Report from Recovery Plank National Summit of Mental Health Consumers and Survivors Portland, Oregon August 26 - 29, 1999

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Introduction: The Recovery plank working sessions were preceded by an educational session presented by the panelists listed above. Their presentations set the stage for the working sessions.

This report grew out of the five working sessions. These sessions focused on the issues (phrased as questions) listed below. During several of the working sessions, the participants brainstormed ideas and then voted on their top five choices.

Issue: What does recovery mean to you?

The facilitators began the discussion of recovery by asking for input from the participants about the personal meaning of recovery in their lives. Due to the personal nature of each story, they are reprinted here rather than summarized. (The paragraphs identified by "Anonymous" followed by a number are from eight different individuals.)

Anonymous 1

Integration of mind, body, and spirit. An acceptance that what society sees as a deficit can be an asset. Having society allow me to use my gifts and talents to their highest potential.

Robin Grupper

Recovery implies that there is something to recover from. For me there were two things: first, I broke down; then I went for help and was harmed.

In my case, the beginning was my realization that there was a huge schism between the way the world is, has been and possibly always will be, and the way the world could be — [the realization] that pain and exploitation were the governing presence for most people's lives; whether they inflicted pain on others or were oppressed by others didn't seem to matter in the individual's loss of humanity. So I broke down. I then had an incredibly hard time finding guidance to a comfortable space. The people saying they were there to help me abused their power by torturing me with restraints and injecting me with potentially brain-damaging substances against my will. They wouldn't explain what they were giving me. I developed my own recovery: getting in touch with my humanity, getting in touch

with nature, and getting connected to other people. Engaging in the world the way I want. My recovery was learning what I truly want. Building the "me" that really is me while living [in] the world I want to live in.

Scott Snedecor

Recovery is looking to the sky and finding a seagull to guide you to the land. Recovery is having a drenching rain come down to soak your garment so that you might ring it out to quench your thirst. Recovery is looking up and seeing a helicopter from the 304 aerospace rescue squadron vector in on your position. Recovery is putting your body in the sling and being raised into the ship. Recovery is drinking a big pitcher of water. Recovery is having a piece of chicken after eating salty seaweed for three weeks. Recovery is standing on land after drifting at sea for an eternity.

Sheila Hill

What does recovery mean to me? To have hope. To feel like a useful, needed person. To be able to utilize the abilities I have. To be able to help others and be a contributing member of society. To have a positive attitude. To be out of the victim mode and be able to transcend the experience I had. To feel connected to the Creator and other people. To take responsibility and take charge of my life. To lead a productive life. Inner healing. Enjoy living. Spiritual wholeness. Living effectively. It's giving back, forgiveness. Helping other people. Believing in yourself. Overcoming obstacles in achieving my goals.

Mark Duffy, Consumer Liaison, Division of Mental Health, New Jersey

Recovery is a person-centered process. It is a journey that an individual undertakes and designs as a step-by-step strategy toward their own idea of wellness. To be recovering is to be taking personal responsibility for the challenges that are associated with mental illness.

Dan Gilbride

As mentioned, a process leading toward integration from fear to hope to faith. Whole selfvalidation. Living effectively. Being responsible for how I am impacted by the things around me. Not a straight and narrow path. Giving back. Not taking for granted. Forgiveness. Strong living toward living effectively with all of who I am.

Anonymous 2

Recovery means regaining control over my life. It means regaining my self-confidence. Recovery means believing in myself once again and being optimistic about my future. Recovery means not giving up.

Ellen Fein

What does recovery mean to me? Accepting that I have this illness: the way it has affected my thoughts, reactions and feelings. Some parts of my illness, I can't change; I need to accept that at this point in my life. There are parts of my personality I cannot change and it isn't my fault so it involves accepting that I have this illness. I need to learn how to separate those parts of my illness I cannot change and stop judging myself because of my

symptoms. Also, I want to learn how to adjust my feelings better — adjust my thoughts to being "more healthy."

Anonymous 3

What does recovery mean to me? Being well-informed about the specific mental illness with which you are diagnosed and having the knowledge, skills, and ability to ease the symptomatology so that you blend in with society (external validation) and have peace (internal validation).

