Mental Health Advocacy in California: Perspectives of Advocates and Decision-Makers

In partnership with the California Association of Mental Health Peer-Run Organizations (CAMHPRO), Live & Learn, Inc. conducted a survey on the impact of stakeholder advocacy on decisions affecting public mental health systems in California. The California Mental Health Stakeholder Advocacy Survey was designed by people with personal experience of the mental health system and related advocacy work from CAMHPRO, Live & Learn, Inc., and Shifa Consulting.

The objective was to pilot an approach to help CAMHPRO evaluate the impact of consumer advocacy in the state and to document the activities that advocates engage in (e.g., legislative testimony, demonstrations, campaigns). We asked advocates and decision-makers how these groups engage in advocacy, what their roles are, the goals of advocacy, and its perceived effectiveness in fostering change.

The survey was conducted in April 2016 and asked about advocacy activities in California in the past 6 months conducted by people who identify as consumers, survivors, ex-patients, or peers. There were different versions of the survey for consumer advocates and for county decision-makers.

The California Mental Health Stakeholder Advocacy Survey is based on an activity logging approach developed by the Ontario, Canada Consumer/Survivor Development Initiative (CSDI).\(^1\) The activity log obtained information about four categories of system-level activities:

- **Public education and relations**: activities that increase awareness or change in public opinions about mental health issues and people who experience mental health issues
- **Community planning and collaboration**: activities that bring about changes in planning practices and existing services, as well as the creation of new supports and services
- **Political advocacy**: activities that work toward changes in social policies and practices
- **Action research**: activities that gather information

The survey developed by Live & Learn, Inc. and CAMHPRO included questions about:

- The **specific activities** advocates engaged in
- The primary **type of improvement** advocates sought: local services, policy or legislation, societal attitudes, or networking for advocates
- The **target system for change** of the activity: mental health system, general health sector, community, and government
RESULTS

DEMOGRAPHICS OF RESPONDENTS

Sixty advocates and 24 decision-makers responded. Responses were received from 26 counties in the five mental health regions of California, with the highest number of responses from Fresno, Orange, Los Angeles, Tulare, and Alameda counties. Most respondents in both categories work in urban areas (67% and 76% respectively), with fewer working in suburban and rural areas.

Respondent Regions

Most respondents were between the ages of 35 and 65; about 32% (n=19) of advocates were 35-44 years old and 45% (n=9) of decision-makers were 45-54 years old.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Advocates</th>
<th>Decision-makers</th>
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<tbody>
<tr>
<td>Urban/City</td>
<td>39</td>
<td>16</td>
</tr>
<tr>
<td>Suburb</td>
<td>10</td>
<td>2</td>
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<tr>
<td>Rural</td>
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Most respondents were between the ages of 35 and 65; about 32% (n=19) of advocates were 35-44 years old and 45% (n=9) of decision-makers were 45-54 years old.

The majority of respondents in either category identified as white. About a quarter of the advocates (25%, n=15) identified as Hispanic or Latino, and 10% identified as black.
Advocates were asked what type of organization employed them; they could choose more than one. Over half (54%, n=32) reported working at a nonprofit organization, and 39% (n=23) in a peer-run organization. Almost one-third (27%, n=16) reported working for a government agency.

Decision-makers were employed by counties as care providers (including peer supporters) (23%, n=5), middle management (18%, n=4), executive management (14%, n=3), clinical supervisors (5%, n=1), administrative support (5%, n=1). Many (37%, n=8) chose to report “other”, including positions like “epidemiologist,” “parent partner,” or “associate.”

FREQUENCY OF ADVOCACY ACTIVITIES

We asked how often advocates engaged in specific advocacy activities in California in the past 6 months. Advocates were asked to report on their own activities, and decision-makers were asked to report on their observations of advocates’ activities in their county.

Figures 1 through 4 report the percentage of respondents that reported their own activities (“Advocates”) or observations of advocacy activities (“Decision-makers”). To a large extent, the groups reported similar frequency of advocacy activities, although respondents did not necessarily work in the same county.

Public education and relations advocacy are activities that increase awareness or change in public opinions about mental health issues and people who experience mental health issues. The most frequently reported Public Relations Advocacy activities were public education events (72% of advocates and 81% of decision-makers reporting) and conferences (62% of advocates and 72% of decision-makers).
Community planning and collaboration advocacy activities are those designed to change planning practices and existing services, and creation of new supports and services. The most frequently reported community planning and collaboration activities were representing consumer/survivor perspectives (64% of advocates, 71% of decision-makers) and collaborations among consumer advocacy groups (64% of advocates and 66% of decision-makers). While 75% of decision-makers reported advocates in their county engaged in local advisory committees, only 45% of consumer advocates reported this activity (respondents did not necessarily come from the same county).

Figure 1: Public Relations Advocacy Activities

Figure 2: Community Planning & Collaborations Activities
Political advocacy includes activities intended to change social policies and practices. The most frequently reported political advocacy activity was meeting with political or policy leaders. However, while 55% of advocates reported meeting with political leaders, close to 80% of decision-makers reported observing this activity.

Action research includes activities that gather information. Over 70% of advocates reported coordinating research access, and close to 60% reported conducting their own research.

Figure 5 shows the 11 advocacy activities reported by more than half of each group (or both) so we can see which activities are most common across categories. Four of the 11 activities are in the Public

**Figure 4: Political Advocacy Activities**

**Figure 5: Advocacy Activities in Any Category**
Relations category and four in Community Planning & Collaboration. The only Political Advocacy activity that was reported by more than 50% of either group was “meeting with political leaders or policy makers;” both Action Research activities were reported by more than half of respondents.

