



IN THEIR OWN WORDS

Trauma survivors and professionals
they trust tell what hurts, what helps,
and what is needed for trauma services

MAINE TRAUMA ADVISORY GROUPS REPORT • 1997

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They Trust Tell What Hurts, What
Helps and What Is Needed for
Trauma Services

Trauma Advisory Groups Report - 1997

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June 1997

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Foreword

In Their Own Words is the work of over 200 courageous women and men in the State of Maine who have dared to hope that the truth and wisdom of their experience will be heard by those in power, and that Maine's mental health and human service systems will respond to the long ignored plight of children and adults traumatized by histories of interpersonal violence. Both survivors of abuse and the professionals they trust give voice in this book to their experiences with individuals, organizations and systems that have been shaped and influenced in such a way that they frequently harm, rather than help, the individuals they serve. Readers will be moved by their accounts of what hurts, what helps, and what is needed from our service systems for healing and recovery. It is our hope they will be moved to action.

It is time to act. It is time to reach out and to bring to an end the alienation, isolation, and maltreatment of individuals whose lives and hearts have been shattered by sexual and physical violence, who have been denied the possibility of recovery through healing therapeutic interaction, and who often end up in our state mental institutions, emergency rooms, crisis services, psychiatric wards, prisons, youth detention and treatment centers, marginal impoverished living conditions, dangerous shelters, and even homeless on the streets. Though they come from and frequently grew up in our own communities, they are stigmatized as "outsiders" as ones "other than us". They bear witness to truths of human depravity that few of us see or want to know about. They are the individuals whose stories are seldom asked about, listened to, believed, or acted upon.

But listen we must, for as long as violence such as rape, battering and the sexual and physical abuse of women and children remains endemic in our culture, and as long as the devastating impacts of such violence are misunderstood, misnamed, and unaddressed by our mental health and human service institutions, survivors will continue to be revictimized and retraumatized by the policies and practices of institutions meant to help them. Interpersonal violence will continue to be perpetuated across and through generations, and the stories and accounts of survivors and professionals contained in this book could become our own stories, or the stories of our children and grandchildren.

The majority of recipients of mental health and substance abuse services in Maine have histories of sexual or physical abuse trauma. This is not a "special population". Multiple studies show that as high as 70% to 81% of persons diagnosed with mental illness and treated in psychiatric settings have a history of sexual or physical abuse or both. Data on children and adolescents suggest even higher percentages, and anecdotal reports in Maine indicate still higher prevalence rates for both adults and children receiving mental health services. Among those treated for substance abuse, the majority of women (conservatively 75%) and a substantial number

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of men have histories of trauma. In addition, many persons with developmental or physical disabilities bear the scars of having been sexually and/or physically assaulted within the context of care-giving situations.

Preliminary studies indicate that correct diagnosis and appropriate treatment for trauma, in addition to alleviating human suffering and disability, may also be more cost effective in the long term. An anecdotal study of one victim of trauma whose life ended by suicide presents striking information. Her inpatient hospitalization, alone, figured at \$640 a day, cost \$2,639,360. This figure does not include residential treatment, case management, legal, medical and other costs estimated to be over \$500,000, making a total cost of over \$3,000,000. In contrast, intensive trauma-based psychotherapy, figured generously at \$150 a session, two sessions a week, for 17 years, would have cost a total of \$265,000.

Our Department has a clear and serious responsibility to ensure provision of the kinds of trauma-based services that will assist our clients who are trauma survivors in regaining their lives. Nowhere can more valid data about what facilitates and what hinders recovery be found than from survivors who have “been there” - both those who struggle daily to cope with and transform the painful sequelae of their victimization, and those who have found their path to recovery. Nowhere can more valid affirmation for what they say be found than from the providers who have been there and stayed there with them. To those survivors who are still seeking to find, somewhere, someone who will understand and help them, we dedicate this book.

Ann Jennings, Ph.D.
Director, Trauma Services

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Introduction

The purpose of this report is to capture and publish information from an exhaustive needs assessment process conducted over a period of nine months by the Department of Mental Health Mental Retardation and Substance Abuse Services (DMHMRSAS) Office of Trauma Services. The study involved nearly 250 participants, including 127 trauma survivors who were past or present public mental health service recipients, and 122 professionals who were recommended by survivors. The report was collaboratively prepared by Ann Jennings, Ph.D., Director of DMHMRSAS Trauma Services, and Ruth O. Ralph, Ph.D., Research Associate, Edmund S. Muskie School of Public Service, University of Southern Maine.

The Statewide Trauma Advisory Groups

Early 1996, in compliance with the terms of the AMHI Consent Decree, the Department began a major initiative focused on developing trauma-sensitive services, treatment approaches, and supports for class members and other recipients of mental health services who are sexual and physical abuse survivors. As a first step, seven Trauma Advisory Groups (TAGs) consisting of self-selected survivor/consumers were formed across the three regional areas of Maine in order to get an expert and geographically diverse set of opinions about what facilitates or hinders healing. Each group met an average of four times to discuss their experiences with existing services and to contribute their knowledge of what is needed for recovery - focusing on “what hurts”, “what helps” and what should be considered in the development of useful and effective services for traumatized individuals. A number of survivors who felt they could not participate in a group setting provided information through writing and individual interviews. Members of the Survivor TAGs represented past and present users of public mental health services, ranged in age from 18 to 65, and included women and men. A number of survivors were also mental health professionals.

Survivors were then asked to identify professionals who they considered trustworthy and competent. These recommended professionals made up seven additional Trauma Advisory Groups, each participating in a similar process to that of the Survivor TAGs. Members of each Survivor TAG and Professional TAG then came together to exchange information and discuss where they agreed and where they differed. Members of the Professional TAGs consisted of a wide range of mental health providers, health care practitioners, pastoral counselors, advocates, educators, and other staff from the criminal justice and human services fields. They ranged in age from 35 to 70, and included men and women.

Essential to the integrity and validity of the data was the fact that the survivors who participated ranged from those who had found ways to cope and heal, to those who still desperately seek help, cycling through emergency rooms, hospitals and crisis

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services. It is important for the planning of insightful, knowledgeable and helpful services to hear from those currently using services. Limiting the needs assessment to trauma survivors and the professionals they trust brought a depth and integrity to the data that could not otherwise be achieved.

Content of this Report

The substance of this report is the forthright sharing of information and experiences from survivors and trusted professionals on “what hurts” and “what helps” their recovery. In each topic area, major themes or concepts have been identified, with quotations from the focus group sessions which explain, elaborate or provide examples. Because the topic areas are not discrete entities, several major themes recur in almost all the chapters. The power of the information provided in these pages can only be appreciated and understood by reading each chapter and contemplating the implications for how trauma is thought about and approached in the provision of services which can help heal these deep wounds.

Statewide Trauma Advisory Group Forum

On November 18, 1996, a Trauma Advisory Group Forum was held in Augusta to bring together survivors and professionals from all over the state. Over 250 attendees included survivors, professionals, those who straddle both groups, state officials, and other interested individuals. This was the first meeting of its kind in the state, and included a powerful opening address by Commissioner Melodie Peet. The text of her remarks is reprinted as an introduction to the substance of this book.

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Maine Trauma Advisory Groups Statewide Invitational Forum November 18, 1996

Opening Remarks of Melodie Peet, Commissioner State of Maine

Department of Mental Health, Mental Retardation and Substance Abuse Services

There are times in any movement when a number of factors come together in the right way to begin to make things happen much faster than we have ever thought or hoped possible. I think we're at that kind of juncture in Maine right now. An enormous amount of work has already gone into us being at this Forum today. It's been a year of enormous struggle and effort on the part of most of you in this room. Trauma is now a major policy area for this Department and will not get lost in the piles of things that are coming at us in the Department each and every day. Today we are going to talk about how we go forward from here and take real action. Our goal is to leave here today with commitments to move on the issues that you identify as priority areas throughout the Forum.

Before I start formal opening remarks, I want to particularly welcome those of you who identify yourselves as trauma survivors. I understand what an act of courage it is to be here today; - what an act of courage it is to start to take part in a movement like this and to find your voices. I can also say that I think it's incredibly important that we find many ways for us to join, so that our individual voices are magnified. Today is an enormously important threshold event in that regard.

Creating a system of care in the state of Maine that is responsive to the needs of trauma survivors is an absolute priority for this department. I will say that over and over and over again throughout the day. We will leave here today with clear next steps of where we're going, but we need you to stay connected. We need you to be part of the group that pushes off from this day and make sure that we're pulling more and more people into this movement. It's through that momentum and push for social change that I think we'll come back together next year and find ourselves much further along the continuum of change than any of us would ever imagine.

A week ago I was given 200 pages of raw data that is feedback from the needs assessment process that so many of you have been part of over this last year. I assure you that I have read every page. The summary is, of course, excellent in the way that it categorizes the information. It is also important I think to read the raw data - because it is raw. It is often hard to read. As the Commissioner of a department that has such a clear responsibility in this area, I can tell you it was hard for me to read.

One of the themes that came through that material loud and clear to me was anxiety about whether your words and impressions were going to be taken seriously,

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and worry about whether I and other people in the Department were going to be honest about the state of affairs in our system as it exists today. One person's comment in particular jumped out. It said something like ". . . it would be helpful if (Governor) Angus King and Melodie Peet and other people in positions of power would speak clearly about the fact that there's no place in Maine today where people can get adequate treatment for trauma issues in a predictable and consistent way." I think the comment was particularly about in-patient care. I share your impression. I haven't seen or heard anything that leads me to believe that a trauma survivor in Maine today can walk into any treatment facility and be assured that they're going to be met with respect; that their issues are going to be treated seriously and that they're going to get a competent response to their issues. My reality is your reality on that one. And I can also tell you that I'm as committed as I can be to changing that reality.

We can take hope in the fact that there are as many professionals here with us today as there are. It is really wonderfully affirming testimony to the fact that professionals are out there struggling as individuals as well, often not getting the kind of reinforcement that they need from their colleagues to affirm the importance of this work. It will be very important for us to stay together in a coalition of interests as we move through the various stages of change that this process is going to demand.

At this point in time ignorance isn't an appropriate defense. For a lot of years people have been saying "well, we don't know enough about trauma; we don't know enough about the impact of abuse; we don't know how to separate it out from what else is going on in mental health systems." That is no longer an appropriate excuse. It is not acceptable in Maine in 1996 to hide behind a defense of ignorance. We need to change our expectations in this culture now. We need to say the needs of trauma survivors are important. There is an epidemic of sexual abuse going on in this country today. We don't like to say that out loud. We don't like to acknowledge it. We don't like to look in the face the reality that that abuse is going on, and that it has implications for all of us who are attached to the mental health systems throughout our country.

I want to say one final thing on where I'm coming from personally on this issue, because underlying lots and lots of the comments in the needs assessment I think I heard and saw a question about whether any of this is really going to go anywhere; whether we have the will or the commitment or the sensibilities in the Department to do something constructive with all of your hard work. Let me tell you that I could not be more committed to any issue than I am to this one and the reason for that is very simple. This is the point for me where my personal experience and my professional experience converge. I'm here today as a representative of a Department who has a huge responsibility to move a system in this regard and we are here to say that we are going to leave today with an agenda for change that's driven by what you tell us. But equally importantly, I'm here today as a person who struggles every day of my life to

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really overcome the demons that were set loose in my psyche by seven years of sexual abuse during my childhood.

Now I don't talk about that publicly very often for a number of reasons, one of which is that I'm worried that the people who want to do violence to this movement will take my personal experience and try to transform it into a reason for inaction. There are people who will say that there's not a legitimate need for systems change in Maine; that this is a personal agenda of mine that I am running because of my own experience. So I can tell you that I thought a lot about whether I wanted to share that reality with you, but decided that it was really the only appropriate way to honor the courage of all of you who have come here today. The only way to pay appropriate respect to that courage was to deal with absolute truth with all of you in terms of where I'm coming from and why this issue is as critically important to me as it is.

I was very lucky ten years ago when I decided to get into treatment and found a therapist who was willing and able to struggle with me and who had both the expertise and the sensitivity to help me heal. My goal is that we work together to create a system in Maine so that it doesn't rely on luck for people to get services that they need. I believe if we commit to embarking on this journey together we can do what no state in this country is doing and that is to create a system where we find ways to build bridges between the professional, the personal, and the political to make sure that trauma isn't the secret and hidden issue in our culture; we can acknowledge that thousands and thousands of people throughout the State of Maine are struggling in ways that we can only begin to imagine every day to reclaim their lives, and we can put in place the supports that will make that struggle ultimately a successful one.

I'll be back at the end of today to listen to what we've come up with in our groups. I'll be here to affirm that work and to pledge to you that we're going to leave here with an absolute commitment to systems change. You can hold us accountable in any way that feels right. And we will come back throughout this year to touch base and make sure that we're moving forward together in ways that make all of our lives better.

Thank you for being here.

Chapter 1

Recognizing (or Avoiding) the Prevalence, Indicators, and Impact of Trauma

SURVIVORS Speak: What Hurts

“The way questions were asked was impersonal, cold and intimidating. I needed understanding and empathy.”

“You have to tell your story all over again and again, even within the same institution.” “Having me tell my story again and again to every Mental Health worker I meet. This upsets me.”

“It is fearful to disclose the abuse. You risk being judged, being penalized, being discredited, invalidated, and having your feelings minimized.”

Not being asked about a history of trauma is also hurtful and can be harmful. “Her sister took her own life. She was in hospitals, including AMHI for years, and no one ever asked her about her abuse history or pursued it.” Not being asked can also contribute to isolation. “Until 10 years ago, when a priest was exposed for molesting children, I thought I was the only one.” Without information about trauma history, behavior and responses to questions are misinterpreted, and treatment planned is inappropriate.

“Misdiagnosis is common.” “They misdiagnose with a mental illness label. Even that label gets changed a lot, so there is not only misdiagnosis but there is no continuity of wrong diagnosis.” “Diagnosis depends on who is doing it. You get diagnosed one way by one psychiatrist and another way by another. Some don’t believe in MPD.”

Trauma symptoms are misinterpreted. “I can’t talk to them about my voices. They just think it’s a chemical imbalance in my brain.” “I hide symptoms like hearing voices, so I will not be labeled schizophrenic.” “It hurt to be misinterpreted as drinking, when I hadn’t had a drink in years.”

“Diagnosis puts a person in a box. It is limiting and does not see the person as a whole.” “The focus is on the label, not on the person.”

Trauma diagnoses are used to refuse to provide treatment. “The Emergency Room won’t treat me because am (diagnosed) Borderline”. “The Partial Hospitalization program turned me down because of my diagnosis.” “The problem with diagnosis is

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that it stamps you forever. When you get a mental illness label, you lose all credibility.”

“Misdiagnosis leads to wrong treatment. They look at symptoms without understanding what is going on with the person. For example, switching can appear to be borderline.” “Treatment for MPD is very different than if you are BPD.” “You are given the wrong kind of medication based on misdiagnosis.” “There are shorter hospital stays than needed because of diagnosis.”

SURVIVORS Speak: What Helps

“Staff who are calm, who will sit and listen in a relaxed manner are essential.” “It helps to have someone that will understand your pain and anguish and be supportive that you will be all right”.

“Having a person you can talk to or having an advocate present during the assessment can be helpful.” “Address the person directly rather than talking with the third party present (e.g. family member).” “Do not treat the person as if she were invisible.”

“Establish some relationship and trust before asking questions.” “Be sensitive to the person’s readiness to answer questions and don’t bombard with lots of questions, especially at a time when the person is in distress.” “Allow time for the person to think about the questions asked and to respond.”

“It is important that provider(s) give as much control as is safe to the client. Decisions should be made together.” “There are healthy ways for providers to influence clients in decision making.”

“The person doing intake should understand the fear (of disclosing abuse).” “Threats from the past are still present. If you tell, you will die, your sister will die.” This can be true even if there is no abuse occurring in the present. Threats made to children can remain psychologically real in adulthood even if there is no present danger.

“Mandate that questions about a trauma history be asked routinely as part of standard interviewing schedules and that histories of trauma be recorded and made part of all data bases and management information systems”. “While retelling the story of one’s abuse over and over is disturbing, it does insure that the new provider is getting an accurate story.” “The new provider can start out by letting us know what she or he knows and her or his understanding of our story, then we can present clarifying information.”

“We need a unified diagnostic system.” “The only way to get the same diagnosis from two doctors is if they are friends.”

“Mental health workers must be willing to go beyond the diagnosis. They must be willing to focus on the whole person.” “Don’t just focus on the trauma piece.”

TRUSTED PROFESSIONALS Speak: What Hurts

Trauma questions are not asked. “A client may not disclose or remember, or the questions are not asked, and so people get misdiagnosed.”

“There is a fear of addressing trauma because the client may decompensate.” “There is nowhere for people to go for treatment if they “fall apart”. “I am hesitant to open up trauma work when unsure that there can be reliable systemic response - when unsure that there can be safety.”

“Survivors are being mis-diagnosed. A review of charts indicated mis-diagnosis of survivors - for example, though their charts showed diagnosis of schizophrenia, horrible accounts of abuse in childhood and in institutions were recorded. In follow-up interviews, it was found that these persons were clearly dissociative.” “It’s common for women and men who get diagnosed as schizophrenic, to have histories of trauma - to have what is really going on with them the result of the trauma. Past mental health practice has created ‘mental illness’. Frequently anyone psychotic gets labeled schizophrenic, though the psychotic behavior may be a brief reactive psychosis, triggered by the trauma.” “Hearing voices also gets diagnosed as schizophrenia.” “Many sequelae of trauma get mistaken for schizophrenia.” “I have seen single individuals go through several institutions with different diagnoses, or even the same institution with different doctors giving different diagnoses.”

“The consequences of mis-diagnosis include: wrongful medication, over-medication, tardive dyskinesia and other reactions to medications, inappropriate and ineffective treatment.” “Mis-diagnosis of trauma survivors results in hurtful or not helpful medications and treatment. Providers presently are not good enough in assessing and diagnosing of trauma. They are not recognizing it and give wrong diagnoses.”

“Stigma in the mental health field is a problem. The field of dual diagnosis may be a safer place to share one’s history of abuse because there is less stigma, less emphasis on diagnosis.” “Male survivors’ problems are not recognized. Men do not disclose their histories of sexual and physical abuse because of the stigma attached to being a male survivor.”