Anonymous 3

Recovery means accepting myself, believing in myself and occupying myself enough so I can tolerate the disconnection between now and my next triumph. There are three parts:

1. Actual physical illness itself (brain/body chemistry)

2. Trauma: the awful things that have happened to me which harmed me that were given in the name of treatment.

3. Losses: consequences, stigma, job, family, etc.

To take small steps in these areas. Autonomy. Must be able to trust one person.

Anonymous 4

Recovery means to be free to sing no matter how weak or quivery your voice. When I was a child, I was abused; one form this took was my mother telling me that my voice was so ugly that no one could stand it. I refused to sing even in church or in private because if I did I would drive everyone away with my voice. It was through recent friends and self-help that during the last year I have felt free enough to sing again in my home. I know I am on the road to recovery because I start each day with a song. And I feel this freedom to "sing" is applicable to the very core of recovery.

Anonymous 5

Recovery means to be free to live my life in a unique, healthy style and have equal rights with any human being. I deserve to be a strong, respected person with hopes, desires and opinions of my own. I need to be allowed the freedom to follow my own path as well as to take responsibility for all parts of my life.

Carole Kay Green

What does recovery mean to me? To function in my own apartment and drive and work or volunteer on meaningful projects. Balanced with recreating. The freedom to be able to choose for myself the level of stress I can handle on a daily basis.

Anonymous 6

Feeling safe. Baby steps. Overcoming fears. Knowing that I am not alone. Overcoming obstacles in achieving my goals.

Debby Cramer

To me recovery is living a fulfilled meaningful life. I don't expect each day to be high, but my goal is to be able to live a fulfilled, meaningful life even when the downs come.

Sindy Ness

I am in the process of recovery and it is real to me that I am a good person with good values who has a need to be helpful.

Kathy Harmon, Kansas

Recovery is a courageous ongoing journey of living one day at a time in the midst of change, challenge and celebration; grounded in respect, honesty, hope, patience, and forgiveness; promoting physical, emotional, and spiritual wholeness.

Bob Hiltner <gimilil2345@aol.com>

Recovery means being able to leave the basement and participate. It means regaining my lost humanity and finding a constructive outlet for the bottomless pit of anger and frustration that overwhelms me. Recovery has been getting the public mental health system to agree with me on my proper diagnosis.

Kerry Hawley, Astoria, Oregon

Basic needs met by getting help with vocational, educational, housing, medication, food, exercise, entertainment, meaningful work, volunteer or otherwise. Post-Traumatic Stress Disorder trauma recovery. Journey: getting over childhood abuse and trauma and moving on with my life. As a secular humanist I believe in rationed recovery leaving abusive relationship behind and living in the here and now.

Anonymous 7

Being able to do things that I want to do, rather than what someone or something else dictates. Also being a working and valuable member of society. I have been advocating for mental health consumers since 1992, and hope to continue as long as I can, through information and education, which has come about via my own personal growth, life experience, networking. Finally, I want to be financially stable and be able to maintain my employment and family relationships.

Lisa Braswell

Recovery means being able to lead a productive life. It means being able to take care of myself, to have hopes and dreams, to achieve these hopes and dreams. Recovery means that I am able to help myself and others, by sharing my experiences with others.

Seven years ago I found myself dieting in a state hospital and was diagnosed with a mental illness. I am now two semesters away from receiving my social work degree. I am hoping that I may help other mental health consumers toward their recovery process as I was helped towards mine.

Linda Corey, Vermont Psychiatric Survivors

Recovery means an individual process for one to set their individual goals to reach their ultimate expectation. Recovery cannot be preconceived or put on one by others. The primary recovery expert is oneself. One is in the driver's seat and picking up what they need along life's path to enrich their own. Recovery is a vision one has as to how they see their future. There are no limits to recovery. I especially thank Mary Ellen Copeland [for helping] me find hope.

Cherie Bledsoe, Kansas

An inner healing — accepting "the whole me." Having a life — your own — with its dreams, goals, and consequences — with or without symptoms. Being in charge of your own self. Living in the kind of life that is of value to me — in my community — contributing to my community — with mutual acceptance and support. Enjoyment of living.

