

Engaging People with Lived Experience in System Change Co-Design: Membership Association Lessons Learned

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Rapid Engagement is a system transformation project with the goal of making it easier, faster and more user-friendly for people to get started with receiving outpatient behavioral health services. Rapid Engagement in Oregon was inspired by the Treat First model in New Mexico and is a trauma-informed and person-centered approach to behavioral health access. Throughout 2021, the Association of Oregon Community Mental Health Programs has been leading a multi-stakeholder planning process to design and launch a Rapid Engagement pilot in Oregon, with the support of a Robert Wood Johnson Foundation Delta Center grant and the Oregon Health Authority.

The focus of the Rapid Engagement pilot is improving the on-ramp for outpatient behavioral health services for members of the Oregon Health Plan. This pathway to access includes the critical pre-engagement services that are provided prior to formal intake and diagnosis, as well as the model for entry once a consumer has decided to engage with clinical care. Improving this pathway includes promoting better documentation and reimbursement for pre-engagement services and changing the clinical model, Oregon Administrative Rules, and billing practices relating to the intake process, so that provider organizations can focus on meeting people where they are and building relationships, instead of focusing on compliance and requirements.

In the current system, prior to billing for any other services, organizations must start with a comprehensive intake, assessment, and service planning visit, which can take two hours to complete. It is not until after this lengthy intake visit that a consumer is offered therapeutic services. The operational vision for Rapid Engagement is that provider organizations can start services with a brief intake and assessment encounter, wherein they provide an initial diagnosis, co-create an initial service plan, and start offering therapeutic services right away.

Using this initial diagnosis and service plan, the provider organization can then start delivering and billing for a range of services needed by the consumer, including peer support, case management, and medication management, as needed. The primary behavioral health clinician can then take up to 6 visits to build relationship, learn more about the consumer's experience and goals, complete a comprehensive assessment and treatment plan, and meet all the requirements stipulated by the Oregon Administrative Rules. In short, rather than front-loading paperwork, Rapid Engagement front-loads services.



We have been committed to engaging people with lived experience in co-design of Rapid Engagement since the beginning of the initiative. Despite our commitment, it has been difficult to both reach and sustain engagement with these important stakeholders. Although it has required multiple waves of effort and a variety of adaptive strategies, we have succeeded in getting the input of geographically and culturally diverse people in the development of this model. This document summarizes some of what we learned along the way.



1. Rely on members of the peer workforce in addition to consumers.

As a membership association, we do not have a direct line of communication with current consumers of behavioral health care. We do, however, partner with agencies who employ members of the peer workforce. Members of the peer workforce have a unique and rich perspective on the behavioral health system, informed both by their own experience, as well as the many people who they support in their professional roles. Members of the peer workforce have been easier for us to reach, are interested in contributing to system re-design, and are very well-informed about what meaningful change looks like for consumers.

2. Engage with existing groups instead of convening new ones.

As membership associations, we are several steps removed from the people receiving services, which poses a real challenge to engaging them as partners. The most successful strategy that we employed was to identify existing consumer advisory groups and to ask for time with their members. We had tried and failed for months to identify consumers who we could invite to the table as partners, and finally turned to our Coordinated Care Organizations (Oregon's version of Medicaid Accountable Care Organizations) to ask for their help. Coordinated Care Organizations (CCOs) are required by contract to host community and consumer advisory councils (CAC), and are staffed accordingly. Staff at four CCOs agreed to help connect us with members of their advisory councils, which include consumers who have already elected to be involved in system redesign and improvement efforts, and are accustomed to discussing these issues and their experiences. Asking for help from our CCO colleagues was by far our most fruitful outreach activity.

3. Build on existing and trusted relationships.

We found that not only was leveraging existing groups most successful, but that building on trusting relationships is also critical. For example, in one CCO region, we decided to host two focus groups, one in English and one in Spanish. We recruited for these two focus groups with a mass email invitation that was sent to all of the CACs in that region; the emails contained the same message, both written in plain language English and translated into Spanish by an interpreter. While we had good turnout for the English focus group, we did not have anyone show up for the Spanish group, despite having affirmative RSVPs from a few people. We followed up by asking the interpreter to assist us in sending outreach emails to that small group, and were ultimately able to conduct an interview with one of them.

