

Beyond Binary Narratives of Mental Health Advocacy: Latent Profiles of Mental Health Activists and Advocates With Lived Experience

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Objective: In this article, the authors used data from a national survey of mental health activists and advocates (MHAAs) with lived experience of psychiatric disabilities to investigate attitudes toward psychiatric care.

Methods: The authors distributed a survey, developed by a team led by researchers who were also service users, to both mainstream and more critical advocacy groups and networks (N=547 participants), and they analyzed the data by using latent class analysis (LCA). Four survey variables regarding beliefs about involuntary hospitalization, assisted outpatient treatment, medication, and diagnosis were used to generate latent subgroups. The authors explored associations between key survey variables and latent classes with chi-square tests and analysis of variance.

Results: LCA indicated an optimal six-class solution. The classes existed on a spectrum of positions, ranging from highly favorable views of traditional psychiatric practices to highly critical views, with classes in the middle representing distinct profiles of attitudes toward treatment and diagnosis. Significant between-group differences were found for participants' psychiatric treatment histories, motivations to engage in activism and advocacy, and views about mental health care and advocacy priorities.

Conclusions: Findings reveal considerable heterogeneity among MHAAs and challenge binary narratives of mental health advocacy.

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Mental health activists and advocates (MHAAs) with personal experience of using mental health services have played a vital role in the historical evolution of psychiatric care, and they have been at the forefront of reform. MHAAs have also served as connectors among clinicians, patients and service users, legislators, and the general public. The attitudes of patients and service users, the general public, and clinicians have been the subject of numerous studies (1–3); however, there is a glaring lack of similar research characterizing the attitudes of individuals who self-identify as activists and who are actively engaged in advocacy efforts.

Contemporary mental health advocacy is often thought to have originated in the 1970s; among service users, prominent early groups, most with a strong anticoercion focus, included the Insane Liberation Front in Oregon, founded in 1970, and the Mental Patients' Liberation Project in New York City, founded in 1971 (4). Moreover, the family-led National Alliance on Mental Illness (NAMI) was incorporated in 1979 (5). Over time, the political landscape of advocacy has expanded, with significant schisms developing within and between groups (6, 7). Ongoing points of tension among service users and survivors have included the relative benefits of psychiatric medications, the role of and justification (if any) for

coercive intervention, and divisions centered on cooperation with versus contestation of existing mental health systems and services (6–8). Patient advocacy and activism have also intersected with professional critique and reform in complex ways; at times, service users and family advocates have allied with psychiatrists and psychologists who have criticized aspects of traditional psychiatry, but at other times they have intentionally distanced themselves from mental health professionals (9, 10).

HIGHLIGHTS

- Latent class analysis was applied to data from a national survey of mental health activists and advocates (MHAAs) with lived experience of psychiatric disabilities.
- Six subgroups of MHAAs were identified, revealing diverse profiles of beliefs about mental health treatment, medication, and diagnosis.
- Findings indicate considerable heterogeneity among MHAAs and challenge binary narratives of mental health advocacy.

The polarization that exists in professional mental health discourse (11, 12) is often also observed in the discourse surrounding psychiatric advocacy, arguably leading to perceptions of a binary advocacy landscape (13). Common iterations of this binary discourse juxtapose “antipsychiatry” (emanating from professional or grassroots organizations) with “propsychiatry.” The former term ostensibly refers to an opposition to medications and traditional psychiatric treatment, whereas the latter term indicates an appreciation of medications and other mainstream psychiatric interventions; for examples, see a Vice News article (13) and a *Psychiatric Times* series of interviews (14). Within the mental health advocacy and service user communities, observations of polarization are commonly reported in the gray literature (e.g., blog posts, magazine articles) (15), given that little peer-reviewed scholarship exists on this specific topic.

