Organized Efforts to Critique, Reshape or Transcend the Dominant "Mental Health" System

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A Discussion Paper on Gaps and Strategic Opportunities

prepared for the Woodshouse Foundation
by
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Introduction

A previous report prepared for the Woodshouse Foundation provided an overview of some of the main US-based organizations and people involved in activities that are part of a loosely affiliated "movement" that is critical of the dominant "mental health" system. Generally, these organizations and individuals were identified as those offering analyses and perspectives, conducting scientific research, providing supports, building alternative approaches, or advocating and litigating in relation to issues such as psychiatric patients' rights, the abolishment of forced psychiatry, non-drug approaches to dealing with distress or unusual inner experiences, psychiatric overdiagnosis and overdrugging, and psychiatric-pharmaceutical industry corruption.

This present discussion paper provides an analysis of gaps in this "movement" and suggestions for strategic opportunities for strengthening it. There is no quantitative or systematically gathered information; rather, this paper is based on qualitative interviews with twelve selected expert informants combined with some of the authors' own analyses. It is primarily intended to help inform the Foundation, but it is hoped that for others it may also prove to be a useful compilation and inspiration for further discussions or actions.

Respondents were invited to provide their personal insights into how both their own work and the critical movement as a whole could be strengthened. Although some of their affiliations are listed below to help identify them, all of the respondents were speaking personally and not on behalf of any particular organizations. The author and Woodshouse Foundation thank the following people for donating their time to be interviewed:

> Monica Cassani, Person with Lived Experience, former Social Worker, Editor/Author of *Beyond Meds*.
>
> David Cohen, Professor and Crump Chair in Social Welfare, School of Public Affairs, University of California–Los Angeles
>
> Haydée Cuza, Person with Lived Experience, Executive Director, Peers Envisioning & Engaging in Recovery Services
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> Sera Davidow, Person with Lived Experience, Executive Director, Western Massachusetts Recovery Learning Community
>
> Deron Drumm, Person with Lived Experience, Executive Director, Advocacy Unlimited and Toivo
>
> Cindi Fisher, Advocate and Director, Movement of Mothers and Others Standing Up Together
>
> Jim Gottstein, Person with Lived Experience, Executive Director, Law Project for Psychiatric Rights
>
> Anna Johnson, Policy Advocate - Psychotropic Medication Use with Foster Children, National Center for Youth Law

Bruce Levine, Psychologist, Author

Jennifer Mathis, Deputy Legal Director and Director of Programs, Bazelon Center for Mental Health Law

Laura-Nicole Sisson, Person with Lived Experience, Development & Communications Associate, Pathways Vermont

And one respondent who requested anonymity.

Additional thanks go to the many other people who have contributed to or influenced the content of this report through private conversations with the author or through their public presentations or published writings.

About Terms and Areas of Focus

There are challenges in identifying the "correct" terms to use in a paper of this kind. Even as the main subject area is defined in a certain critical relationship to the dominant "mental health" system, and all of the respondents defined much of their own work in relation to that system, at the same time all of the respondents also expressed significant concerns about the entire concept of "mental health" and advocated for thinking and taking action outside of the limited frames of reference circumscribed by that concept and indeed entirely outside what we know as "the mental health system." In that context, then, the terms used in this paper also at times exist in varying relationships to conventional mental health terms – and at other times directly question or challenge those terms.

All respondents felt that there are multiple "fronts" that need attention in the effort to change how our society deals with "mental health" issues. These main areas of engagement roughly include the following:

- public education
- political advocacy
- support groups
- services provision
- psychiatric drug withdrawal resources
- alternative approaches
- legal advocacy and strategic litigation
- networking and organizing

Consequently, these are the main topic areas that were explored in the interviews. Though obviously important as well, the advancement of critical scientific research in the fields of psychiatry and psychology were for the most part not discussed for this paper.

Uniting the “Movement(s)”

There are a number of widely acknowledged issues and tensions that often make collaborations within the critical “mental health” movement challenging – indeed, none of the respondents even identified the critical movement as a movement as such, but rather as a plurality of often struggling, fractured “movements.”

One division is between people who identify as “consumers,” or relatively agreeable users of the mainstream mental health system, and those who identify as “survivors” of that system. There are common issues of concern for which both groups often advocate such as access to therapeutic options and choices. However, survivor groups are, for example, much more likely to criticize the scientific foundations of psychiatry and to believe many psychiatric treatments and the use of force cause more harm than good. Similarly, consumers are more likely to focus on improvements and reforms to the system, while survivors are more likely to be interested in abolishing or transcending the system altogether. Those differences can create substantive divides. Some groups are increasingly adopting the term “person with lived experience” to unify those who identify as having had significant experiences of trauma, suffering or oppression in their lives. Regardless, the co-opting of “peer support” going on right now highlights some of the challenges of negotiating such terms and differences in shifting political climates, suggested Sera Davidow. Peer support as conceptualized by governments, mainstream mental health agencies, and the consumer movement becomes little more than a friendly, one-on-one exchange of similar personal stories instead of a system-change effort, explained Davidow, when peer support is purged of its broader historical-political roots and anti-oppression social-change impetus.

