

DAIR
Disability Advocates
in Research

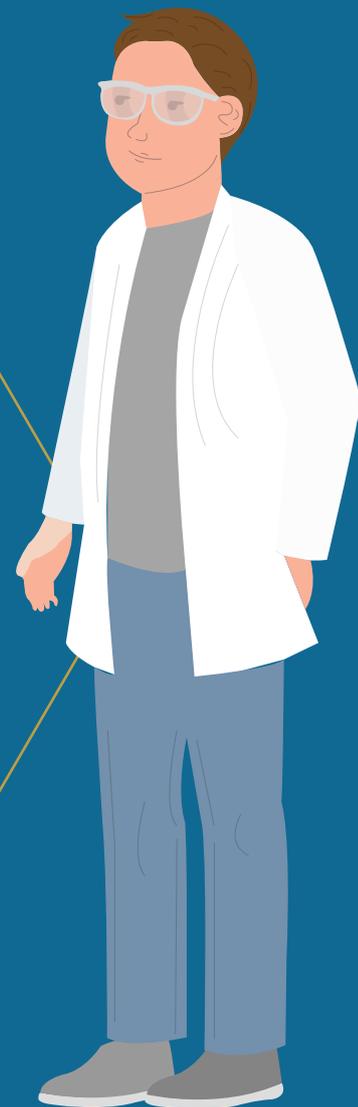


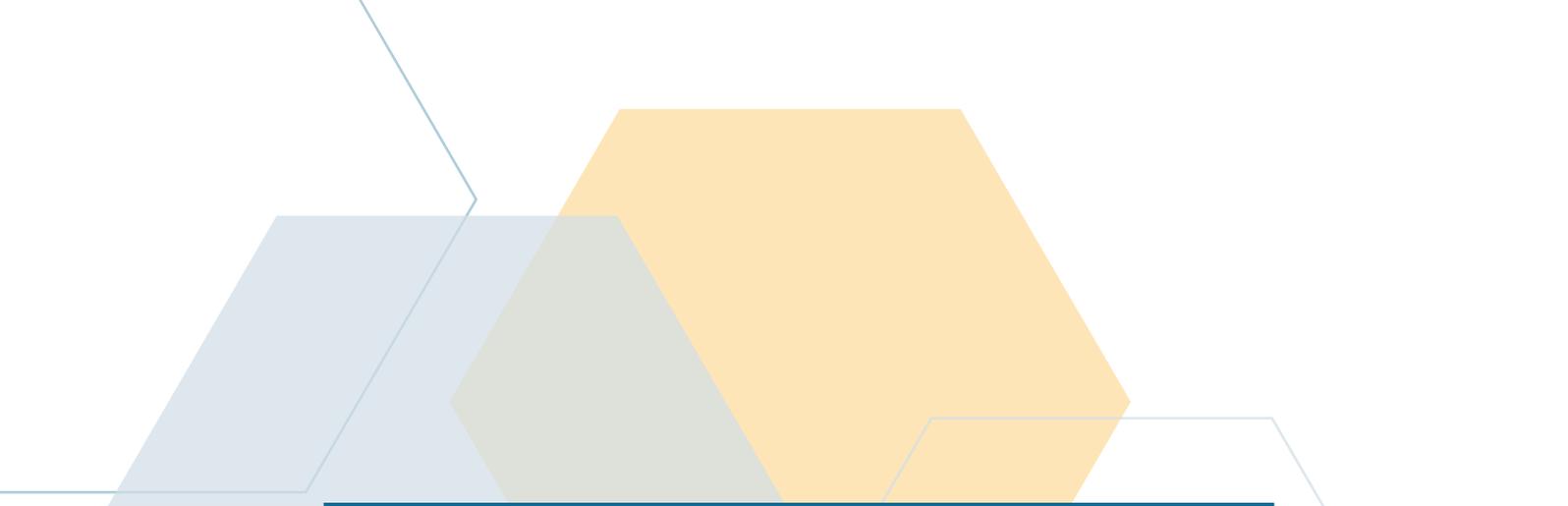
Partnership for People
with Disabilities

Linking people. Changing lives.

How to Build Trust With Research Partners With Intellectual and Developmental Disabilities

A TRUST-BUILDING GUIDE LED BY PEOPLE WITH LIVED EXPERIENCES





**How to Build Trust with Research
Partners with Intellectual and
Developmental Disabilities:
*A Trust-Building Guide Led by
People with Lived Experiences***

VERSION 1.0

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Executive Summary

People with intellectual and developmental disabilities (IDD) are often underrepresented in health research further exacerbating their health disparities.

Trust plays a significant role in whether they choose to participate in research and remain engaged throughout the process.

Researchers must understand how people with IDD define trust and strategies necessary to build it, ensuring inclusive and effective research practices.

This guide was developed in collaboration with Disability Advocates in Research (DAIR), a group of adults with IDD. Over six months, DAIR members defined trust on their own terms, reviewed and evaluated existing literature on trust, and provided their own trust-building strategies for researchers to integrate into inclusive research practices.

The group described trust and trust-building as forming relationships where people feel safe, respected and supported, and where words and actions match. They conceptualized trust as a spectrum to grow or change over time depending on how people treat each other.



Research leaders should strive to:

- make personal connections
- ensure accessibility for team members
- provide clear project descriptions & participation expectations
- empower team members to be actively involved in decision-making
- recognize contributions
- provide regular feedback
- follow-up to help maintain trust over time

DAIR reported that barriers to trust arise when research team members fail to empathize with each other.

Communication that is unclear or superficial also contributes to breakdown of trust. Trust is eroded when expectations are not met or when actions don't align with words. Exclusion, inconsistency and lack of accountability further damage trust.

These factors lead to misunderstandings and weakened connections.

It is important to note that this isn't a one-size-fits-all guide; while you can apply some of these strategies with your own group, they may look different in practice. The key is to consider the recommendations and adapt approaches to fit your unique context.

