

**Report from Organizing Plank  
National Summit of Mental Health Consumers and Survivors  
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Note: The group decided to use its sessions to brainstorm in order to try to reflect the thinking that people might run into when forming an organization. What follows is the notes from these brainstorming sessions.

### **Session 1**

Open meeting with discussion of ground rules as well as the agenda and process of the discussion.

Brainstorming session:

- Suggestion that transportation be added to the agenda.
- Our own fear
- Cultural and language barriers (ethnic as well as geographical)
- Ignorance: is this tied in with stigma?
- Age: intergenerational problems
- Relationships within the movement

#### *Categories of Roadblocks*

- Poverty
- Transportation
- Culture/language
- Lack of education
- Stigma and dignity
- Relations in the movement

#### *National Organizing: Felt Needs*

- Financial accountability
- Personality conflicts/differences
- Training
- Arguing
- United front
- Equal representation (nationally and regionally)
- Being on the same page
- More communication
- Contacts with other groups

Focus on consumer voice  
National organization  
Communication  
Educating consumers to work together for the common good  
Consensus choice  
Well funded (national organization)  
Staffed (national organization)  
Infighting  
Mutual respect  
Panel leadership  
Shared leadership/No hierarchy  
Training to be on boards  
Resource organization  
Membership organization  
Inclusive vision  
Grassroots (two-way communication)  
Public method of inclusion (from top to bottom)  
Public inclusion of development of leaders from top to bottom  
Clean process (based on expertise)  
Oriented by issues  
Coalition-building organization  
Recognized as the “foremost” organization on mental health issues  
Utilize old timers’ expertise  
Backbiting about who steps forward  
Well publicized to consumers  
Register to vote and maintain voting right  
“Each one teach one”  
Mentorship  
Training for consumer board membership  
What do we need to do to get grassroots communication going?  
Look at the people not the diagnosis/seen as people  
Consumer inclusion as well as interest  
National presence needs to reach out  
Regional to feed into a national organization  
Mobilization

*Common Themes*

Inclusiveness as a common theme  
Education  
Unified voice  
Multi-direction communication system  
Leadership issues  
Common interest between providers and consumers  
Common interest  
Consumer organization

Representative of all consumers  
National to also feed local organizations  
Strengthen local organizations  
Unity vs. Infighting

## **Session 2**

The group recapped the morning brainstorming session and highlighted the common themes that came from the brainstorming.

Moving into Vision.

The group then broke into small groups. Following are the reports from the small groups.

### *Green Group*

Consumer involvement in legislation (including all public policy)  
Monitoring and educating the public on current mental health issues  
Five percent of all mental health budgets go to consumer-run organizations with an increase of 1.5 percent annually. [Note: This suggestion came from someone who said that this is what happens in one European country.]  
Monitor and report on international occurrences and trends.  
A national organization must be able to answer questions of its individual members.  
Do national organizations comprise local and regional groups or individual members?  
Basic civil rights for all Americans  
Education and training for all people

### *Red Group: Vision of Organization*

A national congress  
Elected panel of leaders  
Two representatives from each state  
Encourages equal representation or urban v. rural  
Encourages cultural diversity  
Support staff  
Hiring lobbyist  
Keeping dialogue flexible and open and following (side to side and up and down)

### *Visions of activities*

Respect of the person first  
Right of dignity and self-definition and self-determination  
Lobbying of legislators  
Access to all needed services and wellness  
Communication developed to receive information from membership to develop consensus of policy needs for lobbyist to carry forward  
Grassroots define agenda.  
Tolerance of differences

Education of all general population  
Change the terms of and set the issues for the debate (we choose the terminology) National agenda.  
Clearly define rights of consumers  
Cross disabilities and link with others  
Source of information  
Source of assistance  
Develop the resources to meet all the needs

### *Black and Blue Group*

National organization that serves its constituents  
Communication and connectedness from the national to the local level and vice versa  
An organization that is so effective it puts itself out of business  
Consumer/survivor/ex-patient organization membership in coalition with others (providers, professional, families, agencies, government, and other interested persons or groups) to foster mental health awareness, interests and education Meet people's needs  
Afford people the opportunity to become employed in worthwhile endeavors by giving training and education and sharing their knowledge about the recovery process.  
Consumer providers in variable roles locally, statewide, and nationally.  
Equitable, fair pay for work: get involved I all areas.  
National linking to grassroots to give alerts, policies and orientation.  
Early warning to be engaged in the process and develop solutions, action plans, education, etc.  
Internet access for all involved: guaranteed time.  
Equal access and funding for technology and other services, i.e., training, education, facilities, equipment, opportunities.  
Proactive . . . organization  
Inclusive organization but membership levels to include members, associates, etc.

