



The Key



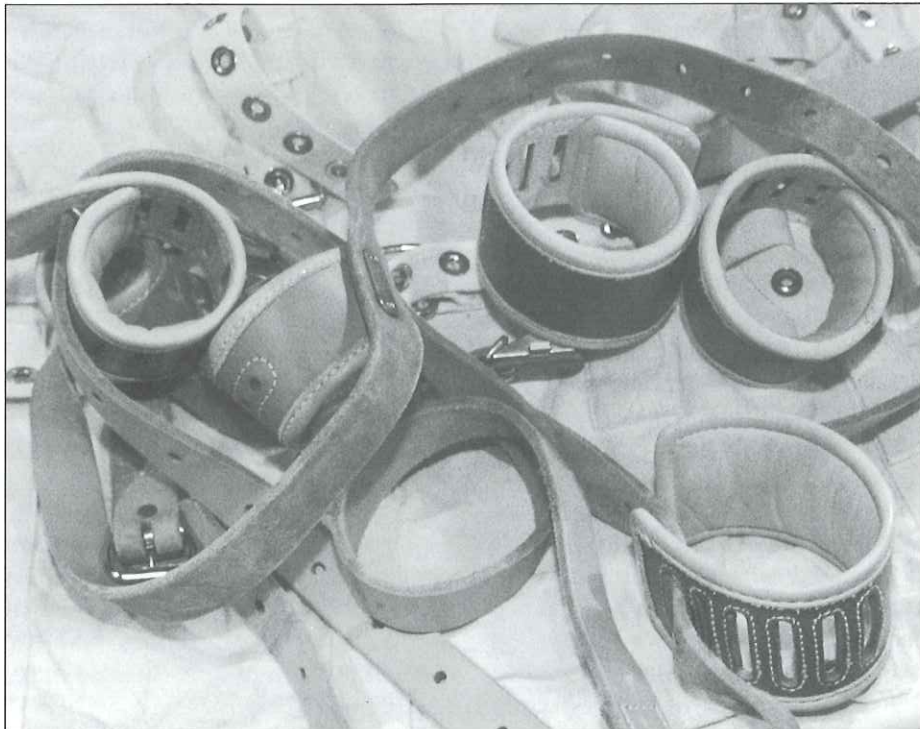
"Knowledge is the key to open new doors"

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NATIONAL MENTAL HEALTH CONSUMERS' SELF-HELP CLEARINGHOUSE NEWSLETTER

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Brutality made real: Leg, arm, and body restraints were displayed at the April 13 Senate hearings in Washington.

Summit: Plans, Strategies Move Forward

BY VIOLET PHILLIPS

Plans are proceeding for the National Summit, coming up August 25 to 29, 1999, in Portland, Oregon. An open advisory committee of more than 60 members has been meeting by teleconference to agree on how the summit should progress, as well as what the issues are that will become the "planks" of the consumer platform to be developed at the event.

"This meeting is going to be different than any other," said Kevin Fitts, director of the Oregon Office of Consumer Technical Assistance, since the summit will focus on building consensus on the issues of greatest concern to the consumer movement.

"This is definitely going to be a political forum," said Marie Verna, program director for the Clearinghouse, "which is different than a workshop— or an education-oriented conference."

Right now, work is underway to

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Fight Against Restraints Goes to Capitol Hill

BY CECE LENTINI

On March 22, 1998, an 11-year-old Connecticut boy died after he was restrained by two attendants at the facility in which he lived because of a dispute over where he would sit at a meal. As a result of the restraint used by the attendants, who

were not familiar with the boy or his medical problems, the boy's chest was crushed.

For many people, the death of little Andrew McClain — he reportedly was 4'6" tall and weighed 90 pounds — may have seemed a horrific aberration reminiscent of the early, unenlightened days of mental health treatment when asylums often restrained inmates by

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Message from the Executive Director

Insights About Our Independence

Over the past year I've had an insight about the consumer movement that has become too insistent to ignore – an insight almost approaching the level of an epiphany. My insight concerns the urgency of consumers to unite.

I now believe, after 20 years of work both inside and outside of the established mental health community, that, unless consumers organize themselves into a strong national presence, the situation is going to get worse instead of better on all the issues that most concern us – issues like the use of force on people with psychiatric illnesses, the availability of resources and dollars for services, and help with employment and income supports.

