Accessible Trauma-Informed Research:

A How-To Guide for Qualitative Research with Survivors with IDD

Accessible Trauma-Informed Research: A How-To Guide for Qualitative Research with Survivors with IDD

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PHOENIX GENDER-BASED VIOLENCE LAB
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TABLE OF CONTENTS

Welcome and Introduction

Goal of this section:

- Understand the purpose of this guide and an overview of materials.

Questions this section will answer:

- Who is this guide for?
- Why is this guide important?
- What can you do with this guide?

Key terms:

- **Patient-Centered Outcomes Research (PCOR)***: A type of research that involves patients in the research process and focuses on outcomes that are important to patients.
- **Stakeholders***: People or groups who are affected by, involved in, or can use the results of research, such as participants, researchers, funders, and decision-makers.

We are so glad you are here! This guide is for people who want to make research better, fairer, and easier for everyone to be part of. Research helps us learn new things about health, support, and services, but it has not always included the voices of survivors—especially those with intellectual and developmental disabilities (IDD).

We believe that survivors should help lead research, because they know what is important in their own lives. This guide is here to help you understand research, how to be part of it, and how to make sure research is done in a way that is safe, respectful, and useful for everyone.

We hope this guide helps you feel confident, prepared, and excited to be part of research that makes a real difference.

Who is This Guide For?

This guide is intended for anyone involved in the research process, including:

- Survivors with IDD who want to contribute their lived experience to research.

- Researchers & clinicians who aim to use trauma-informed and accessible practices.
- Advocates & caregivers who support survivors and want to help shape research.

Survivors with IDD

who want to contribute their lived experience to research.

Researchers and clinicians

who aim to use trauma-informed and accessible practices.

Advocates and caregivers

who support survivors and want to help shape research.

By bringing together diverse perspectives with a kind and empathetic approach, we can create research that is more reflective of real-world needs and challenges.

Why is This Guide Important?

Research can lead to changes in policies, treatment options, and support systems, but too often, it doesn't always focus on what people actually need. Traditional research models fail to prioritize the needs and voices of those most impacted.

PATIENT-CENTERED OUTCOMES RESEARCH (PCOR)

A research approach where patients, caregivers, and other stakeholders actively contribute to the research process. It ensures that studies focus on the needs and priorities of those affected.

Patient-Centered Outcomes Research (PCOR) is a type of research that changes this. PCOR can be used to ensure that survivors, particularly those with intellectual and developmental disabilities (IDD), are not "subjects" of research but active partners.

This guide is important because it gives survivors, researchers, and advocates the tools and knowledge necessary to do accessible, trauma-informed, and meaningful research.

Patient-centered research prioritizes outcomes that matter most to those affected.

Survivors know what works and what doesn't in healthcare, support services, and daily life.

Their ideas make research better and more useful for people in the future.

By including survivors' views in research, PCOR makes sure that research questions ask about real-world problems, that study designs are inclusive, and results lead to real benefits for the survivor community.

This guide will help survivors, researchers, and advocates work together in a way that is fair, safe, and respectful. The guide will also help make sure that research includes and supports people with different needs. This guide can help survivors, caregivers, clinicians, and researchers start to work together to make research better, more fair and more helpful.

What Do We Hope You Do with This Guide?

We hope that after reading this guide, you feel empowered to:

- **Advocate for and participate in survivor-led research** that focuses on encouraging inclusivity and accessibility, making it easy for anyone to participate.
- **Apply trauma-informed principles** to create safe, fair, and respectful research environments.
- **Work with diverse stakeholders** to conduct meaningful and helpful studies.
- **Use the tools and strategies from this guide** to create and carry out research that focuses on survivor voices.

Together, we can create fair research that benefits everyone.

Note About the Words We Use

People may use different words to talk about themselves and what they have been through. There is no right or wrong way to describe your own experiences. As you read this guide, if we use words you don't like, we encourage you to think of words you like instead.

In this guide, we have chosen to primarily use **person-first language** (e.g., "person with IDD") rather than **identity-first language** (e.g., "disabled person"). Person-first language emphasizes the individual before their diagnosis or disability, which some people feel reduces stigma and affirms their full identity. However, we recognize that many people prefer identity-first language as a way to embrace disability as an important and valued part of who they are.

We also acknowledge that **trauma** can mean different things to different people. While some experiences may meet clinical definitions of trauma, others may not — yet they can still have lasting emotional, physical, and social impacts. For this reason, we use the word "trauma" broadly to honor the wide range of experiences that can shape a person's well-being.

Our goal is to be as inclusive as possible while respecting different language preferences. Below is a table explaining some of the terms we use, their meanings, and alternative words you may hear or prefer.

Words Used in This Guide

Words/ phrases we use	Our definition	Other word choices
IDD	Intellectual and Developmental Disabilities: A broad range of conditions characterized by limitations in intellectual functioning and adaptive behavior.	ID/D
Survivor	A person who has lived through a harmful experience, particularly trauma, and continues to navigate life with resilience. It focuses on strength and recovery.	Victim
Sexual harm	A broad term encompassing any form of unwanted sexual behavior or exploitation. It is used to acknowledge that harm can vary in severity and scope.	Sexual assault, sexual violence, IPV (interpersonal violence)

You will also see key terms in the beginning of each section, as well as throughout the guide, **words that are featured in bold type with an asterisk(*) next to them. Definitions of these words can be found in our glossary at the end of this document.**

back to TOC

Basics of PCOR/CER

Basics of PCOR/CER

Goal of this section:

- Learn the basics of patient-centered research.

Questions this section will answer:

- What is patient-centered research?
- Why is patient-centered research important?

Key terms:

- **Comparative Effectiveness Research*:** a type of research that looks at different treatments or health care options to see which one works best for certain people or conditions.

What is Research?

Research is a way of collecting information to answer questions and learn new things. There are two main types:

- **Quantitative Research — Counts and measures things**
  Example: Surveys with number scales, counting how many people do something
- **Qualitative Research — Explores people's experiences through talking and observing**
  Example: Interviews, focus groups, observation

What Does it Mean to be Patient-centered in Your Research?

Patient-centered research focuses on the experiences, needs, and voices of people directly affected by the issues being studied. When researchers, survivors, caregivers, and advocates work together, patient-centered research makes sure that results reflect real-world challenges and priorities, leading to better interventions and policies.

back to TOC

Differences Between Traditional and Patient-Centered Outcomes Research

Traditional Research That is Not Patient-Centered	Patient-Centered Outcomes Research
• Survivors are just subjects being studied. • Researchers decide what is important to study. • Researchers decide how to do the research. • Researchers decide what results are most important.	• Survivors get to help pick research questions, methods, and outcomes. • Survivors' ideas are important in making research that is important, and that people can access. Survivors help decide: -what to study -how we know the research has made a difference

What is Patient-Centered Outcomes Research (PCOR)?

PCOR is a way of doing research that involves patients, caregivers, and others working together as equal partners throughout the research process. The goal of PCOR is to learn more about what the people involved need and care about, so we can inform healthcare decisions, making treatments and interventions better for the needs and values of those affected.

PCOR is based on:

- respect,
- shared decision-making, and
- mutual benefit

PCOR is important because it makes sure that research is not only scientifically careful and accurate but also important to the people it helps.

What is Comparative Effectiveness Research (CER)?