### *Second Red Group*

Visions: resource directories with structure to navigate one-stop shopping  
All inclusive  
All-accepting people rather than illness  
Meet the needs (financially and emotionally) of all people with mental illness  
All people are included and all people are equally accepted.  
More consumer involvement than provider involvement  
The true balance of power  
An organization that can serve every consumer to get their personal goals met  
Educate each other on empowerment and recovery  
No more "we" v. "they"  
The "we" will drive the "they"  
Think outside the box

**Individual work: come up with five or six purposes and/or aims of the national purpose; then put them on the flip chart. Also give a priority rating to each one.**

Sheet 1

Consumers' needs and desires effect system design, funding and policy.  
Promote recovery in persons with mental illness.  
Public education  
Promote early intervention  
Promote prevention  
Link people through the Internet, locally, and nationally. Equal access to all.  
Opening up new levels of achievement for consumers.

#### Sheet 2

1. Collective voice
  2. Current information
  3. Advocacy
  4. Education
  5. Fellowship/support
  6. Outreach to those who may not be able come to you
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10. Represent consumer at a national level
  9. Build coalitions between existing consumer groups.
  8. Act as a mediating body to bridge various viewpoints and opinions.
  7. Create a body of "best practices" based on solid scientific work.

#### Sheet 3

Consumer-run mental hospitals  
National consumers from all over the country coming together and sharing ideas.  
Consumer-run schools for consumers.

1. Get recognition and acceptance as the voice of and for consumers and their issues.
2. Insure the rights of dignity, self-definition and self-determination of each and every consumer
3. Improve access to services/quality of services.
4. Define how we talk about mental health as a national community.
5. Promote awareness and acceptance of diversity (all types: wellness, culture, and life) among consumers.

#### Sheet 4

To assist consumer with meeting needs. Both to empower and enrich.  
To be able to affect legislation/policies that impact consumers.  
To develop coalitions with other groups.

Defuse fears of public and consumers about mental disabilities.

1. More money for needs; less to government.

1. Medical coverage for all
2. Housing for all
3. Transportation
4. No forced treatment

#### Sheet 5

1. Redefine relationship between consumer/provider/agency/consumer leaders
10. Research for alternatives to psychiatry
9. Influence the international arena
8. Fight against stigma and exclusion
7. Fight for user involvement in policy-making bodies.

#### Sheet 6

- 10 Unify consumers
- 5 Information dissemination
- 5 Empower consumers
- 5 Restoration of power and control to “rightful owners”: consumers
- 5 Impact legislation/system change

1. Represent membership at all levels.
2. Influence policy and legislation and funding
3. Become a resource for the membership
4. Education center to total population
5. Develop “think tank” for new ideas, strategies and problem solving.

#### Sheet 7

1. Provider training by empowered and educated consumers
2. Communication worthy of the consumer with providers at initial incidents in agencies
3. Structure from ground-root level to top-level government legislator (communications)
4. Consumer employment and education to a higher level than providers.
5. The incentive and or motivation for consumers to realize “all of the above”

#### Sheet 8

- 10 Grassroots define the agenda for the organization.
- 9 Monitoring and educating all (public and ourselves) on mental health issues.
- 7 Lobbying of legislators

- 10 Equality of individual rights
- 8 People not illness
- 9 Education of the general public, starting at a young age
- 7 Reserve the right of terminology

#### Sheet 10

1. Move knowledge of mental illness forward
2. Teach society what constitutes mental health
3. Fight stigma with education
4. Eliminate that need of forced drugging

1. Eliminate stigma and discrimination

2. Control the financing of the public mental health systems
3. Join all C/S/X together to better serve the needs of the whole and the individual.

#### Sheet 11

- 10 provide a national voice to allow for national legislative and or public policy change
- 9 provide education about mental health issues to all people and to train and educate mental health consumers/survivors on any issue
- 8 Provide positive media recognition
- 10 Provide definitions, education and support on civil rights (responsibilities) to all consumers

#### Sheet 9

1. Coordinate local and state groups so they are consumer-run and meet local needs and are paid for.
2. Help to get financing and where to obtain grants.
3. Encourage belief in oneself, leading to empowerment, leading to advocacy for oneself and others.

