

**A Report for the State Mental
Health Agency Profiling System:**

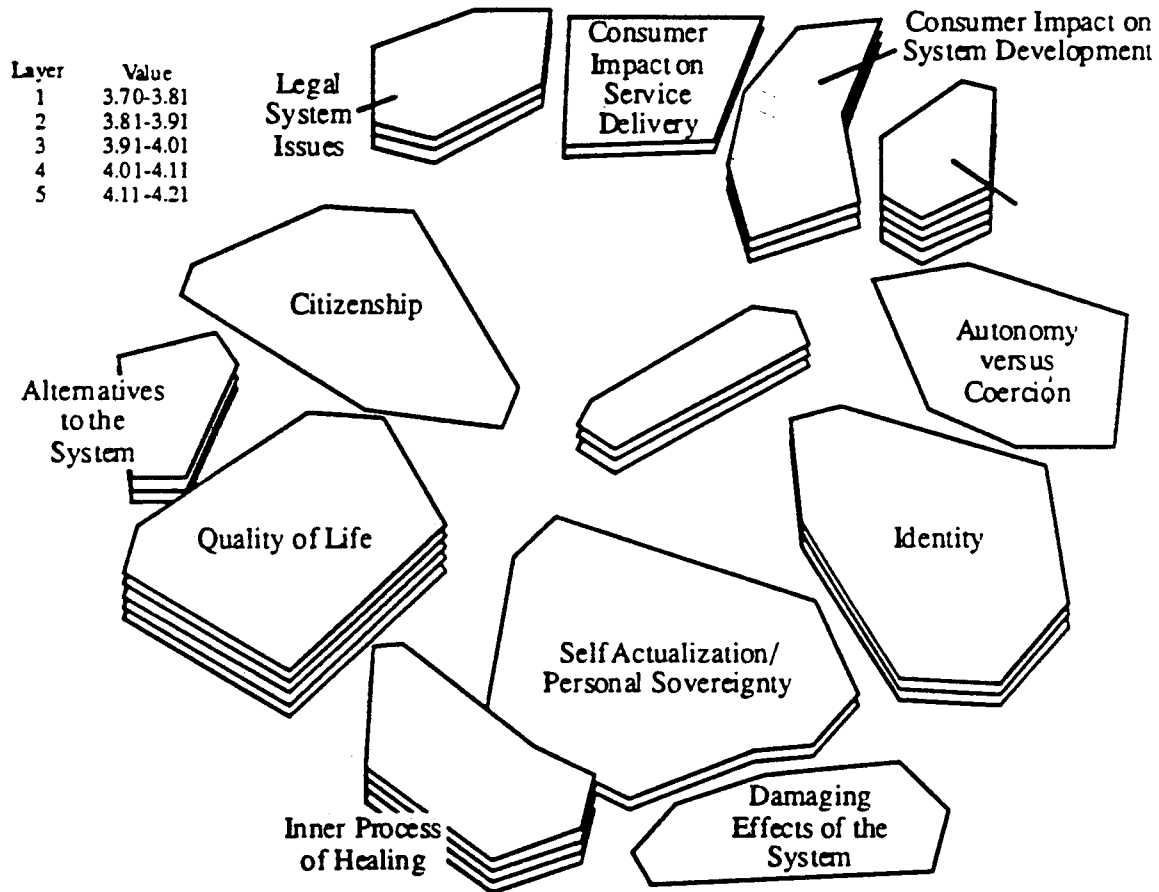
**Mapping Mental Health Outcomes from
the Perspective of Consumers/Survivors**

by

William Trochim, Jeanne Dumont, and Jean Campbell

**A Report for the State Mental Health Agency Profiling System:
Mapping Mental Health Outcomes from the Perspective of
Consumers/Survivors**

**submitted by
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**Concept Mapping Pilot
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Summary

This report summarizes a pilot project using concept mapping to provide input into the State Mental Health Agency Profiling System. This pilot was supported by the National Association of State Mental Health Program Directors (NASMHPD) Research Institute. Seventeen consumers/ survivors met in Wakefield, MA for two days to participate in a concept mapping of mental health outcomes from the perspective of consumers/survivors. William M.K. Trochim, Ph.D. and Jeanne Dumont, Ph.D. facilitated the concept mapping process using computer software developed by Dr. Trochim. Jean Campbell, Ph.D., Chair of the Outcomes Measures Task Force of the Consumer/Survivor Research and Policy Work Group, organized the meeting.

Seventeen people participated in the process with at least fifteen present at any given time. They brainstormed 98 statements that described "...specific consumer/survivor defined individual and/or system outcome indicators or measures that should be part of mental health system measurement". Each participant sorted these statements into piles of similar ones and rated each statement on a 1-to-5 importance rating. The data were analyzed using multidimensional scaling and hierarchical cluster analysis to produce several different types of concept maps. Statements were divided into 13 clusters of outcomes on the maps. Participants labeled the clusters and interpreted the maps. The major classes of outcomes involved those related to: the mental health system; control and voluntariness; personhood (including the damaging effects of the system on individuals); the inner process of healing; and, life in the community.

Recommendations from this study are:

- 1) A separate component of the State Mental Health Agency Profiling System should be developed by consumers/survivors drawing on the results of this concept mapping and subsequent work designed to replicate it. A subgroup of participants from the concept mapping pilot should be contracted by NASMHPD Research Institute to construct such a component.
- 2) As an interim step, questions should be formulated from statements of each cluster to collect information from State mental health agencies about whether and how they are measuring the proposed mental health outcomes.
- 3) The concept mapping process should be replicated with other consumer/survivor groups to better ascertain the validity and generalizability of the results obtained here. Additionally, other methods of collecting such information should be employed to examine the potential for methodological biases in results.

A Report for the State Mental Health Agency Profiling System

Mapping Mental Health Outcomes from the Perspective of Consumers/Survivors

Introduction

In "Caring for People with Severe Mental Disorders: A National Plan of Research to Improve Services," the NIMH identifies the study of service outcomes --whether specific treatments, broad social interventions, or both -- as one of the most critical elements of mental health services research. Until recently, the mental health system has primarily measured only what services are being provided and who the providers and recipients are. The national research plan acknowledges that studies of outcome are not easily accomplished. There are difficulties in assessing social, political, physical, and economic factors that influence the manifestation of mental illness and affect the development of adequate measures and research designs that would permit valid and reliable conclusions (NIMH, 1991; Consumer/ Survivor Mental Health Research and Policy Work Group, 1992).

Treatment utilization, compliance and efficacy are all affected by mental health consumer perceptions (Mirin and Namerow, 1991). However, consumer perceptions have largely been ignored in public-sector services and, in particular, in the research and practice of medicine. When mental health consumer perceptions are taken into account, they often differ with those of mental health professionals and caregivers (Ridgway, review, 1988). According to some consumers and survivors, traditional mental health systems pathologize problems in living, hold low expectations of consumer achievement, are paternalistic, offer a limited range of options, and define anger as symptomatic (Focus Group Meeting on Client Outcomes, June 2, 1992). Some of the key concerns identified by mental health consumers include the threat of involuntary treatments, subtle forms of coercion, lack of respect towards consumers by mental health professional and providers, and the debilitating side-effects from medications (Campbell and Schraiber, 1989). Often, researchers fail to ask questions (e.g., about the presence of personal freedom and decision-making power) that would capture detrimental effects of treatment and care (Campbell, 1992).

