Reflections on Implementation of Human Rights-Based Practices in Community Mental Health Service Systems.

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In June 2021 The World Health Organization (WHO) introduced their Quality Rights framework for guiding mental health service systems from a human rights perspective. The Quality Rights framework was developed in alignment with the UN's Convention of the Rights of People with Disabilities (CRPD) (WHO, 2021). The framework integrates key themes from the CRPD including respect for legal capacity, non-coercive practices, participation, and community inclusion with principles of recovery as described in the "CHIME" framework (Connectedness, Hope and Optimism, Identity, Meaning and Purpose, and Empowerment). The WHO Quality Rights material offers examples of practices that exemplify these principles from across the globe. Our agency, The Counseling Service of Addison County (CSAC) in state of Vermont in the US, had been already focusing on some of the practices described in the Quality Rights guidance. The work of the WHO has served as a further source of validation and of guiding systemic principles to help map our work of system transformation going forward. This paper offers updates from our efforts, with discussion of successes and challenges in hopes our experiences can be helpful to other programs working towards similar ways forward.

Based on the experiences described here it is our view that rights based practices are also highly effective practices, and that for these practices to become further established in our community service systems there needs to be multi- level advocacy and support, as well as a resetting of guiding principles for service system planning that shift from solely a bio-medical paradigm to a more holistic and contextualized understanding of mental health distress and mental well-being as reflected in the Quality Rights framework.

About CSAC

The Counseling Service of Addison County (CSAC) is a private non-profit community mental health agency serving the rural area of Addison County, Vermont as the state "Designated Agency" for the region. We have had some unique circumstances that have enabled us to pilot approaches that are otherwise not well established in community mental health.

Vermont as a state compares favorably in the US for public mental health funding, and that has a long history of leading the way in progressive reform of mental health service models. The state is small enough that direct conversations and relationships with state planners and policy makers is the norm. CSAC as an agency is also small enough that while organized into several different departments it is relatively easy to network and collaborate around system planning working across departments. This is also true on the county level where inter-organizational collaboration is strong. We have been fortunate to have relative stability of staffing with many staff bringing decades of continuity, enabling a relationally based organizational stability conducive to the kinds of rethinking of service systems described in this paper.

Our adult mental health service systems grew substantially in the late 1980's when Vermont embarked on a proactive framework for deinstitutionalization called "Regionalization" where community resources and service systems were built up in advance of concerted efforts to reduce long term use of psychiatric institutions. The guiding values from this effort at planned deinstitutionalization have remained strong since that time.

It was also in the late 1980's that a family therapy team at CSAC made contact with Norwegian social psychiatrist Tom Andersen during a visit to the US. Andersen's publications about the work with "reflecting process" marked a major paradigm shift in family therapy from a more strategic expert based approach of formulation and strategic intervention to a more humbly transparent and collaborative process of engaging with families, with close attention to the language and meaning making used by the families that was responded to by a transparent and speculative process of "reflection" by the listening team (Andersen 1987; 1991). Andersen and colleagues continued with a series of visits for training and consultation at CSAC into the early 1990's.

Themes from Andersen's work as part of a broader relationship-based focus survived with us through difficult shifts in public funding for mental health during the late 1990's and early 2000's and were boosted by the emergence of the recovery paradigm that shifted the definitions of "recovery" from the objectified language of psychosocial rehabilitation to the subjective ownership of the individual regarding how "recovery" is defined (Deegan, 1988).

Open Dialogue

In August 2011 Tropical Storm Irene triggered flooding that forced the closure of the state psychiatric hospital. Progressive leadership from the state shifted funding into community programs with an unusual amount of flexibility of the funds and with encouragement to be creative in finding ways to increase community-based support and approaches that could reduce the need for the very scarce availability of hospital beds. It was in part this flexibility of funds that enabled CSAC and partner agencies, Howard Center (HC) and United Counseling Services (UCS) to consider the viability of implementation of Open Dialogue. At CSAC, some practitioners who had trained with Andersen were continuing with similar family work, which gave us a good base of expertise to begin to implement these closely related approaches.