Many respondents stated that another key “dividing line” separates people and organizations that are completely against the use of any psychiatric force or involuntary treatment, and those who are not. This creates additional difficulties forging alliances with well-meaning or critically-minded practitioners, since many – particularly psychiatrists – are not completely against any and all uses of force. Family members of people who have been patients in the mental health system also often do not see eye to eye with their own loved ones on involuntary treatment and related issues.

Collaborating or working within the dominant mental health system creates even bigger challenges. Organizations in the critical movement are usually required to compromise or silence some of their key beliefs about issues such as the validity of psychiatric diagnoses or the use of force as part of these working relationships, to the point where some respondents questioned whether meaningful collaboration with the existing dominant system is even possible. And even if some organizations and agencies within the dominant system accept certain alternative approaches as “complementary,” mainstream agencies may still regard these approaches as “competition” and a “threat” to their own funding.

There are also sometimes tensions between survivors and “allies” – people who share many of the same values and goals as survivors, but are not themselves survivors. While appreciative of allies’ efforts, some survivor-respondents noted that many ally-leaders in the movement have higher public profiles and are more likely to be financially compensated for their efforts than survivor-leaders, and compared the situation to men leading a women’s rights movement. In addition, survivors may be invited in, but can end up playing “token” roles within ally-run organizations. From the other side, some “allies” may not conceive of themselves as allies per se, but simply as people with their own reasons for taking critical approaches to the dominant mental health system, and so in certain contexts may not even share these particular concerns.

All of these difficulties in forging alliances are an important part of why this movement is as fragmented and struggling as it is.

Several respondents, especially Cindi Fisher, suggested that a beginning step towards better strategic alliances would be to formally organize story sharing. Inspired by ideas from restorative justice and "truth and reconciliation" processes, Fisher advocated for events where all of the many diverse people on all sides of these "mental health" issues would be invited to come together to share and listen to each others' stories and "love each other back to wholeness." Fisher also felt that such a process could help everyone come to better understandings together about the broader, deeper issues affecting our communities that have helped create the dominant mental health system. This, in turn, could lead to better strategic solutions for moving forward.

For organizing purposes, most of the respondents suggested that being against the use of force should be used as the dividing line that best defined "the movement" under discussion in this paper. They argued that making that clear from the outset of trying to build alliances would be a better approach that was less prone to internal fragmentation over the long term than simply trying to unite people under fuzzy visions of "improving the mental health system."

Davidow of Western Massachusetts Recovery Learning Community identified a number of key factors that she thought can make collaborations with the mainstream mental health system potentially fruitful, including the ability and willingness of WMRLC to boldly put forth alternative approaches and even to ultimately forgo funding opportunities if too much compromise on basic principles was being asked of WMRLC.

Specific recommendations that emerged:

- Organize small and large-scale "truth and reconciliation" story-sharing events among people who've been involved with the "mental health" system in different ways, and work to ultimately compile a report with recommendations.
- Build alliances and organizations based on a very clear set of principles – particularly with taking a stand against involuntary treatment as a foundational principle – and be willing to let go of support or funding opportunities to protect these principles.
- Build alliances with progressive-minded "consumers" or practitioners only for specific strategic opportunities where the common goals are obvious, and otherwise do not become preoccupied with them as potential allies.
- Ensure that ally-run organizations – if they purport to be allied organizations – include meaningful decision-making participation and equal compensation for people with lived experience at every level of activity.
- Conduct outreach, education and organizing support to family members of people who have been labeled with psychiatric conditions. (See also "Organizing Families" below.)
- Focus more attention outwards, on building collaborations with people and organizations working outside any "mental health" framework at all. (See also "Cross-sectoral Collaboration" below.)

Leadership

Many of the respondents raised the topic of leadership. All felt strongly that there should be more survivor-led initiatives, and that in particular there should be a nationally prominent organization and voice for survivors/people with lived experience. They also felt that, overall, allies and survivors could be more effectively united. However, many also pointed out that various attempts at creating national groups of these kinds have come and gone, or are currently trying but not succeeding in bringing people together.

So what are the most important qualities of leaders who might be able to bring enough people together to have meaningful impacts?

Some respondents suggested that this question itself highlighted a key leadership quality: The willingness to engage in frequent critical self-reflection about what kind of leadership and roles are needed to help build this movement. Other qualities often pointed to included a capacity to have a clear set of principles and act on those, as well as an ability to be "a vehicle" or "humble" facilitator in helping gather and empower others. In this light, Sera Davidow described some of the efforts WMRLC puts in when developing its organizational leaders. When hiring, Davidow said that they are careful to look not only for an openminded welcoming of diversity and desire to support and encourage others, but for a "spark of anger" and "willingness to speak out on social justice." And WMRLC's training covers the history of the psychiatric rights movement and critical perspectives on the mental health system.

A number of respondents pointed to the fact that many people in the movement have experienced trauma or abuse – either in their personal lives or in the mental health system or both – which can sometimes heighten the interpersonal conflicts that are not uncommon in grassroots organizing of any kind. Deron Drumm said that organizations and leaders could benefit from being more mindful of maintaining a balance between outward political activism and inner self-care and nurturing, and between social protest and community building. Drumm further suggested that the movement may always need two very different kinds of leaders and organizations: Those who are strong in standing up to the dominant system and criticizing it, and those who are better at forging compromises and collaborations and building community. Monica Cassani echoed some of these sentiments, suggesting that different kinds of leaders and approaches are needed for different kinds of situations and scenarios, and that this serves to remind everyone that the movement must be "interdisciplinary" and "holistic."