From the outset, there has been a tendency within psychiatric communities to view MHAAs who have critical perspectives with suspicion: these MHAAs are assumed to endorse goals and priorities aligned with the “antipsychiatry movement” (16) rather than those of real-world patients with serious mental illness and their families. Allegations of antipsychiatry arise from the complex historical background of the figures associated with the movement, as well as from the rhetorical use of the term itself (see work by Daniel Burston for an analysis of this background) (17, 18). Against this backdrop, we sought to examine attitudes toward multiple aspects of psychiatric intervention and policy via a survey of MHAAs with lived experience of psychiatric disabilities. Additional findings will be reported in future publications; this article is restricted to reporting data of latent subgroups that were clustered on the basis of beliefs regarding psychiatric treatment, medication, and diagnosis.

METHODS

Survey Design and Development

An initial survey was developed by a service user-led research team (S.C. and N.J.). The full survey is available as an online supplement to this article. Whenever possible, items were adapted from existing materials; for example, many of the advocacy position statements were adapted from NAMI’s 2017 policy priorities statement and the National Coalition on Mental Health Recovery’s 2017 statement of policy priorities. Additional items were added on the basis of the team’s knowledge of the mental health field, and explicit efforts were made to integrate a mix of perspectives, including those critical of psychiatry as well as those aligned with more mainstream consumer advocacy. The survey development team (led by S.C.) then consulted with a small group of activists with lived experience, who also served as pilot study participants. Refinements, including shortening the survey and modifying its language, were made, and consultants were asked to reevaluate the survey.

Recruitment and Outreach

Survey participation was limited to individuals with personal experience of mental differences or psychiatric disabilities and who self-identified as either advocates or activists. To include the broadest range of MHAAs, we developed two versions of the recruitment flyer: one used the term “mental health advocacy,” and the other used terms such as “neurodiversity,” “mad,” “user,” and “survivor activism.” The activist version was sent to organizations and entities that are more critical of traditional psychiatry, including survivor-led groups; the advocacy version was sent to more mainstream consumer groups. The team directly e-mailed all identifiable contacts at peer-run organizations and NAMI chapters across the United States; in addition, the team posted on social media, mental health subreddits, national advocacy e-mail discussions (e.g., the National Coalition for Mental Health Recovery), and national e-newsletters (e.g., the National Consumers’ Mental Health Self-Help Clearinghouse). The survey was available for 6 months, from July 2018 to January 2019. Survey respondents were not restricted to those living in the United States. The study was reviewed by the institutional review board of the University of South Florida and determined to be exempt. Informed consent was obtained via an online form at the beginning of the survey.

Statistical Analysis

Data were exported to Stata, version 17, from Qualtrics, and latent profile groups were created with native Stata latent class analysis (LCA) syntax. We generated and compared solutions of two to eight latent groups by using Akaike’s information criterion (AIC) and the Bayesian information criterion (BIC). We explored associations with the latent class groups by using chi-square tests (categorical variables) and analysis of variance (continuous variables).

The following four survey items were used as LCA grouping variables: “Greater access to assisted outpatient treatment [AOT] and community treatment orders [CTOs] is needed for individuals diagnosed as having serious mental illness and a history of violent assaults,” “All psychiatric diagnoses are problematic and need to be challenged,” “Involuntary inpatient commitment needs to be abolished,” and “Psychiatric drugs are harmful.”

Responses to all variables were rated on a 7-point Likert scale ranging from 1 (“strongly disagree”) to 7 (“strongly agree”). These four items were selected because of their relevance to prominent themes deemed to be critical of psychiatry that are often expressed by patients and service users on platforms such as Mad in America (<https://www.madinamerica.com>); hence, we had reason to believe that they would be well suited to investigate the nature of polarization in this population.