CER is an important part of PCOR. CER focuses on comparing different treatments, interventions, or care approaches to figure out what works best for specific groups of people. CER helps find the best ways to improve health by looking at real data and what patients go through. By using CER in survivorship research, we can make sure that treatment and care decisions are informed by evidence that is based on what survivors have gone through.

back to TOC

After you've been through something very difficult, like sexual harm, there might be multiple different choices for support. It might be hard to know which choice is the best one for you. CER can help with this by looking at how well each option works for other people who have had similar experiences before.

Key Parts of PCOR/CER

- **Respect:** Everyone's voice is heard and first-hand experience is valued.
- **Shared Decision-Making:** Encouraging survivors, researchers, and others to work together.
- **Mutual Benefit:** Making sure research leads to good for both participants and the community.
- **Partner Contribution Across All Phases:** Involving survivors and other stakeholders in planning the study, data collection, analysis, and sharing the results.

The Importance of Inclusivity and Survivor Leadership in PCOR/CER

Having survivors lead during PCOR and CER is important because it makes sure that research shows the needs and experiences of the people the study is trying to help. In the past, research has often left out or minimized the views of survivors with IDD, leading to gaps in understanding and solutions that do not work well. By having survivors as equal partners in research, we can develop more ethical, inclusive, and impactful studies.

Survivor leadership makes research better in three main ways:

1. It makes sure that studies focus on issues that really matter to the people affected, instead of topics chosen only by academic or clinical priorities.
2. It encourages inclusivity by bringing together different voices and opinions, leading to more complete and equitable findings.
3. Survivor-led research helps support advocacy efforts. It empowers individuals with IDD to influence policies and programs that directly impact their lives.

To create meaningful survivor leadership, research teams should focus on accessibility, trust-building, and trauma-informed approaches. This includes providing training, mentorship, and accommodations to support survivors in research roles. When survivors are actively engaged in designing and running the research study, the outcomes are more useful and can bring positive changes for both individual people and communities.

Trauma-informed Approaches

Trauma-Informed Approaches

Goal of this section:

- Learn to apply trauma-informed approaches to research.
- Focus on accessible practices for engaging survivors with IDD in trauma-informed PCOR.

Questions this section will answer:

- What is trauma?
- What are the elements of a trauma-informed approach?
- What is a trauma informed approach to research?
- How do intersectionality and accessibility relate to trauma-informed approaches?
- What are **barriers*** to accessibility in research?
- What are **facilitators*** to help engage people with IDD in research?
- What are some promising practices to support meaningful research participation for people with IDD?

Key terms:

- **Retraumatization*:** When a person is triggered by something that reminds them of past trauma, causing them to feel distress similar to what they experienced during the original trauma.
- **Marginalized*:** Marginalized people are those who society pushes aside or treats unfairly, giving them less power, fewer chances, and less say in important matters because of who they are - like their race, gender, disability, how much money they have, or who they love.
- **Barriers*:** things that make it harder to do something.
- **Facilitators*:** things that make it easier to do something.

WHAT IS TRAUMA?

Trauma is a natural human response to harmful experiences that, despite their prevalence, are fundamentally at odds with our basic needs for safety and wellbeing.

What Does it Mean to be Trauma-Informed?

Trauma researchers, practitioners, and others who work with survivors have a big impact on survivors' physical and emotional well-being. Researchers need to be sure their work is not harmful and is trauma-informed. The Substance Abuse and Mental Health Services Administration (SAMHSA) is a United States government agency which focuses on improving the lives of people experiencing mental health and/or substance abuse disorders. SAMHSA's idea of a trauma-informed approach includes 4 assumptions and 6 key principles.

Five Assumptions of a Trauma-Informed Approach

To be "trauma informed", there are five things we need to believe are true.

1. Realize the widespread impact of trauma and understanding paths for recovery.

- Trauma can affect many different kinds of people.
  - This means it doesn't matter what their demographics are - they could be any race, gender, age, etc.
- Trauma impacts families and communities as well.
- When we work with others, it is very important to understand that trauma is a common experience.
- By having a "trauma-informed" mindset, we make sure that we are sensitive and empathetic when we work with others. This helps all people feel supported and welcomed.

2. Recognize the signs and symptoms of trauma.

- Trauma can show itself in various ways, influencing physical, emotional, cognitive, and behavioral health.
- Pay attention to signs that others may be upset.
- Noticing these signs helps us keep control of the conversation and make sure that everyone feels okay.

3. Respond in a way that is trauma-informed.

- Learn about and understand the principles outlined in this training manual.
- Know about the safety measures in case of an emergency.
- If you recognize that someone is triggered, have steps in place to help them feel comfortable and not judged.
- Staying calm and caring is important.

back to TOC

4. Resist retraumatization.

- Retraumatization happens when people experience reminders of their past trauma without enough support to help them deal with their reactions.
  - This can happen if we accidentally trigger their trauma and don't provide space for processing.
- To prevent retraumatization, it is very important to help people feel in control by:
  - giving them the chance to make choices.
  - listening to what they have to say.
  - It is important to speak openly and to listen carefully because survivors know best about how their trauma affects them. We need to listen.

5. Reflect on boundaries and self-care.

While not directly included in SAMHSA's framework, it's very important to set boundaries and practice self-care for our safety and to be effective.

We all have our own experiences of trauma, so self-care while doing this work is needed.

Examples of self-care include eating healthy food, getting enough sleep and relaxation, and doing things that help you stay well.

back to TOC

Six Key Principles of a Trauma-Informed Approach

SAFETY	Make sure the staff and participants feel physically and emotionally safe
TRUSTWORTHINESS AND TRANSPARENCY	Build and maintain trust with people
PEER SUPPORT	Give survivors with IDD time to talk to and support each other
COLLABORATION AND MUTUALITY	Help participants take an active role and build a support system
CULTURAL, HISTORICAL AND GENDER ISSUES	Understanding that people from different cultures may think differently
EMPOWERMENT, VOICE AND CHOICE	Focus on using participant's strengths to help them get more involved

Trauma impacts people differently, and survivors each have different needs in different situations. Because of this, there are no very specific procedures in order to be trauma informed. Instead, there are 6 general rules. These are guidelines- you can think of these principles like bumpers when you're bowling. The bumpers still give a lot of space for the ball to go different places but keeps the ball out of the gutter.

1. **Safety**: Making sure the staff and participants are safe throughout the research process is very important. This includes physical and emotional safety. The physical environment, whether in person or virtual, should be safe and welcoming. When people interact with each other, it is important to make sure that everyone feels safe. This means they feel like they can share their experiences and be themselves.
2. **Trustworthiness and Transparency***: In traditional research, study staff normally has more power than the research participants because the staff makes all the decisions about what questions to ask, how to ask them and how to find meaning in responses. Research participants normally

have less power because even though they share data by responding to questions, they do not normally get to make choices about the research itself. Working together, or collaboration, is very important to change how much power research staff and participants have. Healing happens when people work together and everyone gets the chance to make decisions. When we have a collaborative approach, we help participants take an active role in the research process and build a helpful support system for their healing journey.