Specific recommendations that emerged:

- Share more information about leadership challenges and solutions between existing movement groups.
- Expand training for movement leadership, and attempt to embody that training in a manual or guide.

Funding, Expertise and Volunteer Engagement

There are at least hundreds of billions of dollars annually flowing through the dominant psychiatric, psychological and pharmaceutical industries in the US. A 2015 Congressional Research Service report, “The Mental Health Workforce,” for example, estimated that about $25 billion annually goes to mental health clinician salaries – let alone the costs of psychiatric hospitals, psychiatric drugs, non-profit organizations, mental health services provided by family physicians and general hospital emergency departments etc. Conversely, respondents noted how many “organizations” within the critical movement are essentially being driven by one to several energetic people with little or no assistance.

Often, when organizations do get funding and become larger – especially if the funding comes from government – there are strings attached that force compromises that seriously undermine the original principles, values and intent of the organization. Indeed, most of the larger organizations tangentially connected to the critical movement were criticized by the respondents for making such compromises. The chronic low funding also causes people, even as they become more skilled through experience with smaller organizations, to leave for these larger organizations or into the mainstream system simply because they need or want to earn better salaries. The lack of consistent funding has hampered the development and maintaining of different types of professional expertise throughout the movement. In the absence of any foreseeable significant change, Laura-Nicole Sisson suggested that it could be beneficial for an appropriately funded organization to provide skills development training and consulting services to less established groups in fields such as legal advocacy, volunteer engagement, administration, accounting etc. Another approach could be the development of an expert volunteer pool.

And many people not only don’t get funding for critical mental health work, but by speaking out in this controversial field actually put at risk the funding that they do get for other work activities. Becoming a high-profile and successful psychiatric rights activist is a high-risk proposition; it rarely improves funding or career opportunities. Indeed, Monica Cassani spoke to a particular challenge that several other respondents also raised: Increasing prominence in the field often does not translate into any forms of increasing financial compensation, yet it does generate growing numbers of people reaching out for connection and support of different kinds. The need is deep and widespread, explained Cassani, and there are few truly alternative or critical spaces online or in communities for people to turn to. This difficult, untenable situation can eventually cause prominent people to retreat altogether from public view or activism due to emotional overwhelm and exhaustion.

At the same time, there has been a trend among virtually all major funders in recent years away from funding ongoing operational costs of organizations, and towards project-by-project funding. There has also been a shift away from funding administration, education, long-term advocacy and system-change initiatives, and towards direct, day-to-day support services and measurable outcomes. This shift has been affecting non-profit organizations in all fields, and no less in this one. Many respondents – even those involved with organizations with significant budgets – complained about a severe dearth of funding for longer-term systemic-level education, advocacy and networking, which generally don’t produce the same kinds of immediate, tangible, measurable outcomes as support services.

Anna Johnson said that the National Center for Youth Law historically received government funding, but the organization was eventually informed that it could not protest any policies or laws of government in order to continue to receive that funding. So the NCYL took a different approach. Johnson explained that, for example, along with its other funding sources, the NCYL has received funding from endowments set up to disperse money from lawsuit settlements involving the pharmaceutical industry. In addition, NCYL engages in collaborative initiatives where private law firms receive tax breaks for providing pro bono legal services to the NCYL as it is pursuing a lawsuit.

Specific recommendations that emerged:

- Conduct research to identify more funding opportunities.
- Conduct better qualitative and quantitative evaluations and enhance the gathering and sharing of studies and data to help present evidence to governments and to other funders that are in favor of alternative approaches. (See also "Information Gathering and Sharing" below.)
- Identify more ways in which people contacting prominent leaders can be channeled into volunteer support and engagement opportunities.
- Develop more innovative strategies for collaborative projects between organizations that involve resource and expertise sharing.
- Following the model of volunteer service organizations, develop a searchable list of subject-area experts who can provide guidance, consulting, support or services. (See also "Information Gathering and Sharing" below.)
- Work to help a funder understand the importance of supporting longer-term systemic activism, especially networking, in the critical mental health movement. (See also "National Network and Strategic Operations Center" below.)
- Develop a pooled way to resource or fund skills development training and consulting services in fields such as legal advocacy, volunteer engagement, administration, accounting etc.
- Develop or identify non-profit organizations that can be a conduit for funding opportunities for groups or individuals that are not non-profits. (See also "National Network and Strategic Operations Center" below.)

Information Gathering and Sharing

The critical movement is comprised of many small and fragmented groups; many respondents suggested that a national organization is needed to serve as a clearing house for information about what critical, alternative groups and organizations exist, what innovative programs are going on, what legislative initiatives are emerging, and who is having success doing what and how.

Sera Davidow said that, with such small programs as her own organization is often running in Western Massachusetts, it is difficult to measure their impacts relative to the mainstream mental health system. Across the country in California, Haydée Cuza described how small programs are frequently being initiated and then getting their funding cut even when they are successful. She asked where the data is currently going after such programs are lost.