Denise Bayrhan, Kansas City, Kansas

It means when I'm able to get up and do the basic need functions of the day, like bathing, cleaning up, and putting clothes on. It also means getting out and being with fellow peers and socializing, and feeling good for that day. Taking one day at a time. Hearing my voices less.

Anonymous 8

A change in identity toward positive self-chosen goals which give meaning to a newly grown, integrated personhood.

Mary T. Newell, Philadelphia, Pennsylvania

To me recovery means growth. To stop depending on and blaming others or situations for my mental illness. A big part of recovery for me is staying out of the hospital and being more responsible for my life. During the past seven years I was hospitalized over twenty times. I never thought it would end. I have been out of the hospital for over six months now and this is because I became responsible for my recovery. I am finally beginning to make changes in my life toward recovery.

Terry L DeRocher, Ph.D.

To me, to begin, recovery has meant regaining enough self-confidence to let go of fear and shame and to insist that my illness does not mean I lack credibility or value. It has meant overcoming fear and shame enough to ask those who are trustworthy for the support I need to succeed and to recognize when I need more or less support. It has, above all, meant learning to trust myself again.

Dani

Not being ashamed in front of others. Sharing myself with my community. Working a decent job. Helping others as I continue to help myself. My mental state of mind under control. Respect of myself. Having a voice on a national level. And always walking with God in my spiritual journey.

Michelle Bonewitz

Being able to function as normally as possible. Family. Public acceptance. Getting my life back. Accepting my own life. Enjoyment of living. Taking care of me and learning about me. Learning to love myself and accept who I am.

Gary Haffer

A daily victory. Thanks be to God.

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Issue: What are the values that are important to recovery?

- As defined by suggestions from the floor, a VALUE is: something you hold in high esteem, something you appreciate, something you cherish, something of importance, something to treasure, weight, integrity, honesty, clear thinking, worth, an ideal.
- The VALUES important to recovery, as defined by the participants, were as follows: dignity, hope, persistence, compassion, spirituality, honesty, respect, gentleness, resilience, purpose, dream, identity, independence, choice, believable hope, never-giveup attitude, tenacity, helping others, friendship, love, support, freedom from materialism, calculated risk, empowerment, equality, responsibility, gratitude, generosity, knowledge, inclusiveness, patience, forgiveness, clarity, courage, joy, faith, intelligence, celebration, contribution, wisdom, spontaneity, trust, belief in yourself.
- A vote was taken among the participants to select the VALUES most important to recovery. They were:

Hope (15 votes) Responsibility (15) Spirituality (14) Empowerment (14) Sense of humor (13) Respect (11) Belief in self (10) Compassion (10) Courage (9) Honesty (8) Faith (7) Love (7)

Issue: What are the principles that are important to recovery?

- As defined by suggestions from the floor, a PRINCIPLE is: an ideal, guidelines, rules, belief, truth, concept, substance, way to accomplishment, foundation, ethics.
- The PRINCIPLES important to recovery, as defined by the participants, were as • follows: open listening, active participation, belief that people are good, selfdetermination, education, honest introspection, employment, goal-setting, informed choices, balanced lifestyle, sticking around positive people, nutritional balance, transcend all labels, individually paced, you own your own recovery, volunteerism, I do it my way, no coercion, get out of victim mode, personal responsibility, self-worth, change in attitude, pursuing creative interests, consumer-run drop-in centers, belief in recovery, distress-tolerance skills, using experiences to learn and grow and help others, advocate for self and others, not caring who gets credit, actively growing spiritually, realizing that it will take effort to change, serenity prayer, demanding respect from providers or dropping them, symptom management, peer support, instead understand, practice love, humanist philosophy, basic needs met - food and shelter, reason to live, honoring intuition, keep asking until you get the help you want, work opportunities, positive power of prayer, person-first, healthy living and exercise, unconditional positive regard, music and dancing, non-abuse, recovery possible for every person, no limits, positive partnerships in local state and federal governments, dealing with our differences as assets, collaboration instead of coercion, availability of free education on any subject, education, limits and boundaries that are reasonable, golden rule, out of the welfare mode, people not prisons, communitarian spirit, openness to spirit not on my terms but its terms, no single-issue advocacy, decent jobs and living wages.
- A vote was taken among the participants to select the PRINCIPLES most important to recovery. They were:

Basic needs met (14) Recovery is possible for every person (13) Belief in recovery (12) Humanist philosophy (11) Employment (11) Education (9) Informed choices (8) Peer support (7) Consumer-run drop-in center (6) Advocate for self and others (6)

Issue: What are our personal barriers to recovery?