Rationale

People with intellectual and developmental disabilities (IDD) are underrepresented in research and on research teams. Their exclusion from meaningful participation in health research processes may exacerbate health disparities experienced by people with disabilities. Decisions to not include people with disabilities as co-researchers or on research advisory teams may range from incorrect assumptions about their competencies to inaccessible research ethics training. But when they are sought for research participation, trust is one factor that contributes to whether people with IDD decide to enroll in research endeavors (Conroy et al., 2021). Trust also influences their comfort throughout various phases of research from conceptualization to dissemination (Conroy et al., 2021). Therefore, it is useful for researchers to be aware of how people with IDD conceptualize trust and strategies that can be used to build and maintain trust with them.

Researchers may successfully develop trust when the strategies they use are informed by the experiences and perspectives of groups with whom trust is sought (Grieb et al., 2021; Mohebbi et al., 2018).

“People with intellectual and developmental disabilities (IDD) are underrepresented in research and on research teams.”

This guide was developed through the Partnership for People with Disabilities’ collaboration and conversation with Disability Advocates in Research, a group consisting of adults who identified as having a developmental and/or intellectual disability and many of whom had other co-occurring disabilities or special healthcare needs.

During 12 hours of meetings over a 6-month period, the Disability Advocates in Research:

- Defined trust using their own terms and experiences
- Reviewed recommended trust-building strategies
- Provided a series of their own trust-building recommendations
- Developed tools that showed how chosen trust-building strategies could be applied to inclusive research teams



What is Trust and Trust-building?

Before exploring trust-building strategies and providing recommendations, Disability Advocates in Research (DAIR) were invited to develop an emic understanding of trust. Through guided discussions, they drew on lived experiences of trust, distrust and mistrust to shape the dialogue.

Defining trust in their own words was a critical first step in creating this guide. Questions below served as the foundational framework for these discussions.

Think about someone you trust:

- What does that trust look like?
- What does that relationship feel like?

Think about a person or group that you don't trust

- What has yet to happen that's required for your trust?
- Was something done to make you not trust?
- What causes trust to change over time?

Advocates later summarized group discussions and debriefed the whole group. Notes from sub-group and full-group discussions were reviewed to capture DAIR descriptions of

trust. Conceptualizations were reviewed in the subsequent meeting, allowing participants opportunity to check the summary.

The DAIR group described trust as something that contributes to feeling valued, secure and more comfortable making mistakes. In trusting environments and trusting relationships, people feel seen, heard and validated.

Trust also grows over repeated and consistently positive interactions in which people feel listened to and have support needs met. Generally, self-advocates described six key elements of trust (i.e., trusting relationships and environments).

1. SAFETY

Emotional and physical safety are critical components of trust.

2. CONGRUENCE:

Alignment between words and actions is essential for trust.

3. ACCOUNTABILITY:

Owning mistakes and following through on commitments builds trust.

4. EMPATHY:

Demonstrating understanding and care for others fosters trust.

5. GENUINENESS:

Authenticity in interactions strengthens connections.

6. VULNERABILITY:

Trust requires the ability to be vulnerable without fear of harm.

“Deep trust allows people the freedom to not mask—to disclose their “true” selves.”

TRUST DYNAMICS

Trust is a Spectrum: Trust varies in depth and type—from various forms of distrust to the deep trust often experienced through close interpersonal relationships with best friends or romantic partners.

Deep trust allows people the freedom to not mask— to disclose their “true” selves.

Emotional safety is at its greatest in deep trust. Expanding trust often emerged with family, friends and long-term direct support professionals or service providers. Mutual respect and reciprocity are strong at this level and in such contexts people feel seen beyond their disability. However, this guide primarily focuses on basic trust (see Figure 1.) which may be the most common type of trust and is also where relationships with research teams as well as co-workers, classmates and those providing an array of professional services tend to fall.

These relationships are based on:

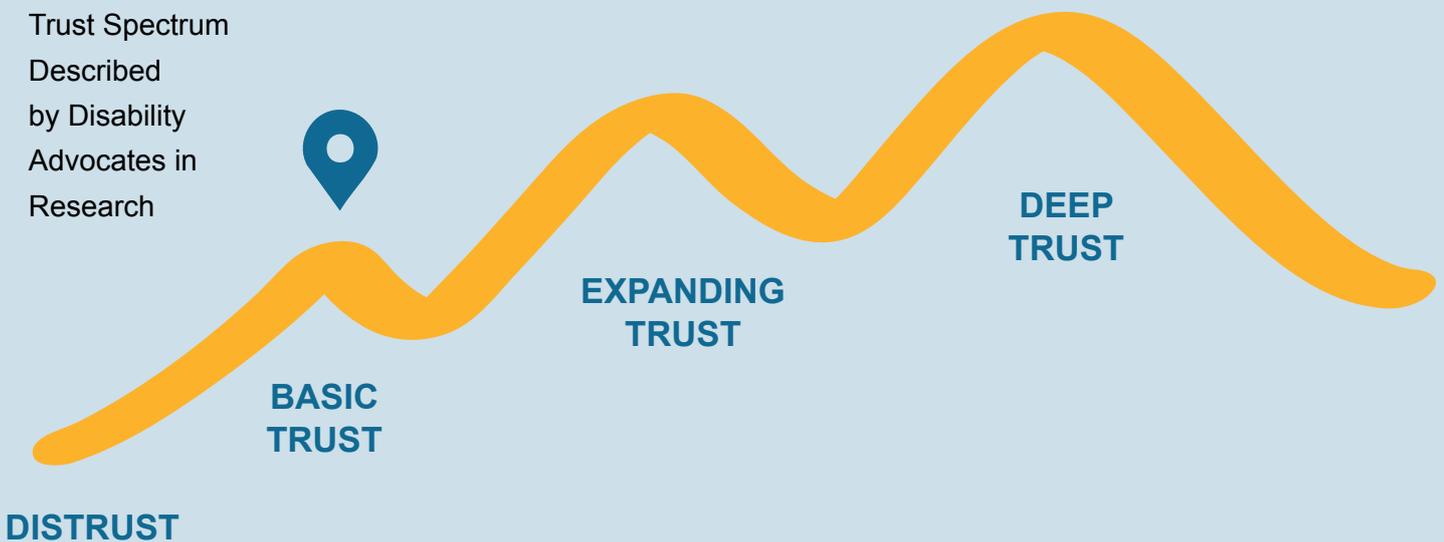


At any location on the trust spectrum, trust can be gained, lost and regained. Because trust is dynamic it matters that the conditions under which trust emerges are maintained to avoid backsliding towards distrust.