3. **Peer Support**: Peer support is important to help people feel safe and hopeful. Giving survivors with IDD time to talk to and support each other, like sharing resources and experiences, can help create a sense of community among survivors.
4. **Collaboration and Mutuality***: In traditional research, study staff normally has more power than the research participants because the staff makes all the decisions about what questions to ask, how to ask them and how to find meaning in responses. Research participants normally have less power because even though they share data by responding to questions, they do not normally get to make choices about the research itself. Working together, or collaboration, is very important to change how much power research staff and participants have. Healing happens when people work together, and everyone gets the chance to make decisions. When we have a collaborative approach, we help participants take an active role in the research process and build a helpful support system for their healing journey.
5. **Empowerment*, Voice and Choice**: It is important to focus on using participant's strengths to help them get more involved in their healing process. We believe that individuals and communities are resilient and can heal after trauma. Supporting participants to make decisions, set goals, and plan what to do is very important because it helps participants feel more in control and get more involved in research.
6. **Cultural, Historical and Gender Issues**: As researchers, we need to ask questions about and challenge cultural stereotypes and biases about things like race, ethnicity, sexual orientation, age, religion, gender identity, and geography. By acknowledging the historical trauma experienced by underserved communities, we can use the strength of cultural connections to help with healing. It's also important to understand that people from different cultures may think differently about trauma. When we focus on being inclusive, we can be more responsive and make a more fair research environment.

back to TOC

The Role of Intersectionality and How That Impacts Trauma-Informed Approaches

EXAMPLE OF EMBRACING INTERSECTIONALITY:

Maria, a Latina woman with IDD, faces multiple barriers: language, cultural stigma, accessibility, and financial insecurity. Researchers can support her by offering materials in Spanish, using plain language, collaborating with trusted community groups, and providing flexible participation options.

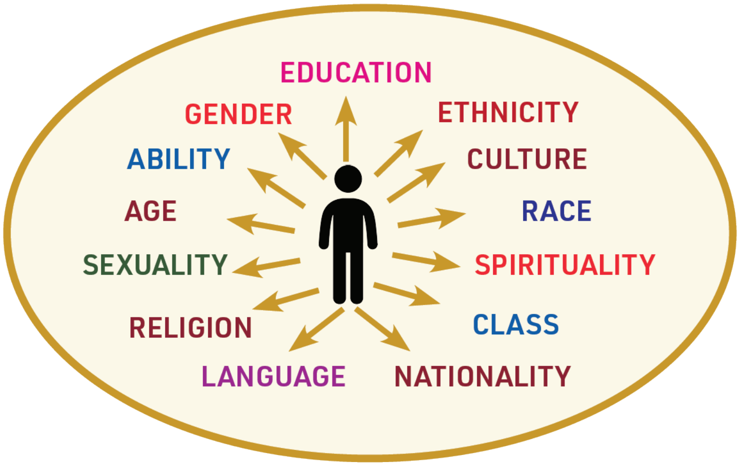
Sometimes, people are treated unjustly because of their identities. This is called “intersectionality”. Kimberle Crenshaw was the first person to use this term.

Intersectionality is important to a trauma-informed approach, because it helps show how oppression and privilege can change the way trauma is experienced and expressed.

We all have many parts that make us who we are. For example, our race, gender, disability, and class can impact our daily lives. All the parts of someone’s life make up their identity.

Understanding intersectionality helps us to identify the unique challenges faced by individuals from diverse backgrounds. For example, a person with a disability may experience trauma differently than someone who is not disabled, and those experiences may also be influenced by their other identities such as race or gender. Understanding the different ways that a person’s identities intersect helps us to better fit our approaches to meet the specific needs of every person, ensuring that our practices are not only trauma-informed but also culturally competent and responsive.

Thinking about intersectionality as part of our trauma-informed work helps us better support people who may face unique experiences because of the various identities they have. This reminds us to advocate for equity and justice in our research and practice because trauma does not exist in a vacuum. It is influenced by many social factors. Embracing intersectionality strengthens our goal to create safe and inclusive environments for all.



back to TOC

Why is Accessibility a Core Part of a Trauma-informed Approach?

Accessibility is a core part of a trauma-informed approach because it ensures that all individuals, regardless of their abilities or experiences, can fully participate in research. Acknowledging and addressing **barriers***— whether physical, communicative, or systemic—creates an environment where participants and survivor partners feel safe and valued. By prioritizing accessibility, we promote equity and inclusivity, allowing trauma survivors to engage in a way that respects their needs.

What is Disability Justice?

Disability Justice means that disabled people are part of diverse communities and will work for justice for all people. This term was first used by Sins Invalid, an organization of disabled artists. (See resource: Disability Justice Principles for more information).

Disability Justice advocates for the rights and dignity of disabled individuals, emphasizing the importance of community support and collective liberation. In a trauma-informed context, embracing disability justice means understanding that trauma can disproportionately affect disabled individuals and that our practices must be inclusive, equitable, and responsive to the unique needs of these populations.

How All of These Ideas Fit Together

To be truly trauma-informed and patient-centered, researchers need to think of everyone's needs to make sure they can access the study. This includes looking at things like a person's different identities and things they have experienced.

So far, you have read a little bit about trauma-informed care, intersectionality, and disability justice. These three ideas all connect with each other and help make research inclusive.

Trauma-informed principles help researchers notice trauma's impact, respond with sensitivity, and avoid retraumatization. Intersectionality emphasizes how overlapping identities, such as disability, race, or gender, shape experiences with trauma and how someone is able to access resources. Disability justice adds to this by focusing on what marginalized people have to say, challenging ableism, and prioritizing accessibility.

Acknowledging the Potential Harm in Research

Understanding research ethics is important for a trauma-informed approach to doing research. Research ethics help make sure research is safe for participants. Some communities have been hurt by research. For example, they may have been involved in a study without their consent, or they did not understand what would happen to them during the study. This led to people getting sick or hurt. When people know that members of their community have been hurt or taken advantage of in research, they may not trust researchers. They may have learned to avoid research to protect themselves. Research has a traumatic history. Researchers need to remember that many people have been hurt by research, and that they do not trust researchers. When people do not trust researchers, they may not want to get involved in research. They may also not trust the results of the research. Researchers who want to acknowledge trauma and work with people who have been hurt by research should build trust with community members.

There are rules for researchers to follow to make sure their studies are ethical, for example:

- Always get permission from participants.
- Be clear about what the research is about.

Being ethical is about more than just following these rules. Researchers can also work closely with community members to build relationships. By including community ideas and needs in research, we can make sure research is respectful, fair, and safe. When community members help design and conduct the research, it promotes accountability and respect between researchers, participants, and communities. Community members have a say in what is studied and how the research is done. When researchers and community members work together, they can break down power imbalances and build trust. By prioritizing ethical research, we can help heal past harm and create a more inclusive, supportive environment for marginalized communities.

There is a lot of information out there about research ethics. Here's one free resource you can use to learn more. Research Ethics for All (https://re4all.org/)

Applying Trauma-informed Approaches to Research

When people talk about trauma-informed care, they normally are talking about clinical settings when people are working with doctors or other healthcare professionals. We can also make research trauma-informed. This can help participants feel safe and comfortable sharing their stories.

The following section gives some examples of how we can apply a trauma-informed approach to the research process:

REALIZE **RECOGNIZE** **RESPOND** **RESIST** **REFLECT**

Realize the Impact of Trauma

- Train research staff on how trauma can impact communication, behavior, and engagement.
- Design research protocols that prioritize participant safety and emotional well-being.
- Create welcoming environments:
  -calming spaces
  -accessible language
  -clear signage

Recognize Signs of Trauma

- Pay attention to any signs that participants are feeling upset. Examples:
  -Withdrawal
  -Agitation
  -Difficulty concentrating
- Be mindful that unexpected emotional reactions may stem from past trauma.
- If a participant seems upset, we can say short, kind sentences to help them feel better and calmer.
- Offer breaks
- Alternative communication methods or supportive resources.