“It takes a longer time for men to disclose abuse than women.” “Being sexually abused is hard for men to talk about, even in a safe place.” “Some men simply can’t handle the pain of being in touch with it.”

TRUSTED PROFESSIONALS Speak: What Helps

There needs to be “an intake system staffed by people who are knowledgeable about trauma; who know how to get information regarding a history of trauma - through both asking questions and recognizing symptoms which may indicate a trauma history.” “We also need an intake system where people are not repeatedly asked for the same information, where people are not required to tell their stories over and over again.” “At intake into mental health services there should be a sensitivity on the part of professionals to sexual/physical abuse issues including an understanding of post-traumatic stress as well as a realistic discussion of what services are available, and if they are appropriate.”

“A uniform assessment mechanism, including DES and DID checklists, should be used to obtain the right kind of information. A universal assessment tool could be used also as a training tool for what to look for and ways to respond.”

“Training is needed in looking for, identifying, assessing and treating mental health clients in the framework of trauma, versus thinking of it all as biologically based.” Training is also needed to insure sensitivity: “how to ask, when to ask, etc. - non-invasive ways of inquiry”. Assessment for trauma history must include “questions asked routinely, part of all intake and recording, part of the information base.”

Training is needed “in putting aside one’s own beliefs and expectations, and meeting clients where they are at, rather than where I think they may be”. A recognition of the complexity of recovered memories can help a survivor deal with present distress. Assessment is not a time to find out what “really happened”.

Chapter 2

Retraumatization via Hospitalization: Creating Safe Places for Healing

SURVIVORS Speak: What Hurts

Psychiatric hospitals/units throughout the State dismiss, devalue and/or mistreat persons with symptoms and histories of trauma. “I would rather die than go back to the hospital.” “I was forced to strip and was drugged.” “They only medicate, medicate, medicate . . . Won't deal with flashbacks, personalities, alters, etc.” “At admission if you're suicidal it's mandatory to put you in a Constant Observation Room (COR) for 24-72 hours. Staff switches every couple of hours, usually male and female staff. They put male staff on female one-on-one. Male staff observes female patient taking a shower. Some CORs don't have bathrooms. You must be escorted to the bathrooms. Sexual abuse victims have problems with bathrooms. Staff stands there, makes you keep the stall door open, very impatient, want you to hurry. Sometimes they make female adults wear diapers. I was given prune juice and had diarrhea, said to staff had to go to the bathroom now, and they wouldn't let me. I shit my pants and they made me clean it up. They tease you, and make you wear 'Attends'.” “I was a voluntary admission. When I got to the unit, I was told I must have a body search. I said I would not tolerate that and said I would go home. As I was refusing, they had me meet with the doctor and it was the doctor who informed me that I would be blue-papered. I dissociated, the body search was done, and despite my further telling them I wouldn't go through with it, they never informed me that I had.”

Restraint and seclusion techniques are retraumatizing and inhumane approaches to managing symptoms. Staff who use restraint and seclusion are abusive. “It is being abused again.” “It's extremely humiliating, awful, to be undressed in front of others (especially opposite gender).” “You feel totally trapped.” “It involves 5-6 guys chasing you down, holding you down - just like rape. So you are terrified and you try to get away from them and you strike out to protect yourself. Then they call you “assaultive” and that follows you to the next hospital and they say to you, ‘I hear you hit someone’.” “When I came to in a seclusion room being held down by six staff (male and female) not knowing why, I cried, then asked questions. These questions were answered like this - ‘You know what happened’, ‘you're just playing games’, followed by ‘if you don't calm down we won't let go of you.’ I was crying, not fighting. One male staff was kneeling on my right shoulder. I was hurt, confused and scared. Next they completely tied me to a bed with a male staff to watch me. I was there for two hours. A female staff who was concerned came in to check on me and she was told to stay away from me. She only wanted me to know she was

there and cared. I felt scared and alone. I was having my period and also when they let me loose I saw I had bled through to the sheets. The male staff present saw the blood. I

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felt very embarrassed, humiliated and afraid because they didn't realize at first where the blood came from and threatened to tie me back down."

There are no Units in Maine specializing in Dissociative Disorders or Trauma Recovery work (including unique considerations for male and female survivors). "You are totally screwed if you have a Dissociative Disorder in Maine and need inpatient care." "When I was splitting (changing alters/dissociating), the psychiatrist told me all I needed was Jesus Christ and to stop that!" "During one hospitalization, after stating numerous times that certain alters were bent on self-destruction, three different members of my "treatment team" suggested to me that I should leave the hospital and 'go home and see what happens.' Shortly after this I was discharged." "After being discharged from a hospital with several alters openly and determinedly threatening self-destruction, I was subsequently denied admission to four hospitals and three crisis stabilization units because they said I needed 'more help than they were able to provide.' They finally sent me home from the emergency room to stay with a friend since I could not be alone." "If you could only say 'I'm MPD' and have this be accepted."

There is a lack of knowledge/training for survivors and staff regarding therapeutic approaches and the link between trauma histories and the presenting symptoms causing the need for hospitalization. "You have to lie to get into the hospital, say you are suicidal when you're not." "Assertiveness is viewed as resistance and privileges are revoked for this. You may be responded to by threats to send you to A.M.H.I. or forced to go in the quiet room."

There is a general disrespect for patients as human beings that should be valued as full partners in the treatment and recovery process. "They take your clothes away and watch you take showers." "The psychiatrist gave orders to all Unit staff . . . that no one was to talk to me, counsel me or in any way work with me on any MPD related issues. My hospitalization was the direct result of an episode of selfmutilation by an alter." "There are serious confidentiality problems. One person was very stigmatized when she disclosed her abuse."

"You are often forced to be medicated when what you need is someone to talk to." "Grossly overmedicating people." Lack of access to psychiatrists that understand appropriate medication management for persons with trauma symptoms. "Hospitals mis-use medications to control behavior."

Insurance payments control the length of hospitalization. "Shorter hospital stays than needed because of diagnosis or lack of insurance." "I went to the institute in Philadelphia for 28 days then had to leave because of insurance. I had no meds, I was

in crisis, and I went immediately to BMHI because that's where I was discharged to and they would not take me." "There is pressure to leave the hospital. They make hospitalization as unpleasant as possible to make you want to leave. You're sick enough

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to stay when you have insurance. You're suddenly improved enough to leave as soon as your insurance runs out."

SURVIVORS Speak: What Helps

Develop Trauma Recovery/Dissociative Disorders Units in the State of Maine that "are calm, safe, create a trauma milieu, and where seclusion and restraint are not used". "This Unit should be staffed by persons who recognize and understand how to deal with flashbacks, personality switching, anxiety due to memories, child alters needing attention, etc." "Have hospitals model for us how to help ourselves and each other; teach us selfhelp skills that empower us." "No restraints, no quiet rooms. But I have always wished for a 'screaming room' - a room with no locks, with comfortable things (pillows, blankets, etc.) where it is safe to let an angry, sad, or scared alter out." "I need a place to go where I would not be locked in." "You should be able to continue seeing your therapist when you're in the hospital."

Provide indepth training in all aspects of trauma treatment and recovery. "Design hospital Units based on that knowledge, and staff those Units with persons sensitive to the needs of survivors and skilled at delivering true recovery services." "Education, education, education in the trauma paradigm!" "As memories release, huge amounts of energy that was contained with the memory needs to be worked with. Teach staff not to be afraid of intensity and to work with the rage, grief, shame and terror that often accompanies it." "Better training of staff in code red to take you down. That process is triggering for person being taken down and for those witnessing."

Create alternative services designed to diminish or eliminate the need for hospitalization such as safe houses, individual therapy, peer support networks, and alternative therapies when trauma survivors express the need or are experiencing intense symptoms. "Teach us selfhelp skills so that, in a crisis, we would not need to continue the dependency mode on hospitalization."

Provide training to psychiatrists regarding known research related to treatment and medication management for survivors. Increase the number of psychiatrists that survivors have access to that are supportive in working with survivors. "We must bring in groups of survivors to do grand rounds and in-service training. To tell the psychiatrists and veteran psychiatric nurses and social workers how they have hurt us, why certain 'standard' procedures humiliate, shame, and traumatize us, and how they can work with us to make it better (an open discussion time would follow a speaker's panel presentation of our stories.)"

TRUSTED PROFESSIONALS Speak: What Hurts

Hospitals are not places for healing and may retrigger symptoms or retraumatize. “Institutions are not good places to go - anywhere. They are not places to recover. Assuming that these are good places, safe - where people can get better - is a mistake. Many people are retraumatized. People are stripped, restrained, forced to take drugs, secluded, etc.” “Hospitals presently are the wrong environment to treat dissociation disorders. One set of staff are helpful, another set are sadistic and retraumatizing. Yes, sadistic, and intentional.” “A hospital environment is so noisy, chaotic, and triggering, due to insufficient funding, staff and space. Violence on acute units is retraumatizing.”

"People who are labeled as the most difficult clients often end up getting restraint and seclusion." “To be put in 4 point restraints, to be held down, must be traumatizing even without a history of trauma.” “One action on the person’s part may have created a history which follows him or her regardless of present behavior. Because of that history they may get treated differently -that is, thought of as people who need to be restrained or secluded. These people might not need restraint if they were negotiated with and talked with.” “It is hurtful to be put in restraints and not be talked to at all.” “There is a belief on the part of some that if you talk to a person in restraints that you might reinforce their being there.” “The client is sometimes left to process on his or her own, during or after restraint or seclusion.” “Clients in inpatient care have been more seriously mentally ill. Safety is an issue both for staff and for other patients.”

“When staff have not received training in alternative ways to work with patients, they will maintain control in whatever way they can.” “Staff feel powerless to really help, empower, or do therapy with the person, so they write off and label the person as something unchangeable.” “There is a staff culture: staff may cover each other in ways that are hurtful to the client, for example, accusing a client of splitting staff when they are really responsible for splitting themselves.” “Direct care staff at hospitals get no training.”

“Medication is harmful when it is used only for control and not for therapeutic purposes.” “Medication can be used as a way of stabilizing, to decrease the use of restraints, yet some people feel too vulnerable being medicated.” “Medication is more invasive into the body of a person than restraints.” “Over-medicating and forced medication are sometimes done.” “Psychiatric inpatient care medicates and offers no real depth of therapy for crisis management.”

There is denial of treatment for trauma, and resistance to the trauma paradigm. “You can’t get a hospital bed if you say the client is dissociated.” “The Medical Director does not believe that MPD exists. Patients are diagnosed as partial complex seizures when they are clearly dissociative. One MPD client was told by the hospital staff that they could cure her in two weeks with Tegretol.” “Denying the

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existence of Dissociative Disorders and generally resisting addressing trauma leads to mismanagement of medication and treatment for traumatized clients.”

“Appropriate, affordable inpatient settings for crisis stabilization or long term care are not available.” “There is a lack of hospitals where trauma is understood and treated appropriately. When a client needs hospitalization, there is nowhere appropriate to refer. Present hospitalization practices and environments are intrusive and exacerbating for persons with histories of trauma. Clients need less intrusive and more soothing inpatient environments.” “Even with a therapist and psychiatrist advocating, there is repeated difficulty finding appropriate inpatient treatment in the state of Maine for clients. Finances are prohibitive even for Medicare services, and it is almost impossible to get insurance to cover out-of-state treatment. Most programs won’t slide their fee at all.” “When you are in the hospital for a limited time, there is not time to do rage work, or to process this kind of work.”

TRUSTED PROFESSIONALS Speak: What Helps

“There is a need for safe, good inpatient care for trauma survivors.” “There need to be environments which provide safety, stability, and containment.” “Create a dedicated trauma unit (not exclusive to Dissociative Disorders), and build in outpatient services.” “Good inpatient services for trauma survivors should be characterized by calm and safety.” “Spiritual, recreational, social, educational, vocational, cultural, physical, family, finances/economics: if you do these, and address abreaction slowly, then the role of the hospital is to help put the vessel back together if it cracks. (This depends on the hospitals’ ability to do this vs. retraumatizing and hurting the person).” “There needs to be consistency within psych units, with regular communication.” “There should be more than one kind of inpatient services - for those who are suicidal and for those who are not.” “Inpatient settings and services should be designed specifically for trauma survivors, and staff should have specific expertise in working with this population.” “There may be value in a general psych unit with staff available who have trauma expertise - so that people who have not been diagnosed for the presence of trauma can be identified. There could also be telephone expertise available to staff (and/or to patients).” “We need an intake/admissions system or unit staffed by people who are knowledgeable about trauma; who know how to get information regarding a history of trauma - through both asking questions and recognizing symptoms which indicate a trauma history. An intake system where there was no repeated asking of the person for information which had already been gained. Where the person was not required to tell her or his story over and over again.”

Staffing issues are important in providing appropriate inpatient (or alternative) services for trauma survivors. “We need psychiatrists who know meds

and trauma - in hospital, in crisis, everywhere.” “Hospital staff do not have the choice that private therapists have regarding the clients they work with. It is important to recognize that within the system (not only in hospitals) there are people who should not be asked to work with severely traumatized clients.” “There needs to be reasonable staff/patient ratio because DID clients can be difficult to handle.” “A client can identify

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staff who work well with her and those who don't. Arrangements should be made in advance." "Create a ward where different specialties and philosophies are recognized and supported; where certain specialists work with certain patients; where staff meet to discuss differences and disagreements and arrive at agreements - but not in front of the clients." "There should be co-attending privileges for trauma survivor's therapist when they are in the hospital. At the patient's request, he or his individual therapist should be part of the treatment team."

"Focus on developing alternatives to hospitalization (while using hospitals in sensitive ways)." "Something that provides support, caring and safety without the heavy duty medical model." "Create a residential program (flexible admission).. treatment would be flexible to meet individual needs.. medical and psychiatric staff.. actual treatment, not just containment to prevent suicide or mutilation." "Somewhere less expensive and restrictive than hospital care is needed at times of crisis and to prevent crisis, i.e. a safe house." "There need to be 24 hour safe houses. Crisis stabilization in Bangor is a model." "There should be a place to be safe at certain times, where the person will be accepted. This should be flexible in terms of admittance, being able to return, etc. They should take panic attacks seriously." "The foster home model should be considered. The family is trained, screened, and it could be a long or short term arrangement." "We should create a Retreat - for a few weeks to a month, to do trauma work precipitated by triggering, memory recovery or breakthrough to another level of recovery." "Create an environment that is safe to do rage and other trauma work." "Create a place in your mind. A model for something concrete. This retreat would be a haven of rest. A big house, lovely setting, community setting with private rooms with their own private entrances. Place where you could express anger safely, be with or without others around you."

Training needs to be offered that addresses all the aspects of trauma recovery (staff and client issues). "Inpatient training must start with psychiatrists." "A training model should be used which emphasizes how to create safety." "Training needs to be done in: (1) how the staff can avoid being reactive; (2) recognizing when the staff or the client is in a state when they cannot receive information, for example, because of high anxiety; and (3) when staff should be interactive."

Survivors need training also. "Rage release: the person can learn they can control their rage." "Help the person get to know the nature of the physiology of trauma, i.e. a 'startle response'." "Address the issue of the person's responsibility of his or her own behavior. Do not automatically put the person in a victim role. Look at

the notion of what the person is doing right now, and the responsibility and choice he/she has for his/her own behavior. In restraint situations, choice and responsibility are not factored in. When asking survivors about seclusion and restraint, ask them about what responsibility they have in the situation. Do not automatically put the person in a victim role."

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Funds for hospitalization need to be made available to persons in need and the “reimbursement for hospital beds should be long term and require that treatment be offered to patients versus ‘filling beds’ for dollars.” “Diversion funds to treat people in the community rather than at AMHI have resulted in cases of great improvement.”

Chapter 3

Responding to Crises as Opportunities for Growth and Recovery

SURVIVORS Speak: What Hurts

Access to Crisis Services is limited. Service may be denied based upon diagnosis (BPD, DID). One person was told by an agency she could not use crisis services because she has an outside therapist. Only severe crises are responded to, e.g. overdosing or self injury. A survivor was told “you must be a danger to call or be seen.” The limitation to severe crisis is thought to be because of understaffing. “You can’t get therapy, you can’t get any service. You end up self-destructing, and calling up hotlines and lying about killing yourself so you can find someone to talk to. You must act out in a violent way to get any kind of help. But if you say you’re going to kill yourself, they blue-paper you, when all you really need is someone to talk with.”

Staff are untrained in how to respond to trauma survivors. “Staff can’t talk to you about the voices except to tell you it is a ‘chemical imbalance in your brain’. They don’t understand at all.” Survivors indicate that staff don’t believe what they say. They (staff) express their disbelief or “stigma” in many ways - even in worker posture. “Professionals and workers are afraid of simply ‘being with’ someone as they go through what they need to go through and feel what they are feeling. You are told to ‘shut it up’ or ‘stop it’ - whatever you are expressing. The intensity of the crisis - of what you are feeling - is denied and minimized . . . You are told they will not deal with the sexual abuse because ‘it’s not what is presenting now’.”

Staff are untrained to respond to feelings of suicide. Some survivors expressed the need to be able to talk through their feelings about suicide to someone safe without the fear of being hospitalized. “If you start to feel terrible, you won’t talk about it because you will be put in a hospital because there’s no other alternative.” “I cover up a lot when people ask if I’m suicidal. Because they’ll think you’re going to kill yourself and then will blue paper you.” Others want staff to listen when they say they need to be blue papered. “I am telling the truth when I say I’m suicidal. They need to blue paper my butt! - Yes, in my case they should blue-paper me quickly.”

Poor quality crisis services deter survivors from seeking needed help. “You can need help, and be afraid to ask for it.” “In crisis services I sometimes feel controlled, patronized, or scared that staff will do something to hurt me.” “I lie to protect myself. If I tell them that I’m not in control and not safe, are they going to lock me up? This is worst, because freedom is all you have.” “I would stay isolated rather than interact with people who don’t know what they are doing.”

The use of rigid protocols and standard mental health clinical practices are harmful and retraumatizing. “Rigid crisis protocols based on a depression model are used. These make no sense for a trauma survivor.” “Sexual abuse is at heart disempowerment and disconnection. In crisis settings you are completely disempowered. There is unilateral decision making. Things are done to you. Decisions are made about you. You have no choice about anything.” “You are dealt with mechanically, as an object - as a pathology. Your diagnosis rules. You get cookbook treatment based on your diagnosis. You are shot up with drugs versus helped with what’s really going on with you as a person (dealing with new memories, flashbacks to original abuse, etc.)” “Some crisis residential programs won’t admit a person with DID unless you can meet extremely unrealistic criteria, i.e. all dissociative parts must respond by your given name, and all altered states must agree to a safety plan.”