Restoring trust that has been lost is possible but requires:



FIGURE 1.
Trust Spectrum
Described
by Disability
Advocates in
Research



IDD Trust-Building Themes & Strategies From Peer-reviewed Articles

A research team from the Virginia Commonwealth University (VCU) University Center for Excellence in Developmental Disabilities, The Partnership for People with Disabilities, led a review of literature on inclusive health research with people with IDD. Four researchers divided and reviewed seven peer-reviewed manuscripts noting specific descriptions of trust and trust-building strategies with co-researchers and research participants with IDD. They also documented strategies employed or recommended.



This information was coded and summarized in five primary trust-building themes. Not all IDD-inclusive health research teams will have the resources available to review the literature. The goal of this summary is to expedite the search for trust-building strategies recommended for inclusive research teams (see Table 1 for list of studies reviewed).

Mutually Beneficial (if not equal!) Partnering

People with IDD are valued and irreplaceable members of the research team and maintain influence over decision-making

- Shared goal development
- IDD leadership and expertise from conceptualization forward
- Implementing guidelines for power sharing and collaboration

Accessibility

Removing barriers to research team recruitment and participation and anticipating the needs of people with intellectual and developmental disabilities (IDD)

- Commitment to regularly accessing and meeting support needs
- Understandable materials (including recruitment, consent, study descriptions, protocols, etc.)
- Diverse and multimodal (graphic heavy; videos; vignettes etc.) materials
- Open to support persons

Building Belonging

Research teams value and nurture relationships among team members while building a cohesive identity

- Explicit and strategic efforts for all research team members to get to know one another
- Value everyone's roles and contributions towards accomplishing common goals
- Take time to celebrate group accomplishments and have fun

Clear, Transparent Communication

Building a culture of honesty and transparency where everyone knows how and why processes are implemented, decisions are made, and language is used

- Everyone knows exactly what they are getting into (i.e., goals, roles, privacy and expectations are clearly and repeatedly reviewed)
- Language used and how it is conveyed is agreed upon by all group members
- Create a safe space for asking and answering questions

Continuous Improvement

Teams and projects seek internal and external feedback to create positive experiences for team members

and stakeholders while promoting intended outcomes

- Evaluate processes, outputs and outcomes frequently and respond accordingly
- Make an effort to use feedback to create positive experiences



Trust-Building Assessment for Research Teams

Disability Advocates in Research (DAIR) reviewed and prioritized trust-building strategies that were described in the seven previously cited peer-reviewed articles focusing on including people with IDD in research processes. Appendix 1 includes a self-assessment informed by research literature and developed by the group. It should serve as a tool for inclusive research teams to review their current trust-building practices and set goals for implementing missing strategies.

The group collectively ranked which trust-building strategies they thought that teams **MUST** have, strategies that were good to have, and strategies that were not necessary. Strategies that were not necessary were removed from the self-assessment.

The goal is for research teams to use the assessment tool to evaluate which trust-building strategies are and are not being consistently implemented in a research team. When “must have” strategies are not consistently used, Disability Advocates in Research recommend that research teams develop action steps to begin implementing them.

ARTICLES REVIEWED

TABLE 1.
Reviewed
Peer-Reviewed
Articles
Describing Trust
in Inclusive
Research

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DAIR Practical Strategies for Building Trust on Research Teams

Disability Advocates in Research reviewed and prioritized trust-building recommendations described in the literature (see Appendix 1), but they also devoted two meetings to discussing practical strategies for building trust in team settings and in health research teams in particular. During these meetings, breakout groups discussed the questions below and shared key takeaways with the larger group.

- On the first day, what would you tell your group/team about what you need from them to build trust?
- Any specific recommendations for building trust in research teams?
 - *What do research teams need to do to partner with you and to help you build relationships with others on the team?*
 - *What do research teams need to do to get rid of barriers to your participation and to help you build relationships with others on the team?*
 - *What do research teams need to do to get your feedback and to help clearly communicate with you?*

Notes from these conversations were content-analyzed and findings were shared with DAIR members to check for

accuracy. The 20 recommendations span six topic areas, many of which overlap with recommendations covered in the literature that describe building trust on IDD-inclusive health research teams.



FOSTERING EMPATHY, INCLUSIVITY AND RESPECT

1. **Emphasize respect** and value for all team members explicitly in guidelines and practice.
2. **Recognize and celebrate diversity** of perspectives, and actively incorporate these into decision-making.
3. **Demonstrate grace**, patience, and compassion in all interactions.
4. **Be Aware of Emotional Cues:** Recognize signs of discomfort and address them sensitively.

BUILDING FAMILIARITY

5. **Personal connections:** Engage in regular personal interactions, such as asking about hobbies, interests or unique traits. Show interest in individuals as people, not just as contributors to the research.
6. **Structured Introductions:** Start with icebreakers or activities that encourage team members to share experiences and interests.

7. Frequent Interactions: Schedule regular meetings or informal gatherings to build personal connections.

ENSURING ACCESSIBILITY

8. Universal Design: Make accessibility measures part of the team's default practices.

9. Provide Multiple Formats:

Share resources in formats that suit diverse needs and ensure long-term accessibility. Provide resources (e.g., guidelines, documents) in accessible formats easy to understand and use.

10. Use Inclusive

Language: Learn from the group terminology and inclusive communication practices that they prefer. This includes identity vs person-first language, pronouns and other descriptive terms.

11. Regular Check-ins: Begin meetings by asking team members how they are feeling or if they'd like to share any updates. Schedule regular check-ins during meetings where team members are encouraged to voice concerns or share updates.

EFFECTIVE COMMUNICATION

12. Describe expectations explicitly at beginning of projects.

13. Define terms. Double-check interpretations of key concepts to avoid misunderstandings.

14. Ask Thoughtful Questions: Use open-ended, empathetic questions to understand team members' current states and

experiences. Actively solicit questions during meetings and engage in clarification to ensure understanding.