For a long time, consumers have worked in coalition with other organizations, but the time has come for us to stand alone. It's not that I think we should stop collaborating and forming coalitions. But we also must be able to stand on our own, strong and well organized in our own right. Quite simply, no one can represent us as well as we can represent ourselves.

Once we are strong and well organized, we can have a real influence on other groups working on these issues – and we can quite legitimate-

BY JOSEPH A. ROGERS

ly take the lead. Others working on these issues, though they're often well intentioned, do not have the stake in them that we do. They will always compromise on positions that we know we cannot afford to compromise on – and they will always compromise to a point that creates problems for us.

My epiphany was born of passion – the passion that we as consumers feel for these issues. Only people who have been restrained – physically or chemically – can really talk passionately about abolishing these practices. Only people who have been denied access to employment because of their disability know the pain and sense of futility that can cause. Other people, who haven't experienced what we have, can too easily make compromises in areas we know must change.

I used to think that by being involved with a lot of other people and organizations that we could move forward. But that's not what has happened. Too often we end up working within another organization's agenda, trying to make our voice heard from there. This has proven frustrating and inefficient. At the same time, taking over another organization is also not practical or wise.

It's true that there needs to be a place where non-consumers can be involved in these issues. We need all the support we can get: it's just that we can't expect all of this support to come from outside sources. Mental Health Associations need to exist, for example. They are well established, broad-based coalitions of consumers and non-consumers. Family organizations also have a right to exist, and we can continue to influence them to involve more consumers and move toward a more rights-oriented approach.

But ultimately, and this is what my epiphany revealed, when it comes to the issues that affect us, the only way to make progress is through our own independent effort.

I say this as a person with a serious disability; I say this knowing there are many challenges in organizing people with serious disabilities. First of all, most organizations rely on their members to financially sustain them. But, generally, people with disabilities don't have a lot of money, so our natural source of funds is limited. It takes a lot of time and a lot of energy just to raise the money to keep going – let alone work on the issues.

Another challenge is that the very nature of psychiatric disabilities gets in the way of our organizing abilities. For one thing, consistency is required in organizing, both in outlook and approach. That kind of responsibility is tough to maintain in the best of circumstances and the strain it puts on people can also make an illness worse.

We can also be a contrary bunch. I know that when I'm not feeling well I can be nasty and find it hard to work in groups. It's also true that the discouragement of being in a psychiatric hospital can change our personalities. We've learned to sit and brood, and so even when we're capable of taking action, we'd rather sit back and be critical – because taking action can be a scary thing.

Still, I believe we can overcome a lot of our disability-related issues by experiencing some successes. I've seen it happen. It's very important that we set doable goals for ourselves and take them on with a grounded, focused attitude. We can't let the obstacles inherent in our work shift us emotionally from one extreme to the next. We need to stay practical in our approach. So rather than say

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Message from the Program Director
Lessons from the Continent

This past February, I had the opportunity to attend the Fourth Conference of the European Network of (Ex-) Users and Survivors of Psychiatry in Walferdange, Luxembourg. The network has spent years attempting to organize the countries of Europe into a cohesive, clear voice for ex-users and survivors. Sound familiar?

As I got to know the representatives from almost every country in the European continent, I couldn't help comparing organizing efforts in the United States, which of course the Clearinghouse is actively involved in, to the organizing efforts in Europe. And, of course, I couldn't help comparing the Luxembourg conference itself with my hopes for the National Summit of Mental Health Consumers and Survivors in Portland, Oregon.

The event and the experience validated many ideas that we've been tossing around at the Clearinghouse with regard to the summit.

First of all, we all need to understand why we're there: to build consensus around the issues we all agree are the ones vital to mental health consumers and survivors. If we invest some energy and time prior to the summit in identifying those issues, we'll arrive in Portland ready to construct a national platform based on substantial planks. In the last few months, the

BY MARIE VERNA

Clearinghouse has been gathering responses to its "Call for Participation," and working with our national Advisory Committee, attempting to identify those issues.

I'm pretty certain that the "issues"

you contribute will be similar to those facing the European Network: access to and alternatives to treatment, work, stigma, marginalized populations, and housing – to name only some. But what about those issues? What is it about them that we all need to analyze together in Portland?