Crisis phone response and Hotlines are not helpful. “You call a crisis number and there isn’t anyone there or there is only one person and they are overwhelmed, undertrained, overworked, tired.” Some people at the phone line are helpful, some are not. “My friend called the crisis line and they called the Sheriff’s department. She was raped by someone in the Sheriff’s department. Before she called she had not OD-ed. After she called, she did.” “Phone volunteers don’t know how to respond to survivors without adding their own prejudices.” “Hotlines need people on staff who can talk you through the crisis.” Phone calls are not returned immediately. “Sometimes it takes an hour to hour and a half to get a return call - yet 15 minutes with the right person can prevent you from going into crisis.”

Inappropriate staff response to anger can cause increased problems. “Rage is about fear and lack of power.” “If staffs’ mindset is that the way to control violence is with more violence, they will produce more violence.” “One episode where a person was assaultive can follow the person for years. It goes into his records. The person is from that point on followed by his history, no matter what the person has been doing in terms of self-control and empowerment. It is important to look at the past. But it is best to look at the here and now. Is the person now psychotic? . . . now violent?” “Getting stuck into a cinderblock wall room with no windows and no clock is traumatizing.”

SURVIVORS Speak: What Helps

Survivors need crisis phone lines, with trained people, to connect with someone who will listen and “...who will call the client, reach out.” “To have someone to call at late hours.” “Toll-free hotlines.” “A trauma survivor hot-line - a crisis line available for trauma survivors - there needs to be one which understands and can assist trauma survivors.”

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Crisis prevention/ways of helping to deal with own crisis should be available. “Have a plan in place prior to crisis to help prevent hospitalization. For example, when you’re feeling unsafe, you can wrap yourself in a blanket - it helps. We call it full body contact. Teach us those things.” “Preparing for the event of another crisis requiring mental health intervention, through writing down with professionals what helps in that situation. Like an advanced directive.”

Use Advanced Directive. Develop a plan when not in crisis, which lists what would be helpful and not helpful, to implement if in crisis again. “This should be part of the Individual Service Plan. Person should keep it with them. It should be kept in medical records with primary physician. You should have an ID card with information saying ‘has an advanced directive’, with # to call to get information.”

Staff must be trained to help in times of crisis. “Someone who can help me to see I have choices - who can help me to stay in the present, keep me from going way down. There is a lot of knowledge about how to do this. It needs to be shared.” “People (staff) need to understand when in crisis you are not always able to initiate a topic or to say what is going on with you. I need someone to just talk to me, and to observe me and tell me what he or she observes.” “Staff who are able to recognize symptoms of trauma.”

“When I am in crisis, I need persons:

- a. who can be with me when I am in distress; be present with me when I am in pain
- b. who will acknowledge my pain without trying to ‘fix’ it. This takes someone who knows his/her own pain and is not afraid of it or of yours
- c. who is not afraid of my sexual abuse. I don’t need someone else’s fear
- d. someone who has worked with their own sexual abuse - another survivor can do this
- e. who will ask what would help and trust I know whether or not I need hospitalization
- f. understands the coping role of suicidal thoughts, as a relief, an end to the pain, as giving a sense of some control
- g. who knows the difference between ‘I want to die’ (despair, hopelessness) and ‘I want to kill myself’ (anger, defiance)
- h. who will understand and control and prevent me from hurting myself when I am in danger, but still give me options and choices, and respect me in a way that doesn’t treat me like an animal.”

TRUSTED PROFESSIONALS Speak: What Hurts

Clients with trauma histories are identified as “over users” of crisis services. “People who are chronically in crisis don’t qualify for crisis services because their crisis is viewed as a way of life.” “The problem is not getting the right kind of crisis service. But many are unable to get other services.”

In some areas, crisis phone help is not helpful. “None of the clients will call phone help now because if they say they are suicidal, the reaction is to call police.” “When a person calls phone help and says she is going to kill herself, the reaction is to call crisis, police, etc., when often all the person needs/wants to do is talk through some of this on the phone.”

“There is a fear of addressing trauma because client may decompensate.” “(I am) hesitant to open up trauma work when unsure that there can be reliable systemic response. When unsure there can be safety.” “There is nowhere for people to go for treatment if they ‘fall apart’.”

“There is no safe place to refer a survivor of trauma in crisis without further traumatizing that person.” “There is no safe crisis stabilization service.” “There is a lack of safe places - alternatives to hospitalization - where an individual can do necessary work on trauma.” “Trauma survivors need a safe place to go to when having difficulty, so the person can have a place to ‘be a basket-case’ and then go out and continue working, etc.”

“Crisis is caused by denying treatment to trauma survivors until after the crisis occurs (i.e. the person cuts his/her wrists) rather than taking preventative measures.” “Panic attacks are not considered crisis in the mental health system. Rather they are considered a ‘self-limiting condition’. What if you killed yourself before the panic attack resolves?”

Emergency Rooms do not help trauma survivors with their immediate crises. “For assessment process in the ER, you frequently must wait for hours. You can be there all night. During regular hours, an appointment can be made providing the client has no substance abuse or medical problems. This waiting is expensive, and the Community Support Worker who waits with the client is also costly.” “People are sent out from the ER when they are still in crisis. A client is discharged from ICU to home with no bridging.”

There are few or no services for trauma survivors to go to after a crisis (or before a crisis). “We have no referrals (resources) for people with histories of trauma. There is a waiting list for two years. We give them the yellow pages.”

“There are few clearly established programs to assist survivors over the long term. Trauma needs reworking as individuals’ lives change. Crisis will occur at different times.” “There is a lack of residential treatment programs where individuals can learn skills of crisis management, grounding, etc. and where they can stabilize.”

Services are inadequate or damaging. “Some people are doing trauma work irresponsibly, with inadequate training, i.e. doing abreaction work in ER, etc.” “There are mixed experiences with staff. Some clients report good experiences, and some report bad experiences with staff at crisis stabilization.”

TRUSTED PROFESSIONALS Speak: What Helps

Create a safe place within the person’s own home. “(Provide) in home support. Have someone to take over the person’s responsibilities at times of crisis. Then the traumatized person can push out from his or her home and test out readiness to become involved in job, community, etc., and if the stress is too great, can come back in.” “There should be a mobile team of people to go to the home of the person in crisis.” “It is best to keep the person in his or her natural environment and provide support.” “Without at-home support of some kind to provide space for healing, the person may go into the hospital.”

There need to be 24 hour safe houses with “environments which provide safety, stability, and containment.” “There should be a place to be safe at certain times, where the person will be accepted. This should be flexible in terms of admittance, being able to return, etc. They should take panic attacks seriously.” “We need a lot of small safe houses to accommodate persons with trauma.” “During crisis provide a safe place and do appropriate after-care planning and follow-up.” “The foster home model should be considered. The (foster) family is screened and trained. It could be a long or short term arrangement.” “New Hope for Women in Rockland has a number of trained volunteers who offer their homes as safe houses to women in danger of abuse.”

A hot-line especially for trauma survivors needs to be available. “A place for folks to talk through their crisis on the phone. People need to be able to make phone contacts and talk with a person who knows what they are doing.” “There should be warm-lines to be able to call about other than crises. - A client support phone system - not a crisis system, but prevents crisis.” “There is a model in Massachusetts, - a peer counseling model with trained survivor volunteers. It is non-profit, tax exempt. It’s called ‘Heartlines, Inc.’ . It is a shoe string operation, open two nights a week, - a good example of survivors helping survivors.”

Crisis workers must recognize that “A crisis may be an important step forward in the therapeutic process - in the process of healing.” “It helps to have

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quick small meetings with staff during the day, and communication with night staff regarding what is happening with the person.” “We must look at the process of healing as being developmental. Crisis can happen after important steps forward in therapy.”

“There should be a continuum of options for crisis.” “Respite care, retreat possibilities, expressive work, refuge” “...a safe house, a day hospital program where clients can switch to more support when needed, small support groups for survivors, a place to go or a way to get support, after working on trauma in therapy.” “Drop-in groups are helpful in times of crisis. They are also educational.” “There needs to be flexibility regarding where the person is seen. For example - the person should be provided or be allowed to be in an environment which she or he perceives as safe, particularly in crisis.”

Chapter 4

Lack of Trauma Treatment in the Community: Needed Treatment, Supports, and the Value of Alternative Therapies

SURVIVORS Speak: What Hurts

There is a pattern of not involving the person in their treatment plan, and evidence of lack of knowledge and practice in planning for treatment for trauma survivors. “My treatment plan was created without my involvement and contradicts the true facts. It refers to events falsely, and to my behavior punitively, rather than finding out and stating why I took certain actions to avoid being hurt. My treatment plan looks like it was written for another human being than me.” “Having a therapist making decisions FOR you or about your treatment rather than making decisions WITH you (is hurtful).” “How ‘personalized’ can a treatment plan be if no one even bothers to spell my name right?”

Treatment plans often indicate that the survivor “does not fully participate in treatment”. Survivors report that they took themselves out of groups which triggered dissociation or other feelings, and treatment plans reported this as “resistant to treatment” or “not participating in treatment.”

Survivors describe unprofessional behavior by staff which is inaccurately reported in treatment plans. “In the treatment plan, they said that my ‘experience with Dr. B. has been very successful.’ This is a bald lie. Working with him was a nightmare. He was the one who said straight to my face when I told him I was DID, ‘I don’t believe you. No one believes you’.” “... an alter was angry with the therapist and left, because he behaved inappropriately and unprofessionally. His behavior was eventually witnessed by professional colleagues and a mental health consumer advocate, and my perceptions were validated. But my treatment plan was made and they haven’t changed it.” “When the therapist sexually abuses a client, there is nowhere for the client to turn for services. How can you go back into the field and trust, when their response to you is that ‘oh, the therapist could not have done that’!” “It hurts to be told to sterilize your razor blades.” “Having your therapist tell a destructive alter who is on the phone and presently cutting, that it is ‘spicy and exciting.’” “My therapist called a child alter a ‘big baby’ when she was hiding behind a couch because she was so scared.”

The lack of appropriate treatment or the recommendation of inappropriate treatment is another major issue. “The treatment plan kept insisting I ‘contract for safety’. How could I do that when access to the coping skills necessary to do so (grounding, awareness of and appropriate expression of emotions, safety, coping with

flashbacks and triggers, etc.) is withheld?” “Classes to teach you ‘relaxation’. They expect you to lie down on the floor and participate in guided imagery. This may cause more dissociation and alters to come out who should not be there. They then blame you for dissociating.” “There is denial of certain diagnoses which leads to inappropriate treatment.” “Partial Hospitalization turned me down because of my diagnosis of Dissociative Identity Disorder. They felt I wouldn’t be able to remain in one personality long enough to get enough out of the groups. (Two months later I was working part time and have been for one and a half years).” “Relaxation classes can be a major trigger big time.” “Professionals lack experience and education and understanding (of trauma). They allow perpetrators in the same groups or programs and then punish victims for protesting.” “I have no transportation to get to groups.”

“I can’t find a therapist to work with.” “I can’t find a therapist who will communicate with all my alters.” “I found a therapist for MPD finally, but I have to travel 60 miles to get there and 60 miles to go back home. After sessions I have to hang around, sometimes up to an hour before I feel safe enough to drive home.” “I can’t find a therapist who will communicate with all my alters.” “You have no choice regarding who you get as a therapist - or in the gender of the worker you are assigned to.” “I’ve spent 4 years looking for someone I could work with who understood what was going on with me.” “It’s common to call 25 counselors and only find one who will take you.” “If you can’t find a therapist, you are stuck with an unhelpful therapist, or put on a waiting list.”

“I don’t make enough to afford a therapist.” “I work full time and have insurance, but it doesn’t cover enough of the therapy.” “The cost of therapy is too high to afford. People in crisis don’t have resources. I have to make choices between food and therapy.” “Insurance doesn’t pay for the intensive treatment that is needed.” “People who need to go to a therapist cannot afford it on their own. There should be a cap on how much a therapist can charge. It’s way out of line.” “You get comfortable with a counselor, then it’s taken away - I was told I had to pay to see her. Then I’m told that Medicaid will only pay for 30 sessions.”

“There is a lack of professional treatment for addictions counseling - not only for alcohol and drug, but also for food addiction, sex and love addiction, gambling and spending addictions. To recover, one must be fully present and participating in treatment.”

“There is no place in the state to do anger work.” “The walls often are paper-thin in therapists’ offices. What are you going to do with the rage and anger? This affects what you will show and express. White noise machines don’t do as good a job as they are said to. Therapists must be flexible enough to provide a safe environment for their clients - when necessary to work in a car, or in an apple orchard.”

“Treatment for perpetrators needs to be separate from treatment for victims.” “Therapists should not treat both perpetrators and survivors. Most survivors don’t feel safe going to a therapist who treats both perpetrators and victims. Just a few unique people can treat both.” “Allowing perpetrators in the same group as victims. Not allowing victims to talk about it. I was stuck in the same group with someone I had a protection order against. I had to drop out of the day program because they would not remove him - but I need that day program.”

“There are limited resources for residential placements and housing - few places and lack of choice.” “Staff are not trained in trauma identification or services.” “Being in a group home, or other placement out of hospital to be safe. But for someone traumatized, it is not safe.” “I was in a shelter, run by volunteers. They made me give up my meds.” “It hurts when I am losing more and more of my ability to function and have no place to go for temporary or longer assistance.” “I was treated like I was hopeless.”

Case Managers and Community Support Workers are “often not trained or willing to empower the client.” “There are not enough of them, they are overworked and underpaid.” “Case workers do not offer any real-time help with difficulties of day to day living.” “Sometimes they do for the client what the client can do for themselves.” “It hurts to have providers making decisions for instead of with clients.”

“Vocational rehab, placements, residential places don’t accommodate for cyclical nature of recovery.” “The time frame for vocational programs needs to be extended. I may need years of small steps before I am able to become a productive employee.” “There is a fear of losing Medicaid if you work. This could mean the loss of therapy, causing a set back which can lead to loss of job.”

SURVIVORS Speak: What Helps

“Therapists must be trained in trauma treatment.” “It helps when someone listens, follows through, understands trauma, accepts you and believes you.” “It hurts to talk about the abuse, but each time it peels a layer off.” “It helps to find someone to tell.” “Therapist to call on who understands the continuum of dissociation and PTSD and issues of survivors.” “Long term individual psychotherapy is essential.” “A trusting relationship is crucial to work through anger and other emotions.”

“It is important that providers give as much control as is safe to the client. Decisions should be made together. There are healthy ways for providers to influence clients in decision making. This may sound basic but needs to be a focus in training, as it is often forgotten.”

“Mental Health workers must be willing to get to know the whole person - not just focus on the traumatized piece.” “A healing relationship is supportive and understanding, not blaming.”

“We need groups that deal with dissociative disorders, teaching me and my system: imagery, grounding techniques, strategies. For example, learning techniques like writing down a list of 10 things to help me when I am going into crisis. The system knows that list is there. Breathing techniques are helpful to calm the chaos inside.”

“We need to work on rage in therapy.” “Anger in the presence of another normalizes it. It takes the shame out of it. The person feeling rage out of control may be terrified of being so out of control, and afterwards, when spent, needs to be comforted, not punished.” “Externalizing rage is essential. You need a safe, nonjudging strong container. Rage is a powerful emotion that can move you forward. Once it starts coming, support it, don’t label, don’t pathologize - rather, encourage it. This depends on the comfort level of the provider.” “To encourage anger in someone who has difficulty feeling it, get angry with her. If she can’t get angry, therapist get angry for her. It helps when someone else can feel and get angry at the injustice done to me. The person working with the survivor must not be afraid. When they are not afraid it is because they have the depth of their own emotions.” “The therapist should be a safe container. Set rational rules: e.g. no weapons and don’t break anything. When rage is allowed, it does increase temporarily. You must provide ways to feel and express rage. Our culture doesn’t deal well with anger, especially from women. When I stopped being clinically depressed was when I felt anger.” “Rage and anger work are important. Sometimes need to be able to request to be held or restrained so can let go of the rage.”

“We need to have alternative therapies, versus one way of doing things.” “Make art therapy available to those with few resources. It helps to make tangible things that I can hang on to. I can judge by what I create how close to the edge I am.” “Acupuncture for anxiety, massage, body/mind work, holo-tropic breath work, movement and sound therapy for soothing and helping with memory.” “Sandtray work, clay work, exercise therapy, grounding techniques, music and drama therapy.” “Tai Chi is helpful to be in your body.” “Cognitive therapy with the BASK model is good. It involved behavior, affect, sensation, and knowledge of what’s going on in the present.” “Being able to focus on something but the trauma or flashbacks. It’s very hard but I find drawing and journaling as a healthy way to vent emotions. Thus it gets easier.” “There should be more training on art therapy. For those who were threatened not to talk, its a way to have a voice. Also because memories get repressed and art is a way of expressing what is repressed.” “It is important to fund and provide materials for survivors to work with.”

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“Working on self esteem helps re-framing thinking to be able to see the positive in myself. Psycho-drama and other groups helped with this.” “A sense of being ‘bad’ is part of your personality structure, the structure of your being. It is not amenable to reason, as an idea you can just get rid of. You must slowly integrate ‘I’m OK’. Very slow. And you must do this in a relationship. Must do it bone by bone. You restructure a personality slowly. Your personality was formed in the crucible of abuse. Therapy should infuse some development understanding - what happens to the personality of an abused child at different ages?” “Alters need to be treated in ways consistent to how they perceive themselves. If necessary, change of that self perception can happen in a safe way without conflict.”

“There should be single sex transition home(s) for people who are not able to live completely on their own. It should be a step-down, a transition from the structure of the hospital back to home.” “I need a safe house - a place to go when I want to work through something and get to the other side.” “Respite care - a place with support staff where you can concentrate on taking care of yourself, a place to retreat to. This keeps you from going into crisis.” “A place to go where I would not be locked in.” “There should be survivor input regarding facility and program.” “We need alternatives to hospitals. They are resistant to doing any work that can’t be done with a pill.” “I would like places to go where you don’t have to work on trauma.”