- Personal barriers suggested by participants include: fear, stress, low self-esteem/selfconfidence, lack of communication/listening, racism, money, negative self-talk, stigma, lack of education, unforgiveness, loss of status at work, repeatedly starting over, unsafe living conditions, lack of support, difficulty in establishing relationships, feeling of hopelessness, not taking care of self — physically or emotionally or spiritually, destructive tongue, expecting too much of/being too hard on self, sleep deprivation, age, isolation, self-fulfilling prophecy, staying in victim mode, learned helplessness, Catch-22: proving ability and disability, fear of success/self-sabotage, coping with grief, lack of coping skills, denial of symptoms, abuse/trauma issues, guilt, bad diet.
- As selected by a vote among the participants, the personal barriers that pose the greatest challenge to recovery are:

17 votes	Fear
10 votes	Low self-esteem/self-confidence
9 votes	Fear of success
9 votes	Negative self-talk
6 votes	Lack of coping skills
6 votes	Personal trauma issues
6 votes	Not knowing your rights
6 votes	Feeling of hopelessness

Issue: What are the barriers that the system places between us and recovery?

Systemic barriers to recovery suggested by participants include: System does not believe recovery possible, Lack of communication / listening, System has stress (overloaded), System emphasizes dependence, Insurance doesn't pay for nutritional / holistic, Money, Diagnostic labeling / Stigma, Lack of education, Organizational system of providers, No insurance for pre-existing conditions, Trapped in system, Loss of work status or position, Transportation, Unsafe living conditions, Lack of support, Legislative mandates vs. recovery vision, Lack of geriatric services, Family conflicts, Discrimination — employment / housing / professional licensing / being on meds / agism / racism / mentalism, providers — discrimination / paternalism / lack of consumer sensitivity, Programs not tailored to individuals' needs, Fear of losing supports: disincentives, Being dropped too soon from benefits, Not being believed / validated by system, Lack of information / referrals / accessibility to alternative treatment, Lack of available legal counsel, Lack of insurance parity, Providers not recognizing limitations, Poor physical plants, Lack of physical medical care, Lack of mutual trust, Lack of housing / lack of community services, Access to medical and mental health records, Failure to educate about rights, Lack of peer counselors in hospitals, Not encouraging spiritual growth / failure to recognize spiritual experiences, Inaccurate charting, No advocates being present during interviews, Poor meals,

Insensitive uncaring providers, Standard treatments can be inhumane, No advance directives.

• As selected by a vote among the participants, the systemic barriers that pose the greatest challenge to recovery are:

15 votes	Discrimination, including:
	- employment discrimination
	- work disincentives
	- housing discrimination
	- discrimination against those on medications
	- ageism
	- racism
	- mentalism
	- discrimination in professional licensing
	procedures
14 votes	• Being trapped in the system / Fear of losing housing,
	benefits
9 votes	• Lack of education
	• System treats all clients the same rather than as individuals
7 votes	• Lack of training for providers in consumer issues,
	consumer sensitivity, and consumer perspectives
	Diagnostic labeling and stigma
6 votes	• Repeatedly starting over
	• Mutual distrust between consumers and system
	• Lack of communication and listening

Issue: what are our top priorities for services necessary to the recovery process?