In the past few years, there has been increased interest in and support of consumer-based research on service priorities and desired outcomes. There is growing awareness of the often conflicting views of consumer/survivors and providers/researchers. And, at least for some groups of consumers, it is clear that there is greater resistance to or rejection of traditional treatment and services. There is genuine concern on the part of some mental health officials that mental health outcomes be assessed from the perspective of consumers/survivors. In a series of focus group sessions supported by the Mental Health Statistics Improvement Program (MHSIP), the Consumer/Survivor Mental Health Research and Policy Work Group has begun a systematic articulation and exploration of consumer values and outcomes. Recovery, personhood, well-being, and liberty have been identified as relevant outcomes that are seldom measured or operationalized in traditional mental health research or program evaluation (Consumer/Survivor Mental Health Research and Policy Work Group Task Force, June 2, 1992; July 13, 1992; September 30, 1992). This changing orientation toward meeting the needs of service recipients and assessing outcomes from their perspective parallels the recent emphasis in business and the government on the importance of the customer.

Background

The MHSIP Ad Hoc Advisory Group initiated a consumer/survivor focus group on mental health outcomes in June of 1992. From this group evolved the Consumer/Survivor Mental Health Research and Policy Work Group with an expanded focus that included a subcommittee on the development of outcome measures from the perspective of consumers/survivors. Categories of key mental health outcomes have been developed over the several Work Group meetings. Given concern about the diversity of persons who come to be recipients of mental health services, plans were developed to conduct fieldwork in various settings. A draft proposal was submitted to and approved by the Advisory Group in February to conduct this research. Concept mapping was viewed as a potential methodology for understanding consumer/survivor perspectives on outcomes. Before using this relatively new method in national field work, it was desirable that the members of the Work Group gain direct experience with the method in order to assess its feasibility and the potential utility of its results. The project described here constitutes the pilot study conducted for that purpose.

Concept mapping (Trochim, 1989a, Trochim & Linton, 1986) combines a structured group process (brainstorming, and sorting and rating of the brainstormed items) with several multivariate statistical analyses (multidimensional scaling and hierarchical cluster analysis). The analyses yield a variety of concept maps that show the original brainstormed statements and how they are perceived to be interrelated by the group. A facilitator assists the participants in examining the maps and developing an understanding of what they mean to the group. Concept mapping has some notable strengths. It is participatory and democratic, with each participant having an opportunity to provide crucial input. Because it is a structured process, it is possible to anticipate how long it will take and the type of product that will result. The maps constitute a visual result that emphasizes the relationships among all of the elements and is comprehensible to the whole group. But concept mapping is not without its weaknesses. The process is not particularly suited to large (> 25 persons) groups. It requires a minimum of two three-hour meetings. And, some groups may have philosophical or other objections to the use of multivariate statistical techniques or computer technology in this type of process (e.g., Linton, 1992).

Concept mapping has been utilized in mental health planning and evaluation contexts (Trochim, 1989a, 1989b). Dumont (1989, 1993) found it a useful and valid tool for theory development and measurement with persons who are consumers/survivors of the psychiatric system.

Participants

Seventeen persons participated in various parts of the concept mapping process. There was never fewer than fifteen persons participating at any given time. An information sheet was filled out by fifteen persons. There were 9 females and 8 males ranging in age from 33 to 62 with a median age of 42 years. Thirteen persons indicated that their racial background is white, one semitic and one celtic. The income range was between \$6,500 and \$75,000 with a median income of \$27,500. Only three months prior, one person had an annual income of \$2,500. Nine persons have advanced graduate degrees at the masters and doctoral level. Three persons have bachelor degrees. Three persons have some college education but not a degree. Most persons are currently employed.

All participants had what is considered a major psychiatric diagnosis (e.g., bi-polar, schizophrenia, depression). Many persons indicated their dislike of and problem with psychiatric labeling although only one person refused to answer the question asking for the primary diagnosis they were given by mental health professionals. The average number of

psychiatric admissions was 10.1. The median was 7.5. The range in number of psychiatric hospitalizations varied from 1 to 30.

Participants have varying degrees of involvement with the mental patient self-help/advocacy movement. Most persons are not registered clients in community mental health programs although a few indicated they had or were involved in psychosocial clubs or rehabilitation. Many persons are connected with the mental health system as providers of services, mental health researchers and administrators.

An attempt was made to achieve diversity in the participants. This was achieved in some respects (e.g., sex; ages spanning four decades). There was some discussion of how many participants have experienced minority status or prejudices in their lives. However, the group did not include any people of color.

It is important to note that this group is not, and was not intended to be, representative of all consumer/survivors. The purpose of this project was to have these participants use their varied experiences to examine the concept mapping methodology in order to determine its potential applicability in more broadly-based field studies. It is precisely because of the idiosyncratic nature of this group that such subsequent field studies were seen as desirable. Nevertheless, the results of this project are seen as generalizable to consumer/survivor groups that share the general perspectives of the participants.

Procedure

The general procedure for concept mapping is described in detail in Trochim (1989a). Examples of results of numerous concept mapping projects are given in Trochim (1989b). The process implemented here was accomplished in two days in July, 1993 (July 17-18, 1993). All analyses were conducted and maps produced using the Concept System[®] computer software¹ that was designed to implement this process. A laptop computer and LCD display panel were used during the brainstorming session so all participants could see the statements being generated. Although it was intended to use the computer display for the interpretation session on the second day, an equipment malfunction made this impossible. Consequently, the interpretation session was accomplished entirely with printed handouts to participants.

A subset of the participant group met on the evening of Friday, July 16th to discuss logistics, the NASMHPD's Profiling System and the focus question. Persons discussed the lack of a consumer perspective of the mental health system in the draft Profiling System document. Of course this was somewhat anticipated; participants were aware that NASMHPD was now requesting some consumer input. Still, reading through sixty pages of the document made the omission of consumer/survivors, the key and most affected stakeholder group of the mental health system, a glaring and disturbing one.

Among other issues, participants were concerned that the focus question of the concept mapping address system-relevant outcomes (in addition to individual-level ones) and that the outcomes not be limited only to consumer/survivor ones (i.e., that they be outcomes *from a consumer/survivor perspective*, but not limited to only consumer/survivor outcomes). They tentatively agreed on a focus statement, subject to revisions of the entire participant group on Saturday

¹ The Concept System[®] computer software is available for IBM-PC and compatible computers. Information about the software may be obtained by writing to Concept Systems, P.O. Box 4721, Ithaca NY 14853 or calling (607) 257-2375.

Day 1 (Saturday): Generation and Structuring of Conceptual Domain. At the first session, participants generated statements using a structured brainstorming process (Osborn, 1948) guided by a specific focus that limits the types of statements that are acceptable. The focus statement or criterion for generating statements was operationalized in the form of the instruction to the participants:

Generate statements that describe specific consumer/survivor defined individual and/or system outcome indicators or measures that should be part of mental health system measurement.

The general rules of brainstorming applied. Participants were encouraged to generate as many statements as possible (with an upper limit of 100); no criticism or discussion of other's statements were allowed (except for purposes of clarification); and all participants were encouraged to take part. The group brainstorming session took less than one hour and yielded 98 statements (see Appendix A).

Participants were given a short break during which the statements were printed and duplicated for use in the structuring stage. Structuring involved two distinct tasks: sorting, and rating of the brainstormed statements. For the sorting (Rosenberg and Kim, 1975; Weller and Romney, 1988), each participant was given a listing of the statements laid out in mailing label format with twelve to a page and asked to cut the listing into slips with one statement (and its identifying number) on each slip. They were instructed to group the statement slips into piles of similar ones. The only restrictions in this sorting task were that there could not be: (a) N piles (where N is the total number of statements); (b) one pile; or (c) a "miscellaneous" pile (any item thought to be unique is to be put in its own separate pile). Participants were encouraged to have between 10 and 25 piles overall. Weller and Romney point out why sorting (in their terms, the pile sort method) is appropriate in this context:

The outstanding strength of the pile sort task is the fact that it can accommodate a large number of items. We know of no other data collection method that will allow the collection of judged similarity data among over 100 items. This makes it the method of choice when large numbers are necessary. Other methods that might be used to collect similarity data, such as triads and paired comparison ratings, become impractical with a large number of items (p. 25).