“I need advocacy (from my Case Manager) to support the reality of my experience, and explain and intervene with agencies like Medicaid, Voc Rehab, Mental Health Centers, etc.” “It helps when providers actually LISTEN to what YOU think YOU need or want.” “Case Managers/Community Support Workers are helpful when they provide individualized case management by listening to the client, to what they say they need - to what they know works for them, versus deciding what they need.”

“I need groups that teach me and my system about: dissociative disorders, imagery, grounding techniques, strategies to help me and my system.” “We need a strong women’s group, where we feel safe, and are accepted.” “We need a support group that is wellness oriented.” “What helps is being in connection with others who understand their experience - support - having a voice.” “The Empowerment Group is based on Charlotte Kasis work ‘Many Roads/Journey’. This builds self-esteem, ego, strength.” “Have someone present with the group who is responsible for monitoring safety and what’s going on with people. This should be someone trained somehow to deal with issues like dissociation. Someone should be responsible for observing the group and its members. This person might also have MANT training so he/she know how to de-escalate without retraumatizing.” “Groups are essential - there is huge shame, particularly for men who are victims of abuse. You must force yourself to

overcome the shame - to speak out - to bring the fact of the abuse out in the open. A safe group helps with that.”

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“Work helps.” “Producing the newsletter has connected me with other survivors, as has coordinating survivor art shows.” “My job both helps and hurts. It hurts because it takes too much time. It helps because I love doing it. It provides insurance.” “Helping someone else helps me. I have an edge over other helpers because I have experience. I get it the first time.” “We need financial counseling on how employment affects SSI/SSDI, PASS plans, etc.” “A way to be productive helps you to avoid crisis.” “Work and vocational opportunities focus on something outside of stress, develop competency and strength.” “A chance to contribute to the community is helpful - to serve on boards, to work in the mental health system.”

TRUSTED PROFESSIONALS Speak: What Hurts

“Treatment is not client directed. Six different doctors can mean 6 different treatment courses for the same client.” “I have seen single individuals go through several institutions with different diagnoses, or even the same institution with different doctors giving different diagnoses.” “Staff splitting around diagnosis in hospitals so patients get mixed messages. There is no consistency.”

“Time-limited therapy is imposed on a person who needs long term therapy to work through the impacts of trauma. With limits on number of sessions imposed by managed care policies, there is not time to establish trust and to even uncover a traumatic history.” “Long term, affordable outpatient therapy with appropriate and affordable medical and psychiatric backup is essential for recovery, but it is not available.”

“There is a failure to recognize the value of alternative therapies; i.e. body work, breath work, movement, art therapies, acupuncture. These therapies are helpful to trauma survivors, with the exception of the services of those alternative professionals who don’t understand or are not able to do well with trauma survivors.” “One-to-one behind closed door therapy is retraumatizing for some clients.”

“There is hesitation to open up trauma work when you are unsure that there can be reliable systemic response, when unsure there can be safety.” “I am concerned about opening the door with a client about trauma, because of inability to follow through because I can’t get reimbursed. This is a clinical ethical issue.”

“There is a lack of residential treatment programs where individuals can learn skills or crisis management, grounding, etc. and where they can stabilize”. “When you make any client leave their natural environment and move elsewhere to get

services, you handicap them even more.” “There are no appropriate residential treatment programs that can be ‘holding environments’ for trauma victims who get into ‘black holes’. Hospitals can be totally retraumatizing and rooming houses are too scary alone. Something in between is needed that provides support, caring and safety without the heavy duty medical model.” “There is a lack of safe places - alternatives to

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hospitalization - where an individual can do necessary in-depth work on trauma. Safe places do not exist.”

“There are no day treatment programs with appropriate options for trauma survivors.”

“Lack of flexibility on the part of vocational rehabilitation and work and employment settings to accommodate for individual work related needs of traumatized persons and the cyclical nature of recovery from trauma.” “The interface of work and Social Security is complex. Survivors need to work and become more functional, while continuing to receive Social Security - not have it cut off. There should be a way to not to lose benefits while working.”

TRUSTED PROFESSIONALS Speak: What Helps

“We need to create healthy environments and structures that are based on the needs of clients/patients: needs as identified and expressed by clients; give individual clients a sense of control; give clients a choice to contribute to something that provides him/her with a sense of joy, control, and an absence of conflict.” “Provide therapy in the context of a comprehensive, coordinated approach to individual trauma survivors involving a team of informed persons. ‘It takes a village’.” “When a person is full of rage, provide safe settings in which he/she can discharge the anger in safe ways, with appropriate time to process and to integrate after this discharge.”

“Essential for recovery from traumatic abuse: (1) stabilization (safety, coping skills development, sobriety, financial security, housing stability, structure for days - work, volunteer, school); (2) consistent and appropriate therapeutic framework; (3) collaboration among treatment providers; (4) well trained emotionally mature mental health providers.” “Essential for recovery from traumatic abuse is self acceptance, recognition of victim status, understanding of how to avoid repeated abuse.”

Survivors need “a healing relationship characterized by caring (empathy), consistency, appropriate boundaries and limits, therapist self-care and self understanding.” “When a person is feeling despair, what helps is validation of their pain, knowing they are not alone, access to support groups or therapy, and understanding that grief is part of the healing process.” “The characteristics of a healing relationship include self-expression, exploration of strengths, unconditional

acceptance.” “Professionals who are human, self revealing, and willing to care are effective with survivors.”

“We need to be tolerant of different clinical perspectives, and not set up a ‘we-them’ situation.” “Emphasize that there are clinical approaches and treatment approaches to guide decisions. We should look at working with trauma as a learning

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process. There are so many questions and passing phases in this field. It would be a mistake to 'wed' to single concepts. Many of the present theories could change."

"We need to include non-traditional approaches such as acupuncture, massage, homeopathy, yoga, meditation, rolfing, externalization of anger or grief (Kubler Ross Model). "More expressive therapies need to exist - art/dance/writing: expressive work within a clear structure." "When using methods such as relaxation, you must know what you are doing regarding trauma." "Clinical hypnosis can be a very useful tool. However, clinicians should be certified by the American Society of Clinical Hypnosis and have treated PTSD." "Expressive therapies must be more available for survivors to express rage, helplessness and distress without mobilizing fears, embarrassment, and stigma."

"Case managers should work with people to expand their options and what they can choose from." "There is a constant need to search for and access needed resources and entitlements." "Phone support is important, staffed by persons with trauma expertise."

"We must create housing components and supports based on the individual conditions and needs." "There is a need for safe spaces - short term residential places, homes." "Create a residential program of one week to one month (or other flexible timing). It should be a program for survivors and treatment that would be flexible to meet individual needs. Although it would need medical and psychiatric staff, the focus would be actual treatment, not just containment to prevent suicide or mutilation. There would need to be adequate work done with appropriate family members, and adequate aftercare."

"All policies regarding housing and residential programs need to be looked at in terms of their impact on trauma survivors." "Single sex housing should be an option."

"Paid work, volunteer work and school are important ways survivors use to help themselves." "Work situations need to be found that accommodate disability, go with the rhythm of the person's recovery. Certainly this is cost effective." "Create a 'Cooperative'; a living and working community. Ways of working which allow for varying levels of disability. Creating things for sale."

Chapter 5

From Alienation and Isolation to Advocacy, Peer Support, and Empowerment

SURVIVORS Speak: What Hurts

“Being a survivor is feeling isolated, not daring to share that part of my life (trauma) with people for fear of being rejected, feeling defective, feeling powerless, lack of understanding from professionals that whatever behaviors we took on was our way of calling for help even if it doesn't fit society's view of what is 'normal' behavior.”

There are inadequate to no support groups, peer advocacy services or peer support systems in place that can assist a survivor in obtaining the necessary help to possibly avert a crisis or hospitalization.

There are inadequate to no funds available to develop the structure within which to create necessary supportive services throughout the State.

There has been no central location in which trauma survivors could obtain information regarding their symptoms, ways to creatively manage them, or resources to access that are viewed as helpful. It has been difficult to discover what therapeutic approaches really work best so that one could advocate for them and better control the therapeutic process.

Some survivors view their “right to have a representative” assisting in the protection of their rights **as a sign of weakness rather than as a source of support and strength.**

SURVIVORS Speak: What Helps

"Form support groups in each Local Service Network. Train individuals who can run these groups.” “Peer support versus professionally lead.” “Rape Crisis can be a model.” Create special “support groups for partners”, for “parents whose kids have been kidnapped”, for “men”, for “people with MPD”, etc. Obtain financial support from DMH for support groups.

Provide training for survivors “-for better control of the therapeutic process, understanding illness, creating a positive attitude, meditation.” “Making a list of things to do to stay more grounded and that help in other ways.” “Learn how to enjoy self, experience pleasure. Make a list of some pleasurable things to do.” “Teach things

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like imagery, techniques that worked specific to dealing with PTSD.” “Being able to focus on something but the trauma or flashbacks. It’s very hard but I find drawing and journaling as a healthy way to vent emotions.”

“Teach us how to support each other. We can be more helpful to each other than the ‘helpers’.” “You talk to another survivor and what takes you two years to explain to your therapist you can say in two minutes to another survivor.” “Helping someone else is helpful. You can’t help someone else without helping yourself.”

Create resource information that provides survivors with tools to manage their own symptoms in non-traditional ways such as “keep a journal”, “Dr. Strong tapes”, reading materials such as Courage to Heal, meditation.” Provide training in the use of these and other resources.

Teach survivors what their rights are “and how to protect themselves from their rights being violated in the mental health system.” Assist them in utilizing options available such as the use of a representative.

Create both DMHMRSAS funded and self-help “warmlines”, “dial a friend”, “someone to call at late hours”, someone to stay with when being alone is too difficult. “A calling list like AA. A group of survivors with enough recovery that they can be a person on the other end of the line for a survivor who needs to talk.”

TRUSTED PROFESSIONALS Speak: What Hurts

“For some survivors, groups are sometimes very depressing, with too much focus on what happened and not enough on moving ahead. Some survivors may not be ready for the group process and intensity.”

“Self-help should be viewed and approached cautiously because of retraumatizing experiences that can occur listening to other people’s traumatic experiences, and because of the suggestibility factor that can exist with dissociative clients.”

Survivors sometimes feel despair, isolated, and stigmatized (if they disclose abuse to persons that do not understand it). They do not have sufficient resources to find ways to help themselves.

“Trauma survivors often have no understanding of their own illness. Education is needed for both survivors and for professionals.”

TRUSTED PROFESSIONALS Speak: What Helps

There needs to be “support groups to share and talk about ways survivors have found to help themselves: work, school, volunteer, supportive friends and family, participation in treatment program.” “When a person is feeling despair, what helps is validation of their pain, knowing they are not alone, access to support groups or therapy, and understanding that grief is part of the healing process.”

“Develop a WEB site in Maine for people all over the state to communicate about trauma. Given the geographic distances in Maine, a WEB Site could assist in educating and bringing people together. This could be a project for a graduate student at UMO.”

Develop “Trauma Information Centers”. “Make materials available for self-education, books and other materials for survivors, in the public library system and elsewhere.” Use television ads or health information pieces to “get general information out about the trauma initiative, about available resources, etc.”

Develop public information materials. “Develop simple publications for trauma survivors about what’s available, who to contact, and educational material about, for example, what abuse is. Distribute these publications to churches, police, hospital waiting rooms, therapists, etc.”

Create means to feel supported rather than isolated through “support groups, newsletters, conferences.” Volunteers who are survivors who have worked on their own issues can be very effective in working with other survivors. There is a model for this in Philadelphia related to domestic violence. It uses few professionals.” “Give these volunteers training.” “Hire someone to coordinate survivors to form peer support services. Get someone with a passion for doing this who would find a way to continue the program.”

Programs should be developed that offer “skills training, such as social skills and job skills”, “writing skills, expressive skills, the arts”, “psycho-education, learning, and skill building groups of all kinds”.

Chapter 6

Professional Attitudes, Behaviors and Practices: Need for Education and Training

SURVIVORS Speak: What Hurts

“There is a general lack of trauma understanding on the part of mental health and related staff.” “Providers say there is no such thing as MPD.” “In the ER, when I tell providers I have DID and PTSD, I get no response.” “Not being believed or validated about the abuse.” “Minimizing - wiping the abuse out - denying it exists.” “Not understanding the cyclical nature of the healing process. They want you to ‘make progress’, go from one step to the next upwards. But that is not how it works when you’re recovering from trauma.” “Expressions of emotions, especially when intense and most especially anger, are not tolerated or allowed by providers.” “Providers don’t take trauma seriously. Because you look normal and sound normal, others expect you to act normal.” “If docs had more education about trauma, they may not need so many meds.” “Professionals need to know how to deal with people’s despair, fear, anxiety, grief, rage/anger, cutting, suicidal thoughts - not make them feel guilty for feeling it or respond with ‘Oh, you shouldn’t feel that way’.” “No one in the legal system, the social service system, the mental health system, and the educational system is educated to work together to address and respond to the fact of the existence of abuse.”

Some professionals avoid working with traumatized persons. “Helping adults and children who have been traumatized by abuse is difficult. It makes you confront your limitations. Professionals don’t want to acknowledge their limitations, where they don’t know. Some may not be cut out to do this work.” “Trauma is often the lowest of priorities with therapists. This is not necessarily intentional. They may be afraid of dealing with trauma. They lack knowledge. They are fearful of being liable - being unjustly accused of creating false memories in a client. If they had education, they might be more willing to work with trauma.” “Professionals need to recognize their limitations. They need to recognize that they can’t ‘fix it’, we have to do that. When they try to ‘fix’ us and we don’t get ‘better’ according to their expectations versus the reality of what the person is capable of, they give up on us, or get angry at us and don’t want to work with us anymore.”

There is little understanding of and treatment for Dissociative Disorders. “Denial, ridicule, lack of knowledge about and lack of services for Dissociative Disorders.” “Providers say there is no such thing as MPD.” “Staff can’t or won’t deal with phenomena of MPD, for example, a child alter.” “Media exaggeration/

misrepresentation of MPD. Focus on violence.” “Providers must learn about the diagnosis of MPD or DID. They must stop looking down on any diagnosis.”

There is little understanding about what can trigger trauma survivors. Therapists can trigger clients by having, in their offices, religious items, or wearing a cross, dressing all in black or all in red, by burning incense, having candles lit. There needs to be education about this.”

“Providers are intimidating, and use humiliating words, behaviors, and attitudes.” “Being laughed at by professionals - being talked about behind your back so you can hear. That really hurts and I end up feeling one inch tall and very unimportant.” “The psychiatrist who rang a lobster bell in my face.” “Hurtful messages are communicated by providers, like ‘pull yourself up by the bootstraps’, ‘it’s a game, cut it out’, or ‘we’re not going to put up with the game plan’.” “Occupational therapy is humiliating and abusive. They make you do stupid things. Draw a happy picture. Draw a sad picture.” “Viewing you as if your aren’t intelligent - as if you don’t have a brain. Message to professionals: ‘crazy’ and ‘stupid’ are different. I may be ‘crazy’ but I am not stupid!”

“Never being asked about trauma is like the abuse as a child.” “Professionals don’t want to hear about or deal with sexual abuse.” “The stigma and silencing of sexual abuse by providers and by society is very hurtful.” “People don’t want to know that abuse happens. It is hard to find anyplace where you can talk about it.”

“Use and misuse of power and control over survivors replicates abuse.” “Attempts to struggle against power imbalance is interpreted as pathological.” “The power imbalance is not recognized.” “Mental health professionals exercise control in a million different ways. This is like incest with your father. Providers are very paternalistic. It is the medical modality, not a partnership.” “You can take a bath if you do the art work.” “Rehab would not let you wear make-up. When going out, you had to ask permission to wear make-up.”

“Pathologizing replicates abuse, makes it ‘your fault’.” “Everything is interpreted as a symptom of the ‘illness’.” “When you are trying to get help, you are viewed as ‘playing angles’ or ‘manipulating’.” “For example, if a case manager sees a 6-pack of beer in your fridge, the automatic assumption is that you are a hopeless alcoholic.” “A case manager came to my house uninvited. I asked him to leave and he wouldn’t so I slammed the door. I got labeled ‘violent’.” “There are double-binds for men. You’re accused of being gay. You’re bashed for being male. It’s automatically assumed that you’re an abuser if you’ve been abused.”

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“Punitive treatment replicates abuse.” “If you say you don’t remember doing something, they think you are lying, manipulating, or not safe so they lock you up.” “Telling the truth gets you punished.” “If you are ‘disruptive to the therapeutic milieu’ - i.e. express your feelings - any intense feelings - you are punished, usually by chemical restraints.” “I have experienced being re-perpetrated by persons in positions of trust, so I quit telling. I’m afraid now of telling.” “Your history follows you no matter what you do in the present. I only got assaultive one time and that was when they tore the head off my stuffed doll that I had for a lifetime. Now providers tell me I’m dangerous and that I terrify people. My history follows me.”

“The language of oppression replicates abuse.” “My, that was an angry feeling!” “Remember, you’ve already lived through the worst.” “Nobody can hurt you now.” “Your behavior is inappropriate.” “The ‘therapeutic we’; ‘How are we feeling today?’, ‘We’re going to have a nice bath now.’ ‘We won’t have any negativity.’, ‘My, we’re in a hostile mood today!’.” “Tearing down your self-esteem. I fight all the time to keep from feeling worthless - to build my self-esteem. Then you get asked questions, supposedly to prove your competency, like ‘How many oceans are there?, How many continents?’ Well, I know I can’t do math, can’t do geography - I might as well kill myself.” “The doc looks at his watch to see what date it is, then asks, ‘Do you know what day it is?’ (Yeah, if I look at your watch!)”

“Being treated like an object is hurtful.” “Clinical reviews, team meetings, all these people. You feel like a specimen on view. It frightens me that professionals, especially psychiatrists, are in this as a business.” “They are fascinated by people as ‘subjects’.” “Lumping people together and not seeing us as individuals.” “Being global in treatment, as if one recipe works for all.” “Being seen and labeled as a diagnosis. Labeling is very damaging. If you’re borderline, they are focused on ‘you are the problem’.” “People are not numbers, though we are treated that way. We deserve respect - the right to be treated with respect ...”