Respond with Trauma-informed Care

- Use clear, simple language.
- Use visual aids.
- Repeat key information.
- Provide flexible participation options (e.g., location choice, interview format).
- Build trust by explaining each step of the research process.
- Offer participants choices.

Resist Retraumatization

- Minimize repeated questioning about sensitive topics.
- Give participants control by allowing them to skip questions or stop the session at any time.
- Share resources for emotional support at the end of interviews or focus groups.

Reflect on Boundaries and Self-care

- Establish clear boundaries for your role as a researcher (e.g., avoid acting as a counselor).
- Encourage self-care practices. Example:
  -Mindfulness
  -Peer support
- Foster a team culture that normalizes breaks and emotional check-ins.

A Focus on Accessibility

Identifying Barriers

Barriers are things that make it harder to do something. Survivors with IDD often face unique barriers that can make it harder to participate in trauma-informed research. It is very important to understand how these things can make it harder for survivors to fully participate in research. If researchers understand common barriers, they can make a plan for their research study to avoid barriers when possible.

Examples of Barriers

- Having different participation options. When possible, researchers should give different options of how someone could participate in a study. For example, in an interview or focus group, giving participants the chance to respond verbally or over chat. This can give participants choice and control and can also help support participation in a way that works best for the individual.

- Working with research staff that have shared lived experience as a survivor with IDD. When research staff also identify as survivors and/or individuals with IDD, research participants have the chance to connect with and feel understood by someone with shared identities. It can feel easier to trust researchers with shared identities.
- Building trust and practicing transparency. When researchers explain what the study involves, let participants know what to expect, and follow through with what they say they will do, this helps participants feel safe in a study.

Facilitators of Engagement

Facilitators are things that make it easier to do something. These are things we can do to make it easier for survivors with IDD to participate in trauma-informed research. By focusing on these facilitators, researchers can create a more welcoming environment that encourages participation.

Examples of Facilitators

- Building trust is very important when working with survivors of IDD.
- Making a connection and building a good relationship with participants can make participants more willing to be involved in research.
- Peer mentorship programs can also work well because they give survivors relatable support from individuals who can understand their experiences.
- Advocacy is important because it helps promote the rights and needs of survivors, making sure their voices are heard and respected during the research.

Promising Practices

Implementing strategies for inclusive and trauma-informed research participation is vital for successfully engaging survivors with IDD. This includes adapting research methods to accommodate the specific needs of participants, such as using accessible language, providing clear explanations, having access to use of assisted tech options, and offering various ways for individuals to express their experiences.

Utilizing trauma-informed approaches can help create a safe and supportive environment, allowing participants to share their stories without fear of re-traumatization. By prioritizing inclusivity and flexibility, researchers can better support survivors in their participation, ultimately enriching the research process.

We asked survivors with IDD and providers who care for survivors with IDD what challenges, opportunities, and promising practices there are to create more supportive research environments for these groups. Here is what they told us.

Challenges and Opportunities for Engaging Survivors in Trauma-informed Research

Challenges	Opportunities
Different goals: Researchers and community partners may have different priorities and expectations for research outcomes.	**Developing mutual understanding**: Creating shared research questions and priorities through collaborative planning and regular dialogue meetings.
Communication problems: Academic language can be inaccessible and differs significantly from language used in community contexts.	**Creating accessible methodologies**: Developing inclusive research approaches that use clear language and honor diverse ways of expressing knowledge.
Time constraints: Building meaningful partnerships requires significant time investment. Partners often operate on different schedules and deadlines.	**Strengthening community partnerships**: Establishing long-term relationships beyond single projects through ongoing engagement and transparent processes.
Power imbalances: Traditional research hierarchies make it difficult to ensure equitable participation and decision-making authority.	**Centering survivor perspectives**: Ensuring research questions, methods, and dissemination strategies reflect what's meaningful and useful to survivors.
Sustainability challenges: Maintaining partnerships and implementing findings after project funding and formal timelines end.	**Honoring lived experience wisdom**: Recognizing the unique expertise that comes from lived experience and integrating this knowledge.

back to TOC

Qualitative Research Skills Training

Qualitative Research Skills Training

Goal of this section:

- Learn how to do accessible, trauma-informed research.

Questions:

- How do we plan a research project that is accessible to everyone?
- How can we explain research to participants to make them feel safe and comfortable?
- What skills do we need to complete a research session?
- How do we fully understand participant stories and translate their words to research findings?
- How can we share what we found and make a positive change with our research?

Key Terms:

- **Ethical*:** Doing what is right and fair. In research, this means treating people with respect, keeping them safe, and being honest.
- **Recruitment*:** Inviting people to take part in a research study. This means reaching out to people and asking if they want to be part of the research.
- **Qualitative analysis*:** When researchers read what people shared, look for common ideas, and try to understand what it all means.
- **Themes*:** Big ideas that show up again and again in people's stories.
- **Dissemination*:** Sharing what you learned from your research. This can mean telling others through presentations, reports, or creative formats so the information can make a difference.

This guide focuses on qualitative research because it lets people share their stories and experiences in their own words.

It means:

- Making sure everyone feels safe and respected
- Understanding that talking about difficult experiences can be hard
- Giving people choices about how they participate
- Making sure no one gets hurt by the research process
- Recognizing that people may have had bad experiences with research before

Throughout this guide, you'll see tips and values that support both participants and researchers. To help you along the way, we've included a supplemental section called **"Supporting Everyone Throughout the Process."** It includes:

- A checklist for supporting participants.
- Self-care tips for researchers.
- Ideas for building long-term relationships.
- A reminder of the core values we return to again and again: safety, respect, real choices, trust, and creating change.

Trauma-informed research puts safety first.

Planning Your Research

Planning the research project includes:

- Building your team.
- Creating a safety plan for research participants.
- Creating good research questions.

Build Your Team

A good research team makes the whole project stronger. Building a team means choosing people who have the skills, experiences, and perspectives needed to do accessible, trauma-informed research.

Key skills:

- Think about what roles are needed.
- Include people with different lived experiences.
- Plan how the team will communicate and work together.
- Train each member of the team about trauma.
- Practice shared decision making.
- Check in with each other regularly.

Who to Include and Why This Matters

- **Survivors with IDD**
  They know what matters most.
- **Community-based researchers**
  They can connect with participants and bring insight to the team.
- **University researchers**
  They know research methods.
- **Support people**
  They can help when the research gets difficult.
- **Community partners**
  They connect with local resources.

Create a Safety Plan

A safety plan is a plan that is in place in case of distress during a research session. Having a safety plan helps protect both participants and researchers. It ensures that if someone feels uncomfortable, upset, or unsafe during the research, everyone knows what to do to support them.

Before starting the research, make sure you have:

back to TOC

- A plan for what to do if someone gets upset
- Support resources ready
- Regular breaks scheduled
- Clear ways for people to take a break or stop completely

Create Good Questions to Ask

Good questions help people share their stories in ways that feel safe and comfortable.

Remember to:

- Focus on questions that matter to survivors.
- Use clear, simple language.
- Use open-ended questions (start with "what", "how", or "tell me about…").
- Ask about strengths and support.
- Avoid questions that might make people feel judged.

SAFETY PLAN

Example: During an interview, a participant starts crying when talking about a past experience. Use safety plan steps:

- Pause the interview
- Gently ask: "Would you like to take a break, stop, or keep going?"

Instead of Asking…	Try Asking…
Were you scared when things were hard?	What helps you feel safe when things are hard?
Are most of your days good or bad days?	What does a good day look like for you?
Does anyone help you?	What kinds of support have been helpful?
How has your disability made trauma worse?	What strengths have helped you through difficult times?