The services important to recovery, as defined by the participants, were as follows: • church services (membership and specific programs), Vietnam [veteran] outreach services, intensive case management, recovery-focused support group, outpatient day treatment, community residential living centers, dual-diagnosis groups, culturally relevant services, availability of competent psychiatrists, subsidized living, "warm line" (telephone support), holistic therapy (Reiki, massage, chiropractic, acupuncture, nutritional), 12-step program, consumer-run drop-in centers, clubhouses, consumerrun conferences, crisis intervention, vocational rehabilitation, relapse prevention plans, counseling, compassionate attorneys, ADA training, college support services, access to (and training with) computers, financial support, job coaching, fun outings, Community Companion programs, safe house, peer counseling, free or low-cost medications, exercise (e.g., YMCA), meditation, spiritual schools, advocacy services, chaplain services in hospital, respite care, hospitalizing when necessary, college counseling, help with public transportation, advance directives, advocates for when you're in crisis, EMDR (eye movement desensitization and reprocessing), DBT (dialectic behavioral therapy), mediation, yoga, breathing exercises, long-term trauma

survivors support group and reading material, smoking cessation programs, budget counseling, WRAP plans, literature, array of support groups, dance therapy, group therapy, services not based on pathology, education about natural therapy, income supports (SSI, SSDI), wellness-based services, wellness and support advocacy services, help in navigating public services, spiritual counseling, healthy grieving programs, services for family too, home health care services.

• A vote was taken among the participants to select the services most important to recovery. They were:

Consumer-run Psychosocial rehabilitation / drop-in centers (10 votes) Counseling (8) Competent psychiatrists (8) Literature (7) Subsidized living (7) Church services (6) Holistic therapy (6) Crisis intervention (6) Peer counseling (6) Help with transportation (6) Financial support for natural treatments (5) Free or low-cost medicines (5) Intensive Case Management (5) Outpatient day treatment (5) Financial assistance (SSI/SSDI/Medicaid) (5) Wellness-based services and support advocacy (5) Consumer-run conferences (5)

• The plank's reporter then grouped the services into categories, which were then presented to the group as follows:

Peer-run services (51 votes)
Consumer-run psychosocial rehabilitation / drop-in centers (10 votes)
Wellness-based services and support advocacy (5)
Peer counseling (6)
Consumer-run conferences (5)
12-step programs (4)
Full range of support groups (4)
Safe house (3)
Advocacy services (3)
Support services for families (3)
Support groups/reading materials (3)
Consumer-run counseling regarding benefits (3)

Club house (2) Professional services (31 votes) Counseling (8) Competent psychiatrists (8) Free or low-cost medicines (5) Intensive Case Management (5) Outpatient day treatment (5) Living supports (27 votes) Subsidized living (7) Help with transportation (6) Financial assistance (SSI/SSDI/Medicaid) (5) Job coaching/vocational rehab (4) Residential living community (3) Housing (2) Holistic (20 votes) Holistic therapy (6) Financial support for natural treatments (5) Exercise programs (3) Yoga/breathing exercise (3) Dance therapy (3) Religious (9 votes) Church services (6) Spiritual counseling (3) Media (7 votes) Literature (7) Other services: Crisis intervention (6) Dialectic behavioral therapy (2) WRAP (wellness recovery action plan) (2) Relapse prevention plan (2) Culturally relevant services (2) EMDR (eye movement desensitization and reprocessing) (2)

Issue: what are our top priorities for supports necessary to the recovery process?

- The supports important to recovery, as defined by the participants, were as follows: faith, supportive work environment, relationship with God, non-coercive support, peer support, lifelong relationship, medical doctor, pets, recovering family members, selfhelp (including books), ritual group, drumming group, friends, significant others, laughter/humor, tapping creative ability, nutritional support group, social support group, celebrations and fun of achievement, supportive and safe neighborhood to heal, music, dancing, art, meditation, sports, on-line support (chat rooms), personal life goals, sex, getting in touch with nature (camping, hiking, gardening), library, writing/journaling, taking time out, helping others, activities in community, regular schedule, no self-harm contract, makeover/hairdo: pampering yourself (including free), personal hygiene, communication/venting/talking, go out to eat, safe neighborhood, sense of history, diet and exercise, encouragement, good night sleep, hot bath / whirlpool / sauna, medication, surrounding yourself with positive people, clean living environment, wellness plan, realistic short-term goals, forcing yourself to get out into the community, peaceful quiet attractive living, lifestyle changes, eliminating toxic people, letter writing / phone call, privacy when you need it, hugs, unconditional love, vacations travels, shopping, renewing interest in hobbies--photography, crafts, playing, napping, baking / cooking.
- A vote was taken among the participants to select the supports most important to recovery. They were:

Relationship with God (19 votes) Friends (13) Online support/chat groups (10) Sex: wild, safe, and good (9) Music (9) Having a regular schedule (8) Diet and exercise (8) Getting in touch with nature: hiking, camping, and gardening (7) Hot bath, whirlpool, Jacuzzi (7) Supportive work environment (6) Helping others (6) Pets (6) Tapping into creative ability (5) Writing and journaling (5)

Issue: What actions should we as a group take to promote the recovery vision?