“Failure to listen and to take us seriously is hurtful.” “Not being listened to when you tell them what you need hurts.” “I got off the meds and felt I had come back to life. Two weeks later I went back to the mental health center and told them I was no longer taking med. They ‘noticed’ I had opinions, and labeled me ‘opinionated and noncompliant’.” “You are not taken seriously when you say what you need. We know what we need.” “Looking to others for information when I have the experience and I am there and can answer your questions with the most authority.” “Professionals and others won’t do what helps, what they are told helps by both survivors and professionals who work with them, because they think it ‘perpetuates the disorder’, ‘encourages negative coping’, and is ‘counter-productive toward therapy’.”

“Inappropriate ways of working with an individual is hurtful. Like the psychiatrist who tried transactional analysis on me. She kept trying even though I said

it was not helping.” “Therapists holding to the belief that integration is the only way of getting better.” “Therapists who claim co-consciousness is pop-psychology even though they admittedly haven’t read anything on the subject.” “Blind treatment. When a therapist wants you to trust and follow him when he isn’t even able to tell you where you’re going, i.e. what the treatment plan is.” “Don’t tell me to ‘just trust you’.” “Community Support Workers who want you to do it all, who don’t believe you when you can’t.” “Lack of knowledge of resources which exist.” “So many professionals and people in the mental health field have their egos wrapped up in being the expert - so when they run into something outside their thinking, even though it’s true or could help you very much, they refuse to consider it.” “Professionals often don’t understand the fact that people dealing with trauma often have poor memories. When you ask a professional to please remind you of something - they say no, that is not our policy, you have to be responsible. Yet even a dentist’s office does reminders.”

SURVIVORS Speak: What Helps

Professional attitudes that are respectful, caring, and healing. “A trusted professional treats all people, as well as me, with respect.” “Treats me like a person, and not a ‘patient’, like this is my life and I have some idea what its about.” “A trusted professional really cares about me as a person. I’m not just another number - another ‘patient’.” “You can talk to them as to a friend - someone on your own level - they don’t think they are better than you” “They treat me with respect. They treat me as an equal.” “Care and let me know you do.” “The only way we will heal is with someone who knows, understands, who is kind, and who we can trust.” “Offers feedback in compassionate and thoughtful manner which allowed for the opening of deep wounds which they then applied salve to before I left.” “They don’t treat me as if I am diseased.” “They work with me in traditional and non-traditional ways.”

“Professionals who accept and reinforce my own reality. Accept that what I say is true for me, believe what I say, and then we work from there.” “People who have believed in me have been the ones who have been helpful.” “Took me seriously.” “Being listened to and taken seriously when you tell them what you need.” “They are validating.”

“Professionals who help me to find tools, ways to help myself.” “Took time to know my history and my current situation, and thought about both.” “Took time to look with me at many different and diverse options before deciding how to treat me.” “If they don’t know - don’t have an answer - they will tell me.” “Give a person choices. Respect they know what they need.” “Used and created many resources personally helpful to me. Had a menu of useful activities, modalities, books, etc. and took the time to go through them all and gave me many options to choose from.” “Trusted professionals encourage independence and growth.” “They recognize my

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accomplishments and growth, encourage me.” “They are always hopeful for me, even when they are seriously concerned.”

“Professionals who are not afraid to let me express my full range of feelings - will just stay with me.” “When you are in grief or despair, it helps to have someone with you simply to witness.” “Someone to bear witness to your present self and emotions, someone who doesn’t have to turn it off, make it go away - who will simply witness it. The essence of the survivor of abuse is being alone with no witness.” “People who identified with my suffering - they were the ones who helped me. They didn’t distance themselves.” “Realize that what gets seen as ‘symptoms’ are normal responses to abnormal circumstances, like being raped at age 2. What people call pathology is really enormous creativity.” “Aware of what’s happening with me, recognize my internal state.”

“Professionals who have the ability to take care of themselves, be centered, and not take on what comes out of me - not be hurt by what I say - sit, be calm and centered, and not personally take on my issues.” “They have good boundaries. They know where they stop and the other person begins. Don’t take on my feelings, for example, being scared when I’m scared. When that happens with a professional, I feel I have to take care of them.” “Do their own recovery work and take care of self. Has the ability to and does share their own experience, strength, and hope, and therefore by example is a powerful positive influence.” “They do their own emotional work.” “Professionals who haven’t dealt with their own abuse can’t be helpful. You threaten her denial. I could hear if she would say, ‘I think you should work with someone else. I can’t deal with these issues.’” “They are self-reflective. Professionals must continually check in with themselves regarding how they are thinking about the people they are supposed to be helping. They need support to do this.” “Trusted professionals are excited about their work with trauma survivors and are informed about trauma and its effects and how to respond, etc.”

“Involve consumers in developing, teaching, evaluation of training.” “Blur boundaries between consumer/survivors and professionals, soften and break down the barriers.” “Dialoging between professionals and survivor/consumers. Crosstalk. Discover where converge, where diverge, where complement or are at odds and why.” “Have panel discussions of clients/survivors to tell your stories. Dispel preconceived ideas. Help them (professionals) to see and understand what they are seeing. This can be a context for understanding people with trauma histories.” “We must bring in groups of survivors to do grand rounds and inservice training. To tell the psychiatrists and veteran psychiatric nurses and social workers how they have hurt us, why certain “standard” procedures humiliate, shame, and traumatize us, and how they can work with us to make it better (an open discussion time would follow a speaker’s panel presentation of our stories).”

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“Require track on trauma at publicly funded universities” “Have something to offer to people to get them to buy in: a curriculum, something to make life and job easier, so wheel doesn’t have to be invented over and over again.” “Tailor make training for specific settings, for specific groups. e.g. Crisis Stabilization workers, etc. Need different skills in different areas.”

Mental health professionals and therapists should be required to take training in trauma. “Train professionals in helpful knowledge, skills and attitudes.” “During times of crisis: ways in which the crisis is also an opportunity; respect and trust client’s knowledge of own needs; how to work with client in development of plan for crisis times (advanced directives, individualized crisis prevention plan, individualized crisis response plan); How to listen and hear what client is saying; See symptoms as search for wholeness - as coping skills developed to deal with the abuse; How to ‘be with’ person in distress, be present with person in pain, be a witness without trying to ‘fix’ it, turn it off, make it go away; knowing your own pain and not being afraid of it; knowledge and understanding of experience of a trauma survivor; suicide thinking as a relief, and end to pain, a sense of control’; ways of controlling and preventing self-harm if person is in danger - that are respectful, offer the person choices, and do not humiliate and retraumatize the person.” “Teach how to de-escalate.” “Don’t respond to us as a ‘hard ass’. But calmly, openly ask us to calm down, do some breathing exercises, visualize a pre-agreed upon image, etc.” “There needs to be education in blanket wrap, grounding techniques, safe places, short stays to stabilize, crisis stabilization.”

Education of professionals needs to include the changing of attitudes. “Teach how to allow a person to be a person - not an illness - and to have their feelings.” “Training needs to include more education on labels and mistreatment of people with certain labels. Change personal attitudes toward certain labels.” “Professional education must include personal development.” “Learn now not to take things too personally. Keep in mind that the anger, pain and fear are not directed at the staff, but at the past. The staff person just happens to be there.”

“Maine leaders need to be educated about trauma.” There also needs to be “public education to inform people of trauma issues - the number of people involved, the types of trauma, - raise awareness and sensitivity to create a validating climate so that people are not afraid to disclose. “”There is stigma and taboo attached to having been abused. The public needs educating to become more accepting of the need for services for survivors.”

TRUSTED PROFESSIONALS Speak: What Hurts

“There is a lack of knowledge and understanding of the effects of trauma on individuals, so interventions utilized can be counter therapeutic and at times

can exacerbate the symptoms experienced by the client. The client comes seeking the help of the system, and becomes more impaired.” “The whole medical model needs re-thinking, starting with diagnosis. It is invariably hurtful.”

“Retraumatization can be caused in a variety of settings and through a variety of practices.” “One-to-one behind closed door therapy is retraumatizing for some clients.” “The dismissal, denial of access to services, and rejection of Axis II labeled persons by agencies and hospitals.” “Attitudes and messages communicated to clients which ascribe blame and shift responsibility for lack of understanding or appropriate treatment - conveyed by statements such as ‘You’ve got to get over this’.”

“Survivors are hurt by not being believed about the experience of sexual abuse.” “Persons who have experienced ritual abuse are losing credibility, not being believed.” “Denial of the existence of Dissociative Disorders, and generally resisting addressing trauma on the part of psychiatrists, is leading to mismanagement of medication and treatment for traumatized clients.”

“Survivors are hurt by attitudes which pathologize behaviors and feelings rather than recognizing them as the individual’s efforts to cope and heal. Pathologizing works against the individual’s efforts to heal.” “The trauma history of a person with Borderline Personality Disorder diagnosis is considered irrelevant. The thinking is that person got themselves sexually abused because of their BPD!”

“Short term, time limited interventions are not helpful.” “Being expected to put trauma behind and move on.” “Turnover in agency staff, lack of recognition of need for continuity with one worker.” “Time limited therapy imposed on a person who needs long term therapy with enough time to work through the impacts of trauma. With limits on the number of sessions imposed by managed care policies, there is not time to establish trust and to even uncover a traumatic history.”

“Mental health workers are uncomfortable with intense anger. They are used to sadness and shame from women. They find male anger scary.” “Anger can be a mask for pain, a way to deflect pain. One way to do this is to constantly be angry and blame the system for personal problems.” “With men, anger is up-front first. It is hard to call or to see an angry person as victim.” “The anxiety level of staff in a crisis may be high. They may have been injured in the past trying to control patients. It is difficult to learn when anxiety is high.”

“A high percentage of mental health professionals and staff in corrections, substance abuse, and mental health are also trauma survivors. This can have positive and negative effects. A negative effect is that many professionals don’t recognize abuse on a subtle level, and sometimes must ask lots of (non-leading)

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questions partly due to their own abuse (all levels) as kids. They may avoid or not see the abuse that is there.” “They can be retraumatized by working in the field.”

“No university courses train students in working with trauma. No curriculum puts major focus on trauma. Psychiatric residents and nurses (or MSW) curricula do not address trauma.” “Professionals in the state are seldom really trained to understand how to actually work with trauma survivors, borderline personality, PTSD or dissociative states. Most graduate schools tell you these things exist, describe them, etc. and undergraduate schools probably do as well. But unless you take a field placement with actual survivors and a good, competent mentor, you begin practice with nothing but intellectual theory. Many of the ‘experts’ in the field who are most qualified and have the most success are those who have created methods themselves and discovered that they work. Many of these experts are survivors themselves.” “Training in an accredited MSW program never addressed issues like self-mutilation, ritual abuse, PTSD experiences in practical ways. Neither did they address the issues involved for yourself as a therapist (in a practical way) in working with this client population.”

“Students trained in trauma-based theory and practice encounter problems when they get into the field for practicums, etc. They meet with resistance from agencies. Other staff see them as threatening. They have difficulty accommodating students.”

“There is resistance from untrained staff because of: fear of legal action from those who accuse therapists of inducing false memories in clients; as a new unfamiliar mode of treatment, trauma based practice does not fit the current treatment model and perceptions; only biological interventions are considered necessary; an understanding and treatment of trauma is not considered a needed approach.”

“The least trained people get trauma victims to work with. They are given no time or opportunity to learn new things - to learn how to work effectively with trauma victims. They burn out fast because they are given no supervision or support in their work.”

TRUSTED PROFESSIONALS Speak: What Helps

“We need to know how to create healthy environments and structures that are based on needs as identified and expressed by clients.” “Give clients a choice to contribute to something that provides him/her with a sense of joy, control, and an absence of conflict.” “We should ask the individual survivor what specifically is helpful to her or him.”

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“Training for staff must be around the personal ability to be non-reactive.”
“Staff members can only take a patient as far as they are.” “A training model should be used which emphasizes how to create safety.”

“We must be sensitive to different cultures. Interventions can be experienced in different ways by different cultures.”

“You must be able to go down into the darkness with them, and sit with them in the darkness, then crawl out with them. You must be able to be with that kind of despair. The main thing that keeps a survivor is to know she or he is not alone.”

“Develop curricula and target professional schools. Courses on trauma should become required part of graduate education.” “Have consumers/survivors review courses on abuse/trauma treatment prior to being adopted in classes.” “Bring in experts and other professionals knowledgeable about what works in trauma treatment.” “Offer more courses in working directly with dually-diagnosed survivors and survivors in general, also substance abuse and (trauma) survivors, eating disorders and survivors, mutilation and survivors, phone calls and crisis, etc.” “Develop field units/placements at the university itself that can be a training/treatment clinic (i.e. for the full semester the student works with actual survivors being supervised by someone who specializes in this area and is paid appropriately as a clinician to work there; bring in trainers from outside, etc.) This would give the students hands on experience.”

“Develop something comparable to a substance abuse license. In order to practice or work with persons who have history of trauma, you would have to be licensed.” “Make the knowledge and treatment of trauma a part of the ‘tests’ for licensing - a mandatory part of licensing in Maine. Require that the professional ‘re-up’ every 2 years to make sure he/she meets requirements and to become updated as to crucial new research and information related to the field.” “The Substance Abuse Board requires 6 hours of ethics for substance abuse professionals to ‘re-up’. Use this as a model.” “Get the support of the Professional boards - Social Work, LCPC, Psychologists, Substance Abuse, Psychiatry, Nursing.”

“A priority focus of training should be on teaching professionals how to teach their clients skills to manage and cope with the various ways trauma affects them. - for example, teach people to be their own occupational therapist, teach clients the skills they need not to be victimized again, teach clients how to work in conjunction with others.” “Education is needed both for survivors and for professionals. Trauma survivors often have no understanding of their own illness.”

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“Training should be given therapists and those doing assessments in putting aside one’s own beliefs and expectations, and meeting the person where they are at, rather than where I think they may be. This is a basic principle of good treatment.” “People need to be trained to meet the pain of clients.” “Therapists and others doing assessment need to be educated to be careful and not jump to conclusions. The real focus of treatment is not in bringing past perpetration to light or on trying to figure out what ‘Really Happened’. But it is in helping the person with their present distress.”

“You need supervision and support to work with survivors.” “Supervisors should receive more in-depth training than workers, in order to provide ongoing support and education.” “Train supervisors of MHRT paraprofessionals concurrent with developing a curriculum on trauma for MHRT formal educational program.” “Create a section on trauma for the MHRT Program. This will affect Community Support Workers, Medicaid reimbursable paraprofessionals (and their supervisors)”

“Create a team to provide education to providers and to the community. This team would offer training to: Mental Health and General Medical providers, Substance Abuse providers, and alternative therapy providers.” “Practitioners need shared ideas, shared cognitive frameworks out of which to practice. There is need for cohesiveness of response to trauma survivors.” “Design training for different settings. For example, addressing problems associated with trauma within a short stay in the hospital or a short term crisis facility.”

Provide methods and materials for professionals and survivors to communicate and to keep up with information in the field. “Develop a WEB Site in Maine for people all over the state to be able to communicate about trauma.” “There needs to be ways to prevent us from slipping back into isolation - ways to continue connections to others. This computerized way of communicating could keep connections alive and expand on them. This could fight against isolation and ignorance. It would be ongoing - a resource for consumers/survivors and professionals.” “Tape presentations of national experts and disseminate them.” “Develop a resource library in each region - collection of materials - videos, audio tapes, books and articles, etc., and place them in various libraries throughout the state.”

Training needs to include ways of coping with the professional’s secondary trauma. “Working with victims takes energy. You must be fully present to work with victims, and you must do your own work on yourself.” “Your own issues are brought up in working with a trauma survivor. This can be unwieldy and shocking. It goes into every corner of your being.” “A support group helps - lunch with one or two other people to talk with. This is true for both survivors and providers.” “On my worst days, the pervasiveness and horror of what I listen to in the experiences of trauma survivors, colors my whole life and perceptions of others. I start to perceive

‘yucky slime’ on everything. I see every father with his child and interpret that he is abusing that child. This is a different spin on cynicism.” “Lenihan’s approach is very useful in helping professionals to work with trauma survivors. It offers concrete things which can be done to sustain life through the process of trauma work. It addresses the overwhelm factor.”

Organizations will need training to provide staff support. “There needs to be organizational awareness of the effects of secondary trauma. Help must be built into the organization - including ready access to a staff support group, individual counseling, etc.” “One organization structured support for staff who worked with trauma survivors and had to deal with secondary trauma. It included: setting aside one day a week for staff related to their work with trauma survivors and to the way in which it affects them; providing case consultation, group supervision for secondary trauma, and individual counseling - a way to do individual work; built in ongoing training for staff. This decreased turnover and increased morale among staff. It built excellent relationships between staff. They worked as a real team. You could always get support from other staff. It kept the clinical standards high. It reduced secrecy and competitiveness. It reduced isolation.”

Training needs to include many content areas, such as:

- Prevalence, definition, and impact of trauma
- Approaching people who have been abused
- Identifying signs of trauma; knowing behavioral, nonverbal indicators
- Techniques for obtaining good trauma history
- Referrals: When needed and to whom and for what
- Dissociative Identity Disorder: recognizing and responding to dissociation
- Teaching survivors skills they need to cope with their own trauma effects
- Managing crises; responding in the ER setting, nonverbal approaches to minimize retraumatizing
- Understanding abuse effects at different developmental stages
- Coping with the legal aspects of abuse: testifying, civil v. criminal, liability fears, etc.
- Working with treatment teams and other providers in collaborative manner
- Borderline Personality Disorder as an indicator of abuse history
- Addressing trauma in short-term stays
- Controversy regarding memory retrieval and “false memory”
- Self-injury issues
- Eating Disorders and abuse
- Substance abuse and untreated sexual abuse
- Boundaries and limits in working with survivors
- Supporting self-help and peer support efforts
- Post-traumatic Stress Disorder
- Alternative therapies for abuse survivors

Family violence training; e.g. effects of witnessing violence
Reaching male abuse survivors
Re-framing and de-pathologizing abuse symptoms
Suicidality issues
Dynamics of ongoing perpetrator involvement
Understanding the Perpetrator-victim-rescuer triangle
Use of relational language
Helping systems and workers avoid retraumatization
Professionals who are also Survivors and other “wounded healer” issues
Using empathy constructively
Dialectical Behavior Training
Supervision and support for the providers
Rage expression, management, and reduction

In addition, it is recommended that all trauma training should:

- Be self-reflective. Include an examination of trainees’ biases, assumptions, and transferences.
- Be survivor centered. It is the individual survivor’s experience which should guide the professional’s work and supersede any prior training model(s).
- Incorporate findings of the Survivor and Professional trauma Advisory Group Needs Assessment.
- Be based on the belief that trauma survivors can “make it”, in whatever that means in their own terms.
- Model the creation of a safe, non-judgmental environment in which 1) there are opportunities for non-shaming, self-reflective process reviews; 2) there is recognition that triggering can take place and provision of support for trainees; 3) there are opportunities to disclose personal issues related to working with survivors; 4) pathologizing and distancing are eliminated; 5) sufficient time and a variety of modes are provided for learning.
- Recognize that not all people can or should be expected to work with trauma survivors.
- Include both survivors and professionals in the design, implementation and assessment of training, as trainers, consultants, speakers, peer support, etc.
- Involve, to the greatest extent possible, various levels and layers of the trainee organization, agency or program in order to ensure a supportive organizational context.