Open Dialogue (which in Vermont we also refer to as "Collaborative Network Approach") offers approaches for meeting with families and other networks that open conversations for different understandings of the mental health crisis at hand, and for collaborative and transparent planning about what to do in response. It also offers guiding principles for organization of the service system - prioritizing responding quickly and flexibly, inviting network involvement, prioritizing relational continuity with the treatment team, and with the principle of tolerance of uncertainty - not rushing to impose clinical definitions or consequential interventions (Seikkula 2014; Olson 2014).

Early on in efforts with implementation the CSAC team began noting that systemic principles and practices for meeting with networks in sessions led to surprising results with clients, substantial positive impact for staff doing the work, and also catalyzed significant focus on the need for transformation of the service system we are part of. We also noted that we found ourselves working in much stronger alignment with long held recovery principles, working in ways that were more truly collaborative and person centered.

CSAC worked with UCS and HC as well as other programs regionally who had been evolving applications of Open Dialogue including Advocates Inc. from Framingham MA, and Project Parachute from NYC, and we developed a practice of meeting annually for "Regional Gatherings" modeled after the northern Europe based "International Network Meetings for the Treatment of Psychosis" where the primary proponents of Open Dialogue and reflecting practices had been meeting for many years prior. This kind of collective network support of our network-based practices has been critical in our efforts to keep moving forward despite the strong currents of the dominant systemic paradigms.

While Open Dialogue is available for most of our treatment populations and has widespread integration across our services systems, we are currently prioritizing applications of Open Dialogue with our Rapid Access project in an effort to offer dialogic network focus seeing people coming in for services for the first time - either through crisis referral or through general non acute self- referral. This project was inspired by

the recent work at UCS where their "FAST" program, offering Open Dialogue informed engagement at the first contact, has shown high efficacy at improving access and reducing the need for long term service engagement. We're also prioritizing availability of Open Dialogue for crisis response, including with our Interlude project, described below.

We have seen clinical efficacy through Open Dialogue with clients reporting feeling better heard and understood both by treatment staff and by others in their personal networks, with positive shifts in the shared understanding of meeting participants happening in most meetings. This has led to stronger treatment relationships and has supported personal networks in staying engaged in high stress times. We have seen countless times when hospitalizations have been averted, and when hospitalizations have occurred, network meetings have contributed to more productive hospitalizations and stronger discharge plans. Client agency in planning services has been strengthened by this highly collaborative and transparent approach to listening and planning (Florence, 2021). Staff have also described this as helping them to realign with the values and interests that brought them to this work, in effect a re-humanizing of practice (Florence, 2020; Smith, 2022). Challenges have included staffing for co-facilitation of meetings; that training can be time intensive; that our funding models don't support this; that clients may be hesitant about having network involvement; and that this way of working is outside of normative assumptions of what treatment looks like.

Our program has increasingly viewed isolation and disconnection as critical variables in determining levels of distress associated with mental health challenges that also can impact the duration and recurrence of those challenges. Open Dialogue decidedly prioritizes attention to all relationships involved with very careful listening and responding to the experiences and meaning making of clients coping with high levels of distress, and also strives to head off trajectories of mental health conditions and treatment that can result in longer term disruptions in relational connectedness and meaningful roles.

Community connectedness and meaningful roles

With this increasing focus on the impact of isolation and disconnection, our program determined that we needed to find new ways to foster interconnectedness between the people we have been responding to and their communities. We were especially inspired by the work of Dr. Alberto Fergusson, from Colombia, on fostering meaningful roles and community connectedness (Fergusson, 2016). Our consultation and collaborations with Fergusson led to the creation of our "Community Bridges" project designed to help create non-stigmatizing bi-directional pathways of connection within our communities. The format for planning these activities is through peer supported collaborative planning work groups. Community Bridges has brought music events and jewelry making workshops to senior facilities, orchestrated community art projects, the creation of "friendship benches", formed work groups to go out cleaning litter for Vermont's annual "Green Up Day", helped with community meal projects, substance free community holiday events, and World Make Music Day community jam events. During the more extremely isolative times of the pandemic Bridges members created online peer support groups, a book group, and online music sharing events and game nights.