After sorting the statements, each participant recorded the statement identifying numbers by pile on the back of the rating sheet. For the rating task, the brainstormed statements were listed in a questionnaire format and each participant was asked to rate each statement on a 5-point Likert-type response scale in terms of how important the outcome is where 1=relatively unimportant (compared with the rest of the statements); 2=somewhat important; 3=moderately important; 4=very important, and, 5=extremely important. Because participants were unlikely to brainstorm statements that are totally unimportant, it was stressed that the rating should be considered a *relative* judgment of the importance of each item to all the other items brainstormed.

This concluded the first day's group session. That evening, the data were entered into the computer, the analyses run, and the materials needed for the second day's session produced.

Data Analysis. For each person an NxN binary, symmetric matrix of similarities, X_{ij} , was constructed from the sort information. For any two items i and j , a 1 was placed in X_{ij} if the two items were placed in the same pile by the participant, otherwise a 0 was entered

(Weller and Romney, 1988, p. 22). A total $N \times N$ (i.e., 98×98) similarity matrix, T_{ij} was obtained by summing across the individual X_{ij} matrices. Thus, any cell in this matrix could take integer values between 0 and M (where M = the number of people who sorted the statements, in this case, 15); the value indicates the number of people who placed the i, j pair in the same pile.

The total matrix T_{ij} was analyzed using nonmetric multidimensional scaling (MDS) analysis with a two-dimensional solution. The solution was limited to two dimensions because, as Kruskal and Wish (1978) point out:

Since it is generally easier to work with two-dimensional configurations than with those involving more dimensions, ease of use considerations are also important for decisions about dimensionality. For example, when an MDS configuration is desired primarily as the foundation on which to display clustering results, then a two-dimensional configuration is far more useful than one involving three or more dimensions (p. 58).

The analysis yielded a two-dimensional (x, y) configuration of the set of statements that best satisfies the criterion that statements piled together most often are located more proximately in two-dimensional space while those piled together less frequently are further apart. The final stress value for the two-dimensional configuration was .3465411.

The x, y MDS configuration was the input for the hierarchical cluster analysis utilizing Ward's algorithm (Everitt, 1980) as the basis for defining a cluster. Using the MDS configuration as input to the cluster analysis in effect forces the cluster analysis to partition the MDS configuration into non-overlapping clusters in two-dimensional space. There is no simple mathematical criterion by which a final number of clusters can be selected. The procedure that was followed here was to examine an initial cluster solution that was clearly lower than the desirable final number of clusters. In this case, we began with a four cluster solution. Then, successively higher cluster solutions that showed how clusters were split were examined, with a judgment made at each step about whether the split seemed substantively reasonable. Examination of the pattern of judgments of the suitability of different cluster solutions lead to the selection of a final cluster solution of 13 clusters that preserved the most detail while at the same time yielding clusters that were substantively interpretable. Nearly half of the participants participated informally in this cluster selection process.

The MDS configuration was graphed in two dimensions (Figure 1). This "point map" showed all the brainstormed statements with those closer to each other generally expected to be more similar in meaning. A "cluster map" was also generated (Figure 2), showing the original statement points enclosed in cluster boundaries.

The 1-to-5 rating data was averaged across persons for each item and cluster. This rating information was depicted graphically in a "point rating map" (Figure 3) showing the original point map with the average rating per item displayed as different size circles, and in a "cluster rating map" that showed the cluster average rating using the third dimension. The following materials were prepared for use in the interpretation session on the second day:

- (1) the list of the brainstormed statements grouped by cluster
- (2) the point map showing the MDS placement of the brainstormed statements and their identifying numbers
- (3) the cluster map showing the cluster solution

- (4) the point rating map showing the MDS placement of the brainstormed statements and their identifying numbers, with average statement ratings overlaid
- (5) the cluster rating map showing the cluster solution, with average cluster ratings overlaid

Day 2 (Sunday): Interpretation of the Concept Maps. The second session was convened on day two to interpret the results of the conceptual mapping analysis. This session followed a structured process described in detail in Trochim (1989a). The facilitator began the session by giving the group the listing of clustered statements and reminding them of the brainstorming, sorting and rating tasks performed the previous day. The facilitator led the group in a discussion where they worked cluster-by-cluster to achieve group consensus on an acceptable label for each cluster. The listing included a "bridging" value for each statement and average bridging value for each cluster. Participants were told that lower bridging values mean that the statement is more central to the meaning of the cluster while higher bridging values imply that the item is more likely one that relates to several clusters and, consequently, should be given less consideration when deciding on a label. In most cases, when persons suggested labels for a specific cluster, the group readily came to a consensus. Where the group had difficulty achieving a consensus, the facilitator suggested they use a hybrid label, combining key terms or phrases from several individuals' titles.

Once the clusters were labeled, the group was given the point map (Figure 1) and told that the analysis placed the statements on the map in such a way that statements frequently piled together are, in general, closer to each other on the map than statements infrequently piled together. To reinforce the notion that the analysis placed the statements sensibly, participants were given a few minutes to identify statements close together on the map and examine the contents of those statements. After becoming familiar with the numbered point map, they were told that the analysis also organized the points into clusters as reflected on the list of clustered statements they had already labeled. The cluster map (Figure 2) was presented and participants were shown that it was simply a visual portrayal of the cluster list. The cluster labels were entered next to the appropriate cluster on the cluster map (as shown in Figure 4).

Participants then examined the labeled cluster map (Figure 4) to see whether it made sense to them. The facilitator reminded participants that in general, clusters closer together on the map should be conceptually more similar than clusters farther apart and asked them to assess whether this seemed to be true or not. Participants were asked to think of a geographic map, and "take a trip" across the map examining each cluster in turn to see whether or not the visual structure seemed sensible. They were then asked to identify any interpretable groups of clusters or "regions." This portion of the interpretation was audiotaped and transcribed.

The facilitator explained that all of the material presented to this point used only the sorting data. The results of the rating task were then presented through the point rating (Figure 3) and cluster rating (Figure 5) maps. Participants were encouraged to examine these maps to determine whether they made sense intuitively and to discuss what they might imply about the ideas that underlie their conceptualization. The remainder of the session was devoted to summarizing the process.

Summary of Results and Interpretation

The mapping resulted in the following data/maps:

- the list of the 98 brainstormed statements (Appendix A)
- the point map showing the MDS placement of the brainstormed statements and their identifying numbers (Figure 1)
- the cluster map showing the 13 cluster solution (Figure 2)
- the cluster listing with bridging values (Appendix B)
- the point rating map showing the MDS placement of the brainstormed statements and their identifying numbers, with average statement ratings overlaid (Figure 3)
- the labeled cluster map (Figure 4)
- the cluster rating listing (Appendix C)
- the cluster rating map showing the cluster solution, with average cluster ratings overlaid (Figure 5)
- the audiotaped and transcribed portion of the interpretation and uses of the maps

In the discussion, participants considered the dynamics of concepts across the cluster map. This discussion contributed to the subsequent understanding of how participants might use the maps to inform measurement. Participants examined what different regions of the map meant and identified underlying dimensions across the map. Generally, participants viewed the northern region of the map as focusing on system issues; the northeast region on issues of control and voluntariness; the southeast region on personhood including the damaging effects of the system on it; the southwest region on the inner process of healing; and the western region on whole life in the community.

In making sense of interrelationships, many persons drew lines dividing the map into regions. The regions previously described best fit a diagonal or X-shape. Others divided the map along the x and y axis. Here, the dimension running north and south has to do with services, from system effects (north) to personal effects (south); while the dimension running east to west, from the personal, individual, individualistic type issues (east) to issues related to interactions, relationships, and responsibilities toward others (west). Persons pointed out that if a line were drawn running southwest to northeast, the east/southeast portion of the map concentrates on concepts central to recovery; the west/northwest concentrates on empowerment.