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- Involve, to the greatest extent possible and whenever appropriate, related agency personnel (i.e., police; human services), and related disciplines (i.e., mental retardation, substance abuse).
- Coordinate, to the greatest extent possible and whenever appropriate, with other training activities undertaken by this Department.
- Continually update training content and materials to include new research findings in trauma.
- Be based on common theoretical frameworks and practices shown to be effective in the field.
- Recognize that trainees may need to open themselves up to new information and insights, and that this will require taking risks, looking honestly at previous learning and mistakes, and transforming their understanding of healing relationships. Recognize the underlying importance of establishing a safe relationship (between survivor and professional) as fundamental to the successful application of skills and knowledge learned.
- Recognize that the experience of abuse and trauma is often shared by both client and professional.
- Do no harm. 1) trainings must not create hierarchical power relationships characteristic of abuse; 2) trainees must learn to recognize potential ways in which clients may be retraumatized by commonly accepted practices and attitudes in the field.
- Recognize that people working with trauma survivors need support and nurturing in applying their learnings in the field, and plan for follow-up to trainings.
- Be supported by state and agency level policies and procedures in training, hiring, licensing and re-certification.
- Have a plan for ongoing evaluation by survivors and professionals.

Chapter 7

Medication: A Double-edged Sword

SURVIVORS Speak: What Hurts

“It is hard to find doctors who will work with you regarding medications.” Doctors “ignore complaints of (medication) side effects.” “There is too great a reliance on medication, to make up for lack of expertise.” “Even my treatment plan said that medications were not useful to me in the long term, and in fact, with them I could concentrate less, was more unstable, etc. Yet the attempt to ‘fix it’ with medication everywhere I went was never-ending. At one point this resulted in a total of eight different drugs being prescribed at the same time!” “In MPD, different personality states respond differently to meds. This is not acknowledged by many doctors.”

“You are frequently given the wrong kind of medication, based on misdiagnosis.” “Wrong diagnosis, wrong medication.” “Many medications did not work for me, and some hurt.” “Misdiagnosis - medicating wrong or non-existent symptoms (e.g. voices).”

“You are often forced to be medicated when what you need is someone to talk with. Drugs are used as a way to get you to shut up - to not express feelings, to stop what you are doing.” “Forced medication when you want to work through something (related to trauma) is hurtful.”

“They need to focus on what’s going on with me vs. medication.” “Some drugs make some people appear to be ‘better’ but the underlying cause of the problem is still not being treated.” “We know we need our meds, but that doesn’t do it.”

“There is resistance to using other techniques that work in place of medications - that can lessen dependency on or eliminate need for medication - such as anger work, movement, music, clay art therapies, etc.” “When put on medication I went from depressed to severely depressed, to suicidal and then was hospitalized. Finally the doctor realized that it was the medication which was making everything worse, and they took me off it. Once off the medication and in therapy with a therapist who was not afraid of ALL the details of my abuse, I then began to make progress. I have not had any medication in 10 years and am doing great.” “I get more out of therapy than meds.” “I got off the meds and felt I had come back to life. Two weeks later I went back to the mental health center and told them I was no longer taking meds. They ‘noticed’ I had opinions, and labeled me ‘opinionated’ and ‘non-compliant’.”

SURVIVORS Speak: What Helps

“When a doctor listens to how medication is affecting you and believes you, it is helpful.” “A doctor who listens to you about what has been helpful, about what meds work for you, and then is willing to treat you with them.” “Having a say in what I do or do not do for medications is helpful.” “Listen, listen, listen to the client.”

“Alternatives to medications are needed.” “Day programs would be a good alternative to over-medicating and to help keep people out of hospitals.” “Homeopathy can support a person’s system while they heal and it does not stop the person from having access to their feelings and being able to work on them.” “Instead of medication, support the use of other methods of healing such as expressive movement, massage, acupuncture, homeopathy. Get insurance companies to change their policies to cover these other methods.”

“Informational groups are needed: for example, on therapeutic levels and what blood levels entail; what’s common practice; allergic reaction to medications; meds that don’t work for you; small doses, certain phases when used; how to keep track of taking meds when you are dissociative.”

TRUSTED PROFESSIONALS Speak: What Hurts

“Medication is harmful if used only for control and not for therapeutic purposes.” “Medication is more invasive into the body of a person than restraints.”

“There is a serious lack of psychiatrists. The docs go in for a few minutes and prescribe medications. Trauma victims get a 3 minute medical evaluation - that’s it.” “Very few psychiatrists are able to see someone on short notice (in less than two weeks to a month), most want a full fee of over \$100 per hour, and the client who is not homeless, is not on Medicaid, but is working for \$5 or \$6 an hour and single parenting without good insurance, cannot afford medical or psychiatric services.” “It is consistently a problem to get affordable, appropriate psychiatric back-up on a regular basis or in a timely manner. Waiting in the emergency room for hours and then being discharged in ten minutes is not helpful.” “Most of the services survivors need are not medications. So it is a waste of money to concentrate on psychiatrists.”

“There is a continuity of care issue, in which there frequently may not be sufficient communication between psychiatrists, in some cases between referring physician and new psychiatrist, and between psychiatrists and primary care physicians. Part of the problem may be due to the fact that there are so few psychiatrists - most carrying large case loads. Also, different psychiatrists may have different belief systems regarding diagnoses - for example, some do not believe in Dissociative

Identity Disorder, and some do.” “There is a significant group of psychiatrists who deny the existence of Dissociative Disorders. Their resistance to addressing trauma is high. This results in mismanagement of medication and treatment for traumatized clients. Frequently psychiatrists are only open to learning from other psychiatrists.”

“Patients with histories of trauma are being mis-medicated.” “There is over-medication, and forced medication. This leads to retraumatization.” “Treatment is not client directed. Six different doctors can mean six different treatment courses for the same client.”

TRUSTED PROFESSIONALS Speak: What Helps

“We need psychiatrists who know medications and trauma, - in hospital, in community, in crisis - everywhere.” “More psychiatrists should be recruited to work in Maine.” “We need a place to see a psychiatrist who is knowledgeable about trauma and about the rights of the client, for consultation and medication - where a person could get medications, free when needed.”

“One way to address the serious shortage of psychiatrists is to train family physicians to give medications which are helpful in the treatment of trauma symptoms.” “Primary care physicians should be able to admit patients to psychiatric units and to consult with psychiatrists on the units. This system is in place in Ohio and some other states. We should look to those states for models. This allows for follow-along for the patient. It makes sense when you consider that, of patients seen by primary care physicians, 70% have psychological problems.”

“There should be reimbursement for consulting, to include communicating with other doctors, making collateral contacts with other physicians.”

“We need a trauma medication team - proactive, not adversarial, with an educational component.”

Chapter 8

Interagency and Cross-disciplinary Connections: Trauma as a Unifying Focus for Collaboration

SURVIVORS Speak: What Hurts

“No one in the legal system, the social services system, the mental health system, or the educational system is educated to work together to address and respond to the fact of the existence of abuse.”

“In the court system, there is no one to really advocate for the child. If you get the perpetrator to the court - appropriate sentencing doesn't happen. So where does the child go for safety?” “Reunification of the family should not always be the goal.”

Law enforcement officers handle persons in severe crisis in ways that are extremely demeaning. "Being put in handcuffs as if a criminal traumatizes you again. You likely have had your hands restrained during the abuse."

“Doctors need education about what might be triggering for a survivor of abuse.” “A GYN gave me a D & C without preparation or without knocking me out. I begged to be knocked out. It was very retraumatizing.” “Every time I go to the emergency room, I tell them I have severe PTSD. They ignore me instead of asking how they can be helpful in managing my symptoms.” “Dentists need to explain what they are doing beforehand. Placing objects in your mouth can cause flashbacks. This holds true for anyone doing hands-on treatment.”

“Substance Abuse services don't recognize trauma.” “When in detox, 95% of the time, trauma issues come up. Staff, environment, and gender issues are important, but are seldom taken into account.” On units specializing in substance abuse, survivors and perpetrators are separated. You can't speak freely about your trauma with the perpetrators present.”

Men's trauma issues are more frequently ignored. “There is an expectation that men can ‘get over it’ more easily than women; the ‘macho image’.” “Men should not be shuttled to substance abuse services.”

Services viewed as helpful may be inaccessible to persons with limited means or ability to arrange transportation. “Transportation programs won't transport me to services I need outside their area.”

SURVIVORS Speak: What Helps

Increase the awareness of all disciplines regarding the complexity of trauma issues and means to support survivors attempting to access various services including the following: **Criminal Justice System** - “We need to educate judges, lawyers, prosecutors, police.” **Medical Profession** - Identify professionals that understand trauma and will work with survivors. Educate others so that choice exists.

Dental - “Identify dentists that understand trauma and will work with survivors. Educate others so that choice exists.” “Dentists need to explain what they are doing beforehand.”

Adjunct Services - create more flexibility in the system for survivors to access services needed (e.g. transportation, funding, etc.).

“Treat perpetrators (who are also victims) separately from victims.

Establish a service delivery system that allows for this to occur in mental health, substance abuse, etc. There needs to be more public awareness regarding perpetrator issues.” “They may put on a front of wanting to be your friend and help you, and end up using and retraumatizing you.” “Perpetrators come from all socioeconomic levels. This is not about poor people.”

TRUSTED PROFESSIONALS Speak: What Hurts

There is a lack of communication and education regarding trauma issues across disciplines that greatly impact a survivor’s access to helpful services.

“Psychiatrists make no attempt to contact physicians or to participate in larger institutions.” There is no “alcohol treatment compatible with needs of trauma survivors.” “Transportation is a problem.” “The criminal justice system has no mental health services.”

There is a “double-bind” in the reporting requirements when a potential perpetrator is identified. “The reporting law is narrowly interpreted.” The reporting mandate discourages perpetrator’s disclosure and treatment. “Men have less of a chance of receiving treatment of any kind.” “It is hard to find treatment professionals who will work with perpetrators.”

“The number of child abuse cases is overwhelming.” “Crisis is caused by not treating children early enough.” “There is a growing tendency to misdiagnose and label as ADHD children who have been traumatized by abuse. Rather than addressing the recent and/or ongoing abuse and helping the child, the child is viewed as defective, labeled and prescribed medication.”

IN THEIR OWN WORDS

“Child abusers were victims themselves. They get out of prison and perpetrate. There is no treatment, nothing to stop the cycle. There are perpetrators and victims in the prisons.”

“Male survivors behavior gets them sent to corrections.” “Males are more frequently put in prison.” “There are situations involving mental health clients who are assaultive in the correctional system. They are getting an increase of angry young men. There is potential for violence.” “Some corrections officers come from trauma themselves, and may act out abusively.”

“It’s not part of policy in the corrections system to do a psychiatric evaluation. So one problem may be wrongful use of medication, making the person worse.” “The sheriff can’t authorize evaluation of a young troubled person, because if he does, he will set a precedent which will open the door to more young persons who need evaluation - and the funding for this is too limited to accommodate the need.”

TRUSTED PROFESSIONALS Speak: What Helps

Increase awareness across all disciplines of trauma issues. Create means to communicate on a regular basis. “Allow for reimbursement for collaborative efforts.” Establish a state-wide collaborative effort, possibly with advisory committees reporting on specific specialty areas.

“We need to impact when people are children. If we do not do early intervention and impact on people when they are children, when they grow into adults, treatment may not be effective.” “There needs to be separate tracks for adults and children.” “We need more training for parents and teachers. I often have parents who suspect abuse and retraumatize their children in their search for the truth. They don’t realize how frightened the children are.”

Provide intensive education/training to schools and professionals regarding symptoms of trauma in children. Establish services that address trauma for children and their families.

“Trauma needs to be addressed with substance abuse clients. Trauma and substance abuse go hand in hand. A large percentage of substance abuse clients have histories of trauma.”

Revise the abuse reporting laws so that abuse occurring 40 years ago (with no evidence of repeat offending) can be managed through the therapeutic process.

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Increase awareness and expand services to perpetrators and perpetrators/victims. “Establish means to support the few professionals willing to do this work (time off with pay, peer support groups, professional trauma debriefing).”

Create an array of services/supports to centralize information and support survivors in various ways such as: “Support for peer support.” “Decent, safe housing free from fear of rape, robbery, drugs, other violence.” “Single sex housing as an option.” “Advocacy across systems.” “Vocational services without fear of losing benefits” “Support/educate regarding helpful services.”

Chapter 9

Creating Trauma-sensitive Policies, Structures, Practices

SURVIVORS Speak: What Hurts

“There is no central clearing place for survivors for resources of all kinds.” “Lack of clear, simple information.” “It is hard to figure out the system. There is lack of information.”

“The system is 3-tiered. Non-class members often don't get services.” The Department of Mental Health, Mental Retardation, and Substance Abuse (DMHMRSAS) prioritizes consent decree class members first, the ‘priority’ population (seriously mentally ill) second, and other persons not fitting these two categories third. “There is a waste in bureaucracy in activities and paperwork. An example of this is finding people (class members) who have not been involved in the system for 20 years.”

The system does not yet recognize trauma as an integral part of the assessment and treatment process for all recipients of services. Within that recognition, issues such as cultural diversity, gender specific issues, and sexual orientation issues need to be addressed to ensure inclusion and equitable service delivery. “People don’t understand how pervasive and long-term the effects of years of abuse are on a person.” “We are talking about lifetime recovery. You cruise, all is fine, then boom - you may need 30 sessions or ten years of therapy.” “There is nothing available for kids, either.”

There is a lack of services for trauma survivors and a lack of understanding of trauma issues by service providers. “There is no where to go for help. Psychiatrists are all booked. You can’t get a psychiatrist or a therapist.” “In isolated areas there is nothing - no services.” “There is a belief that having been abused is something you can put behind you-if you survived it, what's the problem?” “You fall into the cracks. There are too many cracks in the system. People are falling by the wayside.” “You can’t get help. You can’t find anyone to talk with. You can’t get therapy, you can’t get any services. You end up self-destructing, and calling up hotlines and lying about killing yourself so you can find someone to talk to.” “They want to give you drugs rather than listen to you.”

“Continuity of care is an issue. Agencies need to set up continuity of care for individuals between inpatient, residential group home, partial hospitalization, outpatient care, community support, family, crisis stabilization, etc. There are presently huge gaps in services.” There is not enough communication between/among these

services. “Inconsistency is a problem. There is not communication among providers within systems. This creates barriers which leave the consumer feeling isolated.” “Being treated for PTSD at one place, Borderline at the next, and DID at another, with no one looking at your substance abuse problems or childhood abuse - is hurtful.” “Being put on a medication at a hospital which your doctor doesn’t agree with and takes you off of is hurtful.” “There is too much separation between child and adult systems.” “You can’t look at child and adult issues of trauma separately.” “There is high turnover in staff, so no continuity.”

The structural hierarchy appears to reflect an “us versus them” model. “Too much of the available money goes to administration and not to consumers and consumer services.” “The hierarchy is too top heavy.”

The system acts like a perpetrator - using its power to dominate. “The system is perpetrating a silent violence.” “I’ve been a mental health consumer for the last twenty-six years. Overall my experiences have been negative. It seems to me that we’ve built a mental health system that re-creates the environments in which we were raised. We somehow survived, only to find ourselves there again.” “They want us to fit into one mold . . . only one way of having to deal with us.” “If you bend the rules to benefit the client, you get penalized by those with power in the system.” “DHS will use its power to penalize a person who contradicts what DHS wants.” “I had many experiences in the mental health system that were hurtful, including people wanting to help me but not being allowed to. Just as it was for us as children, we were hurt and not listened to by those who were supposed to care for us. We were shamed, threatened, confused, and punished. We became depressed, scared, angry, distrustful. For the most part we felt worthless, a nothing.”

“Money and diagnosis often drive the system. Insurance companies decide your fate without knowing or understanding what is going on with you.” “Some insurance companies require ‘preferred’ providers. You have to pay more if your therapist is not signed up with them. Some providers do not want the hassle of paper work so do not enlist in preferred. This system limits already limited choices for the survivor.” Also, “under the fee for service system, there is no support”.

SURVIVORS Speak: What Helps

“Programs, training, services, policies helpful to survivors need to be built into the system so they don't disappear with changes in administration, political changes, etc.-” “There needs to be consistency. People should know what will happen, what they need to do, both patients and providers, across facilities and services.” There needs to be “predictability - patient has knowledge of what he needs and how to access services.”

IN THEIR OWN WORDS

“Consumer surveys and outcomes should be used as a starting point to develop services.” “The studies are not valid if they don’t consider trauma.”

“There needs to be a belief in the ability of trauma survivors to make it.” Education and training at all levels needs to occur so that services will be seen as valued and focus on the strengths of survivors. “It helps when someone listens, follows through, understands trauma, accepts you, and believes you.” “Hire recovering people in mainstream positions to provide services and to function as a lightning rod for what needs to be changed.”

When entering or moving through the system, survivors should expect “Consistency, Predictability, and a Team Approach”. The Team Approach includes all people involved: the therapist, psychiatrist, helpful family members, church pastor, AA peer or mentor, etc. To sit down with me and think about what I need. This must be person oriented. It’s not OK to say to the person ‘do this and do that’. They must say, ‘How can we help?’.”

Develop a complaint and reporting process that works. Possible solutions include the creation of a single/multiple site “office” that is staffed by survivors/ consumers trained to respond to complaints; change the process outlined in the Rights of Recipients so that clients of services don't have to report the complaint directly to the agency that may have violated their rights; better capability of the system to accept and investigate anonymous complaints; central location where substantiated complaints are filed so that funding/service decisions are based in part on one’s compliance.