### **Session 3**

Recap earlier two sessions. Read individual activity aloud.

#### *Common themes*

Shared leadership  
Education  
Coalition building  
Consumers as providers  
Information sharing  
Resources and funding and financial  
Influencing and changing public policy and legislation  
Unity  
Accepting diversity  
Grassroots movement throughout

#### *Blocks/Barriers to having a national consensus*

Poverty  
Stigma: external and internal  
Transportation  
Culture/language  
Lack of education  
Relationships within the movement

Individual brainstorming about the road blocks.

Small groups about the roadblocks.

### *Roadblocks*

Poverty

Lack of money for needs

Lack of money “trickle down”

Lack of money for necessities: food, shelter, clothes, shower, etc.

Categorization of funding

### *Stigma*

Self stigma

Categorizing others

One consumer fearing another

System “dislikes” consumers

Lack of education to decrease stigma that exists

Lowest layer of social fabric due to lack of parity.

### *Transportation*

Isolation due to not on a bus line, no car, inability to drive for various purposes

Insurance

Not paying for consumer to be part of the process

### *Culture and languages*

Misunderstanding and confusion and offenses due to lack of cultural knowledge

### *Lack of education*

Educate the consumer; then worry about educating “them”

### *Relationship issues*

Family

Meds vs. no meds

### *Strategies*

Think outside the box for funding

Grants, foundation, \$1 drive

### *Educate the consumer*

National web site

National telethon

Inclusion in schools

Consumer-run business

Mandate tolerance

Embrace differences

Demonstration: Live Dignity and Respect

Adopt principles

National organization becomes our insurer of car/transportation as a pilot project

Resource bank for local organization



Congress/participants reflection of celebration of cultural diversity.

*Blocks*

10 Poverty, transportation, housing, power, proper funding

9 Self-esteem: disclosure, fear

Self-stigma: creating survivor guilt because of labels of level of consumer illness . . .

Stigma from outside

4 Philosophical differences with other strong national groups

6a Addressing differences of individual priorities and vocal vs. less vocal input

6 d Control

7 which needs met first: sometimes causes inaction

7 No agreement to find a consensus to move forward

5 Lack of communication

6b Training panels and state representatives — be good facilitators — not delivering their own message. Lack of public education on mental health

8 Representation of all areas and concerns

6c Our assumptions of what others know or do not know about mental illness and definitions

*Strategy*

Public education (includes lobby)

1 Legislature

2 Mental health in states

3 Judicial

4 Policy makers in general

5 Business: community involvement

6 Media

7 Consumers

*Direct requests for funds to:*

Providers

Drug companies

Rehab agencies

Other government agencies

Other mental health agencies

Business/corporations

Granting agencies

*Become proactive*

Develop training needs for panel and members as facilitators

Develop solid implementation strategy, organize committees to parcel out strategy assignments  
Develop data resources bank  
Training/education to assist consumers to step out

*Common Theme/Barriers*

Learned helplessness/hopelessness  
Medical model and people who run it  
Stereotypical American thought and culture  
Media  
Lack of Self-Definition  
Lack of life/interpersonal skills  
Poverty and scarce resources

*Strategies*

Build credibility  
Reveal who are and what we need to people whom control dollars  
Educate medical community on what works.  
Recovery, rehab, wellness and who we are  
Define ourselves  
Educate and support one another  
Role model  
Develop a product we can sell  
Develop positive media tool  
Better use of legislation  
Bridges between consumers and the well

**Session 4**

Cross-disability organizing

Reviewed the process as well as the events of yesterday. Went over the ground rules.

Vision and aim for cross-disability organizing  
Roadblocks, then strategies

Discussion about the definition of consumer and survivor (offer to form a sub-group so that no one is excluded)

- Define “consumer” for the working session
- Also define for the national movement
- People currently struggling with the definition in their home state
- Consider this issue for further attention for development of a national voice
- Using the New York working definition: a serious life-disturbing event of a mental/emotional nature.