RESULTS

A total of 547 participants completed the survey. Demographic and clinical characteristics are summarized in

Table 1. Approximately 81% of the sample (N=444) identified as White, and 66% (N=362) identified as female. In addition, 90% (N=494) reported having received a formal psychiatric diagnosis at some point, with depression reported most often (49% of the sample; N=266). Furthermore, 58% (N=315) of the sample had been hospitalized for mental health reasons at some point, 34% (N=188) involuntarily, and 86% (N=470) had used psychiatric medications. A majority of respondents were living in the United States (68%, N=370), followed by the United Kingdom (11%, N=61).

Both AIC and BIC tests clearly indicated an optimal six-class solution. The classes suggest a spectrum of positions, ranging from highly favorable views of traditional psychiatric practices to highly critical views, with classes 1 and 6 representing the propsychiatry and antipsychiatry views, respectively, and classes 2–5 representing a mix of distinct, intermediate views. The profile characteristics of the six classes are summarized in Table 2. Associations with background variables and pertinent survey items are summarized in Tables 3 and 4.

All but one of the classes endorsed the expansion of AOT and CTOs for individuals with a history of violence. Classes 2 and 4 showed a particularly mixed profile. Class 2 was neutral on the question of greater access to AOT and CTOs; there was disagreement with rejection of psychiatric diagnoses, agreement with abolition of involuntary treatment, and neutrality on characterizing psychotropics as harmful. Class 4 was in favor of greater access to AOT and CTOs, against abolition of involuntary inpatient commitment, and agreed strongly with rejection of psychiatric diagnoses and, to a lesser extent, with characterizing psychotropics as harmful.

Significant differences were found among the classes with regard to history of receiving a psychiatric diagnosis, history of involuntary hospitalization, history of receiving electroconvulsive therapy (ECT), and current psychiatric medication management (Table 3).

Most respondents reported a history of having received a psychiatric diagnosis (>90% in each of classes 1–5 [95% overall, N=408 of 429], and 81% in class 6 [N=96 of 118]). History of involuntary hospitalization was highest in classes 2, 5, and 6. Class 6 had the highest rate of history of ECT (39%, N=46 of 118), followed by classes 4 (26%, N=19 of 74) and 5 (21%, N=22 of 106); the lowest rates were found in classes 1 (18%, N=16 of 91), 2 (17%, N=8 of 46), and 3 (16%, N=18 of 112).

Class 6 had the lowest rate of current psychiatric medication management (20%, N=24 of 118); classes 3 (48%, N=54 of 112), 4 (49%, N=36 of 74), and 5 (34%, N=36 of 106) fell in the middle; classes 1 (63%, N=57 of 91) and 2 (59%, N=27 of 46) had the highest rates. Differences among classes with regard to receiving current psychotherapy did not reach statistical significance. Class 2 had the highest rate of receiving outpatient therapy and counseling (61%, N=28 of 46), whereas class 6 had the lowest rate (33%, N=39 of 118).

Experiences of prejudice and discrimination related to mental health, in terms of motivation to engage in activism and advocacy, were not significantly different among classes, with generally similar ratings (neutral to slight agreement on average). Statistically significant differences were found in reports of involuntary behavioral and mental health treatment experiences serving as motivation to engage in activism and advocacy: average values ranged from disagreement (class 1) to neutral (class 6), with no class in agreement (Table 4).

Generally, strong agreement was found among classes 1–5, with weaker agreement in class 6, with the view that people with mental differences should be given access to treatment instead of being held in prison or jail. Classes 1–5 were in various degrees of agreement that more people need access to professional behavioral health treatment, whereas class 6 was in slight disagreement.

Strong support was found among all classes for access to alternatives to traditional mental health, need for accommodations, and persons with lived experience being in positions of leadership.

DISCUSSION

In our analysis of data from a survey of 547 MHAAs, we identified six latent profile subgroups; these groups reveal a spectrum of views, challenging binary narratives of mental health advocacy. To the best of our knowledge, this survey is the first and currently only U.S.-based survey to report on the perspectives of a large sample of MHAAs with lived experience of psychiatric disabilities. Mental health advocacy is often seen as existing in two different silos; the fact that we had to develop two versions of the recruitment flyer is indicative of the realities of navigating often conflicting perspectives and identities among MHAAs. However, survey responses reveal considerable heterogeneity, suggesting that a binary characterization fails to do justice to the range of views expressed by MHAAs.