Laura-Nicole Sisson, who does program evaluations as part of her work, specifically identified program evaluation itself as a significant gap in this field. Good data and evaluations, Sisson pointed out, are tremendously important to funders and legislators alike, but there is a general lack of information about the alternative approaches that are going on and the outcomes that are being achieved around the country. Along with that, to the extent that data is being generated regionally, it is not being gathered and shared in any readily accessible place nationally.

Specific recommendations that emerged:

- Provide funds, technical assistance, and/or consulting support to help with independent program evaluations of alternative approaches.
- Support the development of a centralized online location for sharing up-to-date data from program evaluations. Proposals, contacts, tips, expert consultants, and other information that would help organizations initiate similar projects in different jurisdictions could also be shared.

Public Education

All of the respondents acknowledged that it is important to educate the general public both about alternatives that work, and about the negatives of the current dominant system. However, a sense of isolation and a feeling of not having a substantial public voice is endemic throughout the movement. Several respondents expressed that survivors need a broader platform to reach beyond each other to the general public, and overall the movement needs to design a progressive policy and legal framework that starts from abolishing force and coercion in mental health services but expands beyond that and speaks to the broader public.

Many respondents felt that it was too difficult to gain access to the kind of platforms necessary to counter the immense and expansive power and influence of the pharmaceutical industry and mainstream mental health system. Instead, they suggested more focused educational outreach to more accessible audiences such as schools and colleges or organizations working on civil rights issues. At the same time, some felt that as much as the content of critical messages needs to be better crafted, so too must the tone, style and manner in which the messages are delivered be better crafted, so that the broader public becomes willing to listen and finds the arguments persuasive. Many respondents spoke about the need for psychiatric rights issues to be expressed through popular art or other, more creative means. However, some countered that these do exist already, but in the absence of an overall strategy of public education going on they do not and cannot have much impact.

Anna Johnson pointed out, though, that gaining mainstream media and general public attention is still one of the few ways that smaller organizations with limited budgets can hope to exert influence on legislators. And certainly relationships with the mainstream media could be better managed. Johnson said that the National Center for Youth Law has used a free set of guidelines for public advocacy work on health issues from the California Endowments' Center for Healthy Communities' "Health ExChange Academy." (See: http://archive.calendow.org/about/Health_Exchange_Academy.aspx) The NCYL recently succeeded in bringing about legislative change with respect to the drugging of children in foster care in California through strategic collaboration with a journalist working for a high-profile news outlet. The NCYL assisted with information access requests, helped bring forth current and former foster youth who wanted to speak out, and identified important independent experts. And while Johnson agreed with other respondents that the stories and perspectives of the people being most affected should play a central role throughout such advocacy processes, she pointed out that one of the reasons this doesn't happen often is because protesting can be risky for vulnerable people – hence the best approach is often this kind of "allied" one. Despite this success, though, Johnson acknowledged that many law firms, journalists, and legislators struggle to understand the basic frameworks and language of critical approaches to foster child and youth mental health issues.

Jennifer Mathis similarly identified a large knowledge and “terminology and language gap” that makes bridging different perspectives and connecting with the mainstream public difficult. Indeed, Mathis said that the terms and ideas that many critics of the mental health system are using are so different from the understandings among legislators and the mainstream public that these latter groups don’t have enough of an understanding of what critics are even talking about to truly agree or disagree with them. Mathis said the starting points for critics are often utter “non-starters” for the mainstream – citing for example the way in which critics challenging the basic concept of “mental illness” often feeds into, rather than undermines, widespread beliefs about “anosognosia” or lack of insight into one’s “illness.”

Thinking along a parallel line, David Cohen suggested that what is needed is a wholesale re-defining for our society of what “mental health problems” even are – both the categories of experience related to “distress” and those related to “misbehavior.” He suggested that a major ad agency or public relations firm be hired to come up with an entirely new vocabulary that is not an illness-oriented vocabulary, to help counter the way in which the pharmaceutical industry has framed public discussion around “chemical imbalances.” Such a new vocabulary would ideally create new concepts and phrases that would serve to re-frame discussions about extreme distress and aberrant behavior, said Cohen, and be usable in everything from academic papers and meetings with legislators to television commercials.

Specific recommendations that emerged:

- Focus on education of smaller, more accessible sectors of the public, such as college teachers and students or civil rights groups.
- Convene a “media working group” to review the HealthExChange Academy guides to political health advocacy and other similar guides and write an adaptation specifically for serious critical “mental health” advocacy.
- Convene a “language and ideas working group” to collaborate with an advertising or public relations firm in developing new frames and terms for “mental health” ideas.
- Explore opportunities for responding to and potentially collaborating in the creation of art that deals critically with mental health issues.
- Develop a robust policy framework – outside the limitations circumscribed by the mental health system and its concepts – for broad social change that speaks to the general public.

Cross-sectoral Collaboration

There are many affinities, overlaps and common underlying roots between the movement to strengthen the civil rights of people facing discrimination and involuntary psychiatric treatment and the movements to strengthen civil rights for other sectors of society. Many respondents identified the importance of building more collaboration between these sectors. The expanding use of psychiatric drugs and involuntary treatment laws against people who are homeless or living in poverty, the elderly, children and youth, people with physical or intellectual disabilities, and at above-average rates against people of color, provide specific opportunities for connecting and collaborating across sectors. At the same time, much like the voices of caregivers and family members often supplant the voices of psychiatric survivors in public debate, policy development, and decision making, the voices of caregivers and family members also often supplant the voices of vulnerable sectors like children and the elderly. This makes cross-sector collaboration all the more important, but also challenging. Generally, respondents said that people working on rights issues related to gender, sexuality, poverty, race, ethnicity, ageism etc. often do not understand psychiatric rights, psychological difference, mental disability or mental freedom issues, nor understand how these share common underlying roots with other civil rights issues. Therefore, targeted educational efforts are crucial.