15. Provide Clear Examples: Use applicable examples to explain concepts or tasks, ensuring clarity for all team members. Provide examples and use scenarios to clarify complex ideas or instructions. Use concrete, relatable examples to explain practices or concepts.

16. Foster Mutual Listening: Emphasize importance of listening and encourage team members to respond constructively to one another.

EMPOWERING TEAM MEMBERS

17. Value Contributions: Actively acknowledge and celebrate team members' ideas and input.

18. Encourage Personal Expression: Create opportunities for team members to discuss their ideas, needs and experiences. Create a supportive environment where team members feel comfortable expressing themselves and taking initiative.

19. Promote Collaboration: Involve team members in decision-making and problem-solving processes to enhance their sense of ownership. Share decision-making responsibilities and encourage team members to take ownership of their roles.

FEEDBACK AND FOLLOW-UP.

20. Create a system to log recommendations, actions taken and follow-up responses. Ensure feedback is reviewed and implemented where possible to demonstrate responsiveness.



Leadership and Trust

Whether project principal investigators or trained facilitators, research teams (including advisory boards) are guided by chosen or defacto leaders. In one meeting, Disability Advocates in Research held a discussion about, “What characteristics and actions do you need from group leaders to build trust?” Collectively, they shared that leaders who proactively address needs, empower others, and foster a sense of community can create environments where individuals feel supported and valued.

QUALITIES OF A TRUSTWORTHY RESEARCH TEAM LEADERS/ FACILITATORS

- **Empathy:** Acknowledging struggles, offering solutions and showing care
- **Awareness:** Understanding individual and group dynamics, including disabilities and accommodations
- **Reliability:** Consistently following through on promises and commitments
- **Inclusivity:** Using accessible language, providing accommodations and creating a safe environment
- **Proactivity:** Anticipating needs and addressing barriers before they become problems
- **Collaboration:** Encouraging community contributions and empowering others to lead



PRACTICAL STRATEGIES FOR RESEARCH TEAM LEADERS/FACILITATORS

1. Empathy in Action

- Check in regularly with team members to ensure they feel seen, heard and supported
- Provide options for support, such as solutions to challenges or accommodations

2. Modeling and Consistency

- Demonstrate inclusivity by using accommodations openly and consistently to meet group needs
- Be reliable and follow through on commitments to foster a sense of stability and trust

3. Proactive Accessibility

- Make accessibility the standard by offering accommodations (e.g., printed materials, digital copies) without needing to be asked
- Use inclusive language and provide explanations when needed to ensure all members can engage effectively



4. Empowering Others

- Create opportunities for individuals to take on leadership roles or contribute their skills
- Address power imbalances by fostering a collaborative, community-focused environment

5. Responsive Communication

- Ask intentional questions that show genuine care and responsiveness to group needs
- Encourage open dialogue and make room for all voices to be heard



APPLYING TRUST-BUILDING STRATEGIES

Disability Advocates in Research used one meeting to develop trust narratives that could actively capture trust dynamics: the application and absence of their recommended trust-building strategies for team research settings.

To build their narratives, three Disability Advocates in Research subgroups each chose a trust-building topic and responded to the following questions:

1. What does it look like when a researcher performs a trust-building action in the “right” way (i.e., it helps build trust)?
2. What does it look like when they do it wrong (i.e., add to feelings of mistrust)?
3. How can they recover and improve after sowing mistrust?
4. What are the key recommendations or “takeaways” from the story?

Stories were transformed into three different formats. The first was a one-page vignette, the second was a comic or graphic novel format and the third was a short animated film.

These examples are shared in Appendices 2-4.



Barriers to Trust

The opposite of trust, clearly, is distrust and mistrust. Over the course of discussions on trust, from conceptualization to the development of specific recommendations, mention of how trust could be diminished was fairly common. Many of the factors leading to distrust are transposed recommendations for building trust. Nonetheless, for fidelity to the conversations held with Disability Advocates in Research, it is a worthwhile task for teams to identify any of these habits, characteristics or common pitfalls for one's research teams or team leadership.

The elements listed below will either contribute to loss of trust or deepen initial mistrust from collaborators with IDD:

- **Lack of Empathy:** Failure to recognize or address team members' struggles
- **Poor Accessibility:** Limited access to materials or exclusionary language
- **Exclusion:** Not prioritizing accessibility or inclusivity in communication and practices

- **Superficial Communication:** Neglecting to ask meaningful questions or actively listen
- **Assumptions:** Making assumptions about someone's abilities or struggles without asking
- **Inconsistency:** Failing to follow through on commitments or meet expectations or actions that are reliable only in isolated instances
- **Incongruence:** A mismatch between words and actions
- **Lack of Accountability:** Failing to deliver on promises, avoiding apologies and dismissing others' input
- **Authoritarian Leadership:** Leading from a place of authority rather than collaboration or community
- **Lack of Clarity:** Not fully expressing needs or expectations
- **Perceived Burdens:** Fear of being a "bother" can inhibit open communication, leading to a lack of connection



Conclusions

Building trust with people with intellectual and developmental disabilities (IDD) in research teams is essential for creating inclusive and effective collaborations. **Trust is dynamic—it evolves through consistent respect, empathy, and accountability.** Disability Advocates in Research (DAIR) highlighted that trust begins with clear communication, genuine relationships and accessible practices that ensure everyone feels valued and supported.

The practical strategies shared in this guide offer actionable steps for fostering trust and avoiding **common pitfalls, such as inconsistency and exclusion.** While these strategies may need to be adapted to different contexts, the underlying message is clear: trust grows when researchers prioritize inclusion, listen to lived experiences, and actively support all team members. By applying these principles, research teams can build stronger connections, improve outcomes, and set a standard for ethical and equitable collaboration.



Disability Advocates in Research are one group with a certain set of experiences, expectations, and recommendations for trust and trust-building. We challenge you and your research teams to continue adding recommendations based on conversations with people with IDD. Listening to them and refining strategies to best suit their needs will strengthen team cohesion and build trust.

Trust is dynamic—it evolves through consistent respect, empathy, and accountability.