Within this sample, MHAAs' views about mental health policy appeared to have been shaped in part by histories of psychiatric treatment. For example, the rate of ever being involuntarily hospitalized was the highest in classes with more unfavorable attitudes toward involuntary inpatient commitment. History of ECT also appeared to align with the degree of opposition to psychiatric interventions. Interestingly, MHAAs did not appear to see their advocacy as motivated by their experiences of involuntary psychiatric care, with no class in overall agreement that such experience served as a major source of motivation. Our survey was limited to individuals with lived experience of psychiatric disabilities, and >90% of the participants reported having received a diagnosis; therefore, our sample was a subset of the larger community of patients and service users. How the views and attitudes of MHAAs with lived experience differ from those of patients and service users generally requires investigation in future research studies.

TABLE 1. Demographic and clinical characteristics of the 547 MHAAs with lived experience who completed the survey from July 2018 to January 2019^a

Characteristic	N	%
Diagnosis ^b		
ADHD	96	18
Obsessive-compulsive disorder	42	8
PTSD	151	28
Anxiety disorder	224	41
Depressive disorder	266	49
Borderline personality disorder	68	12
Bipolar disorder	130	24
Schizophrenia spectrum disorder	65	12
Psychotic features or traits	27	5
Eating disorder	13	2
Dissociative identity disorder	17	3
Autism spectrum disorder	96	18
No diagnosis	43	8
Race-ethnicity ^c		
White	444	81
Black or African origin	24	4
East Asian	5	1
South or Southeast Asian	13	2
Middle Eastern	9	2
Latinx	9	2
Indigenous or American Indian	12	2
Sex-gender		
Male (cisgender man)	91	17
Female (cisgender woman)	362	66
Transgender woman	6	1
Transgender man	7	1
Nonbinary	52	10
Other	18	3
Missing	11	2
Country or region of residence ^c		
United States	370	68
Canada	36	7
United Kingdom	61	11
Australia or New Zealand	37	7
European Union	20	4
South and Southeast Asia	8	1
Kenya	1	<1
History of psychiatric hospitalization ^b		
Voluntary	236	43
Involuntary	188	34
Never hospitalized	222	41
History of medications ^b		
Voluntary	416	76
Involuntary	76	14
Never used	67	12
History of ECT ^c		
Voluntary	36	7
Involuntary	20	4
Never experienced	418	76
Current mental health service use ^b		
Psychiatric medications	234	43
Therapy	241	44
Case management	42	8
Peer support	112	20
No treatment or services	164	30

^a MHAAs, mental health activists and advocates; ECT, electroconvulsive therapy.

^b Totals sum to greater than 547 because individual respondents reported multiple, overlapping answers (e.g., more than one diagnosis or histories of both voluntary and involuntary hospitalization).

^c Totals sum to less than 547 because of missing values.

Although recruitment efforts explicitly sought to reach participants across the spectrum of views on psychiatric care, the sample was nonprobabilistic; moreover, it is not possible to determine the extent to which our findings can be generalized to the general population of MHAAs. There are good reasons to think that we oversampled those with critical views, and it is possible that individuals with more polarizing views were overrepresented because they may have been more motivated to respond. To our knowledge, no other surveys of MHAAs have been published, precluding comparison. Similarly, we are unsure of the extent to which the demographic and clinical disproportionalities present in our sample could be generalized.