• After a series of discussions about recovery in which a significant percentage of the participants attended each session, the facilitators asked the participants to reach consensus on action plans for promoting recovery. The group reached consensus on the following courses of action:

1. Creation of a national self-help clearinghouse to share the best practices of recovery. This would include a directory of groups and individuals who promote the recovery vision. The Clearinghouse would take an active role in distribution of literature promoting recovery. *National Level*.

2. Creating speakers' bureaus of consumers (including public figures) who can personally demonstrate to the public and provider groups that recovery is possible. *Local, State, and National Levels.*

3. Creating coalitions to promote the recovery vision. *Local, State, and National Levels.*

4. Meaningful involvement (not tokenism) on boards and committees. *Local, State, and National Levels.*

5. Working for legislative change in favor of alternative medicines. *State and National Levels*.

6. Taking an active role in educating medical groups and medical review boards about the recovery vision. *State and National Levels*.

7. Empowering consumers, including: strength-based training, leadership training, voter registration, advocacy, teaching recovery and coping skills, working to end discrimination and increase sensitivity. *Local, State, and National Levels.*

8. Increased training and education about recovery, including learning conferences. An important type of conference is the regional conference, which allows information to be shared among states. Conferences and other types of training should be made available to: consumers, medical professionals, educators, administrators, legislators, employers, criminal justice systems/forensics. An important topic of education for consumers should be self-employment/career opportunities. *Local, State, and National Levels*.

9. Form watchdog groups to monitor legislation, public policy, and public statements contradictory to the recovery vision. These watchdog groups should also monitor systemic abuses that harm individuals' recovery efforts, such as sexual and other forms of abuse. The watchdog groups should monitor managed care organizations, local, state, and national governments, mental health groups and providers, etc. *Local, State, and National Levels*.

10. Increasing the number of consumers in the mental health workforce, especially as providers and managers. This includes having more consumer-run services.

11. Mobilizing behind consumers running for public office. *Local, State, and National Levels.*

12. Promoting stricter enforcement of the ADA so that consumers are not denied meaningful employment opportunities. *National Level*.

13. Working to direct money in mental health budgets into recovery visions. This includes finding new funding sources in the private sector and coordination of resources. *Local, State, and National Levels.*

14. Advocating for effective offices of consumer affairs (or the equivalent). *State Level.*

15. Working to make it safe for consumer providers to self-disclose. *Local, State, and National Levels.*

16. Creating a national mental health ombudsman organization with state offices. *National Level.*

17. Seeking employment in managed care entities so that consumers will have a voice. *Local Level.*

18. Accepting responsibility and recovering so others will see that it is possible. *Local Level*.

19. Getting more consumers onto the Internet, including making access and training available. *Local Level*.

20. Legislation for the homeless, written by the homeless. *State and National Levels*.

21. Creating and staffing "warm lines" to provide support for other consumers. *Local and State Levels*.

22. Creating a national newsletter emphasizing recovery (including an online version). *National Level.*

23. Collaborating with the dual diagnosis recovery movement. *Local, State, and National Level.*

24. Promoting incentives for recruiting providers who believe in the recovery vision. *Local, State, and National Levels.*

25. Opposing laws permitting or expanding forced treatment. *State and National Levels*.

26. Increasing consumer involvement in planning and implementation of mental health services. *Local, State, and National Levels.*

27. Working to change Social Security income limits to allow transition into workforce or business ownership. *National Level*.

28. Improving access to other alternatives in hospitals and by doctors. *Local Level*.

29. Promoting equal payment for consumers in the mental health workforce. *Local Level.*