

CBHL Member Roundtable: The Role of Families and Relationships

(March 23, 2023)

Roundtable Summary

At our February 2023 Member Roundtable, [Deconstructing Non-Compliance and Exploring a Counterargument to Forced Treatment](#), the role of families and/or close relationships was raised as important to avoiding the conflation of public health with public safety issues. The deep divide around these important issues seem to preempt potential collaboration that could strengthen wanted and needed change.

For our March Roundtable, we continued this thread of conversation and further explored areas of alignment where people or places have concerns about mental health or public safety, opportunities to bridge the gap, and the idea that investing in families and relationships throughout recovery is essential to keeping people out of forced situations.

The Roundtable centered around these areas of discussion:

- Where can families, consumers, and advocates join forces?
- Where can families be enlisted to support the goals of consumer movements?
- How do we reach a broader audience (legislators) with this message?

**If you missed the February Roundtable, we encourage you to view the [summary](#).*

Where can families, consumers, and advocates join forces?

- Opportunities to build coalitions with families around the issues that we agree on
 - Dignity and respect are shared desires among consumers, advocates, and families
 - It is clear there are a number of things these groups disagree on – let’s acknowledge that this is real and exists, but there are so many things we can talk about that we share (e.g., opposition to criminalization of mental health challenges, unneeded hospitalization, seclusion and restraint, and hospital beds vs. community-based services)
- Families should not be the substitute voice for their relative – everyone has their own voice and there should be nothing about us without us, but families can be enlisted to support peers and opportunities for independence with dignity
- There are areas that can be used to become part of coalition building:
 - Housing

- Jobs (including peer service jobs)
- Self-direction
- 988
- Disability rights
- Self-direction
 - When a person in recovery has the ability to choose services that work for them, this could reduce the burden on the family of having to fill the role of choosing or providing services

How to reach a broader audience, including legislators

- This is a political issue
 - Part of what we should be doing is activating political networks around voting, lobbying, advocating, etc.
- Relation to other social issues
 - Some of our issues can be tucked into other social issues that can seem invisible - should not lose sight of other areas that could provide opportunities for insertion of our needs into something broader
- These are also local issues
 - How to organize locally so that each of our concerns is brought to the appropriate body that is going to be making decisions
 - Consider this for how to lobby effectively
- Biden budget - FY24 Budget Proposals will promote many of the services that are lacking or insufficient
 - *See [Biden Administration's FY24 Budget Proposal Reaffirms Urgency of Addressing Nation's Behavioral Health Needs – March 2023](#)

Exploring alternatives

- Need more focus on strategy and research for alternative models
 - Alternatives to having to rely on calling 911 (e.g., 988)
 - Peer-operated or peer-designed respite services
 - School-based services
- Community-based models
 - Having community-based treatment available in the immediate is critical
 - Could have community-based relationship building opportunities before we get to more down-stream interventions
 - Consider community defined practices vs. evidence based, especially for communities of color
- Collaboration among programs
 - How to “unsilo” programs
- Effectiveness of services

- There need to be effective, positive places for people to go in crisis that resolve the crisis rather than further damage
- Use of coercion is a signal that the system has failed
- Underperforming behavioral health system has forced resolution by way of crisis (need to create mobility – meet people before they are in crisis)
 - Think about crisis - particularly crisis that results in involuntary treatment - as a negative outcome of an underperforming system
 - Crises will never be completely eliminated, but theoretically: in a full and robust community-based system with high-quality and culturally responsive services that people want and value, the need for crisis services and particularly coercive services would be kept to a minimum. We're nowhere near that.

Other Areas of Discussion

Medicaid and Self-Direction

- There has been an expansion in the ways in which States can use Medicaid to pay caregivers
 - Expanding Medicaid to make these services available
 - Regarding Medicaid - there's some wonderful advocacy happening around Medicaid Home and Community-Based Services (HCBS) least restrictive settings and person-centered planning. Because Medicaid HCBS is only a small part of behavioral health budgets, it hasn't been on the radar of advocacy in our space. BUT the values and purpose of the work are well-aligned, and many behavioral health services are funded through Medicaid HCBS (see <https://hcbsadvocacy.org/>)
- The availability of self-directed services is restricted to HCBS services, which are often only available for people who have been determined disabled
 - This bridge between independence and dependence on the family is the challenge
 - How to help individuals develop an understanding of their capabilities for independence – needs a set of services that we are not well equipped as a system to provide
 - How we promote resources for life-building opportunities

Resources

Past CBHL Roundtable Summaries and/or Recordings:

- [Deconstructing Non-Compliance and Exploring a Counterargument to Forced Treatment](#) - February 2023
- [The Intersection of Poverty, Lived Experience, and Mental Health](#) - January 2023
- [Roundtable: Mental Health Reform and the Recovery \(R\)Evolution](#) - January 2023

Peer Respite:

- Peer respite research repository: <https://livelearninc.net/peer-respites>

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- [The Effectiveness of a Peer-Staffed Crisis Respite Program as an Alternative to Hospitalization.](#) *Psychiatric services* (Washington, D.C.), 69(10), 1069–1074.
 - [Experiences of Parachute NYC: An Integration of Open Dialogue and Intentional Peer Support.](#) *Community Mental Health Journal*, 56(6), 1033–1043.

Other:

- [Biden Administration's FY24 Budget Proposal Reaffirms Urgency of Addressing Nation's Behavioral Health Needs](#) – March 2023
- [Beliefs of Psychiatric Nurses about Schizophrenia: A Comparison with Patients' Relatives and Psychiatrists](#) - January 2005, *International Journal of Social Psychiatry* 50(4):319-30
- [A Multicenter Italian Study of Patients' Relatives' Beliefs About Schizophrenia](#) - December 2001, *Psychiatric services* (Washington, D.C.) 52(11):1528-30
- Mark Ragins, *Journeys Beyond the Frontier: A rebellious guide to psychosis and other extraordinary experiences* (2021). Available on [Amazon](#).