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Key Takeaways

- ✔ **Trust building is a dynamic process** that should start with deliberate planning before collaboration is initiated and be re-visited throughout the process.
- ✔ **Consider each recommendation** in terms of concrete actions that can be taken by your team as well as actions to be avoided. As you work with your collaborators with IDD, ask them what is working for them and what isn't.
- ✔ **There is no one-size-fits-all approach** that works for all teams or all members of a particular team. Keeping in mind that each team member is an individual with individual needs, consider how to tailor communication and decision-making in a way that respects these differences.
- ✔ **Be humble and acknowledge missteps** so that you can rebuild trust based on the recommendations of your team.



The opposite of trust, clearly, is distrust and mistrust.

APPENDIX 1.

Trust-Building Assessment for Research Teams

Trust-Building Assessment for Research Teams

Disability Advocates in Research (DAIR) split into three smaller teams to review recommendations from the literature about how to build inclusive, trusting research teams. Each team voted on whether these actions were important. A “thumbs-up” meant the action was a priority, while a “thumbs-down” meant it was not a priority.

The actions were sorted into three groups:

TIER 1:

Actions everyone agreed were important.

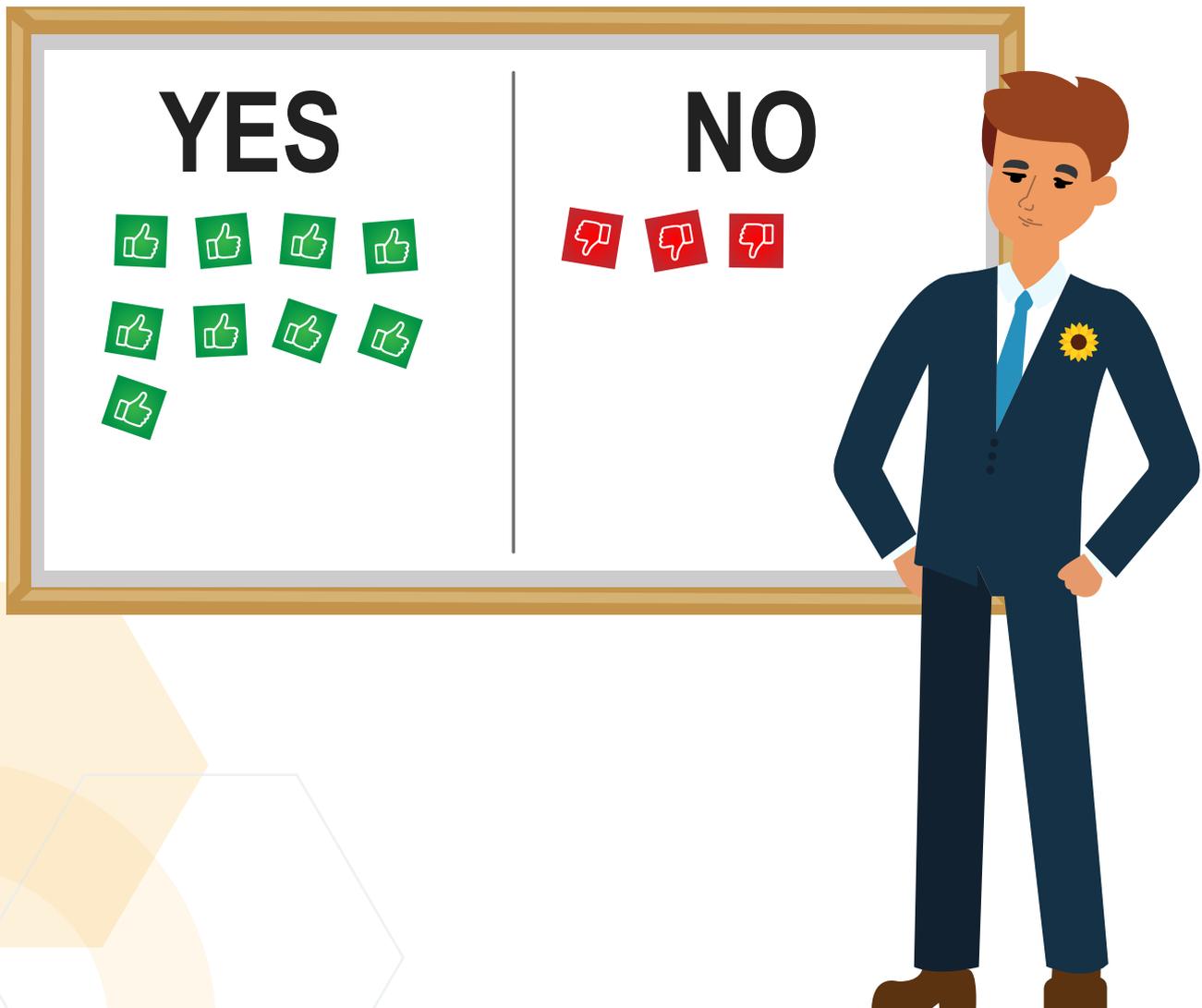
TIER 2:

Actions that had mixed opinions.

REMOVED:

Actions that were not prioritized and taken out.

The actions left will help research teams see how well they are building trust. By knowing what they should do but aren't doing yet, teams can set goals to improve trust in their inclusive groups.