Do Research Ethically and Get Approval

This module teaches how to make sure your research is ethical (which means fair, respectful, and safe). Before starting a study, you must get approval from a group called the **Institutional Review Board (IRB)***. This protects everyone involved in the research—especially people who have experienced trauma or who may be more vulnerable.

What is the IRB?

Before a research study can begin, a group of experts must review and approve it. This group is called an Institutional Review Board, or IRB for short.

- The IRB checks to make sure people will be treated fairly and safely.
- They make sure the study follows rules that protect participants.
- The study cannot start until the IRB gives approval.
- Ask the person leading your research team how your project got IRB approval.

The Research Code of Ethics

The research code of ethics is a set of rules and values that help researchers do the right thing. It's a guide for how to treat people with respect, protect their safety, and make sure the research is fair and honest. Ethics is not just rules— it's about treating people with care and respect.

Research Principle and What It Means in Plain Language

- **Respect for people**
  Ask for permission, listen to what people want, and honor their choices.
- **Do no harm**
  Avoid anything that could hurt people emotionally, physically, or mentally.
- **Fairness**
  Include people fairly and treat everyone with the same respect.
- **Be honest**
  Tell the truth about what the research is and what will happen.
- **Protect privacy**
  Keep people's personal information safe and private.

Creating Materials Everyone Can Understand

To create research materials that everyone can understand, we should

- Use plain language.
- Make visual support.
- Offer different formats to explain information.

Use Plain Language

Plain language helps make sure everyone understands the research. It makes your questions clear, respectful, and easy to answer. Please refer to our plain language resources for more information on this topic.

back to TOC

Instead of Writing	Write This Instead
The research protocol will be implemented...	We will do the research by...
Participants will be asked to respond...	We will ask you...
Upon completion of the interview...	After we talk...
This study investigates the experiences...	This study looks at what happened to...

Make Visual Supports

Some people understand information better when they can see it instead of just hearing or reading it. Good visual support helps participants feel confident and included in the research process.

Key skills:

- Pictures, icons, charts or timelines that help explain ideas
- Choose clear and simple images
- Use plain language text to support images
- Use color carefully— pick colors with good contrast
- Avoid too many visuals to keep pages simple

Offer Different Formats

Everyone understands and communicates differently. Offering different formats makes your research more accessible, respectful, and trauma-informed. It gives participants choice and control over how they want to engage.

Format and why it helps

- **Written materials with pictures**
  Helps people who learn by reading and seeing
- **Audio recordings**
  Helps people who learn by listening
- **Videos with captions**
  Combines visual and hearing information
- **Digital and paper options**
  Gives choices for how to access information

- **Large print**
  Helps people who have trouble seeing small text
- **Braille**
  Helps people who are blind or have very low vision

Example: Create a research information sheet with pictures, simple text, and an audio version.

Inviting People to Participate

Inviting people to participate in the research study, or recruitment, includes making sure:

- **Study materials are accessible** to everyone.
- The **research is explained clearly**.
- **Offering choices for participation** for people who want to join.

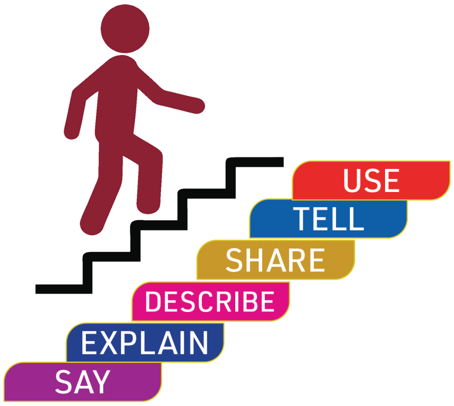
Accessible Recruitment Materials

Recruitment materials, like flyers, videos, or social media posts, help invite people to join the study. Good materials should be easy to understand, friendly, and welcoming to everyone.

Key skills:

- Use plain language.
- Make the materials accessible (easy to read, hear, or see).
- Share important information clearly.
- Make it feel like an invitation, not a demand.

Steps to Create Good Recruitment Materials



What to Include	How to Say it in Plain Language
Say what the study is about	We are learning about people's experiences with support services.
Explain who can join	You can join if you are 18 or older and have used support services.
Describe what participants will do	You will be asked questions in a one-on-one interview. You can skip any questions you don't want to answer.
Share important details	The interview will take about 1 hour. You will get a $25 gift card for your time.
Tell people how to sign up	If you want to join, call us at 555-123-4567 or email study@email.com.
Use simple, welcoming words	Your story matters. Thank you for thinking about joining!

Explain the Research Clearly

When we introduce a research study to a potential participant, it's important to explain what the study is about, why it matters, and what the participant will be asked to do. This helps the participant make an informed decision about whether they want to take part. Clear and honest communication builds trust, safety, and respect.

Key skills:

- Use plain language to explain what the research is about and what you are asking them to do.
- Break information into small parts - do not give too much information at once.
- Check for understanding - pause and ask, "What questions do you have?"

back to TOC

- Be honest about risks and choices to allow the participant to make an informed, voluntary decision.
- Repeat important information if needed.

Checklist of What to Include When Explaining Research

✓What the research is about
✓Why the research matters
✓How it might help others
✓What people will be asked to do
✓How much time it will take
✓Any possible risks or discomforts
✓Important details, such as compensation

Offer Choices

Offering choices helps participants feel empowered, respected, and in control of their involvement in the research process. It shows that you value their preferences and are committed to making their experience comfortable and respectful.

EXAMPLES OF OPTIONS:

"Would you like to meet at our office, or somewhere else?"

"What time works best for you?"

"Would you like to have someone you trust come with you?

Key areas to give participants options:

- When and where to meet
- Who they want with them for support
- How they want to share their thoughts: (talking, writing, drawing)
- What topics they're comfortable discussing

Talking with Participants

Talking with participants is a key part of the research process. Before each session with participants, we should **create a safe space** for interviews or focus groups, and **prepare for different communication needs.**

We should start each session with a warm welcome. During each session, we must:

- **Make consent accessible for everyone.**
- **Ask questions carefully and with respect.**
- **Listen without judgement.**
- **Watch for signs of distress.**
- **End each session on a positive note.**

back to TOC

To Do Before the Session

Before a session with a participant, we should set up for success by creating a safe space for research and by being ready to offer different communication methods.

Create a Safe Space for Interviews or Focus Groups

When participants feel safe, they are more likely to share honestly and feel respected. A safe space means emotional safety, physical comfort, and feeling in control during the research.

Your space should have:

- Quiet, private room without distractions
- Comfortable seating, lighting, temperature and noise levels
- Water and snacks available
- Clear paths to exits and bathrooms
- Fidget toys or comfort items
- Option for virtual meetings if preferred

Consider Communication Needs

Good communication is about meeting people where they are. Participants may use different ways to express themselves. All ways of communicating are valid.

When we support communication needs, we show respect, inclusion, and care, and we make sure everyone has a real chance to share their story.