“There needs to be communication among providers within systems. Inconsistency is a problem. Inconsistency leads to insecurity and resistance. “We must define trauma, and be precise, so the term does not become meaningless.” “The plus side to this is there is a consistent language and consistent approaches.” If a person sees providers not able to agree about her, then how can she ‘integrate’ this into her therapy?” “Have a universal release form. If in hospital, can enlist outside supports (perhaps case manager can coordinate with clinician) for all to have an input. Set up a plan before there is need for more help. Have everyone know what their part will be.”

TRUSTED PROFESSIONALS Speak: What Hurts

“There is no organized model (system) of resources for traumatized persons.” “Disorganized system.” “There is no system.” “The system’s problem is like a blind man feeling and seeing different parts of an elephant.” “Disorganization leads to isolation of professionals. It’s difficult to know who is who, and to exchange information.” “The mental health system is very fragmented (specifically in the

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Portland area). There is duplication of some services (several day treatment or outpatient programs that clients may be participating in at the same time) without appropriate and adequate coordination of services.” “As long as the mental health system is as fragmented as it is and services are uncoordinated, clients will be at risk and healing will be impaired.”

“Treatment approaches vary from provider to provider and service to service (especially mental health to substance abuse) .” “The State is committed to only one philosophy (psycho-social rehab).” “Clients have to adapt to each provider’s shift in beliefs and approaches.” Clients needing mental health and substance abuse services encounter from those fields different philosophies and different practices within the system.”

“There is a lack of understanding of trauma, at all levels of the mental health service delivery system and throughout related systems.” “The least trained people get trauma victims to work with. They are given no time or opportunity to learn new things - to learn how to work effectively with trauma victims. They burn out fast because they are given no supervision or support in their work.” “Trauma related conditions are not ‘seen’ - recognized, validated as important, treated, etc. - because the paradigm is still medical. Yet trauma affects the person biologically. There is lots of biologically based data on the impacts of trauma.” “Trauma based practice does not fit the current treatment model and perceptions.”

“There is a lack of services needed specifically by survivor/consumers.” “At times, inpatient, outpatient, crisis services, day treatment, residential, vocational programs and expressive therapies can be helpful to survivors, yet existing programs are not structured to work with trauma survivors and almost no staff have had training.” “There is a need for appropriate substance abuse services.” “Clients are isolated. They encounter difficulty in accessing resources and feeling safe in mental health and other environments.” “Many clients are going in and out of services without getting help.” “Treatment is not client directed.”

There is limited access based on funding source i.e. Medicaid not reimbursing L.C.P.C.’s or L.C.S.W.’s, limits of Medicaid reimbursement for newly licensed mental health agencies, managed care issues, etc. “The parity law in Maine requires that certain ‘biologically based’ mental illnesses are funded at the same level as medical illness. Yet though PTSD, for example, has biological impacts, it is not included.”

TRUSTED PROFESSIONALS Speak: What Helps

“The state (Department of Mental Health, Mental Retardation and Substance Abuse) must say that addressing trauma is valuable. They must state

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that they are willing to finance services and staff to help trauma victims.” “The state must mandate, require, that attention be paid to trauma.” “The Commissioner should make a public statement regarding trauma as a priority of the Department, and back up her statement with allocation of resources. This would convey support for those out there who are trying to help clients with trauma.”

"Need creativity/flexibility in dealing with multiple regulatory processes: Licensing Standards, JCAHO, Rights of Recipients of Mental Health Services, DMHMRSAS mission and philosophy, DHS hospital licensing, private practice providers, etc. all need to recognize the seriousness of trauma issues affecting most recipients of services and develop a system that brings this issue to the level of other supported mental health services both in principle and in policy, access to funds, and in a changed belief system. “Highly creative approaches are needed to provide for flexibility while dealing with issues such as JCAH standards, liability, insurance policies, licensing.”

Create a continuum of care “so that survivors can tap into different levels of care as needed, rather than be forced into a prescription or order of care. This continuum should include the non-traditional approaches such as acupuncture, massage, homeopathy, yoga, meditation, rolfing, externalization of anger or grief (Kubler-Ross Model).” “The New York system operates in a circular model with inpatient at the center, then gradual movement to transitional settings, then movement out into the community. But many survivors never go into inpatient care.” There should be “fluidity: ways to move from one level of support to another”. “There needs to be a full continuum or menu of services so people can get what they need, when needed.”

“Whatever is done or created in the system should come from the needs that come from the survivors.” “We should ask survivors what specifically is helpful to them. This should drive the system of services for people with histories of trauma.” “In evaluating what is helpful to clients, ask those who are further along in recovery, ‘what made the greatest difference to you?’” “We need to know how to create healthy environments and structures that are based on needs of clients/patients as identified and expressed by them.” “Give individual clients a sense of control.” “Give clients a choice to contribute to something.”

“There needs to be consistency in the system, so that people know what will happen, what they need to do - both clients and providers. This consistency should be across facilities and services.” “Predictability is important. The client should know what he or she needs and how to access it.” “We must identify outcomes, what the clients want to accomplish, and what the providers want to accomplish.”

“There needs to be organizational awareness of the effects of secondary trauma. Help for this must be built into the organization - including ready access to a

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staff support group, individual counseling, etc.” “There need to be guidelines for orchestrating the flow of clients in and out of the Mental Health Centers so as to not burnout staff from overload.” “Co-workers can help the traumatized staff worker at the time when he or she needs help in dealing with it.” “Supervisors must be trained to understand the traumatic impact on staff.”

Build into the system an ongoing review process to allow for "flexibility" as new theories or approaches are identified as helpful to survivors. "The system needs a central information clearing point."

Chapter 10

Managed Care, Medicaid, and Other Insurance: Stumbling Blocks or Supports?

SURVIVORS Speak: What Hurts

“If you are on Medicaid or Medicare, the only professionals you can see are psychologists and psychiatrists” (in private practice). “LCSWs and LCPCs are not reimbursable by Medicaid in their own practices.” “Medicaid is a problem. There is refusal of services, and of transportation.” “There are therapists who would accept Medicaid if the process of reimbursement was not so long. It takes six months to get reimbursed.”

Financial barriers create trauma. “One major factor that compounds the problem, (creates) confusion and feelings of helplessness, is knowing that the expenses (bills) are adding up out of control and you'll be paying the rest of your life.” “Sometimes most of your session is a hassle from the office person saying ‘We need money now!’ . . . It's like being kicked when you're down.”

Diagnosis drives the system. “The emergency room won't treat me because I'm (diagnosed) Borderline, yet I have to keep an Axis II diagnosis for insurance purposes.” “There is an incredible waste of money billed to insurance companies because of inaccurate diagnosis and treatment.” “Shorter hospital stays because of diagnosis or lack of insurance.”

“Insurance companies are working on false theoretical concepts. The whole goal is to get you out of inpatient service but there is nothing to be discharged to.” “Insurance companies try to keep it simple, short and cheap. This creates disaster for the person in need of help.” “If covered by insurance, still can't get enough therapy to not need therapy.” “Insurance, limited or lack of, is a big obstacle to getting services and to being able to stay in the hospital long enough to stabilize.” “Insurance coverage is inadequate for long term care.” “It makes for more crisis in me when insurance companies limit hospital time and I get discharged before I'm ready.”

“Lack of insurance operates as an obstacle to getting the kind of services I need.” “If you don't have insurance, you're passed from one person to another.” “The cost of therapy is too high to afford. People in crisis don't have resources. I have to make choices between food and therapy.”

“The whole process of trying to get social security entitlements is humiliating. While going through disability hearing, the process takes a long time.

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You're forced to live with no income, no housing, have to go to a shelter." "People don't get adequate help getting their entitlements. They are kept ignorant. Consumers need education regarding how to get entitlements." "You get traumatized by the system when applying for SSI. There is need for a trained person who can explain things like forgetting."

"Once on SSI/SSDI, there is a limitation on the money I can earn." "The viability of my life diminishes when I can't even try to be somewhat financially self sustaining without losing Medicaid and Medicare assistance."

SURVIVORS Speak: What Helps

Change the laws/legislation regarding insurance, Medicaid and Medicare reimbursement. "Make the paperwork more convenient." "Allow more licensed professionals to be Medicaid reimbursable." "Let the need for services drive the system rather than diagnosis." "There needs to be a way to reimburse a commitment to the time it takes to go through the process of working on the trauma."

"Create a block of funding to reimburse people who are qualified to treat trauma but are not reimbursable under the present regulations, yet are well trained."

"The Department needs to find ways to fund survivor groups - anything that would allow abuse survivors to be supported"

Funding sources (as above) need "education ... regarding treatment standards, evaluation standards (and allow for) specialized evaluation when certain symptoms are seen". There should be "competency based funding".

TRUSTED PROFESSIONALS Speak: What Hurts

"Managed Care/Insurance Company policies promote practices which have damaging impacts on both survivors and professionals." "Walmart mental health care." "Force agencies and therapists into quick-fix solutions." "There is a tendency on the part of the mental health professional to slip into the 'headset' promoted by managed care, for example, 'I should be doing this quicker'." "No payment for appropriate treatment of persons with histories of trauma." "Managed care is dangerous to survivors because it limits their access to the long term treatment they so desperately need. This work cannot be done in a brief treatment model." "There is no concern for cure or healing. We must prove trauma treatment is profitable." "The larger cultural context supports the pathologizing of traumatized persons by managed

care/insurance companies.”

“Managed Care is interested in keeping people from using hospitals.” “There is an economic mandate to force medication.” “Even with therapist and psychiatrist advocating, there is repeated difficulty finding appropriate inpatient treatment in Maine. It is almost impossible to get insurance to cover out-of-state treatment.” “Most programs won't slide their fee scale.” “Cease payment for hospitalization when person does not meet criteria for involuntary commitment.” “Managed Care and limited inpatient stays present problems for clients who are dually diagnosed (mental illness and substance abuse). When they get off of the drugs and/or alcohol, their memories surface.”

“There is need for more outpatient treatment than Medicaid allows.” “There is presently no funding supports unless you see a psychiatrist.” “LCPCs (and LCSWs) should become reimbursable. Now services are restricted. This leads to crisis intervention which is costly.”

Many trauma survivors cannot afford insurance and/or don't qualify for Medicaid. “Clients without insurance and without money are consistently denied services in Maine or are offered totally inadequate, inappropriate services.” “There is no place available to meet with other peers (such as a drop in center) if a survivor is not sick enough to get Medicaid for disability. Drop-in groups are not funded when they are private.” “When a person has multiple medical issues and no insurance, it's difficult to get adequate medical care. Especially when they are dissociated from their bodies.”

Therapists are fearful of “opening the door with a client's trauma history because of not being able to follow through (when) you can't get reimbursed.... This is a clinical and ethical issue”. “The reimbursement source determines where a survivor can get services rather than the needs of the individual experiencing trauma symptoms”.

“Access to services that address trauma is a serious problem. Either the services don't exist or there is no funding to pay for them.”

TRUSTED PROFESSIONALS Speak: What Helps

Managed Care programs and policies in mental health should “pay for appropriate treatment” as determined by the expertise of the therapist and the choice of the survivor. “Understand that there is an (ultimate) cost value in approving services for non-biologically based problems.”

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“Insurance/Medicaid/Medicare must achieve equal parity - coverage of mental health services (equal to that of) other physical health problems.” “Must reimburse all persons qualified to treat trauma survivors.” “Medicaid reimbursement is needed for master’s level clinicians (LCPCs, LCSWs), many of whom are trained and experienced in working with victims of abuse.”

“Form a committee to take an in-depth look at Medicaid and DHS reimbursement policies and practices related to recovery needs of clients with histories of trauma.” “Draw in insurance companies, and do an organized effort with State government.” “Discuss issues, raise questions, and formulate recommendations to make to the State.” “Consider the fact that the ultimate cost of not providing services includes not just mental health, but affects medical, family, and society, where trauma gets passed on to children and costs involve judicial, police, emergency services, medical costs, over generations.”

“Create a pool of designated money for trauma.” “Low or no fee treatment to persons suffering from long-term impacts of trauma, without requiring (survivor) to be diagnostically labeled or pathologized.”

“Create Trauma Recovery/Dissociative Disorder Units in Maine and ensure that money will not be a barrier to receiving the services needed for the length of time necessary as determined by knowledgeable, trained professionals and survivors working in partnership.”

SURVIVOR PANEL REMARKS

November 18, 1996

Following Commissioner Peet's speech, trauma survivors offered their individual stories of trauma and their searches for help. Here all the issues laid out in this book are woven together into real and touching life experiences.

SANDY DEARBORN: This really is stressful. I've spoken a couple of times about both my illness and my recovery in a public setting but in a totally consumer-oriented setting. This is a unique perspective. Also when I've done some rights training I've shared some of my personal experiences because I really felt like they were valuable to the training that I was providing. This is different.

I can't talk about recovery until I tell you a little bit about where I've been - because where I've been is really important. As with many other people in this room I endured a childhood replete with sexual abuse, emotional abuse, emotional neglect, physical abuse, and as early as age 13, I was exhibiting severe symptoms of emotional illness: depression, suicidal ideation and strategizing about how I could get out of a family that I didn't want to be in. The one hope that I had of getting out of there was a grandmother who lived pretty far away. When I was just building up the courage to tell my parents that I wanted to leave, my grandmother died. That was the end of the hope, or the possibility in my mind at least, of getting out.

I continued on through childhood into adult life; got married; had a couple of little kids and tried to live what was supposed to be a normal life. In 1972 I was introduced to the mental health system due to severe depression and suicidal ideation. From 1972 to 1990, I can tell you that I lived in a hurricane; I lived in this storm that was as black as a storm in the middle of the night. There were peaks and valleys - including five psychiatric hospitalizations. Throughout that time the system was apparently unable to adequately assess or to diagnose what was going on with me. It's the same story I've heard from so many other survivors. My first hospitalization was due to severe suicidal ideation and gestures. I was diagnosed with major depressive illness and got started on a continuous series of medications. I left that hospitalization, but went back relatively quickly because I started to hear voices, very distinct voices; one, an adult voice; one, a child voice. "Hearing voices; you must be psychotic! Let's diagnose you as depressive with a psychotic disorder and start you on some neuroleptic medication as well". And on and on it went.

When I started to behave in self-destructive ways and started using substances, they added on a question of a Borderline Personality Disorder. At that time it was pretty frightening because I wasn't very familiar with the system and I was afraid all

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the time. When somebody told me that I had a Borderline Personality Disorder, I was afraid to ask about it. I thought if you're on the border of something and there's personality involved (if you're somebody who has absolutely no self-esteem), I must be on the border of not having a personality and it was pretty scary to sit home and wonder those thoughts.

There were more varying medications, and I started being prescribed cocktails of medications. Another hospitalization with severe symptoms and severe mood swings; the diagnosis was manic depressive disorder with psychosis. Somewhere in the process of all that I got to the place where I could get to substance abuse treatment. When I started to recover from that process, from abusing substances, was when I could start to see a little bit clearer about what was really going on with me. What I discovered at that time was a number of things: that the self- help recovery program that I was attending was incredibly valuable in terms of accepting me as a person; allowing me to be there, to support me, to let me call them at any time. That was something that I really had not experienced in my life before.

Within that process I had been bobbing in and out of therapy time and time again. Doctors just continuously gave me different types of medications and finally, I went to a doctor and told him that I was having a problem, of "lost time". Do you remember those 8 days that I was in the hospital? Well, I have no recollection of those 8 days. I remember standing at a nurses station and my thinking became "clear". I didn't remember being there and I was joking with people at the nurses station. The doctor was standing there and he says, "Gee, it looks like you're ready to go home." I looked at him and said "Oh yeah, right," because I thought I'd just gotten there. Then I went back to my room and I asked somebody what day it was. It was 8 days later...8 days subsequent to my admission to that unit. Being free of substances helped me to realize that I had also done a lot of other things like lose possessions. I used to blame drinking on not being able to find my car, my pocketbook and those kinds of things in the morning. Then I discovered I was losing those things before I started drinking. I was going to places that I don't recall going to. I was meeting people that said "Hi, Sandy, how you doing?" And I had to apologize and say "I'm sorry, I don't know who you are". Then I had to find language to cover up the fact that somebody was expecting me to be friendly to them and I didn't know who they were.

I continued on that roller coaster for 18 years and in 1990 a miracle happened to me. It was a traumatic miracle because I was standing outside my office. I was a crisis worker at that time. I went out to smoke a cigarette and all of a sudden the person that went out to smoke the cigarette was observing another entity. That person was telling me what her name was. I just kind of said "Oh My God, what is this?" Shortly after that I was admitted to MacLean Hospital and that's where my recovery began. At MacLean's I was on a dissociative disorders unit; I was given an appropriate assessment. I was finally diagnosed with multiple personality disorder and PTSD.

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Before I left the hospital I was taught some skills to help me to survive in the world with this new way of looking at myself. Also there was a great deal of relief because finally all of the chaos of 18 years made sense to me. That's what it was; that's why I don't remember; that's why they were diagnosing me with a manic depressive illness. It was actually different personality states presenting at different times. For those of you that don't have a severe dissociative disorder, I understand that it could be hard to appreciate, that you could be having this happening in your mind. But please trust me; it's true.

MacLean Hospital taught me some techniques to manage on a day to day basis. I carry with me at all time pictures of my children and grandchildren. When I start to feel like I'm a child or somebody who can't manage a situation, I'm able to pull something out and look at it, and ground myself in the present.

Of critical importance, obviously, is getting an appropriate diagnosis and having an appropriate assessment. In all my years of working in the mental health field, I have never gone to a mental health agency and read a record in which there was a trauma assessment or for which there was an assessment for dissociative disorders. The research is replete with information and diagnostic tools that could be helpful. I don't know why they aren't incorporated into the mental health system in Maine. Part of that, I think, can only be that people don't wish to identify the fact that there are such things as severe dissociative disorders or think that MPD doesn't really exist. It's in my mind . . . it is in my mind.

I can't emphasize enough what it means to be listened to. One brief example of an experience during my treatment history of not being listened to is: I was seeing a psychiatrist and a medical doctor and I was taking anti-depressants and medication to help me sleep. I was not feeling depressed. However, I started doing things like falling asleep at the wheel or getting groggy and having to pull over. I went to one doctor and told him I was taking these medications, and that something doesn't feel right. He told me I was depressed. I said "I'm not depressed. I wake up in the morning; I feel good; I start to drive to college or I start to drive to work; I get groggy. Something else is going on here." He dismissed it. Sent me to a medical doctor and I got the same story there. He told me I was depressed and I said, "I'm not depressed. Something else is going on here." He told me to take caffeine tablets; drink more coffee, get on with it, and continue to get treatment for my depression. What happened one day is pretty horrific because I came to with bits of glass all over my face with my car wrapped around a telephone pole. At that time I was living below the poverty line, raising two children, and really trying to make it. My only means of transportation was laying in the street. That's what not being listened to can do to people. It actually is a life-threatening issue.