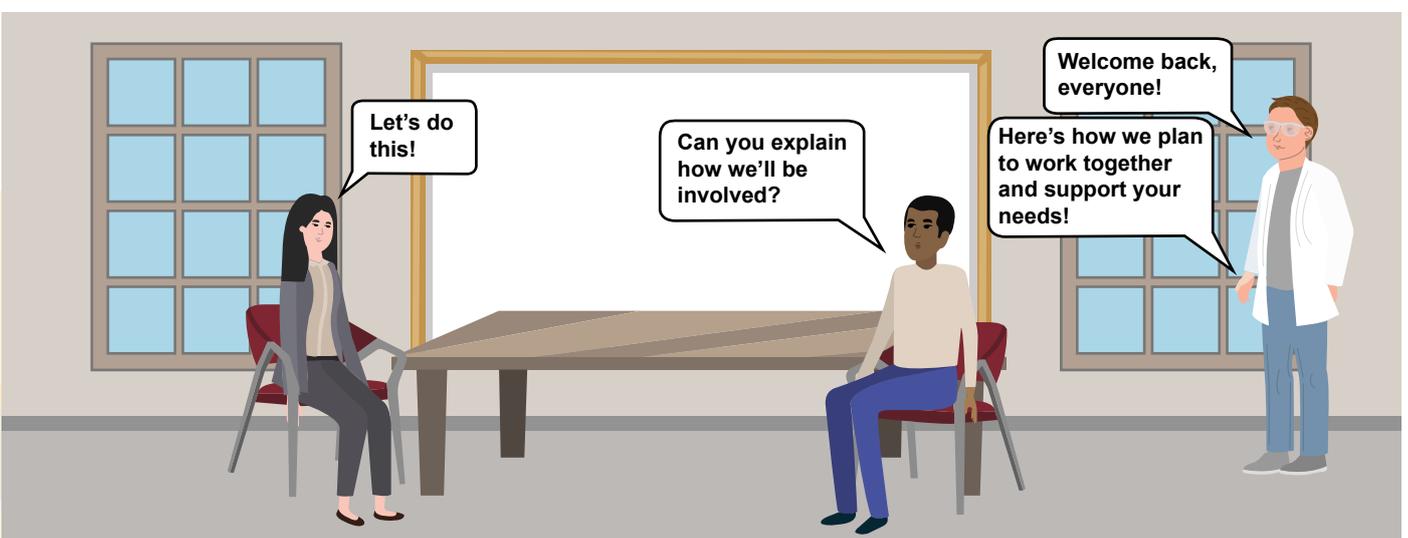
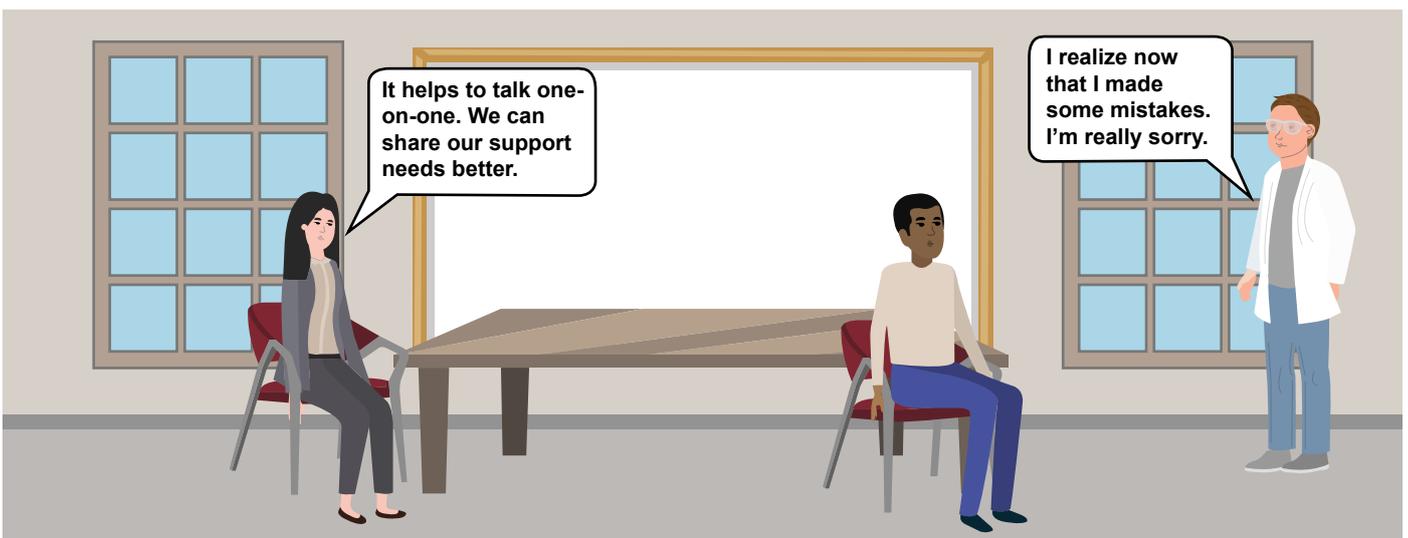
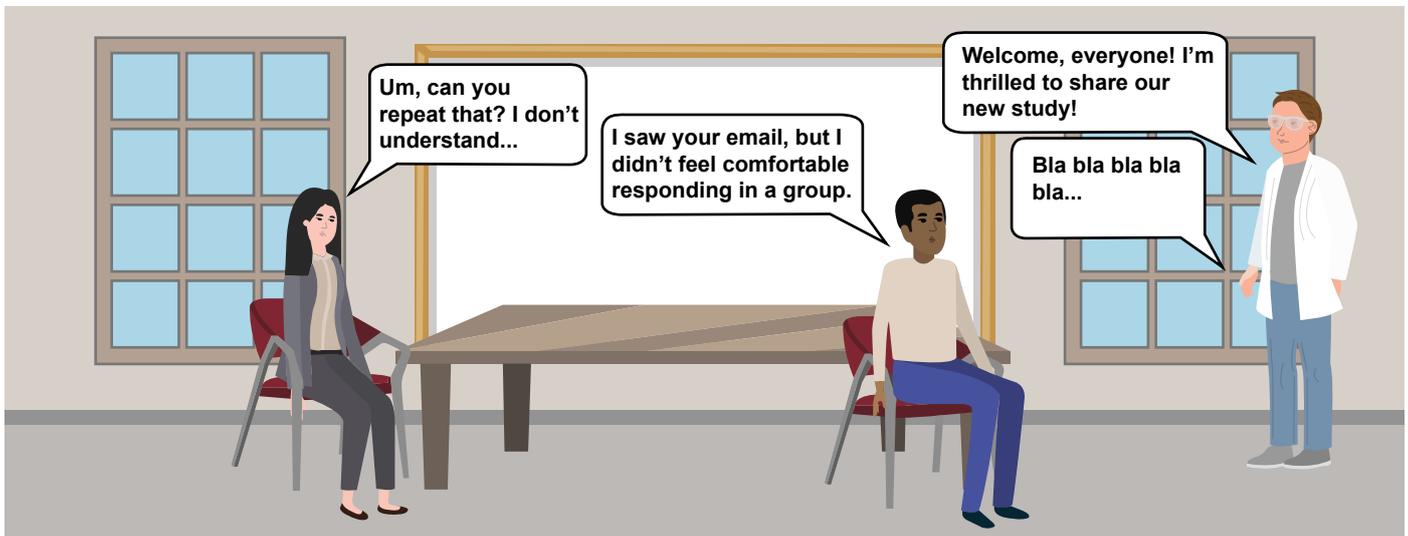