More recently we also arranged two rounds of the Citizenship Program developed at Yale designed to offer curriculum and peer-based group support based on work on Rights, Relationships, Responsibility, (meaningful) Roles, and Resources (Ponce and Rowe, 2018). While participation is supported by a modest stipend we have seen broad success with meaningful engagement with the program deepening with participants as time went on. Notably we have seen this be effective with people experiencing marginalization who are not otherwise choosing to engage in mental health services, including people coping with the extreme life stress of being unhoused.

The efficacy of these projects is indicated by the deepening engagement of the participants and reduced isolation. Inclusion increases experiences of self-worth, personal agency, resulting to reduced effects of internalized stigma. These projects also support normalization of the experience of isolation as an issue

that is far larger in our culture than the impact of mental health conditions, a public health concern that has received much attention and media coverage, especially post- pandemic.

Challenges mostly have to do with the impact of stigma, both that which is overtly expressed and internalized stigma. Many of the people we have been working with for a long time have expressed valuing the experiences of helping in our communities together as a group, but then we have found it difficult to go further towards supporting the growth of individual connections and meaningful roles beyond the group activities. It is likely also a factor that our previous intensive community support approaches have produced a level of connection and support bolstered by staff presence that maybe gets in the way of the formation of new organic connections with people who we have worked with for a long time.

To further counter stigma in all its forms and cultivate more inclusive community dynamics we have determined we need to do more to cultivate bi- directional engagement in our communities we are serving. One way we are trying to get at this is through offering community education trainings including the Emotional CPR (eCPR) model developed by Dr. Dan Fisher together with other experts by experience based at the National Empowerment Center. eCPR offers training in responding to people having mental health crisis by using a normalizing framework for understanding and responding to emotional distress (Fisher, 2022).

Trieste framework/ Interlude Project

In our work with clients through Open Dialogue we became more vividly aware of the often traumatizing and relationally disruptive effects of involuntary hospitalization, a concern also being raised by colleagues attending the Regional Gatherings. This led us to inquiry into the work being done in Trieste, Italy where they have sustained the lowest recorded rates of involuntary admissions that can be found in developed countries. Our efforts were informed by their work on community inclusion and meaningful roles as supported by “social cooperatives” and “micro-area” projects where members reach out to support other community members in need. Their community mental health programs are designed to offer very low barrier 24/7 access with a welcoming and very intentionally non-institutional atmosphere, prioritizing open doors and transparency (Mezzina, 2014).

A work group of clients, family members and our staff met monthly for two years to develop ways to prevent involuntary hospitalization. Grant funds enabled us to launch the “Interlude“ project which draws upon peer support based with the Intentional Peer Support model, Open Dialogue, and offers a welcoming and comfortable space as also informed by the “Living Room” model embracing the theme of “hospitality” emphasized by Trieste practitioners (Shattell, 2014). While this project is still in the first year of full operation we have seen it help to avert hospitalizations and emergency room visits. Guests have commented that this is a resource that feels more comfortable to access during times of crisis: "Instead of calling crisis and going to the hospital, I can come here."; "I don't feel ashamed to talk about my experiences here. I feel like I am not alone finally."; "It's like my providers have given up on me, they've tried everything. But here I feel hopeful."; "I felt like I was being coerced into talking about my trauma in therapy. Here, I can talk about what I want to talk about."; "I am smiling inside because this is the first time my wife is talking to people who understand, who get it."

Beneficial outcomes include increased choice and agency, and the averting of traumatizing experiences of coercion. Person chosen engagement is strengthened by avoiding the trappings of setting and treatment dynamics that might heighten fears of things turning coercive, thus reducing the disruption of relationships and life engagement activities that often come as a side effect of psychiatric hospitalization. Barriers to accessing support are reduced by offering a space that we hope to be the kind of place people would want to go toward when experiencing mental distress and that would be the antithesis of a busy hospital emergency room. In a recent project report to the state, the project coordinator noted the physical and relational spaces created by Interlude and the team invites participants to “be with and move through their experience, instead of creating resistance to their healing by suppressing, numbing and rushing the process.” She goes on to note

that it is important to "highlight the power of connecting over lived experience and how this unwinds the helper/helpee dynamic, taking the shame out of these human experiences and redirecting us to trust and believe in ourselves" (Hodder, 2024).