It was generally agreed by participants that the ratings were relatively high because of the importance of each brainstormed outcome indicator or measure and that the rating instruction may have been too vague. Even so, there may be patterns in terms of the ratings (e.g. those things that are more pro-active and bring power either to the individual or the consumer survivor movement tend to be higher, and those things that are negative that decrease one's power or ability tend to be lower). However, such hypothesized relationships have not been confirmed. It could be that such a relationships may be more

an artifact of the method than an indication that consumer/survivors think it is more important to measure, for example, the inner process of healing than the damaging effects of the system. We think exploration of possible patterns in the current rating warrant our further exploration and discussion.

A key conclusion regarding the various interrelationships and the relatively high ratings was that any set of questions developed based on this mapping process should respect the contextual integrity of the maps, i.e., questions must cover the gamut of the concepts and particular concepts should not be pulled out to stand alone. As Dr. Campbell explained,

...if you have a healing scale, that by itself could be totally distorted and seem like a self-esteem scale, but if you were forced to analyze that in the context of some of these other things like coercion, damaging effects of the system, it would prevent it from being misinterpreted or co-opted.

Recommendations

1) A separate component of the State Mental Health Agency Profiling System should be developed by consumers/survivors drawing on the results of this concept mapping and subsequent work designed to replicate it. A subgroup of participants from the concept mapping pilot should be contracted by NASMHPD Research Institute to construct such a component.

2) As an interim step, questions should be formulated from statements of each cluster grouping to collect information from State mental health agencies about whether and how they are measuring the proposed mental health outcomes. Using cluster 1, for example, the agencies could be asked:

Does your state measure potential damaging effects of the system such as

- illiteracy from taking psychotropic medications? _____ How? _____
- long-term memory loss from ECT?
- unresolved psychotic hallucinations (from treatment system in general)?
- magnification of one's own weaknesses (from treatment system in general)?
- learned helplessness (from treatment system in general)?

and so forth with each statement for each cluster grouping. Alternately, a subgroup of participants from the concept mapping pilot could be selected to reduce the number of questions for this interim step if 98 are viewed by the NASMHPD Institute as too many.

In addition, it would be valuable to know what outcomes in general are being measured by SMHAs and by what means.

3) The concept mapping process should be replicated with other consumer/survivor groups to better ascertain the validity and generalizability of the results obtained here. Additionally, other methods of collecting such information should be employed to examine the potential for methodological bias in results.

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Figure 1. Numbered Point Map.

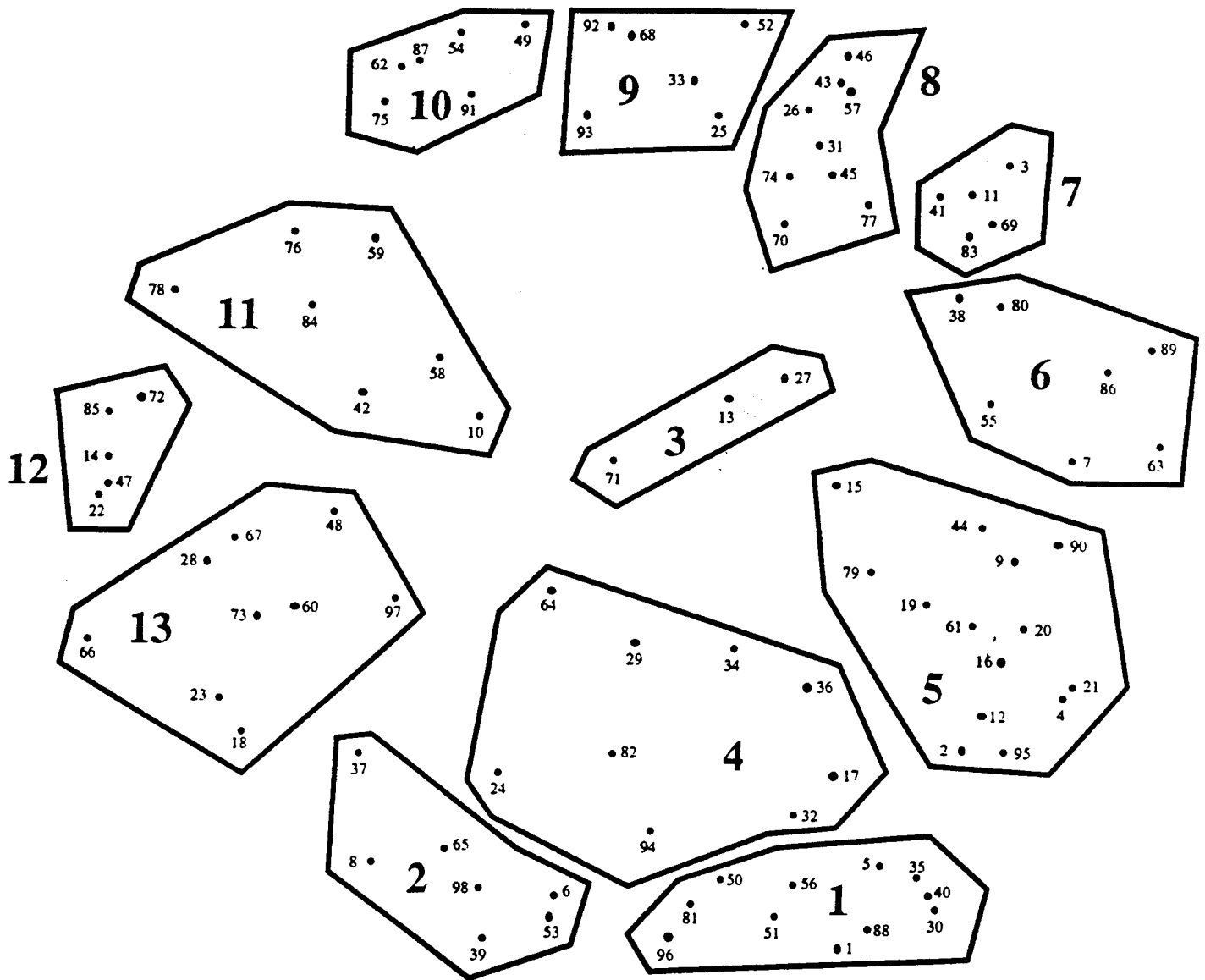


Figure 2. Cluster Map.