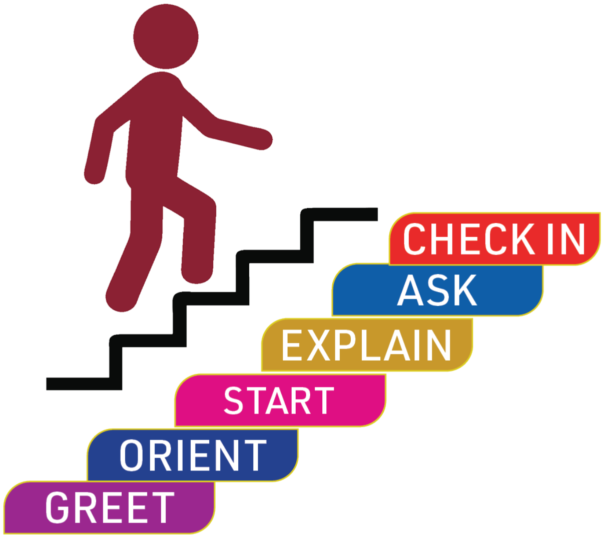
Communication Need and How to Help

- **Different ways of speaking:** Be patient, don't interrupt. Do not speak too fast. Ask for clarification as needed.
- **Uses supportive typing device:** Allow extra time; learn basics of their system.
- **Needs visual supports:** Have picture cards ready.
- **Uses sign language:** Have a qualified interpreter.
- **Needs time to process information:** Share information in small chunks; give extra time; check in about pace; check understanding.
- **Gets overwhelmed by too much talking:** Take breaks; use written options.

Warm Welcome

The way a session begins shapes how comfortable and safe a participant feels. Comfort and safety are very important to the success of a session. A warm welcome builds trust. Clear information helps participants feel confident about what to expect

How to Begin Your Conversation with Examples of What to Say



STEP 1: **Greet** participants warmly—"It is really nice to meet you!"

STEP 2: **Orient** to the space—"Water is here if you need it."

STEP 3: **Start** with easy topics:– "How was your trip here today"?

STEP 4: **Explain** what will happen—"First we'll talk about…"

STEP 5: **Ask** about preferences—"What communication methods work" best for you"?

STEP 6: **Check in**—"Do you have any questions before we begin?"

Make Consent Accessible

- Informed consent is about respect, choice, and trust.
- Participants must understand what they are agreeing to, and they must know they can say yes or no freely.
- Accessible consent means sharing information in a way that everyone can make an informed decision.

Why Informed Consent Matters

WHY INFORMED CONSENT MATTERS

Consent protects the rights of participants.

Consent builds trust between researchers and participants.

Consent helps make sure people are treated with dignity and respect.

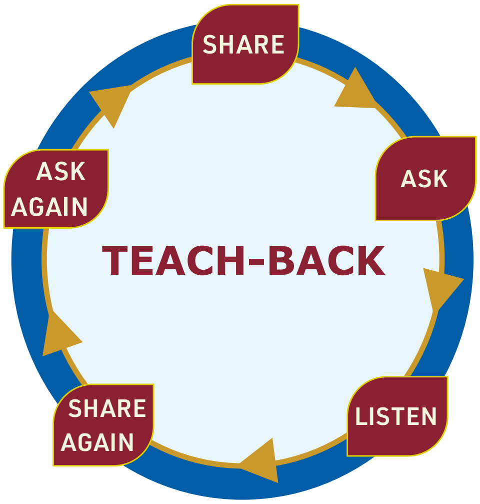
Consent is required by law and ethical research guidelines.

Steps to a general informed consent process and what to do:

STEP 1: Explain the project clearly
STEP 2: Share what the project involves
STEP 3: Talk about risks (if any)
STEP 4: Talk about privacy
STEP 5: Make sure participants know they have a choice to participate or not
STEP 6: Give them time to think
STEP 7: Ask the participant to explain their understanding of the project (The "teach-back" method)
STEP 8: Get verbal or written consent

What is the Teach-back Method?

The teach-back method is a way to make sure someone understands what you've shared with them. After you explain something, you ask the person to explain it back to you in their own words. This helps you know if you explained it clearly, and gives you a chance to go over anything that was confusing.



Completing the Research Activities

While this part of the research is usually unique to each study, there are a few key ideas that we should keep in mind for conducting research activities with participants.

Ask Questions Carefully

DO	DON'T
Ask one question at a time	Ask multiple questions at once
Wait patiently for answers	Pressure for responses
Offer breaks between topics	Rush through the questions
Use clear, simple language	Use technical terms or jargon
Follow the participant's lead	Stick rigidly to your question list

Listen Without Judgment

- Pay full attention.
- Don't rush or interrupt.
- Accept all answers.
- Thank people for sharing.
  Example: "Thank you for sharing that with me. Would you like to take a break now, or should we continue?"

Watch for Signs Someone is Uncomfortable

Sign	What It Might Mean	What You Can Do
Looking away or down	Feeling uncomfortable or shy	Offer to take a break, switch topics.
Fidgeting more than usual	Feeling anxious or restless	Offer movement break.
Changing the subject or talking about something other than the research	Topic may be upsetting	Follow their lead to new topic.
Becoming very quiet	Might be shutting down	Check in: "Should we take a break? You may also choose to skip questions or stop at any time.".
Becoming very talkative	Might be anxious	Gently refocus or offer break.
Saying they want to leave	Clear boundary—respect it	End session positively and try not to take it personally.
Becoming angry or raising their voice	A boundary may have been crossed	Speak in a gentle calm tone, offer a break if needed.

End on a Positive Note

Wrapping up in a thoughtful and kind way helps participants feel valued, respected, and cared for. It also gives them a chance to ask questions, share any final thoughts, and leave feeling positive about their experience.

Ways to end a session well:

- Talk about something good or hopeful.
- Do a calming activity (deep breathing, stretching).
- Offer a chance for final thoughts.
- Thank the person for their help.
- Explain what will happen next.
- Make sure they have support/resources if needed.

Understanding What People Tell You

Understanding what people tell you, or qualitative analysis, means getting to know the stories you have collected, grouping similar ideas together, and making meaning of your findings. This includes:

- **Keeping a journal** to organize your thoughts.
- **Getting to know the stories** that we shared with you.
- **Grouping similar ideas together**.
- **Making meaning of the data collected**.

QUALITATIVE ANALYSIS

means getting to know the stories you have collected, grouping similar ideas together, and making meaning of your findings.

Keep a Journal

An audit journal helps you stay organized while you're working with people's stories. It keeps track of your ideas and helps you notice if your own opinions might be affecting the research. This kind of journal is sometimes called an audit trail.

Sections of an Audit Journal and What They Do

1. **Analytic section**
    - Document your decision making.

  - Write down the codes (labels for ideas) you find and the date you found them.
  - Shows how your ideas grow over time.

2. **Theoretical section**
   - Document your thoughts along the way.
   - Write any big ideas or patterns you notice. You can also write questions to come back to later.
3. **Personal section**
   - Document your feelings as you navigate the process.
   - Write down how you're feeling, what personal thoughts are coming up, or any bias you might have. (This part is just for you.)
   - This helps you stay focused on the participants' voices, not your own.

Tip: You can write in a notebook, a Word doc, or wherever works best for you!

Get to Know the Stories

When we interview participants, we collect their stories to learn from their experiences. Collecting the stories is just the beginning. We also need to look closely at those stories to find patterns, feelings, and ideas— this is called qualitative analysis.

Steps to Get to Know the Stories and Plain Language Example

STEP 1: **Read** or listen to each story slowly.
"I'm reading each interview one at a time, just to take it in."

STEP 2: **Take** simple notes about what stands out.
"This person talks a lot about feeling safe at home. I'll write that down."

STEP 3: **Think** about the big picture.
"What do these stories help me. understand about the research topic?"