Our other success story in engaging Spanish-speaking people with lived experience was through partnership with a culturally-specific service provider. They were able to bring together members of their community to provide input in a small focus group. In that conversation, they reinforced that to reach their community, partnering with a trusted community member or ambassador will yield much better results.

4. Expect people to step in and out of participation and learn as much as you can while they are there.

Although we have been trying throughout the year to engage people with lived experience in co-design, our results have been uneven. Rather than lamenting the lack of consistency, we have decided to operate with a catch-as-catch-can mentality. We take whatever input we can get, at whatever time people are available to give it. We have had really valuable insights



shared by people who have only engaged with us at one timepoint, and a small number of people who have been available to participate repeatedly over time. Regardless of what they are available for, we are grateful for any time that people can spare for us.

5. Expect lower yield from outreach efforts. Don't give up! But do plan for the additional time and effort it will take to engage people.

Our outreach efforts have included recruiting both members of the peer workforce and consumers. Although we have had quite a few peers who were interested in contributing to our efforts to re-design behavioral health outpatient access, we have repeatedly come up against their competing priorities. For example, peers might join a workgroup call, only to receive word that someone at the local jail needs their support, or there is a person in crisis down the hall, or a family that needs them in that moment. Although peers describe their own experience as a source of motivation to contribute to system re-design, they are also clear about their priorities. Their job is to serve clients and families, and we have had multiple occasions where members of the peer workforce come to a meeting, only to leave suddenly because a client needs them elsewhere. We have continued to invite peers to our workgroup meetings and have also held one-off peer focus groups that were devoted to getting their input and that dedicated time has been very productive.

6. Acknowledge power differentials and create trauma-informed and accessible conversations.

Although we recognize that having people with lived experience at the table for every step of a planning and implementation process is the gold standard, we found it very challenging to bring peers, consumers, and organizational leaders into the same conversation. In order to advance this type of system re-design, it is critical to get into the weeds of the technical details, ranging from staffing models, billing codes, and documentation systems, to Administrative Rules, Centers for Medicaid and Medicare Services policies, and CCO metrics. Some of the peers who attended these meetings reported feeling alienated by this type of discussion and intimidated by the power differentials among the people in the group. For those people, it ultimately worked better for them to have a separate conversation that was dedicated to discussing the issues most relevant to them, and avoiding the jargon and technicalities that are not pertinent to their roles. For others, they have enjoyed attending the workgroup meetings, regardless of the technical focus. We have been glad to offer both options and support people to participate according to their preference.

For the focus groups we conducted with consumers, we were careful to design our approach using the principles of trauma-informed practice and health literacy, including putting our explanations and questions into plain language, maintaining transparency, and communicating autonomy support relating to self-disclosures and participation.

Final Thoughts

Bringing a pragmatic and adaptive mindset to our consumer engagement efforts enabled us to gather input from a broad range of people with lived experience, and to use their input to shape our planning and implementation practices. We are confident that the goals and operational vision for Rapid Engagement are aligned with consumer priorities relating to decreased wait times, reduced barriers to getting started, and greater continuity of experience. We are also realistic about the challenges facing the public behavioral health system, and we recognize that Rapid Engagement alone will not address all consumer and workforce concerns.



With many thanks to the consumers, peers, and leaders with lived experience who shared their insights, we want to call out the following organizations for their partnership:

- Willamette Health Council Marion and Polk Counties
- Central Oregon Health Council Deschutes, Jefferson, and Crook Counties
- Eastern Oregon Coordinated Care Organization Baker, Gilliam, Grant, Harney, Lake, Malheur, Morrow, Sherman, Umatilla, Union, Wallowa and Wheeler Counties
- Deschutes County Behavioral Health Deschutes County
- Center for Human Development Union County
- Puentes (culturally-specific program at Central City Concern providing mental health and substance use disorder services to the Latinx community) – Portland Metro Area
- Flip the Script (culturally-specific program at Central City Concern, which supports formerly incarcerated African Americans as they exit Oregon prisons – Portland Metro Area



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