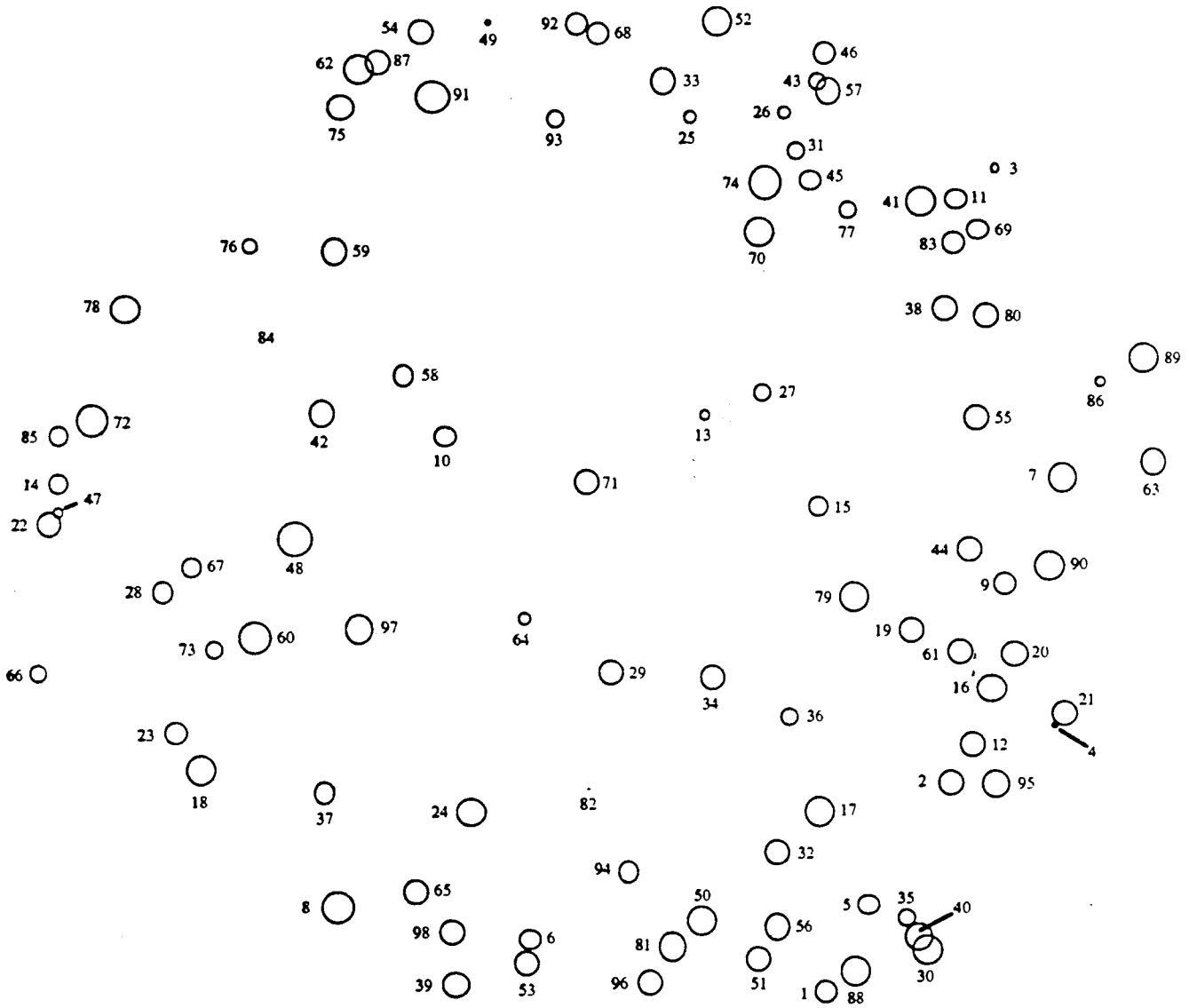


Figure 3. Point Rating Map (bigger circles indicate higher average importance ratings)

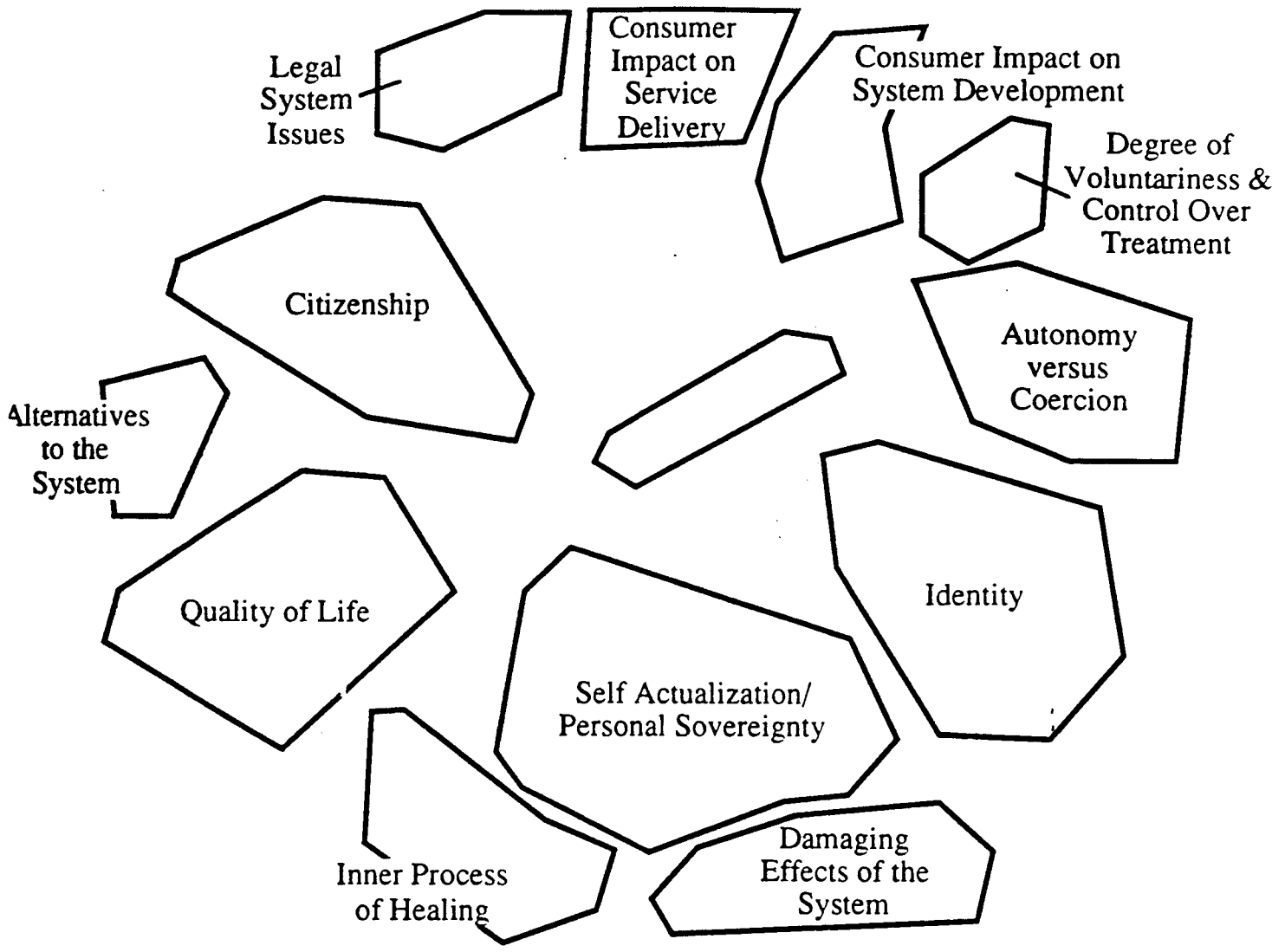


Figure 4. Labeled Cluster Map.

Appendix A: Listing of Brainstormed Statements

- 1 illiteracy due to psychotropic medications (can't read, concentrate, focus)
- 2 ability to articulate and name their experience (as a narrative; human story)
- 3 voluntariness of services delivered
- 4 how close is person's life situation to where they want it to be
- 5 learned helplessness
- 6 being able to transform painful situations into positive life experiences
- 7 individual responsibility that doesn't 'blame the victim'
- 8 the impact of poverty on quality of your life
- 9 ability (or lack thereof) to change one's circumstances
- 10 true citizenship (feeling like a free agent in society)
- 11 desired services not contingent upon accepting undesired services
- 12 ownership of one's own emotional life (being able to name and experience one's own emotions)
- 13 being able to live one's life without parental supervision or interference
- 14 access to a broad range of holistic health approaches
- 15 being able to be medically treated for what we say is wrong (in terms of symptoms we describe)
- 16 ability to articulate symptoms
- 17 self-mastery over our emotional life
- 18 potential for forming significant emotional/love and/or sexual relationships
- 19 ability to express your spirituality (meditation or positive withdrawal) and be a member of a spiritual community
- 20 freedom to engage in spiritual expression without that being determined as delusional or manifestation of psychotic symptoms
- 21 ability to form life strategies
- 22 natural healing through natural herbs and minerals and ecology concerns being brought into the movement
- 23 access to food, shelter and clothing and choices and types of same
- 24 recognition of commonality of experiences and behaviors versus psychologizing
- 25 the ability to fire inept psychiatrists, psychologists and social workers through a determined means of egress
- 26 an effective feedback mechanism from users of services to providers
- 27 non-compliance to forced treatment as a positive or healthy response
- 28 loss of or preservation of pre-existing family relationships or friendships
- 29 crisis as an opportunity for change rather than recovery to former status
- 30 violent behavior provoked by the system/professionals
- 31 elimination of status hierarchies and dichotomy between allegedly healthy staff and 'sick' clients
- 32 recognition of delayed effects of violence (e.g., sexual, psychological, physical abuse)
- 33 closure of all state hospitals in U.S.; MH services given in community of choice
- 34 recognizing the uniqueness, dignity, worth and potential of all consumer/survivors
- 35 trauma due to psychiatric modalities including involuntary commitment, seclusion, restraints, etc.
- 36 inability to select appropriate resources for solving specific problems
- 37 capacity to support healing from abuse (e.g., physical, sexual, emotional trauma)
- 38 freedom of consumers to research the derivatives of medications
- 39 recognition of overt anger as a healthy and positive response