The psychiatric rights and “mental freedoms” movements have also had a somewhat ambiguous relationship with the disability rights movement, and Jennifer Mathis asked if there might be ways to improve that relationship. Though there are many natural affinities in the goals of the two groups, and there are increasing and increasingly successful efforts to unite them, many survivors simply do not see themselves as “disabled” and believe that identifying differently-minded people or psychiatric patients as disabled unduly fuels the assumptions and intentions of the dominant mental health system. They instead see themselves as advocating for basic human rights for all, including for those people within the psychiatric system, not for special rights for specific subgroups. Meanwhile, there are many “disability rights” groups that actually strongly and openly support systemic psychiatric oppressions. There seems to be, however, a fledgling growing unity among some groups around a shared understanding that everyone is different and differently abled, and that “disability” can be understood as socially constructed limitations on a person’s opportunities rather than as a lack of ability inherent in that person. This could open new opportunities for collaboration.

Many respondents pointed to a lack of diversity within the psychiatric rights and/or mental freedoms movements nationally that is not representative either of the general American population nor of the population involved in the “mental health” system. Overall, there is an obvious predominance of people who are white and Anglo-Saxon, and a number of respondents also said that, from their observations and experiences, males predominate in leadership roles. Several respondents said that this movement is no less susceptible to sexism, racism or ageism than the rest of society, and so that fact is likely playing a role in the lack of diversity among movement leaders. However, there are a number of other likely contributing factors, some of which were identified by Cindi Fisher. People from groups with less access to privilege are often experiencing more oppression in all areas of their lives, making it harder for them to find opportunities to join in activism, speak out and organize, suggested Fisher. And whether they are professionals in the mental health field, psychiatric survivors, or others, the risks of speaking out and protesting are often higher for people from groups experiencing more daily oppression as well, she added.

On the general topic of cross-sector collaboration, however, Deron Drumm pointed out that there is an important difference between the rights movement(s) under discussion in this report and other civil rights movements. Historically the oppression and subjugation of certain groups was often done with knowledge and intent – such as in the context of race or gender prejudices, slavery, apartheid or colonialism. However, many people enter mental health professions with a desire to help others, not subjugate them, and consequently the mental health system of domination cannot be understood or explained in the same way as other systems of domination. That difference is obviously not absolute, though – some of the people involved in the turn-of-the-century residential school systems in North America, for example, arguably believed that they were “helping” indigenous children by taking them from their parents and trying to culturally assimilate them. And perhaps a more appropriate comparison point for human rights in the face of the psychiatric system might not be racial rights at all, but rights in the civil and criminal justice systems – where all members of society potentially have a stake in the operations of an oppressive system and could become subject to it, or can be subjected to its power in different ways even if they never get sued or land in prison. In any case, all of this serves as an important reminder that building alliances with other civil rights groups requires a sophisticated educational approach. Tellingly, for example, in the past decade there has in fact been an increase in the number of civil rights-sensitive organizations that have made mental health issues an area of focus – but often these groups are advocating primarily for everyone's "right of access" to the dominant mental health system and its treatments.

Bruce Levine, who also strongly advocated for increased cross-sectoral collaboration, specifically highlighted some of the other challenges that such an approach presents. Levine pointed out that it is enlightening and inspiring for some to understand the psychiatric rights movement as part of a much broader set of anti-authoritarian civil rights movements. However, he also noted that, for others, such a perspective can be very upsetting. Levine suggested that for some people it is easier to blame psychological distresses on those who experience them and on individual brains than to grapple with one's own complicity and bigger issues such as institutionalized racism, environmental destruction, economic oppression, wars, and education system breakdowns. Growing understanding of the social roots of inner distress, said Levine, can make people begin to feel that they will have to change their whole lives and all of society to solve anything – which can be daunting and discouraging for some. Consequently, Levine emphasized that the manner of delivering this radical, cross-sectoral, unifying message to the public always needs to be appropriately crafted and delivered, or it can alienate rather than inspire.

While many respondents' perspectives focused on cross-sectoral collaboration to strengthen political advocacy, Drumm highlighted the work of Toivo, which is making significant efforts to increase collaboration in the building of holistic health approaches such as mind-body exploration and healing practices. One of the distinct advantages of such approaches, pointed out Drumm, is that they provide opportunities to give integrated services to both the general public and people who have been or are involved with the "mental health" system, i.e. due to our culture's high level of interest in such practices already, they bring a built-in capacity for cross-sectoral connecting.

Specific recommendations that emerged:

- Conduct outreach to under-represented groups to learn more about why they are not involved in the critical movement and what would help them become involved or take leadership.
- Provide more services tailored specifically to under-represented sectors, such as services in languages other than English, or to particular age groups.
- Affirmatively support more diversity in leadership positions of existing critical organizations where possible.
- Explore opportunities to collaborate with disability rights groups that understand disability as socially constructed limitations imposed on differently-abled people, and see mental freedoms or psychiatric rights as one part of a much broader universal human rights agenda.
- Develop more strategic alliances with people and organizations who are not "mental health" oriented, but are engaged in offering healthy mind-body practices or services.
- Conduct targeted educational outreach to groups working on related or overlapping issues, such as prison reform, police brutality, victims of violence, homelessness, race, gender, guardianship, overdrugging of the elderly etc.

