In June 2008, a historic apology was issued within this nation's own medical community. The President of the American Medical Association apologized to the National Medical Association for past wrongs and discrimination against African American physicians and communities.

"I unequivocally apologize for our past behavior. We pledge to do everything in our power to right the wrongs that were done by our organization to African-American physicians and their families and their patients. We've expressed our heartfelt contrition, and I hope that we can continue down a path toward stronger and stronger collaboration and partnership."

*President of the American Medical Association (2008)*

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### What is Truth and Reconciliation?

#### U.S. Examples

In May 2011, former Governor LePage joined Native American officials from Maine's five tribes in signing a Declaration of Intent to create a process to shed light on the terrible injustices of the past, promote healing, and improve public policy. This was the first truth and reconciliation process in U.S. history to be developed by both sides in partnership.

Source: <http://www.afsc.org/story/maine-launches-historic-truth-and-reconciliation-process>.

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### Applying a Truth and Reconciliation Model to Research

The Georgetown University National Center for Cultural Competence (NCCC) conducted a truth and reconciliation project entitled, The Legacy of Research in Culturally Diverse Communities: Acknowledging our Past....Shaping our Future. It was designed to answer the question:

**Can barriers to participation in research by racial and ethnic groups (other than non-Hispanic White) be reduced by “truth and reconciliation” community forums?**

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### Applying a Truth and Reconciliation Model to Research

To implement the project, the NCCC adapted a truth and reconciliation model comprised of four phases that engaged both those communities that were historical victims of exploitation and those communities that historically committed the exploitation – intentionally or unintentionally.

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### Applying a Truth and Reconciliation Model to Research

The model involves the following four phases

- Truth Telling
- Acknowledging
- Restoring
- Collaborating

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### Applying a Truth and Reconciliation Model to Research

- 1. **Truth Telling** – an authentic open exchange regarding the damage of past research practices
- 2. **Acknowledging** – affirming and learning from the past and embracing new possibilities for future research



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### Applying a Truth and Reconciliation Model to Research

- 3. **Restoring** - addressing the problems of the past and ensuring the safe conduct of research based on established policy and practice.



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### Applying a Truth and Reconciliation Model to Research

- 4. **Collaborating** - acknowledging the inherent power of communities to recognize their own problems, including the health of their members, and collaborating with these communities in the conduct of research which values and respects community solutions for community problems.



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### Applying a Truth and Reconciliation Model to IDD-MH Research

Truth and Reconciliation has significant implications and is highly applicable to the IDD-MH due to the history of exploitation, harms, and exclusion. We adapted the NCCC's original model for our PCORI project. We ask you to join us as we take this journey to reconcile the past and change the future.



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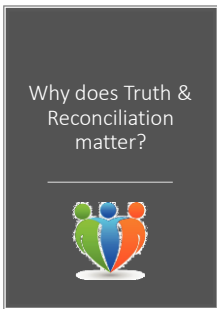
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- Micah Peace
- Destiny Watkins



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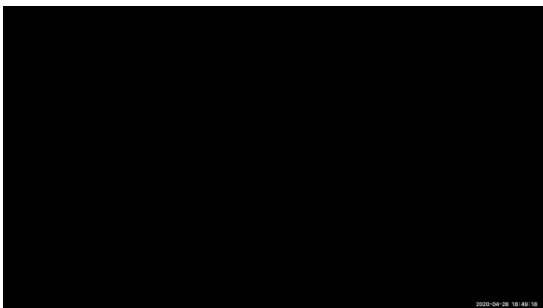
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- Researchers make mistakes and need to apologize and learn from their mistakes.
- Learn to work with someone with a disability.



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- Micah Peace
- Destiny Watkins



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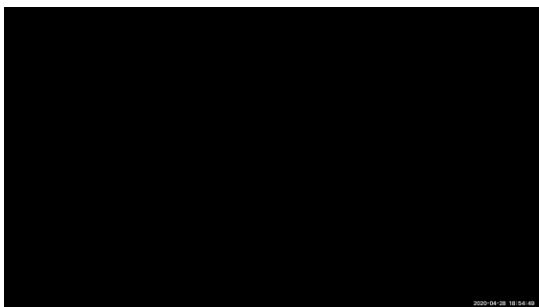
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Why is it important to engage people with IDD-MH in research?




- People with IDD-MH know what other people with IDD-MH may want or need.
- They can make sure research is accessible to other people with IDD-MH.

RECONCILING THE PAST AND CHANGING THE FUTURE  
 Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research

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RECONCILING THE PAST AND CHANGING THE FUTURE  
 Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research

### How Does This Fit the Mission of START?

- Our mission is to know better in order to do better
- We are dedicated to humanism and best practices
- False beliefs cannot change, and inferior practices cannot improve, without inclusion of people with lived experiences
- We must face our history and ourselves in this process
- This project allows us to move forward with our goal to develop research opportunities that make a difference.

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