Second, we need to understand what the actual "issue" is in every case. We need to think in terms of problem statements, statements of what's not being done already, to identify the

actions we recommend. For example, "parity" is not necessarily an issue. The issue is: on both federal and state levels, insurance discrimination continues to prevent access to treatment.

Third, we need to understand the background behind each issue. What obstacles have remained? What events led to success in the history of the work done on this issue? Why should we analyze this particular issue? What consensus exists on this issue? What division exists on the issue? What actions should we take on this issue?

We all need to understand why we're there: to build consensus around the issues we all agree are vital to consumers and survivors.

Once we've identified the important topics, we need to seek out leaders who can facilitate working sessions on those issues. I've become convinced that our efforts to facilitate and document throughout the summit will mean the difference between success and failure. To that end, the Clearinghouse is hoping to offer technical assistance at the summit in conflict resolution and facilitation. While many of us have knowledge of issues, programs, and policy, many of us have never actually had the opportunity to acquire the formal skills necessary to negotiate, compromise, or resolve conflict.

At the summit, as they were in Europe, those skills will be more important than any others. We'll be trying to focus our minds on issues, consensus, and action in our efforts to create a platform that we can all stand on together. If we value that goal, it'll be necessary to learn from our history of organizing – both its successes and its failures.

After the summit, we'll need those skills to implement the action plans we develop and to support our national platform. So far, there's little evidence that the world wants to hear our voice – be it European or American. But with a solid, well-analyzed platform, which we build together, we'll be prepared to state our goals in a clear, collective voice to those who discriminate against us, oppose us, or ignore us.

KEEP CURRENT —

Get the latest info on the National Summit. Read Joseph Rogers' Senate testimony against restraints. Call up the Clearinghouse Web site at www.mhselfhelp.org.

PeopleWho Network Gets Under Way

The Clearinghouse has joined forces with Sylvia Caras and Eileen Lopp to increase and improve services for users of the PeopleWho Information Center. Through funds from the Center for Mental Health Services, PeopleWho will now be able to develop new e-mail lists and expand existing lists.

"I anticipate a surge of new lists being created," said Caras, co-director of PeopleWho and founder of the original Madness Group and Madness list. The goal now is "to provide a hospitable resource for the different ways that people construct their thoughts and beliefs around psychiatric issues."

The Madness list began in September, 1997, and quickly reorganized into several others – including Act-Mad, Club-Mad, MadGirls and MadSpirit – eventually reaching 20 in all. The lists were run out of St. John's University, which was offering a host site for approximately 600 disability-related lists. But when the university imposed an embargo on new lists "we couldn't grow," Caras said. However, "the Clearinghouse had always been active on the Internet, so we knew they'd understand our project."

"We believe the Internet is a great

way to connect consumers and get the consumer voice heard," said Marie Verna, Clearinghouse program director. "Helping get PeopleWho started was a logical step for us."

"The Internet is for people who believe in self-help first," Caras said.

Over the next three years, the goal of PeopleWho is to build value on the Internet for "people who" experience mood swings, fear, voices, and visions. It is run by Caras and Lopp out of Lopp's Seattle-based Rainier Web Services. The first year will involve creating a hosting service for e-mail lists using Lyris software and for developing StateNet, a series of consumer lists to encourage state-focused discussions. "By the time you read this," said Caras,

"consumer lists will be running in half of the United States."

PeopleWho is also charged with starting many new consumer lists – for older adults and consumers of different cultural backgrounds, for example – and will start a library in its second year of operation and an archive in its third. In the meantime, Caras and Lopp will maintain the established Madness lists; participants are being invited to move over to the new software, though this won't be required.

"We're hoping that the idea of PeopleWho will provide a broader umbrella for those who are uncomfortable with the word madness – and for those who aren't," said Caras.

The possibilities are enormous, especially with the growing interest in self-help in all quarters. "The Internet is for people who believe in self-help first," Caras said. "This is where people are going for information, and I want as much of it to be available as possible. I also want this to be available for greater advocacy efforts – so people can work together when issues come up such as forced restraint and outpatient commitment. This can be a tremendous resource."

—Violet Phillips

Clearinghouse Web Site Needs Your Voice

The Clearinghouse Web site – that's www.mhselfhelp.org – is now updated bimonthly. Use this site as a valuable tool to get the latest news on conferences, research, new Web resources, consumer listserves, publications, managed care, and advocacy.