Legal Advocacy and Strategies

There was a general feeling among respondents that both individual-level legal advocacy and systemic-level strategic litigation play very important roles in the critical movement. State and federal governments have funded a variety of organizations to help provide advocacy and legal services to individuals diagnosed with mental illnesses such as state Protection & Advocacy and Disability Rights organizations, and sometimes these groups work on broader issues such as facility standards; however, Jim Gottstein and most of the respondents felt that there is a severe shortage of strategic, systemic-level litigation going on. At the individual level, added Gottstein, there is “universally inadequate” legal representation for people facing involuntary commitment or forced treatment. Gottstein further explained that the judges and even many of the public defenders who handle such cases often implicitly accept claims made by mental health professionals, and are often biased against people diagnosed as “mentally ill.”

According to Jennifer Mathis, the Bazelon Center for Mental Health Law’s strategic focus has shifted over time. Starting in the 1970s, Bazelon often took legal cases that challenged the laxity of involuntary commitment standards. However, over the decades, involuntary commitment laws and standards, judicial appointments, and the politics of forced treatment have developed in ways that have reduced opportunities to challenge those laws, and most of Bazelon’s work in this area has become simply “defensive” – attempting to stop even worse developments emerging from legislators. In recent years, Bazelon’s policy and litigation focus has been more on choices, options, and issues relating to community integration. The *Americans with Disabilities Act* and US Supreme Court decision in *Olmstead v. L.C*, explained Mathis, have provided strong opportunities to work with the US Department of Justice and to launch court cases related to improving psychiatric patients’ access to better living conditions and integration into their communities. The US Department of Justice’s Medicare Fraud Task Force has also successfully improved living conditions and standards at state mental health facilities that it has chosen to investigate and challenge. In a not dissimilar vein, Johnson discussed some of the legislation that the NCYL has been working on, such as bills establishing mental health rights for children in foster and group homes, giving stricter guidance to courts around authorizing psychiatric medications, and making the number of psychiatric medications prescribed, high dosages, or black box warnings “triggers” for closer, independent monitoring -- which usually decreases psychiatric drug prescribing.

One of the problems that some respondents expressed about that kind of litigation, however, is that it often must work within established laws and principles that are already fundamentally “compromised.” And there is a distinct lack of litigation going on that challenges the foundations of the dominant mental health system such as involuntary treatment, systemic prejudice, use of pseudo-scientific approaches etc. Jim Gottstein of the Law Project for Psychiatric Rights has been the most prominent, successful – and possibly the only consistent – strategic litigator in America in those kinds of areas. Gottstein successfully challenged Alaskan law around specific aspects of forced treatment, and one of his current efforts is to challenge the legality of Medicaid reimbursing physicians when they prescribe psychiatric drugs to children – drugs which are in large part not actually approved by the FDA for use in children.

The United Nations Convention on the Rights of Persons with Disabilities prohibits involuntary psychiatric commitment and involuntary psychiatric treatment. Though the CRPD has not been ratified by the US, some respondents said that it could nevertheless potentially be used more effectively in the context of public education, advocacy and litigation initiatives. Indeed, there is risk that, in the absence of such efforts, these CRPD declarations could be increasingly misinterpreted or watered down.

In concert with Mathis' general observations about the hostile climate in the US against psychiatric rights, some respondents suggested that it might be better to attempt to establish a precedent by doing strategic litigation to abolish forced treatment in a country other than the US first, where the chosen country's legislative framework is more amenable to challenge. Coincidentally, Johnson said that the NCYL sometimes provides support or collaborates with legal teams in other countries on legal challenges pertaining to its mandate.

Currently, although many groups and individuals engage in it from time to time, there is no single organization that co-ordinates or engages in regular lobbying of legislators either for or against particular legislative agendas. None of the respondents could point to any existing organization that they thought was well-placed enough, well-funded enough, able, and appropriate to take such a lead role – though everyone felt it to be important. Alongside that, both Gottstein and Mathis argued that public education, political advocacy and legislative change alone are often ineffective if not coupled with litigation. There are too many vested interests and too much inertia in the existing system, said Mathis, for persuasion alone to effect change. She pointed, for example, to how the Olmstead-related, legally required, community integration plans from state governments were largely business-as-usual, until lawsuits started and politicians and government agencies began to "feel the pain" of liability.

Specific recommendations that emerged:

- Develop a more formalized way for people and organizations to collaborate on legislative and political lobbying initiatives nationally and at state levels.
- Conduct a study to attempt to better quantify the extent of involuntary commitment and forced treatment in the United States, and the extent and nature of legal representation being afforded to these people.
- Bring interested parties together to study and identify the best strategic opportunities for litigation with national relevance related to foundational aspects of involuntary commitment and forced treatment, and collaborate to find non-government funders and/or private sector legal partners to help move it forward.
- Do education on legal issues and litigation initiatives specifically to legal professionals, as well as to the general public.
- Consider a precedent case challenging the poor legal representation often afforded to people facing involuntary commitment.
- Find ways to more vigorously publicize the significance and ramifications for rights related to the psychiatric system of the UN Convention on the Rights of Persons with Disabilities and International Convention on the Elimination of Racial Discrimination, and explore possibilities for their use in litigation.
- Explore the possibility of a multi-organizational collaboration to abolish forced psychiatric treatment against children and youth – perhaps starting in a country with laws more amenable to such a challenge.