DESIRED IMPROVEMENTS FROM ADVOCACY ACTIVITIES

We wanted to know how advocacy contributes to policy dialogues through concrete actions. Advocates were asked to identify which activities they engaged in as well as what kind of improvement was desired and which sector was targeted to achieve this outcome. Advocates could choose more than one sector targeted by an activity, but only one type of change. Figure 6 shows what kind of change was desired by engaging in specific categories of advocacy.

Public Relations advocacy was most often intended to improve societal attitudes (31%). Community Collaborations activities were most frequently intended to improve local services (35%). Political advocacy was aimed at changing policy and legislation (69%), and Action Research was intended to improve local services.

Figure 7 shows which sector was targeted by advocacy to achieve changes in local services, policy/legislation, societal attitudes, or networking. Advocacy activities intended to change local services were most commonly directed toward the mental health system (45%) or the government (75%). Advocacy aimed at improving societal attitudes were most commonly directed toward the community (50%).
PERCEIVED EFFECTIVENESS OF ADVOCACY ACTIVITIES

We were interested in the perceptions of advocates and decision-makers about whether participation was substantial and meaningful, if it was conducted in a way that contributes to concrete policy and practice changes.

Decision-makers were asked to rate their county, as compared to other counties, in terms of engaging and collaborating with advocates. The results were fairly normally distributed, with about a third rating their county above average, a third about average, and a third below average. This suggests that respondents rated their county’s effectiveness rather accurately, as this is the distribution we would expect.

Both advocates and decision-makers reported on the effectiveness of advocacy in their county. The darker shading at the bottom of the columns indicates greater rating of effectiveness. For instance, about 50% of advocates rated their advocacy as either “extremely or very effective” in improving local services; about 37% of decision-makers rated advocacy as “extremely or very” effective in improving local services. Both groups rated advocacy as effective at improving networking for advocates (61% of advocates and 47% of decision-makers). The lowest ratings of effectiveness by both
groups of respondents was in changing policy/legislation; advocates were rated “slightly or not effective” by 38% of advocates and 42% of decision-makers.

DISCUSSION OF FINDINGS FROM THE SURVEY

Advocates in California engage in a wide variety of public relations, community planning, political advocacy, and action research advocacy activities. The most commonly reported activities are related to Public Relations, Community Collaborations, and Action Research, and less frequently to Political Advocacy.

The survey provides insight into the goals of advocacy. The most common improvement desired by advocacy was to affect policy and legislation, and the least common intention was to improve networking for advocates. The government sector was the most common target of advocacy intended to change policy and legislation.

While improving networking was not an intended outcome, it was most frequently rated by advocates an area in which their activities were effective. Policy and legislative change was rated as effectively a minority of advocates and decision-makers.

While this approach needs further development and ideally should be combined with other approaches in order to understand the impact of advocacy, there are some potentially interesting patterns. For instance, these data raise questions such as: If policy change is a frequently desired improvements, but one of the lowest ranked in effectiveness, how could activities be changed or adapted to have more of an impact?

CONCLUSIONS AND RECOMMENDATIONS ABOUT MEASURING ADVOCACY

Stakeholder advocacy includes activities by people directly affected by policy decisions, with the goal of guiding or changing policy through collective action. People directly affected by mental health policymaking are frequently a marginalized, under-resourced group, and there is very little information available to support decisions about what kinds of advocacy activities are most effective for achieving what kinds of results under what circumstances.²

The principle reason for the scarcity of research evidence is that the advocacy process does not lend itself to traditional program evaluation methods.¹³⁴ It is usually complex and non-linear. Policy change usually occurs as a consequence of multiple groups and social forces working in diverse ways, often with different specific goals and interests, over a long period; this makes it difficult to identify specific cause and effect relationships.⁵

Though randomized controlled designs are generally considered the “gold standard” in evaluation, the complexity of the advocacy process precludes using this method in this context. A more suitable method is an activity logging approach, in which a system is established for recording advocacy activities and attempting to identify associated outcomes. The conventional approach to assessing advocacy outcomes is to enumerate activities (what evaluators refer to as “outputs”)—for example, numbers of meetings with legislators, media events held, petitions signed, position papers produced, etc.
Although the objective impact of advocacy cannot necessarily be judged using this type of method, it does allow for broad-based sample of perceived impact. When paired with other approaches, this may be helpful in understanding the impact of and investments in advocacy. A similar study, whose methods we adapted, the Ontario Consumer/Survivor Development Initiative (CSDI)\(^1\), found that the activity log had practical benefits for consumer/survivor initiatives. The data were used to bring attention to the systems change efforts of consumer/survivor advocates. The tool helped advocates recognize the breadth of their efforts and provided them a sense of credibility and accomplishment. The activity log was also useful in reporting to funders, organizational boards of directors, and other stakeholders.\(^1\)

The obvious limitation of enumerating activities is that it is usually impossible to determine which activities actually produced a particular change in policy. All activities likely have some effect. But the ability to assess the relative impact of each activity over time would allow for continuous refinement in choosing how and where to focus resources for maximum impact. Other research used single questions asking respondents to assess whether goals were achieved in order to measure advocacy effectiveness. Earlier research has shown self-report to be reliable, and there are typically few incentives for respondents to misrepresent.\(^2\)

One difference in evaluating advocacy -in contrast to other types of activity- is the unpredictability of the process. Advocates typically respond to opportunities as they occur, such as new policy initiatives, leadership changes, etc. We therefore recommend that evaluation be approached from a learning perspective: that researchers and advocates share an understanding that advocacy is complex and usually unpredictable, and that evaluation is an ongoing process aimed at tailoring strategy to continuously improve advocacy outcomes.

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REFERENCES