- 40 systematic measures of iatrogenic disease/disorder personality deterioration due to pharmaceutical/electro shock
- 41 ability to effect a total divorce from the MH system if one so chooses
- 42 ability to retain custody of one's children
- 43 influence of and access to information about clients/consumers/survivors experience with MH system
- 44 self-definition of need/want
- 45 all treatments should be evaluated with respect to their effects on the person being treated rather than convenience of staff
- 46 informed consent regarding treatments and information dissemination
- 47 creation of a network of sanctuaries, oases of healing where nutritious food, comfortable peaceful surroundings and affirming people are available
- 48 full access for physical health care needs
- 49 recognition and enforcement of civil rights and patient rights
- 50 measurement of the effects of prejudice and discrimination on individual's emotional and psychological well-being and recovery
- 51 recognition of trauma due to unresolved psychotic hallucinations (repression & denial or delusion & denial) and ability to recognize healthy intuitive living & resolve past related traumas
- 52 documentation of and public access to client complaints
- 53 enhancement of creativity/imagination/capacity to make metaphors
- 54 elimination of any legal status differentials based on history of psychiatric treatment
- 55 degree to which your life choices and behavior are limited by your fear of forced treatment/commitment
- 56 magnification of your own weaknesses
- 57 satisfactory resolution of complaints from viewpoint of person registering complaint
- 58 physical and emotional safety including right to be protected from victimization
- 59 efforts to recruit & hire consumer/survivors at all levels
- 60 educational and employment opportunities for client/survivors both in mainstream & alternative settings
- 61 freedom to reclaim cultural & ethnic identity & autonomy
- 62 the legal clause 'dangerousness to oneself or others' invoked only when a violent act actually occurs, not when a bystander imagines one might happen in future
- 63 measure of MH system to either evoke or agitate feelings of suicide within its treatment recipients
- 64 enhancement of quality of life through personal choices for meaningful work or education as opposed to being earmarked to food, filth and filing
- 65 measurement of the effects of support and lack of support of one's dignity, respect, experience, knowledge, voice
- 66 involvement in and effective using of self-help groups and/or projects
- 67 ability to form and maintain healthy parent-child relationships
- 68 prevalence of court-ordered treatment compliance in community consumer population
- 69 deference to wishes of primary consumer of MH care even when those wishes conflict with wishes of a family member
- 70 how status/power/funding are maintained/increased by MH/pharmaceutical industry by interface with mentally-labeled people
- 71 de-medicalization of crisis so people are better able to seek out support at times as defined by them

- 72 widespread availability of a variety of methods of helping individuals deal with crisis
- 73 living in an integrated setting with non-psychiatrically labeled people and having regular contact with them
- 74 money allocated to services be re-allocated to individuals to use as they choose
- 75 distinction between MH and criminal justice systems so that expressions of mental illness aren't treated as criminal behavior and criminal behavior not treated as mental illness
- 76 recognition of interests of families or other systems asked to provide supports
- 77 recognition of competing interests of clients, family, professionals with client being final arbiter of what constitutes beneficial outcomes
- 78 full-time work week redefined as 4 days a week, 32 hours, flexible schedule with 6 weeks vacation and full health benefits and leave-of-absence policy
- 79 removal of a psychiatric diagnosis as the determination for human growth and potential
- 80 when choosing treatment, that it be with the consumer/survivor not to, at, or for
- 81 measurement of the effect of respect or lack of respect of one's physical body including one's time, place, physical deformity due to drugs & treatment
- 82 ability to acknowledge and recognize stigma and to remain functional and engaged
- 83 consumer control over consumer's treatment record including destruction thereof
- 84 freedom for client survivor to parent children if they choose to and a massively more progressive policy for client survivors to keep custody of children
- 85 development of small, non-hospital residential crisis facilities as alternatives to involuntary hospitalization
- 86 measures of scape-goating tendencies (projection of dark side) by 'providers' and 'consumers'
- 87 elimination of insanity defense and not guilty by reason of insanity plea as a reclaiming of full citizenship
- 88 long-term effects of ECT-induced memory loss on quality of life
- 89 measures of involuntary treatment as system failures
- 90 individual takes responsibility for that which is her/his responsibility
- 91 absolute right to engage in any legal or law-abiding behavior regardless of psychiatric label or lack of one
- 92 expeditious access to rights protection, lawyers, other legal advocacy
- 93 credentials and licensure of MH professionals shall be contingent upon having consumers/survivors as faculty at every level/stage of training
- 94 measurement of effects of support or lack of support of individual coping styles and choices in response to emotional distress
- 95 feelings of increased authenticity with one's identity (sense of self-definition, self-ownership, personal efficacy)
- 96 measures of effects of social and interpersonal precipitators of emotional and psychological distress
- 97 measures of satisfaction with one's ability to participate in the civic, democratic, and policy-making arena in one's community
- 98 measurement of effects of impoverishment or support of one's life expectations, hopes and dreams

Appendix B: Cluster Bridging Listing

Cluster 1: Damaging Effects of the System		
1	illiteracy due to psychotropic medications (can't read, concentrate, focus)	0.19
88	long-term effects of ECT-induced memory loss on quality of life	0.18
51	recognition of trauma due to unresolved psychotic hallucinations (repression & denial or delusion & denial) and ability to recognize healthy intuitive living & resolve past related traumas	0.10
56	magnification of your own weaknesses	0.14
5	learned helplessness	0.13
30	violent behavior provoked by the system/professionals	0.26
40	systematic measures of iatrogenic disease/disorder personality deterioration due to pharmaceutical/electro shock	0.22
35	trauma due to psychiatric modalities including involuntary commitment, seclusion, restraints, etc.	0.27
50	measurement of the effects of prejudice and discrimination on individual's emotional and psychological well-being and recovery	0.22
81	measurement of the effect of respect or lack of respect of one's physical body including one's time, place, physical deformity due to drugs & treatment	0.43
96	measures of effects of social and interpersonal precipitators of emotional and psychological distress	0.17
	Cluster Average	0.21
 Cluster 2: Inner Process of Healing		
6	being able to transform painful situations into positive life experiences	0.36
53	enhancement of creativity/imagination/capacity to make metaphors	0.45
39	recognition of overt anger as a healthy and positive response	0.56
65	measurement of the effects of support and lack of support of one's dignity, respect, experience, knowledge, voice	0.54
98	measurement of effects of impoverishment or support of one's life expectations, hopes and dreams	0.54
8	the impact of poverty on quality of your life	0.66
37	capacity to support healing from abuse (e.g., physical, sexual, emotional trauma)	0.79
	Cluster Average	0.56
 Cluster 3		
13	being able to live one's life without parental supervision or interference	0.41
27	non-compliance to forced treatment as a positive or healthy response	0.40

