

Key Stakeholders:

People with Lived Experience



Familiar Faces Initiative is a project of the National Association of Counties that seeks better outcomes and lower incarceration rates for individuals who frequently cycle through jails, homeless shelters, emergency departments and other local services. This brief is one in a series outlining different roles and duties in establishing and maintaining FFI in communities as outlined in the <u>Data Driven Justice Playbook</u>.

This document is for PEOPLE WITH LIVED EXPERIENCE who want to identify ways to be involved in planning or developing a coordinated behavioral health continuum of care in their community. It is also for STAKEHOLDERS of local Familiar Faces Initiatives who want to include people with lived experience in policy planning and development. People with lived experience can include people with mental health conditions as well as family members, friends, loved ones or anyone impacted by mental illness. Most importantly, people with lived experience (also referred to as peers) are individuals who have experience navigating systems to access mental health services and support. They play a key role in developing efficient systems and are fundamental to any mental health systems changes. Below are some ways that people with lived experience can support a community's FFI efforts.

BUILDING STAKEHOLDER CONSENSUS

PEOPLE WITH LIVED EXPERIENCE AND PEERS

Your experiences and relationships can play a key role in developing or furthering FFI efforts in your community. Key activities could include:

- Participate in stakeholder groups implementing data-sharing initiatives.
- Help identify other active initiatives in your community that could help further the goals of a data-sharing efforts.
- Identify and help recruit missing stakeholders to help build consensus within your community.

FOR STAKEHOLDERS

Seeking and including the perspectives of people with lived experience will not only help you identify and effectively implement best practices, but also build goodwill for your FFI efforts with the broader community. Key activities could include:

- Include people with lived experience as members of your core stakeholder group in a meaningful capacity.
- Consult with a variety of mental health advocacy organizations to ensure you are incorporating a wide array of perspectives.
- Engage people with lived experience to provide feedback on plans and policies for your initiative.



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UNDERSTAND THE PEOPLE YOU HOPE TO SERVE

PEOPLE WITH LIVED EXPERIENCE AND PEERS

Sharing your story can contribute valuable information to local stakeholders to improve their understanding of the impact potential policy and practices could have on the people they hope to serve. Key activities could include:

- Share your story to FFI stakeholder groups to help them better understand the human impact behind the data. Talk about how mental illness and the mental health services system has affected your life.
- Suggested discussion points: What has been challenging? What has been helpful?
 What changes would you like to see in your community?
- Offer to organize a listening session with other people with lived experience to help inform the work of stakeholders.

FOR STAKEHOLDERS

People with lived experience have personally navigated the mental health system and can offer a wealth of experience and knowledge that can enhance your work. Ensure you are engaging a variety of perspectives. Key activities could include:

- Identify key organizations that represent the community, such as churches, mental health advocacy organizations (e.g., NAMI), veterans' groups or local civil rights organizations. Many of these can connect you to people who can share their lived experience.
- Incorporate opportunities for people with lived experience to provide feedback on your developing goals and plans.
- Include opportunities for people with lived experience to share ongoing feedback to better understand how your efforts are addressing community needs.
- Ask peers and other people with lived experience to present their story and/or experiences at educational opportunities such as trainings and conferences for stakeholders, and value their time.



ESTABLISH A FRAMEWORK FOR DATA GOVERNANCE

PEOPLE WITH LIVED EXPERIENCE AND PEERS

If an integrated health and justice initiative already exists in your community, learn about the framework that has been established for data governance.

Ask questions to the stakeholder groups so you understand how data are being used and who has access to it. Once you are ready to offer your support you can:

- Share your experience with agencies that might be reluctant to participate in data-sharing protocols by discussing the challenges of navigating multiple systems to receive services.
- Offer to write letters of support for inter-agency coordination noting how it could reduce barriers to effective care.
- Present at board meetings to bring attention to areas that need improvement.

FOR STAKEHOLDERS

Sharing data across systems can raise many concerns for people with lived experience; it's important to engage them in the process for developing standards and norms for data governance. Key activities could include:

- Learn what concerns people with lived experience might have with information being shared between systems.
- Incorporate people with lived experience into the development and review process for data governance. This builds reciprocal trust and understanding.
- Work with people with lived experience to create materials that promote awareness throughout the broader community.

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CONDUCT A RESOURCE SCAN AND IDENTIFY GAPS IN SERVICES AND TREATMENT

PEOPLE WITH LIVED EXPERIENCE AND PEERS

Participate in your community's systems mapping exercise (e.g., Sequential Intercept Model (SIM) mapping) to help identify availability and gaps in services, resources and processes. Key activities could include:

- Discuss your experiences working with multiple systems to access mental health care.
- Bring forward any innovative policies or services that have improved care and reduced incarceration for people with mental illness in other communities that you have learned of through other lived experience circles.

FOR STAKEHOLDERS

Ensure the inclusion of peers and people with lived experience within your county's Sequential Intercept Model (SIM) mapping exercise. Key activities could include:

- Ask people with lived experience to advise on practices related to each intercept.
- Use feedback provided by people with lived experience to improve system and service-level responses for people with mental illness.
- Create opportunities for a feedback loop, to regularly assess your efforts and whether it is meeting the needs of your community.



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BUILD CONTINUAL DATA USE AND INFORMATION SHARING INTO CROSS-SYSTEM ORGANIZATIONAL OPERATIONS AND POLICY DISCUSSIONS

PEOPLE WITH LIVED EXPERIENCE AND PEERS

Engaging in conversations and promoting public awareness is important to making changes to mental health services and systems. Your personal story, paired with the cross-systems data from your community's initiative, can be powerful to motivate the changes you want to see. Key activities could include:

- Contact your elected officials and ask to meet to discuss the community's needs and how your initiative addresses those needs.
 Incorporate cross-systems data into materials, talking points and other resources to help inform policy change.
- Offer to help stakeholders present at community meetings or events to educate the public about the intersection of mental health and the criminal justice system.

FOR STAKEHOLDERS

Continue incorporating the voices of people with lived experience in ongoing operations and policy discussions. Your initiative will benefit from their perspective as part of a continuous process of assessment and improvement. Key activities could include:

- Engage in continued evaluation of organizational operations impacted by the initiative's efforts. Request ongoing feedback from the people who are engaging in the services.
- Incorporate people with lived experience in any efforts to seek funding or policy change. Pairing their personal stories with data can help drive the change you want to see.
- Engage the stories of people with live experience who have benefited from these changes to help raise public awareness about the successes of your initiative. When engaging people with lived experience in events or media opportunities, support them with talking points or data about the effectiveness of the initiatives.

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The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI provides advocacy, education, support and public awareness.



NACo would like to thank Jessica Tornabene, Senior Manager of the Justice Diversion Task Force with NAMI for contributing this key stakeholder brief on people with lived experience. Ms. Tornabene can be reached at itornabene@nami.org.

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