The absence of published research on MHAA perspectives is possibly a consequence of attitudes, often implicit, that such perspectives are of marginal relevance to research and policy (as one example of these sorts of attitudes, Robert Spitzer referred to the involvement of nonprofessionals such as patients and family members in the *DSM* process as “politically correct nonsense”) (19). When MHAA perspectives are discussed, there is often considerable ambivalence regarding advocacy positions that are antagonistic toward contemporary psychiatric practices. Recent exchanges in publications such as *Psychiatric Times* (20, 21) and *Psychiatric Services* (22, 23) reflect these tensions. Engaging with people with critical perspectives in good faith, however, is foundational to democratic pluralism. Impulses to exclude individuals with certain views a priori reinforce existing power structures and hinder reform. As our survey suggests, those with views that are the most hostile to mainstream psychiatry are often those with histories of more invasive or involuntary treatment. We can tackle unpleasant dimensions of psychiatric care only if we take perspectives born from such experiences seriously.

Despite differences in assessment of traditional psychiatric practices, there was strong support among all groups for access to alternatives to traditional mental health services, provision of accommodations, and leadership by individuals with lived experience of psychiatric disabilities. This support is in alignment with our calls for investment in building a pipeline of researchers with psychiatric disabilities (24, 25). Access to

TABLE 2. Latent profiles of the mental health activists and advocates who completed the survey from July 2018 to January 2019^a

Item	LCA 1 (N=91)		LCA 2 (N=46)		LCA 3 (N=112)		LCA 4 (N=74)		LCA 5 (N=106)		LCA 6 (N=118)	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Greater access to AOT and CTOs is needed for individuals diagnosed as having serious mental illness and a history of violent assaults.	5.4	1.5	4.1	1.6	5.0	1.5	5.4	1.5	4.9	1.2	1.2 ^b	.5
All psychiatric diagnoses are problematic and need to be challenged.	1.6	.7	2.9	.8	4.4	1.2	6.7 ^b	.7	6.4 ^b	.7	6.8 ^b	.6
Involuntary inpatient commitment needs to be abolished.	2.1	1.0	5.9 ^b	1.0	3.3	1.2	3.1	.9	6.3 ^b	.8	6.6 ^b	.8
Psychiatric drugs are harmful.	2.7	1.8	3.6	1.7	3.7	1.6	5.0 ^b	1.5	5.3 ^b	1.6	6.0 ^b	1.3

^a LCA, latent class analysis; AOT, assisted outpatient treatment; CTOs, community treatment orders. Responses were rated on a 7-point Likert scale ranging from 1 ("strongly disagree") to 7 ("strongly agree").

^b Average values leaning toward views critical of mainstream psychiatry.

alternatives to traditional mental health services and the need for disability accommodations had widespread support in our survey. Amid other agreements, these shared priorities may provide productive common ground.

Findings from our survey should be complemented by emerging qualitative research on the priorities of different groups of individuals in psychosocial disability advocacy and global mental health (26). For instance, it is relevant here that in the Movement for Global Mental Health, the need to center advocacy identities on psychiatry is being challenged by some activists from the Global South, even when these identities are adversarial (e.g., "psychiatric survivor"), because this framework can lead to the discourse being stuck in debates about psychiatric diagnosis and treatment (26).

Limitations of our study include reliance on an online sample of convenience, the description of participants as MHAAs being based on self-identification, most participants identifying as White, most participants being from the United States and the United Kingdom, and considerable uncertainty regarding the degree to which these findings could be generalized to other groups of MHAAs.

The heterogeneity of MHAA views identified through our analyses has practical implications for those within and outside activist communities. For example, a majority of participants, even those opposed to involuntary commitment, endorsed the view that AOT and CTOs should be expanded for individuals with a history of violent assaults. This finding suggests nuances or tensions that do not seem especially visible in public deliberation. Moreover, psychiatric leadership also has a responsibility to engage more fully with people along the entire spectrum of activist perspectives and to resist oversimplistic binary narratives. These findings give further impetus to psychiatrists and lived experience researchers to find ways to depolarize contemporary mental health debates.