71	de-medicalization of crisis so people are better able to seek out support at times as defined by them	0.53
3	Cluster Average	0.45
Cluster 4: Self Actualization/Personal Sovereignty		
17	self-mastery over our emotional life	0.04
32	recognition of delayed effects of violence (e.g., sexual, psychological, physical abuse)	0.35
34	recognizing the uniqueness, dignity, worth and potential of all consumer/survivors	0.25
36	inabilities to select appropriate resources for solving specific problems	0.39
24	recognition of commonality of experiences and behaviors versus psychologizing	0.50
82	ability to acknowledge and recognize stigma and to remain functional and engaged	0.54
94	measurement of effects of support or lack of support of individual coping styles and choices in response to emotional distress	0.31
29	crisis as an opportunity for change rather than recovery to former status	0.34
64	enhancement of quality of life through personal choices for meaningful work or education as opposed to being earmarked to food, filth and filing	0.48
	Cluster Average	0.36
Cluster 5: Identity		
2	ability to articulate and name their experience (as a narrative; human story)	0.00
95	feelings of increased authenticity with one's identity (sense of self-definition, self-ownership, personal efficacy)	0.11
12	ownership of one's own emotional life (being able to name and experience one's own emotions)	0.10
4	how close is person's life situation to where they want it to be	0.24
21	ability to form life strategies	0.28
16	ability to articulate symptoms	0.26
20	freedom to engage in spiritual expression without that being determined as delusional or manifestation of psychotic symptoms	0.27
61	freedom to reclaim cultural & ethnic identity & autonomy	0.31
9	ability (or lack thereof) to change one's circumstances	0.19
90	individual takes responsibility for that which is her/his responsibility	0.41
44	self-definition of need/want	0.21
15	being able to be medically treated for what we say is wrong (in terms of symptoms we describe)	0.49
19	ability to express your spirituality (meditation or positive withdrawal) and be a member of a spiritual community	0.29

79	removal of a psychiatric diagnosis as the determination for human growth and potential	0.32
	Cluster Average	0.25
Cluster 6: Autonomy versus Coercion		
7	individual responsibility that doesn't 'blame the victim'	0.48
63	measure of MH system to either evoke or agitate feelings of suicide within its treatment recipients	0.83
86	measures of scape-goating tendencies (projection of dark side) by 'providers' and 'consumers'	0.65
89	measures of involuntary treatment as system failures	0.54
38	freedom of consumers to research the derivatives of medications	0.42
80	when choosing treatment, that it be with the consumer/survivor not to, at, or for	0.35
55	degree to which your life choices and behavior are limited by your fear of forced treatment/commitment	0.56
	Cluster Average	0.55
Cluster 7: Degree of Voluntariness & Control Over Treatment		
3	voluntariness of services delivered	0.27
11	desired services not contingent upon accepting undesired services	0.16
41	ability to effect a total divorce from the MH system if one so chooses	0.21
69	deference to wishes of primary consumer of MH care even when those wishes conflict with wishes of a family member	0.31
83	consumer control over consumer's treatment record including destruction thereof	0.25
	Cluster Average	0.24
Cluster 8: Consumer Impact on System Development		
26	an effective feedback mechanism from users of services to providers	0.22
43	influence of and access to information about clients/consumers/survivors experience with MH system	0.11
57	satisfactory resolution of complaints from viewpoint of person registering complaint	0.13
46	informed consent regarding treatments and information dissemination	0.07
31	elimination of status hierarchies and dichotomy between allegedly healthy staff and 'sick' clients	0.24
45	all treatments should be evaluated with respect to their effects on the person being treated rather than convenience of staff	0.26
74	money allocated to services be re-allocated to individuals to use as they choose	0.25

70	how status/power/funding are maintained/increased by MH/pharmaceutical industry by interface with mentally-labeled people	0.33
77	recognition of competing interests of clients, family, professionals with client being final arbiter of what constitutes beneficial outcomes	0.27
	Cluster Average	0.21

Cluster 9: Consumer Impact on Service Delivery

25	the ability to fire inept psychiatrists, psychologists and social workers through a determined means of egress	0.08
33	closure of all state hospitals in U.S.; MH services given in community of choice	0.29
52	documentation of and public access to client complaints	0.16
68	prevalence of court-ordered treatment compliance in community consumer population	0.31
92	expeditious access to rights protection, lawyers, other legal advocacy	0.04
93	credentials and licensure of MH professionals shall be contingent upon having consumers/survivors as faculty at every level/stage of training	0.24
	Cluster Average	0.19

Cluster 10: Legal System Issues

49	recognition and enforcement of civil rights and patient rights	0.11
54	elimination of any legal status differentials based on history of psychiatric treatment	0.00
91	absolute right to engage in any legal or law-abiding behavior regardless of psychiatric label or lack of one	0.33
62	the legal clause 'dangerousness to oneself or others' invoked only when a violent act actually occurs, not when a bystander imagines one might happen in future	0.27
87	elimination of insanity defense and not guilty by reason of insanity plea as a reclaiming of full citizenship	0.24
75	distinction between MH and criminal justice systems so that expressions of mental illness aren't treaded as criminal behavior and criminal behavior not treated as mental illness	0.57
	Cluster Average	0.25

Cluster 11: Citizenship

10	true citizenship (feeling like a free agent in society)	0.53
58	physical and emotional safety including right to be protected from victimization	0.65
42	ability to retain custody of one's children	0.49
59	efforts to recruit & hire consumer/survivors at all levels	0.79

76	recognition of interests of families or other systems asked to provide supports	1.00
84	freedom for client survivor to parent children if they choose to and a massively more progressive policy for client survivors to keep custody of children	0.56
78	full-time work week redefined as 4 days a week, 32 hours, flexible schedule with 6 weeks vacation and full health benefits and leave-of-absence policy	0.78

Cluster Average 0.69

Cluster 12: Alternatives to the System

14	access to a broad range of holistic health approaches	0.35
22	natural healing through natural herbs and minerals and ecology concerns being brought into the movement	0.18
47	creation of a network of sanctuaries, oases of healing where nutritious food, comfortable peaceful surroundings and affirming people are available	0.31
72	widespread availability of a variety of methods of helping individuals deal with crisis	0.55
85	development of small, non-hospital residential crisis facilities as alternatives to involuntary hospitalization	0.29

Cluster Average 0.34

Cluster 13: Quality of Life

18	potential for forming significant emotional/love and/or sexual relationships	0.63
23	access to food, shelter and clothing and choices and types of same	0.88
66	involvement in and effective using of self-help groups and/or projects	0.68
28	loss of or preservation of pre-existing family relationships or friendships	0.43
67	ability to form and maintain healthy parent-child relationships	0.39
60	educational and employment opportunities for client/survivors both in mainstream & alternative settings	0.61
73	living in an integrated setting with non-psychiatrically labeled people and having regular contact with them	0.48
48	full access for physical health care needs	0.64
97	measures of satisfaction with one's ability to participate in the civic, democratic, and policy-making arena in one's community	0.59

Cluster Average 0.59

Appendix C: Cluster Rating Listing

Cluster 1: Damaging Effects of the System

1	illiteracy due to psychotropic medications (can't read, concentrate, focus)	3.80
88	long-term effects of ECT-induced memory loss on quality of life	4.13
51	recognition of trauma due to unresolved psychotic hallucinations (repression & denial or delusion & denial) and ability to recognize healthy intuitive living & resolve past related traumas	3.07
56	magnification of your own weaknesses	2.73
5	learned helplessness	3.80
30	violent behavior provoked by the system/professionals	3.73
40	systematic measures of iatrogenic disease/disorder personality deterioration due to pharmaceutical/electro shock	4.29
35	trauma due to psychiatric modalities including involuntary commitment, seclusion, restraints, etc.	4.73
50	measurement of the effects of prejudice and discrimination on individual's emotional and psychological well-being and recovery	3.73
81	measurement of the effect of respect or lack of respect of one's physical body including one's time, place, physical deformity due to drugs & treatment	3.80
96	measures of effects of social and interpersonal precipitators of emotional and psychological distress	3.93
	Cluster Average	3.80

