From System Involvement to System Improvement: Lessons on Collaboration from Lived Experience

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Welcome & Introductions

Agenda

1. Welcome & Introductions
2. Background and History
3. What is Lived Experience
4. How to collaborate with lived experts
5. Power, Ethics, and Boundaries
6. Future of Lived Experience

Mentimeter

What is your role?

What does lived experience mean to you?

One word that describes your philosophy for your work?

Biography

What is Lived Experience?

The **knowledge, perspective**, and **understanding** that **develops** from personally experiencing a system, circumstance or challenge **overtime**. Unlike a past experience that can be placed in the past, lived experience can be **ongoing**. You continue to **navigate** its consequences, carry its lessons, encounter the **systems** connected to it, and make **meaning** from what you have experienced.

Small Group Discussion

You are a client-oriented attorney for a 17 year old placed in a group home. During your visit your client shares their concerns:

- Your client is not allowed to go to school and instead given packet work
- The group home forces your client to see a psychiatrist who does not listen to their medical needs
- The group home escalates incidents to law enforcement vs handling them internally. Which leads to your client being arrested and charged

How to collaborate with Lived Experts?

- **Invite lived-experience partners early** — before policies, programs, or processes are finalized.
- **Co-design solutions** — ask, “What would have made this process work better for you?”
- **Include them in training** — compensate parents/youth to help train professionals.
- **Build feedback into the process** — create regular, safe opportunities for families to give input.
- **Partner on system improvement** — involve people with lived experience on committees, workgroups, and court improvement efforts.
- **Close the loop** — tell people what changed because of their input.

How to collaborate with Lived Experts?

Collaborate in the Moment

Instead of	Try
“Why didn't you complete the service?”	“What got in the way?”
“This is what you need to do.”	“What would make this plan realistic?”
“The caseworker says…”	“How do you experience what is happening?”
“Do you understand?”	“Can you tell me what you understand the next steps to be?”
“We already tried that.”	“What would need to be different for it to work?”

Power, Ethics, Boundaries

Meaningful collaboration requires shared power, clear boundaries, and respect.

Recognize expertise: People define the value of their own lived experience.

Address power differences: Professionals hold institutional authority; lived-experience partners may not.

Avoid tokenism: Don’t invite someone simply to “check a box.”

Compensate and recognize: Lived expertise is work and should be valued appropriately.

Protect consent and confidentiality: Be clear about what participation involves and how information will be used.

Honor emotional boundaries: Don’t require people to repeatedly share painful experiences.

Power, Ethics, Boundaries

BEFORE

Explain the purpose and person's role

Discuss consent, confidentiality, and boundaries

Agree on compensation and expectations

AFTER

Explain what happened with their input

Give credit and recognition

Show what changed because they participated

DURING

Share power and decision-making

Ask for expertise—not trauma

Respect “no” and different perspectives

Future of Lived Experience

Moving from “doing things to people” → “doing things with people.”

Shared decision-making: Lived-experience experts have a meaningful role in decisions.

Co-production: Design research, services, and policies with the people affected.

Redefining expertise: Professional knowledge and lived experience are complementary.

Train together: Professionals learn alongside people with lived experience.

New ways to share experience: Technology can expand opportunities for participation while protecting privacy and choice.

Participatory research: People with lived experience help shape the questions, methods, interpretation, and outcomes.

Questions?

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