One person’s observations about the discussion of “consumer” definition.  
Please consider:

- Parents of minor children with serious emotional disturbances have unique responsibility for treatment decisions and to support treatment must be (secondary) consumers/intimately a part of therapeutic process.
- What does this New York definition say to parents of a child born with spina bifida (or other serious disorder/disability)?
- How do we relate to young/youthful consumers (especially 14-21) and 14- to 18-year-olds who have right to treatment in some states with out parental consent?
- How do we relate to 14- 18-year-olds with serious emotional disturbances who may be incarcerated, even tried as adults, and no longer eligible for children’s mental health and educational services?
- Do we address issues impacting transitional-age young adults as they enter the adult mental health system?
- Definitions of consumer greatly impacts:
  - Service access (how does managed care define consumer?)
  - Funding access: do people with “adjustment disorders” with transient issues mean to providers that they are “consumers”? If so, they are eligible for funding intended for consumer-run services.
- Also, family members (parents of adult children), if defined as “consumers” (by New York definition or NAMI definition), may allow consumer voice to be drowned out by others (power given to others). National consumer group could be run by others.

Discussion about agreement between existing groups (i.e., NAMI, NEC and Family Foundations)

Vision and aim for cross disability organizing  
Roadblocks and then strategies

Brainstorm individually for vision for cross disability organizing.

### *Group 1*

- Unite with others with one voice to come together on common issues, i.e., transportation, housing, employment, stigma and inclusion in the mainstreamed community — anything people need to cope with their environment
- Organizing to force bureaucracies to decategorize funding: no more excuses
- Unite so that various funding sources cannot force us to compete with one another to see who survives to get the money.
- Take co-morbidity seriously
- Promote awareness that persons with all disabilities are stigmatized by providers and others
- People have equal access to current knowledge and information and resources through “telemed” technology.
- Treat the whole person with needs and concerns that need to be addressed
- Education to reduce stigma, increase inclusiveness, better understand one another’s needs: cultural type of cross-disability trainings
- Align ourselves philosophically with those with similar views, values and principles.
- Be mentored by others who we emulate

### *Group 2*

- Educating people that mental illness is a “real” disability
- Financial Parity
  - Blended funding
  - Blended services
  - Blended assistance
  - Collaboration

### Vision

- Promote the philosophy that all people have strengths and contributions to share as well as needs to be met
- Reach out and offer assistance to all consumers regardless of disabilities
- Enhance the power (voice) of people with disabilities
- Joint training and services for people with dual diagnosis
- Build relationships and share resources with other national, regional and local organizations of people with other disabilities.

### *Group 3*

- One voice
- Voting members would be the person with the disability or the parent of a child with the disability
- Resources
- Policy making
- Learn from experiences of other disability groups
- Build coalitions with groups of a similar nature
- Support other groups who are having basic civil rights and human rights threats
- Media resources
- Speakers bureau
- Outreach to fringe population
- Working together to support and to gain power and strength
- Monitor and educate on all issues that affect cross disabilities
- Be “grassroots upward” always

## **Session 5**

### *Blocks/Strategies cross-disability organizing*

#### Individual brainstorming

### *Group One*

#### Blocks

- Turf conflicts between organizations competing for resources (including government)
- Different focus
- Philosophical differences
- Stigma, discrimination and ignorance from within and outside

- Hierarchy of disabilities
- Lack of parity
- Fear of the unknown
- Separate funding streams

#### Strategies

- Organize around common issues (transportation, insurance, social security)
- Statistical Information: power in numbers
- Educating people, organizations, etc., about disabilities
- Multi-disabilities, multi-issues education/training
- Seek cross-disability peer support
- Appropriate compensation and timing (local, regional and national)
- Find new and less restrictive funding sources: think outside the box
- Keep legislative funds but blend, etc.
- INCLUSION TO THE GREATEST EXTENT POSSIBLE: PHILOSOPHICAL CHANGE IN AMERICA

#### Group 2 (*Strategies are in italics*)

- ✿ People willing to work together: *knowledge, communications, education. Mutual assistance: pledge volunteer hours. Do things for people with other disabilities.*
- ✿ Lack of legislation to mandate cross disability: *UNITE. Find common points around which we can band together.*
- ✿ Political careers and other livelihoods dependent on singular systems: national, state, local on each disability. *Bring up to NCIL (National Centers for Independent Living). Consumer boards hire “at will” CEO of provider organizations.*
- ✿ Turf issue: *cross train. Dialogue. Accommodate. Give up ownership*
- ✿ No real communication between offices of different disabilities. *Give up ownership. Lobby for integration.*
- ✿ Internal stigma and discrimination. *Education: tolerance. Identify commonalities, stop power struggle.*
- ✿ Competition for money. *Equal funding: more. Control over administration budgets (U.S.). Guard against backlash.*
- ✿ Lack of understanding on need accommodations of other disabilities, nor do they understand us. *Look at other models already in place with other disabilities groups.*
- ✿ More fragmented than other disabilities groups: *Value our own minds: compassion and sensitivity. Value spirituality we get through recovery.*