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I have a curable illness and unfortunately it's been 24 years now since I've been in the mental health system trying to get well. Without a correct diagnosis and the correct course of treatment you can't get there.

The other part is the fact that my insurance company won't pay the doctor I need to see to get well. He's a non-preferred provider. And as a non-preferred provider and a psychiatrist, he costs \$110.00 an hour. With what my insurance pays, I have to pay him \$50.00 a session. What has become quite clear is that I can't get over the biggest hurdle that I need to get over without going more often. My managed care company recently said that I could trade in the security of my in-patient hospital days to go see a doctor twice a week. "We can do that and you're still going to have to pay the copay". So if I want to get well, I would have to live on the street because it's going to cost me at least \$400.00 a month and a little bit more probably if I have times of crisis to get well. Insurance is a problem. Managed care is a problem. Having no place in Maine to go is a problem. I would like to tell you that I do feel hopeful. I'm not the person that I used to be years ago because I've been able to go to therapy at least once a week and see someone trained to treat my illness. I have learned enough that I can live my life fairly comfortably. I'm not able to have relationships the way that other people can. I can pull it together and work hard but when I go home, I crash and you probably wouldn't recognize who I am when I get there. Someone called me last night and it was really hard to just pull the words together to talk with her. I sincerely hope that today will be a positive experience and a starting point for a lot of help for many people throughout the state that desperately need it. Thank you.

KYLA REY ESSENCY: I'm really terrified right now. I've always successfully avoided public speaking in the past. When I was requested to do this I almost declined, but I thought about it and I realized that I do things every day that terrify me and I really would like this one to mean something. I'm not an expert on Medicaid or insurance companies or managed care providers of any kind, but I can speak about my own experiences and they are not by any means unique. That's important.

I'm kind of in trouble right now in terms of my own recovery because Medicaid won't pay my therapist. They won't pay her because she's an LCPC, in private practice, and because I chose her. If any of those three things were different there wouldn't be any problem. If she were a Ph.D., they'd pay her. If she worked in an agency, they would pay her. If I had been referred to her through DHS, they'd pay her. But now they're refusing. And they readily pay \$1000.00 a day for me to be in the hospital in a crisis but they won't pay \$42.60 an hour for her and I to work together to keep that from happening. I really want to keep that from happening. I've been in the hospital many times and I can tell you that in-patient trauma services in Maine are non-existent. Progress in recovery is mostly made in out-patient on-going therapy; not in the hospital, not here. Hospitalization can get a person through a crisis

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in one piece, which is a very good thing, but the coping skills for getting through a crisis without hospitalization or for preventing a situation from becoming a crisis are skills that are learned and strengthened and reinforced in on-going therapy.

A day in the hospital here for me is just another day that I've lived through. An hour in therapy for me is an hour that's going to make a difference in my life, and I want to have a life, not a treatment plan. And it isn't just any therapist that can make that difference. I know this because I've spent the last 15 years of my life going from therapist to therapist trying to find someone I could work with safely and effectively. Some of them were very, very bad therapists and some of them were very good therapists but they knew nothing about treating trauma. They either overlooked or minimized or completely discounted some of the most basic and vital issues for trauma survivors, for example, trust, or safety. Trauma survivors are people who don't feel safe, ever, and whose ability to trust has been very badly damaged, if not completely destroyed. We don't trust easily or quickly. It takes a long time to build a relationship that provides enough safety for a trauma survivor to begin to open up. In certain instances such as with DID or MPD, this process takes a long time because it has to be repeated over and over again as different parts come forward to participate in therapy.

Safety and trust in a therapeutic relationship are only even possible if the therapist is competent, experienced, compassionate, honest and understands trauma. But there's one more thing; this therapist has to be someone who is going to be around for a while. This is where I run into trouble with the Medicaid requirement, that LCPC's and LCSW's need to be working for an agency to be reimbursable. I've spent the better part of the last 4 years working with therapists from an agency and please note that I said "therapists", plural. What you find in agencies more often than not, are people who are new in practice; just starting out, inexperienced, generally have no trauma training whatsoever, many of whom don't believe in trauma-based disorders such as DID. The pay is very low; the case load is overwhelming; the burnout rate is incredibly high and the turnover is tremendous. I started out with a therapist who seemed mostly confused by me and she diagnosed me with schizotypal personality disorder with paranoid tendencies, and then she got married and left the agency. So I was shuffled to another therapist who seemed completely overwhelmed by me and reacted by being very dishonest and passive/aggressive and doing much more harm than good. Shortly after I stopped seeing her she also left the agency and for a while I had no therapist. Then I began seeing a psychiatrist in the area who had an opening in his schedule but he refused to deal with any trauma-based issues. He called it dwelling in the past and said it was unhealthy. So I left.

And how did this impact on my life? During this time I had 13 hospitalizations in 12 months. The longest I was out of the hospital during that year was 3 weeks, and Medicaid paid for it. Then I got lucky and a therapist joined the agency who had just moved to Maine. She had experience with trauma work. She even had experience with DID. She was competent and honest and understanding and compassionate and

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for the first time in my life I started to feel hopeful. We worked together for about a year and a half and then one day she tells me she's moving back to her home state. So I got passed off to another therapist, new to the agency, fresh out of school. She didn't know how to deal with me and lashed out at me whenever she felt overwhelmed. Finally I said fine, that's it and I left the agency, entirely.

During the times that I've been between therapists with this agency, I have spent months altogether trying, unsuccessfully, to find a therapist in private practice who had the experience that I needed; who had an opening in their schedule and who was Medicaid reimbursable and let me tell you, I found not a single one. Not one. So when I spoke to the person that I'm seeing now and she offered to take me as a client I was so thrilled it scared me. We got paper work from Medicaid, for Medicaid reimbursement, and we got an initial okay and I thought finally! So we went to work, and now Medicaid is saying no, you have to go somewhere else. There is no where else first of all. Second of all, this woman is my choice. I'm supposed to have a choice. She's someone that I know, who knows me. She works on an in-patient unit where I have been 15 times. We've worked together before and we have a relationship already established. We have some trust and some sense of safety and she's aware of my issues and she's very experienced and I know that she can help me because she already has. Not only that, she's not going any where. She lives here; she likes it here; she's staying here. Imagine having the same therapist for two whole years. Think of the possibilities. This is the person that I want, that I choose to do my recovery work with and Medicaid is saying no. We have this little book of rules and regulations, and it says this is unacceptable. So, I don't know what's going to happen and that's my story. Not uplifting but that's it.

JOHN MANGUM: I want to honor my fellow panelists. Their stories are really incredible stories. Thank you. Kyla Rey, you did a wonderful job. It wasn't so long ago that I came out as a survivor, too, so I really know what you just went through.

I guess I first need to say how I am right now. I'm very full; that's how I am. I'm very excited to be here. I appreciate very much being asked to sit with this group. I am the only male up here, and I recognize that any other of a great number of men could be here in my stead. I hope that I can speak for them, but I will tell my story and not somebody else's.

I feel vulnerable. I'm on stage. A piece about having been abused is that you are made to feel exposed and vulnerable. Sitting up here I am both, and it's frightening. It takes great courage to do this. I say that out loud to honor myself for this effort.

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Friday night I was driving home thinking about what I was going to say up here in front of everybody--thinking about what my message was to be. I started thinking about what this forum and participating on this panel means. After a life of feeling different; feeling ashamed; feeling frightened; feeling less than; feeling constantly vulnerable and unsafe; and after years of being confused and depressed; of entering into one destructive relationship after another; after self- medicating with drugs daily for a good number of years; after years of therapy--of confronting my demons; of recognizing the irretrievable loss of my childhood and the effects that sexual and emotional abuse and neglect have had on my life, as I was driving home, I realized that by sitting up here today speaking to you about what my experience and life has been, that I am being validated and honored as I never imagined possible. And I wept. I had to pull over off of the road and cry. It was an incredible experience. I hope that the other survivors in this room, women and men, can know what that feeling (of validation) is--if not now, then sometime in their lives.

We were asked to talk about what helps. Well, this helps--sitting up here today and not having a secret. Naming my experience is part of the healing process. This is a piece of what helps.

I'm going to read some passages from Judith Hermann's book, *Trauma and Recovery*, which are particularly meaningful to me. "Psychological trauma is an affliction of the powerless. At the moment of trauma, the victim is rendered helpless by overwhelming force Traumatic events overwhelm the ordinary systems of care that give people a sense of control, connection, and meaning" (p. 33). Later she says, "Traumatized people suffer change to the basic structures of the self. They lose their trust in themselves, in other people, and in God. Their self-esteem is assaulted by experiences of humiliation, guilt, and helplessness. Their capacity for intimacy is compromised by intense and contradictory feelings of need and fear. The identity they have formed prior to the trauma is irrevocably destroyed" (p.56).

Judith Hermann's words name my experience. My trauma resulted from physical and emotional abandonment, emotional incest, and sexual abuse when I was a child. I don't care to say anything more about that. I don't think it's useful, except to acknowledge that a product of those experiences was to internalize and carry for many years a huge amount of anger and rage. Talking about what has helped is most useful now. As a prelude to doing so I want to name the abuses experienced by so many people, and I'm going to do that--name them: physical abuse, sexual abuse, emotional abuse, spiritual abuse, witness abuse, sexual incest, emotional incest, ritual abuse, neglect, and system abuse. (A lot of folks know what system abuse is. I believe we don't talk about it much.) Probably there are other abuses that unfortunately some of you can name.

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One more thing about abuse: it's another quote from Hermann. She talked about child abuse. When a child experiences abuse, she says, the child ". . . must construct some system of meaning that justifies it and inevitably the child concludes that her innate badness is the cause." And again, Hermann names my experience.

I've already mentioned to some extent the resulting sensations and behaviors of my personhood from the abuse--the loneliness, the shame, the fear, the confusion, depression, drugs, destructive relationships. If I was going to try to characterize my person I guess I would say that I had a poverty of spirit which I actualized in my life. I finally got to a place in my early 30's where I had no friends; I had estranged myself from most of my family; I had no money; and I lived in a condemned building, although I was trying to make my way on my own. One day I was overcome by a rage attack which took me back to my experience of being a 5-year-old. From that I realized that I was (emotionally) trapped and that what I had left to me in my life was death. I had to make a decision about whether I wanted to live or whether I wanted to die.

Here I am. I made a decision to live. So how did I get here and what helped? Well, making that decision was the first step. I have heard three other stories here today in which that decision was made. I honor you and your stories for the courage it takes to make the decision to live. When your experience is one of not being heard and not being cared for and, in fact, being used for other people's purposes, it's hard to find one's own purpose.

My fellow panelists have talked about going into therapy and how important that was for them. This was true for me, too. I went into therapy; I continue in therapy. I would not be here now without having gone through the therapy. I want to say that what the therapy meant was validation, definition, connection, and voice. I was validated. I found therapists who honored who I was and did not scoff at what I had to say. They helped me find definition in the sense of helping me be clear about who I am, where I end and begin, what my boundaries are, and where I am responsible and where other people are responsible. I got connection-- mainly through group therapy, which was a major piece of my recovery. Also, in both places, individual and group therapy, I found my voice. I was able to name what my experience was and to find the words to describe it.

Another support that helped tremendously was my family-of-choice. I was very lucky. I entered into a new family early in my healing. It provided me opportunity to try new ways of relating. A family embraced me, but it also was a family who itself was grappling with abuse issues. They really understood and supported what I was going through. They were patient with me. That was only half of it. The other half was that they were open to my being supportive of them. That was new for me and something that took a while to learn how to express.

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Another thing that helped was changing professions. I had been a woodworker for years which was a wonderful experience and which helped to keep me sane, but it was an isolating kind of activity. I worked alone. Because of my therapy, I was able to realize that, yes, I had something to offer other people, that I could work with people, and that it was something that I really wanted to do. So I went back to school and graduated with a social work degree. Now I call myself a social worker. I'm very proud of that. It very much represents a kind of completion - - a recognition that a lot of my recovery work is done to the point that I can function in the world; that I can be connected to people; that I can have voice and share that voice with others; and that I can help others find their voices.

I was lucky to have attended the University of New England School of Social Work. This is because it has a curriculum there that includes oppression theory, which looks at power issues. It has a curriculum that also talks about feminist theory, family systems, and abuse and trauma theory. I do not know of any other program, at least in New England, that has as extensive a program on abuse and trauma. At UNE I was given the opportunity to learn in cognitive and academic ways what it was that I had experienced. This is very, very important, I think, in people's recoveries because it helps depersonalize the trauma. It puts it outside of yourself. Also at UNE, I was accepted into and by a community that afforded me a safe environment to experiment with being a different kind of person relating to people differently. On a larger scale, it was an informal group therapy opportunity.

Before I end there are two other things to mention that have helped: one is about living my beliefs. Here I am; I am acting on my beliefs. I'm in front of you saying what helps, and I am taking action to try to do something to make this world a better place for myself and for other folks. This action re-enforces my new construction of myself. The last thing that has really helped me is time. Time is really, really important. It takes a lot of courage to embrace time--to be patient, particularly when you are dealing with trauma and abuse issues, but it helps. Embracing time is about learning to trust.

That's my experience. At another time I will have more to say, but I am excited about hearing what your ideas are now. I look forward to conversation with you. I truly believe that we can change the system and that we will change the system. Thanks.

SUMMARY

In Their Own Words represents the official “coming out” of those in Maine who have wrestled in frustrated isolation with their own, a loved one’s, or a client’s history of sexual and physical violence. It details the often shocking feelings and facts about the failure of the mental health system even to acknowledge, much less sensitively address, the reality that the majority of its clients are trauma survivors.

The most *unique* aspect of this process was that it gave a very disempowered client group the power and a platform from which to *a)* detail bluntly and openly the system’s inadequacy and abuses, and *b)* identify by name and invite collaboration with those professionals seen as trustworthy and competent in responding to trauma issues. The resulting dialogue brought a number of individuals from places of cynical alienation into a collective place where there is now hope. The most *striking* aspect of this dialogue was the extent to which survivors and providers agreed on both what hurts and what helps. Together, these abuse survivors and those who *have* responded to their needs offer far more than an indictment of the present “system” as it relates to trauma; they offer a compendium of specific insights, ideas, and recommendations that point us in the direction of a more responsible and healing way to look at and address the painful and disquieting results of childhood abuse in adult survivors.

Summarizing over 200 people’s often impassioned feedback is not easy. However, we feel that nearly all participants in this Needs Assessment project would agree that *What Hurts* consolidated into several major points:

1. Isolation and Denial. “The essence of the survivor of abuses being alone with no witness.” Over and over we hear that abuse survivors feel isolated and stigmatized by their histories and its symptoms. Over and over we hear that the pervasive response from society, its institutions, and even many helping professionals is to deny, diminish, and avoid the whole issue of interpersonal violence and its consequences.

2. Mistreatment and Retraumatization. When those seeking help feel diminished or even disbelieved, and when abuse is ignored as a core issue, then the diagnosis, treatment plan, and therapeutic alliance are all compromised from the outset. When a power struggle ensues between client and professional, or client and institution, the survivor is once again the loser, being hurt by the very people who are supposed to help heal the hurt.

3. Lack of Responsive Services. Survivors and providers alike describe not only the absence of any services specifically targeting abuse issues, but also the exclusion of survivors with certain diagnostic labels from existing programs or places. What survivors need is not a mystery and is clearly articulated in this book; what it

will take to create trauma-sensitive services and to integrate them into a larger system is a much bigger question.

4. Lack of Training and Education. There is essentially no formal trauma training, either theoretical or practical, in any academic or professional training curricula for any of the disciplines. Misinformation, strong biases, and resistance to change and relearning abound, contributing to the overall sense among both survivors and their “trusted” providers that there is little informed, respectful support available to them.

Similarly, the input on *What Helps* can be condensed into several central and crucial recommendations:

1. Relevant Education and Training. From all quarters, the strong assertion is made repeatedly that education about the prevalence, indicators and consequences of trauma is badly needed. It is also vital that this training be offered in both work and academic settings, that it include unlearning as well as new learning, and that it address attitude as well as information and research.

2. Responsive Practices and Services. Most agree that creating an entire new system of services for trauma survivors is both impractical and unnecessary. Existing mental health, medical, and social service systems can and should be modified, enlightened, and augmented to better address the needs of those with abuse histories, a majority of their existing clientele.

3. Policies that Reflect Trauma Understanding. Both survivors and providers reiterate the need for planning and policy development -- at all levels -- to be trauma-sensitive and supportive toward both those using services and those providing them. Policies and plans that impact on service accessibility, provider training, clinical practice, continuity of care, and public perception must all be carefully considered from a trauma perspective -- and preferably with direct survivor/consumer input.

4. Empowerment. For those who have felt diminished and stigmatized and unheard, it has been a major piece of healing to begin to feel respected, supported and heard. Moreover, listening to the experiences and stated needs of trauma survivors is not only empowering for them, but it is also a key way to educate others. Ultimately, however, the collective energy, shared experience, and continuing activism of the Trauma Advisory Groups has shown the power inherent in people organizing and working together for a common cause.

Creative, focused and persistent leadership at grassroots and policy levels is needed to transform our responses to trauma survivors in all categories of service recipients, but especially to those diagnosed as mentally ill and treated in mental health

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settings. Such transformation is possible only if we allow ourselves to see and admit to the magnitude of the problem, own whatever responsibility is ours for its existence and perpetuation, and finally take concrete steps to act expeditiously in unison with others to change our individual, organizational and systemic responses to the huge numbers of people who have been affected by physical and sexual violence.

We confront these issues at a pivotal time in this country's history when federal attention is focused on violence as a major public and mental health issue. Maine's mental health system is the first in the nation to commit substantial resources toward training its workforce and developing a system of services responsive to the needs of trauma survivors. We owe this distinction primarily to the energy of over 200 men and women who made a choice not to be silenced or isolated again and to include their voices in this growing movement on behalf of all trauma survivors.