Challenges include that this is a grant funded project, which enables flexibility, but it is not yet supported through long term funding. We are continuing work on how to co-respond to crises with other agency staff carrying different roles and responsibilities while also carrying the ethos of IPS and Open Dialogue. We are also working on getting the word out with better descriptions of what guests can anticipate from this alternative.

Conclusions

Human rights based practices are also clinically effective practices

Our program came to these approaches out of our intentions to seek better outcomes by developing more relationship oriented practices, prioritizing engagement, paying meaningful attention to person centeredness and personal agency, working with subjective experience and meaning making, reducing trauma by reducing and eliminating coercive approaches as much as we can. We also offer a range of more established treatment approaches (including those formally designated as "Evidence Based Practices") as well, but our clients aren't likely to benefit from those if we are failing them in our efforts at engagement and in offering trusting relationships. These approaches also align strongly with recovery principles as described by SAMHSA (hope, person-driven, many pathways, holistic, peer support, relational, culture, addresses trauma, strengths and responsibility, respect) and more recently and concisely by the CHIME framework (Connection, Hope, Identity, Meaning, Empowerment) (WHO 2021).

Some themes of clinical efficacy in human rights based practices we've identified include:

- Crisis as a key moment for engagement - Slowing things down and tolerating uncertainty as means to de-escalate crises and find alignment with the person in distress can help with finding useful meaning leading to well thought out and engaged crisis responses and allows for sufficient attention to contextual stressors that might be triggering and exacerbating factors - and often averts more coercive responses.
- Low barrier, trauma informed, engagement focused practices that work from a normalizing continuum help reduce durations of untreated conditions, including psychosis, and can increase treatment accessibility for marginalized populations.
- Taking into account the impact of systemic marginalization, social determinants broadens the range on contextual understandings of experiences of mental health distress which then can broaden the understood options for approaches to treatment and recovery.
- Prioritizing relational connectedness and meaningful community roles – combats stigma, bolsters personal agency and self-esteem, and reduces subjective experiences of distress associated with isolation and disconnection and can reduce long term reliance on service systems.
- Attention to subjective experience and personal meaning making both strengthens engagement and supports broader inquiry into person determined directions of recovery.
- By prioritizing focus on relationships, subjective experience, and contextual understandings of distress, these practices also help to re-humanize the experience for service providers which can then lead to better efficacy in their work.
- Focusing on personal agency and attention to power dynamics – service users are more likely to stay engaged with services they have chosen, with practitioners who listen carefully to and honor their preferences and concerns.

There can be many challenges

- Regional socio- economic, cultural, legal, and political issues can make a big difference in what is within reach and in how experiences and services are defined.
- These are not the organizing principles of most publically funded service systems and funding models –

In the US, public Medicaid funding emphasizes requirements that interfere with low barrier engagement and pull for overly medicalized definitions to support treatment.

- There is insufficient awareness of these alternative approaches and what they can do.
- The nature of our work is such that these are almost always complex situations where human rights can often conflict.
- With rights go responsibilities – There are very complex issues of values and laws around community accountability and safety that are beyond the scope of this paper to address. Fergusson notably speaks to being held accountable as also a "right" (Fergusson, 2016).

Strong systemic values, treatment philosophies, and guiding principles are needed to sustain these approaches

Trying to implement these practices in publically funded service systems in our context in the US is very difficult, with those funding structures that allow flexibility enbling the most progress. While recovery values and "person-centered care" are referenced by federal and state regulators, the funding structures are still highly medicalized in how eligibility for services are defined, prioritized, and paid for, fueling a persistent tension to medicalize and decontextualize care for mental health conditions. These challenges are not unique to the US, as noted by former UN Special Rapporteur, Dainius Puras, rights based services system transformation is hindered by obstacles of "dominance of the biomedical model", "power asymmetries", and "biased use of evidence in mental health" (Puras 2017).