CONCLUSIONS

Our analysis of data from a survey of MHAAs revealed six classes on a spectrum ranging from highly favorable views of traditional psychiatric practices to highly critical views, with classes in the middle representing distinct profiles of

TABLE 3. Latent profiles of mental health activists and advocates who completed the survey from July 2018 to January 2019 and their associations with history and background variables^a

Item	LCA 1 (N=91)		LCA 2 (N=46)		LCA 3 (N=112)		LCA 4 (N=74)		LCA 5 (N=106)		LCA 6 (N=118)		p ^b
	N	%	N	%	N	%	N	%	N	%	N	%	
History of receiving a psychiatric diagnosis	85	93	43	93	106	95	74	100	100	94	96	81	<.001
History of involuntary hospitalization	24	26	17	37	27	24	21	28	45	42	54	46	.002
History of receiving ECT	16	18	8	17	18	16	19	26	22	21	46	39	<.001
Current psychiatric medication management	57	63	27	59	54	48	36	49	36	34	24	20	<.001
Current psychotherapy	45	49	28	61	54	48	33	45	42	40	39	33	.061

^a LCA, latent class analysis; ECT, electroconvulsive therapy.

^b From chi-square tests.

TABLE 4. Latent profiles of mental health activists and advocates who completed the survey from July 2018 to January 2019 and their associations with pertinent survey items^a

Item	LCA 1 (N=91)		LCA 2 (N=46)		LCA 3 (N=112)		LCA 4 (N=74)		LCA 5 (N=106)		LCA 6 (N=118)		p ^b
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	
Motivations to engage in activism and advocacy													
Experiences of prejudice and discrimination related to mental health	3.9	1.7	4.6	1.6	3.9	1.7	4.8	1.3	4.8	1.5	4.8	1.5	.152
Experiences of involuntary behavioral and mental health treatment	2.2	1.7	3.2	2.1	2.3	1.7	2.9	2.1	3.4	2.3	4.0	2.3	<.001
Views about mental health care and advocacy priorities													
People with mental differences should be given access to treatment instead of [being held in] prison or jail.	6.06	1.49	6.05	1.41	6.19	1.08	6.04	1.45	6.21	1.37	5.28	1.67	<.001
More people need access to professional behavioral health treatment (e.g., therapy, medication).	6.58	1.09	5.93	1.62	6.51	.93	5.89	1.77	5.14	2.00	3.34	2.00	<.001
More people need access to alternatives to traditional mental health treatment (e.g., peer support, holistic care).	6.00	1.56	6.45	1.30	6.54	.73	6.48	1.17	6.69	.87	6.64	.89	<.001
It is important to attain mental health parity to ensure that mental differences and disabilities are treated equally to physical illnesses and disabilities in most insurance plans.	6.55	1.16	6.36	1.43	6.58	.79	6.46	1.28	6.21	1.53	5.08	2.09	<.001
People with mental differences or disabilities need access to more school, workplace, and housing accommodations.	6.36	1.31	6.50	1.36	6.66	.63	6.54	1.12	6.61	1.07	6.61	.88	.485
Tackling structural and institutional discrimination is more of a priority than “stigma reduction” campaigns.	5.15	1.83	5.76	1.67	5.73	1.35	6.13	1.32	6.48	1.04	6.86	.49	<.001
Persons with lived experience should be in positions of leadership over policy, services, and research.	5.97	1.37	6.15	1.66	6.15	1.31	6.29	1.14	6.61	1.01	6.68	.79	<.001

^a LCA, latent class analysis. Responses were rated on a 7-point Likert scale ranging from 1 (“strongly disagree”) to 7 (“strongly agree”).

^b From analyses of variance.

attitudes toward psychiatric treatment and diagnosis. Significant between-group differences were found for participants’ psychiatric treatment histories, motivations to engage in activism and advocacy, and views about mental health care and advocacy priorities. These results are indicative of substantial heterogeneity in attitudes and

do not align with binary perceptions of polarization with regard to the psychiatric advocacy community.

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