Targeted Institutional Change

A number of respondents talked about targeting specific sectors and institutions with educational efforts. David Cohen discussed the pressing importance of this, in light of the ways in which the needs of certain institutional sectors inherently resist progressive changes with respect to “mental health.”

For example, Cohen suggested that it’s important to work with organizations and governments to figure out a new “administrative mechanism” or evaluation process for people in American society to obtain needed social services and supports. Currently, it is often a requirement that people get a mental health diagnosis and corresponding psychiatric label before governments will determine that they are eligible for certain kinds of disability payments or other supports. This acts as a funnel into the mainstream mental health system for many people of all ages who might not otherwise have become involved with the system. Cohen said that, in certain European nations, many social support services are more readily accessible upon request.

Cohen said the insurance industry also relies on these scientifically invalid diagnoses for billing purposes, and the courts defer to psychiatric experts and diagnoses in many types of decisions. The prison system, too, is becoming more reliant on mental health diagnoses and approaches.

Cohen wasn’t the only person to identify such problems. Anna Johnson pointed out, for example, that giving psychiatric medications does not affect group home providers’ own budgets, but giving other kinds of supports to clients often does – hence creating institutional resistance to alternatives to psychiatric drugging. Laura-Nicole Sisson noted that the desire for meaningful work is high among many people with lived experience – so, she asked, is the current disability payment system the right supportive approach over the long term?

Cohen suggested a research effort should conduct an inventory of the challenges that different institutional sectors face in trying to move away from psychiatric diagnoses and treatments, as a basis from which to begin proposing alternative approaches.

Specific recommendations that emerged:

- ➢ Conduct a research inventory of the challenges that different institutional sectors face in trying to move away from psychiatric diagnoses and treatments.
- ➢ Work with people with lived experience, other creative thinkers, and progressive institutional actors to develop practical alternatives to using psychiatric diagnostic categories and psychiatric treatments for different sectors and institutional contexts.

Building Alternatives for People in Crisis

For people experiencing crises, there is a severe dearth of alternatives to psychiatric drugs either within or outside the dominant mental health system. And there is even less for those without very substantial financial resources at their disposal – which is particularly problematic when there are widely-recognized overlaps between psychological distress and poverty. Most of the respondents spoke to a need for more short-term, crisis respite houses and for facilities allowing longer-term stays. They also identified a need for supports for people trying to withdraw from psychiatric drugs, and for people wanting readier access to non-drug interventions.

Within the dominant system, Sera Davidow suggested that more training is needed for practitioners who genuinely want to do things differently; but at the same time, she added, these practitioners themselves need more regular support. While individual workshops, conferences and training courses are valuable, many practitioners continue to encounter difficulties, frustrations and resistances getting their new skills and approaches integrated into their conventional workplaces, and they need places where they can obtain ongoing training, support, encouragement and networking with other progressive practitioners.

Outside the system, it is problematic that alternative practitioners generally exist in isolation. As Monica Cassani pointed out, a person experiencing either a short or long-term crisis that is serious may well need more than simply two one-hour visits per week with an alternative practitioner – the person may need ongoing support of different types from different people in their daily lives over days, weeks or longer.

Certainly some communities have relatively low-barrier, regular access to mind-body practices such as yoga, meditation, qi gong, and combined physical-spiritual exploration programs, and some – particularly those closely linked to religious organizations – have communities that have grown up around them. According to Deron Drumm, Toivo is in the process of working with mind-body practitioners to adapt some of these mind-body approaches for people in crisis, in withdrawal, or inside mainstream mental health facilities.

A small number of alternative respite houses exist in America that receive significant government funding. Cindi Fisher has been trying to develop a model for low-cost respite homes that could be readily made available to anyone in every neighbourhood, by housing a mix of a person in crisis, subsidized renters, and volunteer practitioners in training. Meanwhile, David Cohen, Monica Cassani and others discussed the need to re-think and re-design what we as a society even mean by a “mental health intervention” or “therapeutic encounter,” and look to develop more ways for all people to collaborate in mutual support in daily life, sharing the process of getting through challenges and “learning to live well.” This vision in many ways overlaps with Fisher’s vision, which in turn notably overlaps with the growing number of organizations and governments working on building local-level “resilience” with respect to economic self-reliance, emergency preparedness and social cohesion.

Specific recommendations that emerged:

- Collaborate to test several models for low-cost, low-barrier, neighbourhood-based respite houses.
- Explore options for organizing progressive practitioners for the deliberate purpose of providing ongoing training, advice and support to each other in changing practices and shifting the dominant system.
- Collaborate with groups and organizations that offer mind-body practices, to explore deliberately extending and expanding their work to incorporate mindfulness of inner diversity and withdrawal syndromes and help build mutual support opportunities.
- Collaborate with groups and organizations doing community resilience-building to explore how to seed and build community-based, interpersonal mutual support systems and “inner resilience.”