Tier 1 Trust-Building Actions	No	Sometimes	Yes
The group uses practices and procedures designed to make participants feel safe and equal to one another.			
Group facilitators implement activities to help team members get to know one another.			
Team members with disabilities have key roles in helping the team meet goals.			
Plain language is used to help everyone understand health and research terms.			
All written materials use easy-read and plain language formatting.			
There are easy and private ways for team members with disabilities to ask for accommodations or supports.			
Group facilitators design opportunities in meetings to frequently check for understanding or questions.			
All team members have a clear and detailed description of their role on the team and project.			
All team members have been informed, in detail, about the amount of time that they are expected to commit to the project.			
Opportunities are given to people with disabilities on the team to describe exact language that they prefer when talking about disabilities and other identities			
Intentional efforts are made to develop a safe space that protects all team members' privacy.			
Clear descriptions of the project's goals and purpose are shared and repeatedly clarified.			

Tier 2 Trust-Building Actions	No	Sometimes	Yes
Project leaders give the time and effort to know team members beyond what they contribute to the project			
There are non-verbal signals or tools that team members can use to signify that they have a question or need a break.			
All team members actively contribute in the development of research goals.			
The project team celebrates our accomplishments and successes.			
All team members have a role in creating and sharing products and outputs.			

APPENDIX 2.

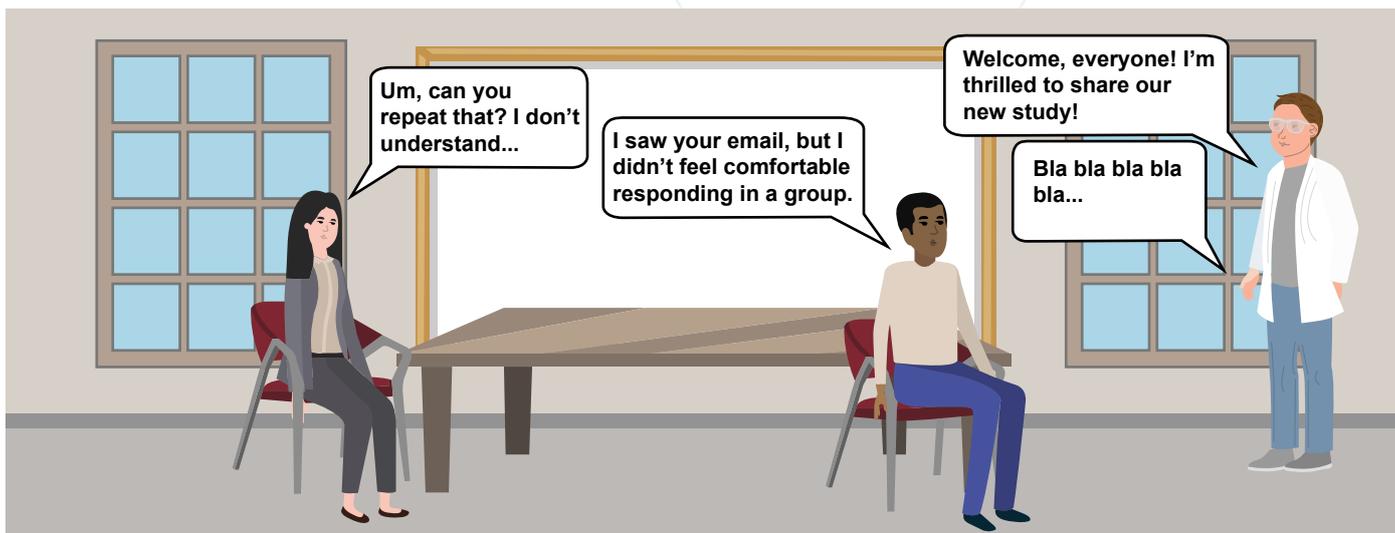
An example of how clarity in communication can build or diminish trust.



APPENDIX 3.

An example of how clear guidance and being forthcoming with information can help establish trust between researchers and participants with disabilities

COMIC TITLE: “The Better Way to Connect”



Part 1: The Miscommunication

Panel 1: A conference room filled with a diverse group of participants looking puzzled. Dr. Cranberry stands in front of a whiteboard, excitedly gesturing to a complicated chart.

Dr. Cranberry: “Welcome, everyone! I’m thrilled to share our new study!”

Panel 2: Close-up of a participant raising their hand, looking worried.

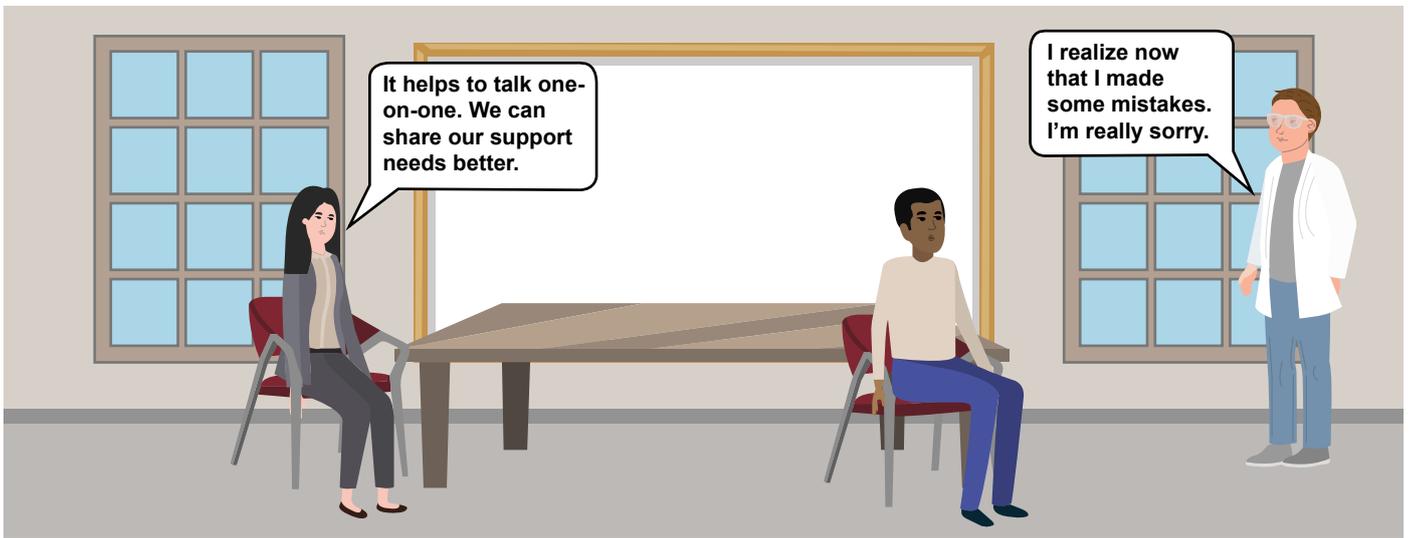
Participant 1: “Um, can you repeat that? I don’t understand...”