It is striking to us the extent to which service systems like those in Trieste and Tornio (where Open Dialogue was developed) have strong guiding principles and values that bring together what can be known from the science with other values that notably also align with human rights based practice themes as described by the WHO. Both of these systems are also rooted with substantial philosophical guidance that help bolster the importance of themes like inter-subjectivity, dialogue, meaning making in the case of Tornio, and the viewing of deinstitutionalization in a much deeper context in Trieste where they speak of "whole systems, whole person, whole community" approach (WHO, 2021).

Meanwhile in the US things are moving in a different direction from a human rights perspective in some regions, with initiatives in New York City and in California to increase use of involuntary hospitalization as a means to deal with complex socio-economic issues associated with homelessness. Areas of progress with human rights-oriented systems changes here have been driven by the peer movement, increased attention to issues of systemic injustice and marginalization, and by work on service systems becoming more trauma informed.

The WHO Quality Rights paradigm offers such a framework

If our public mental health service systems were guided around the themes of "respect for legal capacity, non-coercive practices, participation, community inclusion, and the recovery values of "Connectedness, Hope and Optimism, Identity, Meaning and Purpose, and Empowerment" our funding models, oversight systems, and the kinds of conversations we would be having with service providers, service users, their families, communities and other stakeholders would be very different from the types of issues our structures prioritize now.

Without this systemic level of prioritization models such as those cited in the WHO guidance can quickly get swept away in the strong currents of the dominant biomedical paradigm, political factors driving funding structures, transitions in leadership and other staffing, and insufficient availability of research funding and shortsighted research frameworks. Of the WHO cited models, the long established Trieste system has been recently been under threat from the regional government. In Western Lapland, Finland changes in regional management of health care systems threatens the fabric of their long established network based practices. At the time of this writing, news has been posted that an Open Dialogue project in Ireland has just been

stopped despite an independent review suggesting these approaches need to be expanded (Mad In Ireland, 2024). There's also the notable example of Project Parachute in New York City that offered a combination of Open Dialogue, Intentional Peer Support, and an alternative crisis bed system was abruptly stopped in 2018 due to lack of systemic buy in (Hopper, 2020).

We need research models that also better reflect these kinds of systems priorities

To support these guiding principles we need research models that better capture their efficacy within the contexts where they are being applied. The research standards that are most likely to get funded and published, such as those used for evidence based practices, work against the promotion and sustenance of the kinds of systemic level models of care that are needed to better align with the human rights practice paradigm. In Tornio and Trieste the results they have seen are a product of systemic levels of response and are informed by the systemic evaluations of those responses. In Tornio it is the "naturalistic design" of their research together with longitudinal follow up that enabled the striking findings regarding long term outcomes of early episode psychosis (Seikkula, 2020). In Trieste, the relatively easily collected data point of involuntary admissions is a striking indicator of the successes of their service system.

To implement, sustain and build on the systemic scope of changes called for in the WHO's Quality Rights paradigm will require everything from a global level of momentum, to very local experiences of service users putting their voices to the need for better frameworks of care, community awareness efforts to help engage normalizing models of promotion of mental health and inclusion, and the collection of meaningful qualitative and quantitative data to help inform and sway policy makers.

Some of the standards in the CRPD and WHO framework set a very high bar. For example, zero coercion is something that no regional service system, including ours, has been able to achieve. But without this high aspirational goal from the WHO it is too easy for systems like ours to lapse into complacency and to be swayed by other external pressures that are not in the service of the rights and recovery needs of the people we are there to serve. The path of following the guidance of the Quality Rights framework shows much promise for re-humanizing of our systems of care in ways that prioritize the voices of service uses, attends to their close personal relationships, and supports meaningful community connectedness in the most effective and transparent, and least coercive ways possible.

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