Organizing Families

Nearly every respondent felt strongly that there needs to be a new organization with a degree of focus on educating, supporting and uniting family members of people struggling with psychological distress. Many people pointed to the National Alliance on Mental Illness (NAMI) model of community-based affiliate organizations linked to a single national organization as a very good one, because the affiliates allow for in-person, local-level accountability, meetings, support groups, and events, while the centralized national office creates a strong, unified, high-profile, public political voice. However, NAMI receives enormous amounts of funding from the pharmaceutical industry and generally promotes the bio-medical model of mental illness and the use of forced treatment, and has thereby contributed significantly to a cultural polarization of opinion with some family members on one side and many survivors of forced treatment on the other.

While it is commonly asserted that NAMI speaks for most family members, Haydée Cuza in particular expressed strong skepticism and indicated that, through her work, she has observed a lot of common ground between family members and people with lived experience on issues such as living conditions, community integration, and therapeutic options. This commonality of perspectives often grows even broader as family members – often feeling desperate and afraid – have opportunities to meet with survivors who were doing well, see alternative approaches working, and experience family crisis interventions such as Open Dialogue.

Cindi Fisher has actually started such an organization – Mothers and Others Standing Up Together – but she explained that she receives no funding and at this time she mainly provides support and advocacy in individual cases and does not see herself as an “organizer.” However, Fisher affirmed the sense that there are many family members who are wanting such an organization.

Cuza added that not everyone has a family or feels close to his or her family, so it’s important to bear in mind that framing political or legislative change around the perspectives of families sometimes creates an unnecessary political divide right at the outset. Therefore, Cuza and many other respondents felt that such a new organization should include people with lived experience who are against involuntary treatment in positions of co-leadership and perhaps have a generally broader mandate, while including within its aims giving a sense of community, advocacy support, and greater political voice to the increasing numbers of family members who are becoming frustrated with the dominant mental health system.

Specific recommendations that emerged:

- ➢ Develop a national organization, led or co-led by survivors, with a strong emphasis on organizing family members of people experiencing psychological distress. This national organization should be buttressed by community-based affiliate organizations around the country. (See also “National Network and Strategic Operations Center” below.)
- ➢ Create events and meetings where family members can more frequently meet survivors and other family members and share stories and offer supports to each other.

National Network and Strategic Operations Center

There was widespread recognition of a need for a national organization, although there were different ideas about exactly what such an organization could do and how it might work. There was some question as to whether two separate national organizations are needed – one to strongly fight the medical model, and another to more creatively engage the existing system. But most respondents focused on the need to create a single organization.

As previously discussed, the most common unifying principle cited was being against involuntary psychiatric treatment – and Jim Gottstein pointed to the Highlander Statement of Concern and Call to Action as a potential guiding document for such a group. (The Call to Action is available at http://www.mindfreedom.org/kb/history/highlander-2000)

Most respondents described a national organization that would essentially be a group of people funded to help develop movement strategies and innovative alternatives, do outreach, education, training, consultation, and systemic-level advocacy, and be a credible national voice. However, many felt that this model could likely not work in isolation, and state and regional affiliate groups would be needed to help develop ongoing relationships and take advantage of local-level opportunities around the country.

A different version described the organization as more like a “think tank,” conducting research, issuing reports and positions, and providing funding to other initiatives.

The possibility of a national organization that also served as a conduit for funding to other organizations, groups and individuals appealed to many respondents, since in part it could become a dynamic, flexible way to provide grants to many applicants who would then not have to battle through the entire process of educating traditional funders about all of the issues. For example, small travel grants could be given to speakers or expert court witnesses, or seed grants to fledgling community survivor groups – people who would otherwise probably have no possible source of external funding.

A less ambitious suggestion, or one that could function as an intervening step towards a national organization, was simply to develop a funding framework to help create and maintain a network of people doing systemic critique and advocacy around the country, perhaps through a combination of online communications and occasional in-person meetings. MindFreedom and the National Association for Rights Protection and Advocacy were sometimes cited as organizations that have in the past taken on some of these roles and whose efforts could potentially be built on. But most respondents identified a need for a new organization, unifying survivors, allies and others, with a broader set of mandates.

Specific recommendations that emerged:

- Create a “think tank” to do foundational research, issue reports, develop policy, and speak to media.
- Develop a national organization with community-based affiliate groups, guided by a strong set of principles.
- Consider options that could create a framework for smaller organizations and less formal groups and individuals to apply for funding with the assistance of, or through, or from a larger organization.
- Under the unifying banner of being against all forced psychiatric treatment, research the level of

interest in, and possible ways of creating, a more dynamic national network for people, groups and organizations.

Final Thoughts

It is evident that there is no shortage of opportunities for strategic action to address key gaps in the disparate efforts in the United States to critique, reshape, or transcend the dominant “mental health” system. However, it seems that the most obvious challenge that flows through the heart of every issue is a lack of networking and collaboration at the national level that would be necessary to advance most of these proposals. Furthermore, at this time, it seems that this lack of organized collaborating is based not on a lack of interest or will, nor on fundamentally irreconcilable political positions or conceptual differences; rather, it seems to be based on the lack of appropriate leadership with sufficient resources available to support such networking and collaboration.