Panel 3: Dr. Cranberry looking confused, unprepared for the responses. Participants glance at each other, some with worried expressions.

Dr. Cranberry: “Uh, I sent the details in an email, remember?”

Panel 4: A thought bubble from Participant 2, who speaks hesitantly.

Participant 2 (Thought): “I saw it, but I didn’t feel comfortable responding in a group...”



Part 2: Acknowledgment of Mistakes

Panel 1: Dr. Cranberry stands before the same group, looking earnest, a notepad in hand.

Dr. Cranberry: “I realize now that I made some mistakes. I’m really sorry.”

Panel 2: Participants looking attentive, some nodding sympathetically.

Dr. Cranberry: “Not everyone may feel comfortable sharing in a group email.”

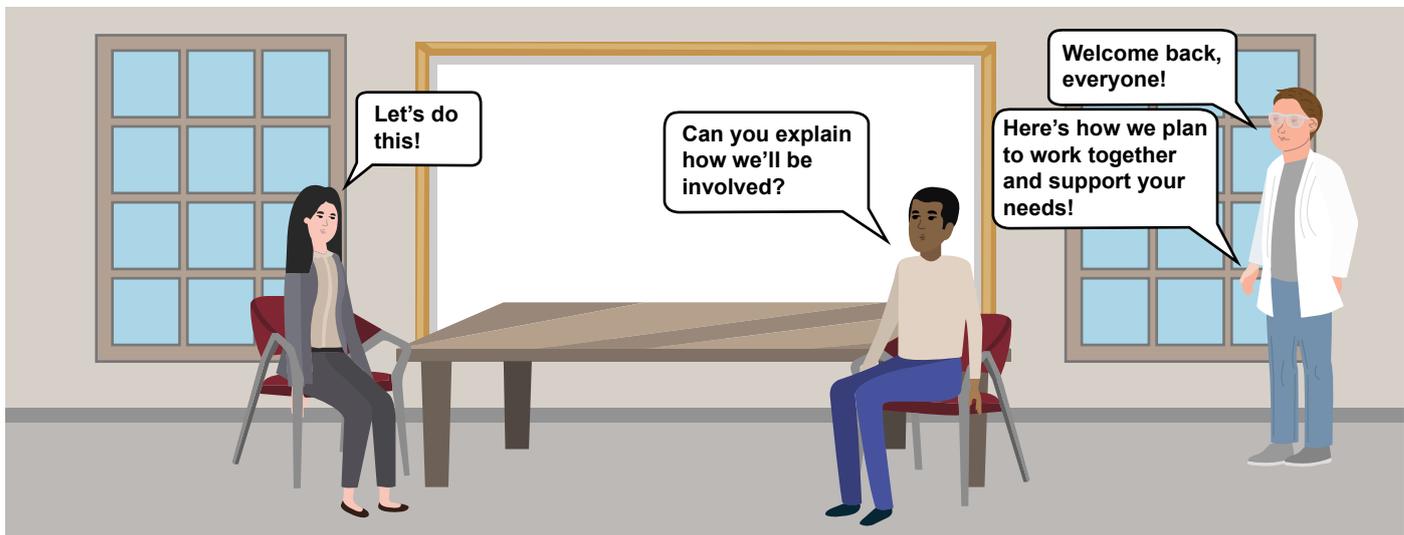
Panel 3: Close-up on a participant expressing gratitude.

Participant 3: “It helps to talk one-on-one. We can share our support needs better.”

Panel 4: Dr. Cranberry taking notes sincerely, looking determined.

Dr. Cranberry: “Thank you all! I’ll make sure to listen and learn from you.”

Part 3: A Confident Meeting



Panel 1: A new, brightly lit meeting room. Comfortable seating and fidget toys scattered on the table. Participants are relaxed and engaged.

Caption: “Weeks later...”

Panel 2: Dr. Cranberry confidently addressing the group, smiling.

Dr. Cranberry: “Welcome back, everyone! Today I’ll share the study details clearly and openly.”

Panel 3: Participants looking engaged, some using fidget toys, nodding and smiling. One participant raises a hand.

Participant 4: “Can you explain how we’ll be involved?”

APPENDIX 4.

How the creation of a safe space can help researchers provide comfort and establish comfort for participants with disabilities

Panel 4: Dr. Cranberry eagerly pointing to a projector screen displaying clear visuals.

Dr. Cranberry: “Absolutely! Here’s how we plan to work together and support your needs!”

Final Panel: A Group Shot

The group is smiling and engaged, with colorful diagrams in the background. Dr. Cranberry looks relaxed and happy.

Caption: “By listening and learning together, we can build better communication!”

Participants (in unison, speech balloons): “Let’s do this!”

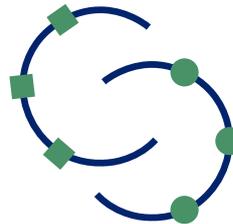
Video Link:

<https://video.pictory.ai/preview/22641428064550540848491730397923468>



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