STEP 4: **Talk** with your team about what you noticed.
"Let's all share what stood out to us before we start coding."

STEP 5: **Keep** coming back to the stories as you analyze.
"Even after we find themes, let's keep checking the stories to make sure we're getting it right."

Key skills/tips:

- Read or listen to the stories more than once.
- Pay attention to feelings, tone and meaning.
- Keep an open mind: do not try to assume.
- Take breaks if stories are emotional.

Group Similar Ideas Together

After you've spent time getting to know the stories, the next step is to look for patterns. Patterns are ideas or experiences that show up in more than one story. These patterns are called themes. Themes help us explain what we've learned in a way that makes sense to others— while still honoring each person's voice.

1.Start with Coding

- Read the stories carefully and begin coding— coding means marking or labeling important sections of the text.
- Create short labels , or "codes", that describe specific ideas.
  For example, if a participant talks about feeling unsupported, you might label this "lack of support."
- Highlight repeated ideas that appear in multiple stories.
- Codes can be descriptive (such as "hospital wait times") or interpretive (like "feeling powerless").

Tip: Use participants' own words to describe codes when possible.

NOTE: Because qualitative research is shaped by the perspective of the researcher, different people might code the same text differently. That's expected— and even valuable. Part of the process is coming together with your team to discuss these differences and work toward a shared understanding.

2.Group Similar Codes Together

- Once you've coded the data, look for patterns. Group similar codes together to form broader categories.
- Talk with your team to see if they notice the same patterns.

3.Identify Themes

- Themes are big ideas that summarize and show patterns.
- Name each theme clearly, and ensure the name captures what participants are sharing.

4. Organize and Discuss

- After finding potential themes, you can refine them by organizing related themes or combining those that overlap.
- Check back with the participant stories to make sure the themes represent the full range of experiences.

Make Meaning of the Data Together

While making sense of all of the information that you have collected, it is important to include those with lived experience. The people who shared their stories, or who have similar life experiences, can help us understand the themes in deeper and more accurate ways.

How to involve people with lived experience:

- Include them on your research teams.
- Share the themes you have found.
- Have them help identify important ideas.
- Check if you understood correctly: "Did I get that right?".
- Use their feedback to adjust your themes or add meaning.
- Collaborate on next steps and action efforts.

Sharing What You Learned

Sharing what you have learned during the research process is important to using the information to make a change. This includes:

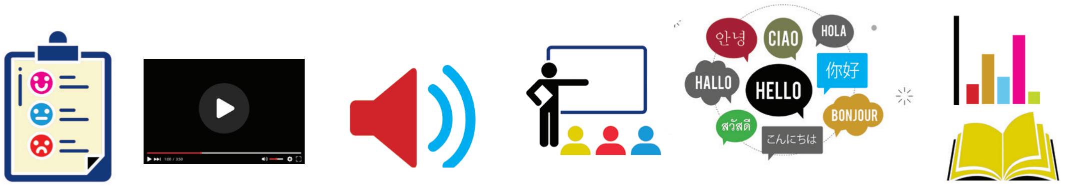
- **Choosing an accessible way to share information**
- **Sharing the results with participants first**
- **Making sure the research leads to positive change**

Choose an Accessible Way to Share the Information

After you finish a research project, it's important to share what you learned in ways that are accessible, respectful, and meaningful to everyone who was part of the work.

When choosing how to share the information from your research, think about what format would work best for your audience:

Formats and Benefits



- **Short summaries with pictures:** Easy to understand quickly
- **Videos explaining findings:** Good for visual/auditory learners
- **Audio versions:** Accessible for people benefit from hearing the text spoken
- **Presentations (online or in person):** Allows for questions and discussion
- **Materials in multiple languages:** Reaches diverse communities
- **Different versions for different reading levels:** Meets various comfort levels

Share Results With Participants First

People deserve to know how their stories made a difference. It builds trust and shows respect. Sharing what you have learned from people's stories builds trust, honors people's contributions, and helps make sure the research makes a real difference.

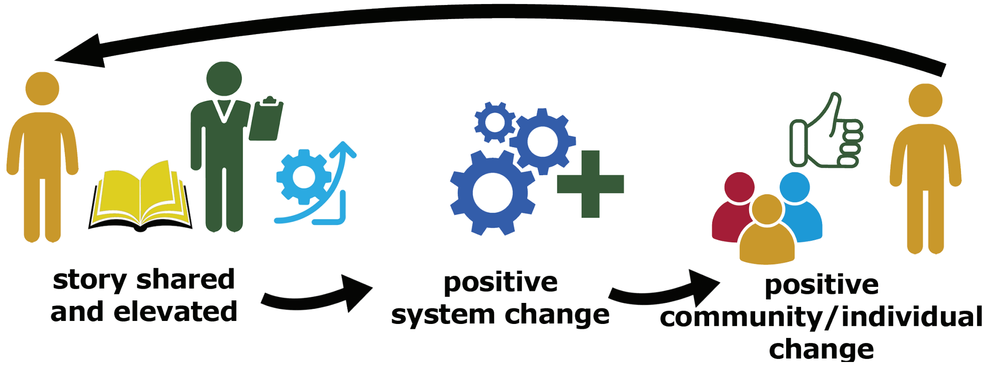
Follow this order:

1. **Create a thank-you summary of the results in plain language.**
2. **Show findings to participants before anyone else.**
3. **Ask if they agree with what you found.**
4. **Then share with others (funders, organizations, public).**

Make Sure Research Leads to Positive Change

Doing research is not just about collecting information—it's about making a difference. When we work with people with lived experience, we need to be sure the research leads to something useful, helpful, or healing. This is how we honor the time, energy, and stories that people share.

The process starts with an individual sharing their story. It then goes to the researcher with a responsibility to elevate it. This should lead to a positive systems level change that goes back to have a positive effect on the community or individual.



Level of Change with Examples

- Individual—Connect participants with helpful resources.
- Community—Train service providers based on findings.
- Organization—Change policies to be more accessible.
- System—Work with policymakers on new funding or laws.

> Research should never just stay on a shelf. When we do research with people—not just about people—we have a responsibility to turn that knowledge into action.

Example: Create a one-page summary with pictures showing the three most important things you learned and what should change.

Conclusion

Conclusion

You have learned a lot in this training!

Now you know how to support people with disabilities and survivors of trauma in research. You know how to make your research accessible, respectful, and trauma-informed—every step of the way.

What We Covered

- How to build a strong, inclusive team
- How to communicate clearly and kindly
- How to make choices and materials accessible
- How to get consent in a way that supports understanding
- How to gather and understand stories through interviews or focus groups
- How to analyze stories and find patterns (themes)
- How to share what you learn in ways that are helpful to others
- How to make sure your research leads to positive change

Research is not just about collecting data — it's about listening to people's experiences and treating them with care. Everyone deserves to feel safe, heard, and respected in research spaces.

Your voice and your perspective as a researcher are important. When we do research the right way, we can help create a more just, inclusive, and healing world.

This guide is a starting point. It's okay to ask questions, get support from your team, and keep growing.

back to TOC

Thank you for being part of research that matters. Your work makes a difference.

Call to Action

We invite survivors, researchers, advocates, and community members to actively engage in trauma-informed PCOR. This means ensuring that survivor voices are heard, valued, and integrated into every stage of the research process. By adopting trauma-informed, inclusive research practices, we can work together to build a research landscape that is equitable, representative, and impactful for all communities.