Cluster 2: Inner Process of Healing

6	being able to transform painful situations into positive life experiences	4.13
53	enhancement of creativity/imagination/capacity to make metaphors	3.00
39	recognition of overt anger as a healthy and positive response	3.93
65	measurement of the effects of support and lack of support of one's dignity, respect, experience, knowledge, voice	3.93
98	measurement of effects of impoverishment or support of one's life expectations, hopes and dreams	4.47
8	the impact of poverty on quality of your life	4.47
37	capacity to support healing from abuse (e.g., physical, sexual, emotional trauma)	4.33
	Cluster Average	4.04

Cluster 3

13	being able to live one's life without parental supervision or interference	4.00
27	non-compliance to forced treatment as a positive or healthy response	4.00
71	de-medicalization of crisis so people are better able to seek out support at times as defined by them	4.00

	Cluster Average	4.00
Cluster 4: Self Actualization/Personal Sovereignty		
17	self-mastery over our emotional life	4.00
32	recognition of delayed effects of violence (e.g., sexual, psychological, physical abuse)	3.80
34	recognizing the uniqueness, dignity, worth and potential of all consumer/survivors	4.47
36	inabilities to select appropriate resources for solving specific problems	3.33
24	recognition of commonality of experiences and behaviors versus psychologizing	3.33
82	ability to acknowledge and recognize stigma and to remain functional and engaged	3.40
94	measurement of effects of support or lack of support of individual coping styles and choices in response to emotional distress	3.73
29	crisis as an opportunity for change rather than recovery to former status	4.13
64	enhancement of quality of life through personal choices for meaningful work or education as opposed to being earmarked to food, filth and filing	4.33
	Cluster Average	3.84
Cluster 5: Identity		
2	ability to articulate and name their experience (as a narrative; human story)	3.40
95	feelings of increased authenticity with one's identity (sense of self-definition, self-ownership, personal efficacy)	4.20
12	ownership of one's own emotional life (being able to name and experience one's own emotions)	4.07
4	how close is person's life situation to where they want it to be	4.07
21	ability to form life strategies	3.50
16	ability to articulate symptoms	3.47
20	freedom to engage in spiritual expression without that being determined as delusional or manifestation of psychotic symptoms	3.87
61	freedom to reclaim cultural & ethnic identity & autonomy	4.07
9	ability (or lack thereof) to change one's circumstances	4.00
90	individual takes responsibility for that which is her/his responsibility	4.07
44	self-definition of need/want	4.27
15	being able to be medically treated for what we say is wrong (in terms of symptoms we describe)	4.07
19	ability to express your spirituality (meditation or positive withdrawal) and be a member of a spiritual community	3.60
79	removal of a psychiatric diagnosis as the determination for human growth and potential	4.20
	Cluster Average	3.92

Cluster 6: Autonomy versus Coercion

7	individual responsibility that doesn't 'blame the victim'	3.87
63	measure of MH system to either evoke or agitate feelings of suicide within its treatment recipients	3.73
86	measures of scape-goating tendencies (projection of dark side) by 'providers' and 'consumers'	2.93
89	measures of involuntary treatment as system failures	4.60
38	freedom of consumers to research the derivatives of medications	2.80
80	when choosing treatment, that it be with the consumer/survivor not to, at, or for	4.33
55	degree to which your life choices and behavior are limited by your fear of forced treatment/commitment	4.00
	Cluster Average	3.75

Cluster 7: Degree of Voluntariness & Control Over Treatment

3	voluntariness of services delivered	4.33
11	desired services not contingent upon accepting undesired services	4.13
41	ability to effect a total divorce from the MH system if one so chooses	4.20
69	deference to wishes of primary consumer of MH care even when those wishes conflict with wishes of a family member	4.20
83	consumer control over consumer's treatment record including destruction thereof	4.20
	Cluster Average	4.21

Cluster 8: Consumer Impact on System Development

26	an effective feedback mechanism from users of services to providers	4.13
43	influence of and access to information about clients/consumers/survivors experience with MH system	3.77
57	satisfactory resolution of complaints from viewpoint of person registering complaint	4.00
46	informed consent regarding treatments and information dissemination	4.53
31	elimination of status hierarchies and dichotomy between allegedly healthy staff and 'sick' clients	4.00
45	all treatments should be evaluated with respect to their effects on the person being treated rather than convenience of staff	4.43
74	money allocated to services be re-allocated to individuals to use as they choose	4.00
70	how status/power/funding are maintained/increased by MH/pharmaceutical industry by interface with mentally-labeled people	3.13

77	recognition of competing interests of clients, family, professionals with client being final arbiter of what constitutes beneficial outcomes	4.07
	Cluster Average	4.01
Cluster 9: Consumer Impact on Service Delivery		
25	the ability to fire inept psychiatrists, psychologists and social workers through a determined means of egress	3.60
33	closure of all state hospitals in U.S.; MH services given in community of choice	3.67
52	documentation of and public access to client complaints	3.67
68	prevalence of court-ordered treatment compliance in community consumer population	3.87
92	expeditious access to rights protection, lawyers, other legal advocacy	4.33
93	credentials and licensure of MH professionals shall be contingent upon having consumers/survivors as faculty at every level/stage of training	4.13
	Cluster Average	3.88
Cluster 10: Legal System Issues		
49	recognition and enforcement of civil rights and patient rights	4.60
54	elimination of any legal status differentials based on history of psychiatric treatment	3.60
91	absolute right to engage in any legal or law-abiding behavior regardless of psychiatric label or lack of one	4.60
62	the legal clause 'dangerousness to oneself or others' invoked only when a violent act actually occurs, not when a bystander imagines one might happen in future	4.07
87	elimination of insanity defense and not guilty by reason of insanity plea as a reclaiming of full citizenship	3.20
75	distinction between MH and criminal justice systems so that expressions of mental illness aren't treaded as criminal behavior and criminal behavior not treated as mental illness	3.60
	Cluster Average	3.94
Cluster 11: Citizenship		
10	true citizenship (feeling like a free agent in society)	4.47
58	physical and emotional safety including right to be protected from victimization	4.33
42	ability to retain custody of one's children	4.13
59	efforts to recruit & hire consumer/survivors at all levels	4.27
76	recognition of interests of families or other systems asked to provide supports	2.47

84	freedom for client survivor to parent children if they choose to and a massively more progressive policy for client survivors to keep custody of children	3.73
78	full-time work week redefined as 4 days a week, 32 hours, flexible schedule with 6 weeks vacation and full health benefits and leave-of-absence policy	2.53
	Cluster Average	3.70

Cluster 12: Alternatives to the System

14	access to a broad range of holistic health approaches	3.93
22	natural healing through natural herbs and minerals and ecology concerns being brought into the movement	2.93
47	creation of a network of sanctuaries, oases of healing where nutritious food, comfortable peaceful surroundings and affirming people are available	4.13
72	widespread availability of a variety of methods of helping individuals deal with crisis	4.43
85	development of small, non-hospital residential crisis facilities as alternatives to involuntary hospitalization	4.47
	Cluster Average	3.98

Cluster 13: Quality of Life

18	potential for forming significant emotional/love and/or sexual relationships	4.29
23	access to food, shelter and clothing and choices and types of same	4.53
66	involvement in and effective using of self-help groups and/or projects	3.87
28	loss of or preservation of pre-existing family relationships or friendships	3.60
67	ability to form and maintain healthy parent-child relationships	3.93
60	educational and employment opportunities for client/survivors both in mainstream & alternative settings	4.33
73	living in an integrated setting with non-psychiatrically labeled people and having regular contact with them	4.20
48	full access for physical health care needs	4.33
97	measures of satisfaction with one's ability to participate in the civic, democratic, and policy-making arena in one's community	4.00
	Cluster Average	4.12

APPENDIX D

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