Trust and Distrust in IDD Research

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Presentation Purpose

- To share our plan for a paper on trust & distrust in IDD research

AND

- To invite DEEP members to join our writing team as co-authors

Problem

- Adults with IDD experience unique health challenges, but do not always participate in health research.

Paper Goals

- Understand **why individuals with IDD may distrust research participation**
- Identify **inclusive strategies to build trust**
- Share a **model to guide inclusive IDD research**

Four Parts of this Paper

1. Sources of Distrust

2. Building Blocks of Trust

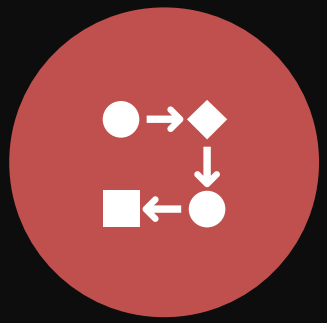
3. IDD Inclusion Strategies

4. Shared Power & Co-Research

Why join our team?

- To talk about what has been reported on trust & distrust
- To think about missing ideas
- To add recommendations and strategies for inclusive research

You are welcome to partner with us



YOUR IDEAS ARE IMPORTANT

YOU ARE AN EXPERT

WE WANT TO KNOW WHAT YOU THINK

Break Out Room Discussion

Making Research Better with You

From participants to co-researchers by building trust and working as equal partners.

Paper Objectives

Understand	Understand factors that add to trust and distrust in research among people with IDD
Determine	Determine how inclusive approaches impact research (e.g., importance to community, individual empowerment, fair treatment and outcomes)
Develop	Develop statements about how inclusive practices may improve both research participation and quality
Share	Share a model to guide future inclusive research studies

What makes you trust or not trust research?

The Four Areas of Research Distrust by Participants
Why People Say "No" to Research (Based on the Smirnoff Model(Smirnoff et al, 2018))

Distrust Area	
General Trustworthiness	Attitudes towards the motives of researchers - *Why are you doing this research?*
Perception of Deception or Lying	Concerns that researchers withhold or hide information - *What are you hiding or not telling me?*
Perception of Exploitation or Using People	Belief that researchers use participants for personal gain - *What is in it for me and my community?*
Perceived Bias or Discrimination	Differences in practices based on personal identity - *How will you treat me based on my disability, race, ethnicity, sex, gender, etc…?*

Source: Smirnoff, M., Wilets, I., Ragin, D. F., Adams, R., Holohan, J., Rhodes, R., … Richardson, L. D. (2018). **A paradigm for understanding trust and mistrust in medical research**: The Community VOICES study. *AJOB Empirical Bioethics*, *9*(1), 39–47. https://doi.org/10.1080/23294515.2018.1432718

Theme 1 –General Trustworthiness

- ❑ Some people worry researchers do not care about their safety.

What researchers and research processes feel trustworthy?

Theme 2 – Communication & Clarity

What helps you understand what a research study is about?

Theme 3 –Exploitation

- **Some people worry researchers use them for personal gains**

What feels fair to you?

Theme 4 – Respect and Privacy

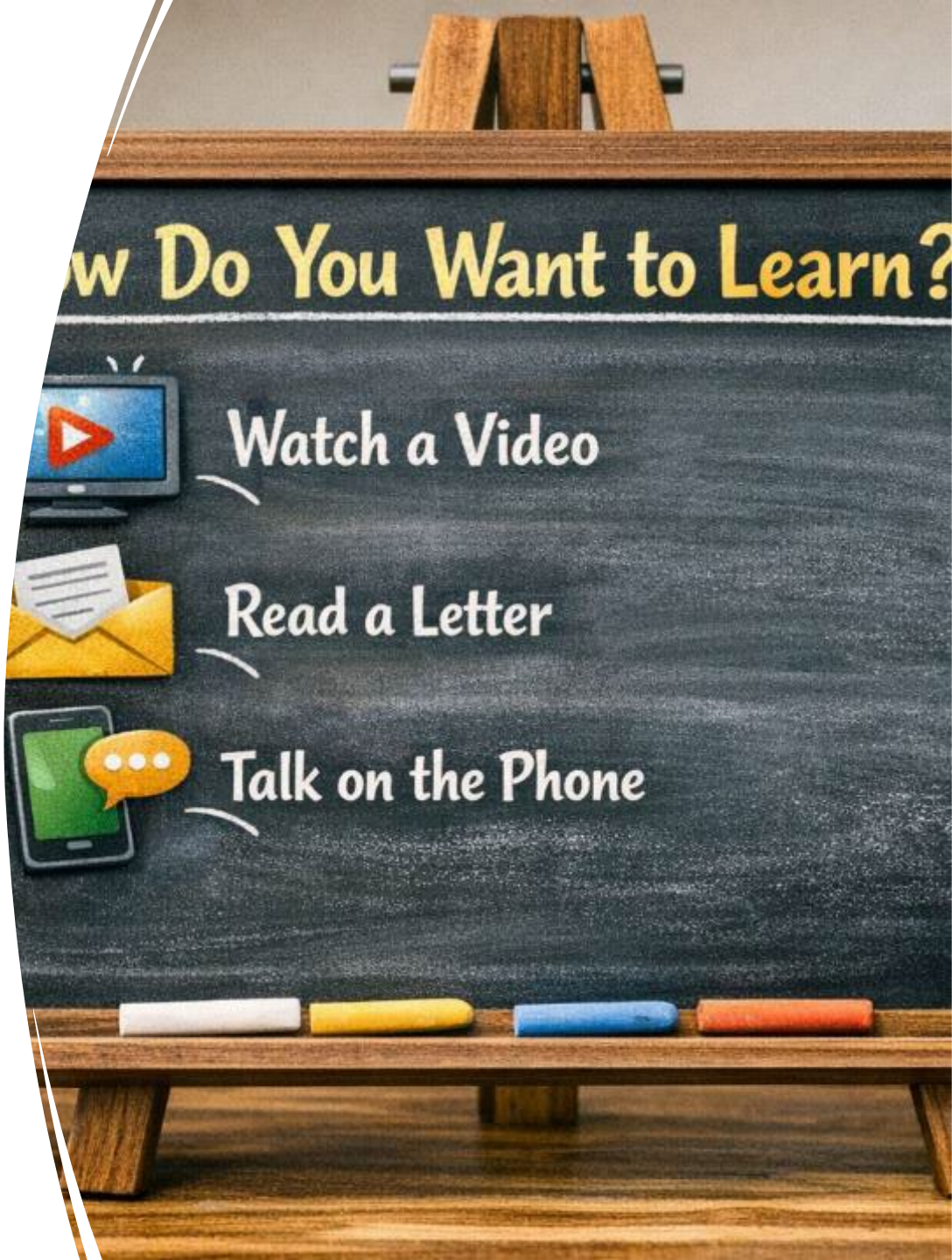
- Some people notice different treatment based on identity.

What helps you feel respected?

Theme 5 – Hearing or Sharing Results

- **Sharing findings in meaningful and inclusive ways**

How best should we inform you of what we learned together?



You as a Co-Researcher

How can you become a full research partner?

- You help make decisions and recommendations.
- You share ideas

THANK YOU FOR DECIDING TO PARTNER WITH US!

YOUR EXPERIENCES, IDEAS AND INSIGHTS ARE HIGHLY VALUED!