#### Session 6

“Organizing people who are unorganized” discussion (by Ed Knight)

1. Extensive Strategy: people reaching out to people
2. Intensive Strategy: demonstrate that consumers can do this
3. Research and development: develop new ideas for self-help as well as research what you are doing and putting in place.
4. Framing (also known as “flanking”): neutralize anyone who is going to be your enemy

5. Story and Symbol: words like “self-help” and “hope”

“Empowering the Disempowered”: Call 518-434-1393 and ask for the “information packet.”

Who are the unorganized?

Organizing is the aim.

Write five blocks and strategies of “organizing the unorganized”: individual work.

Sheet 1

**Blocks/Strategies**

- Those of us “in the know” aren’t organized: how can we lead others to where we haven’t been? *Organize model/be example*
- Hopelessness/recovery/unity change not possible. “*Stories*” and lives shared “*walking proof*” of hope and recovery.
- Fear of rejection, non-acceptance. *Active outreach: touch, relate, concrete help/assistance*
- We are unable to see importance/worth of self and each individual’s gifts and strengths to bring to movement (worth of self and others). *Meaningful engagement relationships and work (volunteer “for the cause” or toward self-sufficiency). Stronger [individuals] responsible for initiation*
- Human disconnection and lack of community. *Build community one person and one relationship at a time.*
- Difference in values and identified needs: *Accept and meet where they are: find common ground.* Some may totally want to remain homeless. *If so, accept.* If their identified needs are clothes, food, whatever: *offer to seek out what is needed.*

**Blocks**

Poverty

Denial

Lack of motivation

Stigma

Perceived internal conflict within groups

**Strategies**

*Learn how other disenfranchised groups did it (NAACP, people with developmental disabilities, farmworkers)*

*Education in schools as early as possible*

*Education nationally in churches*

*Pamphlets (drop-in centers in all, Double Trouble, Doctor’s Office and Social Agencies)*

*Promotion of consumer-run services on public TV channel very creatively done*

**Blocks**

Transportation

Confidentiality

Stigma issues

Lack of education

Lack of money

Apathy on part of consumers, frustration on part of organization. Too much to do, overwhelming other people/organizations, people who deal with only one issue

### **Blocks/Strategies**

Professionals: *Mass mailing to professionals, staged communications of professionals*

Lack of knowledge of consumers: *Talk to consumers*

Denial of consumers

Hopelessness of consumers

Money: lack of resources of consumer groups

Fear of some consumers if unorganized people

*FLYERS EVERYWHERE*

### **Blocks**

Apathy

Learned helplessness

Self-victimization

Opportunism

Public antipathy

### **Strategies**

*Promote collective identity*

*Develop a "voice" medium for communication*

*Focus on a positive future rather than a negative past*

*Political participation (voting/rallies)*

*Attack opportunism*

### **Blocks**

Denial

Stigma from organized

Lack of time and resources

Isolation

Fear

Lack of money

### **Strategies**

*Telethon*

*Systemic consumer education*

*Strategic/repetitive positive publicity*

### **Blocks**

Hostility from recipients

"Mainstreamers" involved. Consumers fearful, prejudiced against

Reaching out to "them"

Lack of resources (money, medicines, housing, transportation)

Too many jobs, too few workers  
Value of not “imposing” on others or not wanting to “force” participation

### **Strategies**

*Be good role models.*  
*Assume each person has something to share with the community*  
*Be tolerant and accepting*  
*Recruit*  
*Train*  
*Get resources*  
*Trained recovering consumers*  
*Promote sharing strengths and resources*  
*Accept and value desire to be free*

### **Blocks**

Episodic “get well” and do not want to identify as disabled  
Lack of interest  
Lack of follow-through  
Lack of commitment  
Laziness  
Denial  
Lack of money  
Transportation

### **Blocks**

Usually isolated from community  
No trust  
Might not be reachable through TV and newspaper  
Might not want help

### **Strategies**

*Outreach: go where they are*  
*Be honest and sincere*  
*Let them know they matter*

### **Other Strategies**

*Speakers’ Bureau for the public*  
*Unions for training*  
*Sensitivity training for police*