Now is the time to commit to research that prioritizes survivors' well-being, respects their experiences, and fosters meaningful change. Let's work together to create a future where all research is trauma-informed, accessible, and survivor-led.

- Resources and Tools
- Glossary

Resources and Tools

Get Help

Here are some free resources people can use when they may need to talk to someone for support or if they are struggling.

- Suicide and Crisis Hotline
  Call or text 988
  VideoPhone available–call 988 with a VP number
  Chat options (https://988lifeline.org/)

- Thrive Lifeline
  Text "THRIVE" or 313-662-8209
  Get in Touch (https://thrivelifeline.org/)

- National Sexual Assault Telephone Hotline
  Call 800-656-HOPE (4673)
  Text HOPE to 64673
  Chat Online (https://hotline.rainn.org/online)

- National Domestic Violence Hotline
  Call 1-800-799-7233
  Text START to 8878
  Chat Online (https://www.thehotline.org/)

Sexual Violence and Disability

Here are some resources to learn more about the intersection of sexual violence and disability.

- A Peer to Peer Guide About Domestic and Sexual Violence
  (https://selfadvocacyinfo.org/wp-content/uploads/2017/04/GMSA-A-Peer-to-Peer-Guide-About-DV-and-SV.pdf)

- A Plain Language Guide About Ableism & Violence
  (https://gmsavt.org/resources/a-plain-language-guide-about-ableism-violence)

- Supporting Survivors with Intellectual/Developmental Disabilities (IDD)
  (https://pcar.org/resource/supporting-survivors-intellectual-developmental-disabilities-idd)

- Forging New Collaborations A Guide for Rape Crisis, Domestic Violence, and Disability Organizations
  (https://www.endabusepwd.org/wp-content/uploads/2021/02/accessible_version_pdf_forging_new_collaborations.pdf)

Disability Inclusive Violence Prevention and Response

This resource is a big hub of other resources and information.

- Indiana Disability Justice (IDJ)
  A program of Indiana Coalition Against Domestic Violence
  Disability Justice & Violence Prevention Resource Hub
  (https://indisabilityjustice.org/)

Here are some other resources about sexual harm and violence prevention that are specifically designed for people with disabilities.

- Disability Justice, Violence Prevention, and Abolitionism Curriculum
  (https://pcar.org/disability-justice-violence-prevention-and-abolitionism-curriculum)
- Survivor Support Packet Resources: A Guide for Survivors of Sexual Abuse
  (https://www.wearemass.org/survivor-support-packet)
- Learn How to Become a Peer Supporter of a Person who was Abused
  (https://gmsavt.org/resources/learn-how-to-become-a-peer-supporter-of-a-person-who-was-abused)
- Peer to Peer: Bridging the Gap through Self-Advocacy
  (https://rise.articulate.com/share/T_s9Ps3ohCzUh0iinhTn_3r71czyyX5_#/')

Programs for Survivors with IDD

- ABLE South Carolina
  Domestic Violence & Sexual Assault Support
  (https://www.able-sc.org/get-support/violenceprevention/
- The SAFE Alliance
  Disability Services
  The SAFE Alliance (Stop Abuse For Everyone)
  (https://www.safeaustin.org/our-services/prevention-and-education/disability-services/)
- Activating Change
  Creating Pathways to Healing
  (https://www.activatingchange.org/creating-pathways-to-healing)
  End Abuse of People with Disabilities Project
  (https://www.endabusepwd.org/)
- The Arc of the United States
  Talk about Sexual Violence Initiative
  (https://thearc.org/our-initiatives/criminal-justice/talk-about-sexual-violence/)
- Barrier Free Living
  (https://www.bflnyc.org/)
- Lumina Alliance
  (https://luminaalliance.org/survivors-with-disabilities)

Accessible and Inclusive Research Resources

Here are resources that can help with making your research more accessible and tools and trainings for research teams that include people with IDD.

Plain Language

These resources can help research teams use more plain language in their materials.

- One Idea Per Line: A Guide to Making Easy Read Resources
  (https://autisticadvocacy.org/resources/accessibility/easyread/)
- ABC's of Plain Language
  (https://systems.aucd.org/docs/urc/2020_ABCs%20Short.pdf)

Inclusive Research Trainings

These online trainings offer more information about doing research.

- Research Ethics for All
  (https://re4all.org/)
- Kaiser Permenente Autism Research Program Resources
  Research Basics Community-based Training
  (https://divisionofresearch.kaiserpermanente.org/research/autism-research-program/resources/)

Tools for Inclusive Research Teams

These toolkits give helpful suggestions for inclusive research teams.

- Toolkit for Remote Inclusive Research
  Overview: This toolkit teaches different ways we can include research team members with IDD on teams that do not meet in person.
  (https://yell.ot.phhp.ufl.edu/research/engaging-in-research-during-emergencies/toolkit-for-remote-inclusive-research/)
- Peer Support Toolkit for Inclusive Research
  Overview: This toolkit teaches different ways that research team members with IDD can provide peer support to other researchers with IDD on inclusive teams.
  (https://yell.ot.phhp.ufl.edu/research/engaging-in-research-during-emergencies/peersupport/)

Glossary

- **Barriers:** Things that make it hard for someone to take part or do something.
- **Patient Centered Outcomes Research (PCOR):** A type of research that involves patients and others in the research process and focuses on outcomes that are important to patients, helping them make better healthcare decisions based on what matters most to them.
- **Comparative Effectiveness Research*:** A type of research that looks at different treatments or health care options to see which one works best for certain people or conditions.
- **Dissemination:** Sharing what you learned from your research through presentations, reports, or creative formats so the information can make a difference.
- **Empowerment:** Helping people feel strong, confident, and in control of their own choices. In research, it means supporting people to speak up, make decisions, and know that their voice matters.
- **Ethical:** Doing what is right and fair. In research, this means treating people with respect, keeping them safe, and being honest.
- **Facilitators:** Things that help someone take part or make something easier.
- **Institutional Review Board (IRB):** A group of people who review and approve research studies to make sure they are ethical and safe for participants. They check things like whether people are being treated fairly, if risks are minimized, and if participants are fully informed before they agree to join a study.
- **Marginalized:** Marginalized people are those who society pushes aside or treats unfairly, giving them less power, fewer chances, and less say in important matters because of who they are–like their race, gender, disability, how much money they have, or who they love.
- **Mutuality:** Working together in a way where everyone gives and receives. It means listening to each other, sharing power, and making decisions as a team.

back to TOC

- **Patient-Centered Outcomes Research (PCOR):** A type of research that involves patients in the research process and focuses on outcomes that are important to patients. Qualitative analysis: Looking at people’s stories, words, or pictures to find important ideas and meanings. This helps us understand how people feel, what they think, and what their experiences are.
- **Recruitment:** Inviting people to join a research study. It means sharing clear information about the study and letting people choose if they want to take part.
- **Retraumatization:** When a person is triggered by something that reminds them of past trauma, causing them to feel distress similar to what they experienced during the original trauma.
- **Qualitative research:** A type of research that focuses on understanding people’s thoughts, feelings, experiences, or behaviors. Instead of using numbers, it uses words, stories, or observations to explore how people make sense of the world around them.
- **Stakeholders:** People or groups who are affected by, involved in, or can use the results of research, such as participants, researchers, funders, and decision-makers.
- **Themes:** Big ideas that come up again and again in people’s stories or answers. Themes help us understand what is most important to people.
- **Transparency:** Being open and honest about what you’re doing and why. In research, it means sharing clear information so everyone understands the process and decisions.