New features have also been added to the site. These include the "Your Voice" page, which allows consumers to write in and share their expertise with others in the self-help movement. This is a great

place to talk about your self-help group or describe a successful fundraising event. We also welcome new book recommendations or announcements of upcoming events.

The on-line bookstore on our site now offers more than 45 selections recommended by consumers and Clearinghouse staff. The Amazon.com search box located here also allows users to search Amazon.com for books, music and videos related to mental health. To use this new fea-

ture, click on the Amazon.com icon on the Clearinghouse home page and search by topic, author, title, or ISBN number. A portion of the proceeds Amazon earns on products purchased through our site will be donated back to the Clearinghouse.

For more information, or to offer suggestions for the site, visit the Clearinghouse at www.mhselfhelp.org or contact the Clearinghouse Webmaster at eknapp@mhasp.org.

—Michelle Dillin

Clearinghouse Submits Brief in Olmstead Case

On April 21, the Supreme Court heard arguments in *Olmstead v. L.C. and E.W.* – a case with direct ramifications for integrating people with disabilities into the community. The decision by the judges will not be released until the summer, but the Clearinghouse supported the respondents in the case – Louise Curtis and Elaine Wilson – by filing an amici (friend of the court) brief in March.

Olmstead v. L.C. and E.W. comes out of the “integration mandate” of the ADA.

“The case is an opportunity for the highest court in the country to rule on the importance of ensuring that people with mental disabilities rightfully belong in the community,” said Joseph A. Rogers, executive director of the Clearinghouse. “Given the mission of the Clearinghouse, it’s right and fitting that we support the women involved in the case.”

Olmstead v. L.C. and E.W. comes out of the “integration mandate” of the Americans with Disabilities Act (ADA). Under this mandate, the services that public agencies provide must be offered “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” This case began in 1995 when Susan Jamieson, a Legal Aid attorney in Atlanta, GA., sued the state of Georgia on behalf of Curtis and Wilson: both women have mental disabilities and were repeatedly hospitalized and then placed in inappropriate settings over the course of 20 years.

Because of the lawsuit, Curtis and Wilson were moved to a group home. However, the state of Georgia appealed a lower court ruling that

BY VIOLET PHILLIPS

stated the Georgia Department of Human Resources violated the ADA’s integration mandate. That appeal sent the case to the Supreme Court.

The brief was filed with the support of several other organizations: the Alaska Mental Health Consumer Web, C.H.O.I.C.E.S. in Georgia (Consumers Helping Ourselves with Information,

Communication, Empowerment and Support), the Contac national technical assistance center based in West Virginia, the Madness Group, the Mental Health Empowerment Project, Inc., Pennsylvania Protection and Advocacy, Inc., Plusabilities – also out of Georgia, United Self-Help in Hawaii, and the Well Mind Association of Minnesota. Additionally, seven individuals who are also consumers signed on.

The Clearinghouse amici brief was prepared by Jo Halberstadter, director of advocacy and support programs at the Mental Health Association of Southeastern Pennsylvania (MHASP) – with which the Clearinghouse is affiliated – and Susan Rogers, director of special projects for MHASP and the Clearinghouse. It was submitted by Loralyn McKinley as counsel of record, an attorney with the Philadelphia firm McKinley and Vonier and a member of the MHASP board of directors.

The brief argues the benefits of deinstitutionalization by citing the stories of six people and research on

the personal and economic benefits of community-based support services. The Clearinghouse also joined with a diverse group in filing its brief. Some of the other briefs supporting the respondents included one from former United States Attorney General Dick Thornburgh and the National Organization on Disability. (The ADA was enacted during Thornburgh’s tenure and his office oversaw the implementation of the regulations.) A brief from 30 national organizations and seven Georgia groups was co-authored by the Bazelon Center for Mental Health Law and includes the support of the American Association of Retired Persons and Catholic Charities U.S.A.

In an interesting turn of events, of the 22 attorneys general who originally signed onto a brief supporting the state of Georgia, 12 withdrew by the filing date. And in response to the remaining states, a group of former commissioners of mental health and directors of developmental disabilities submitted a brief on behalf of the respondents.

“All in all, a very strong case was made for supporting the integration mandate,” said Joseph Rogers. “Though we won’t know the outcome right away, the evidence presented for the improved lives of people outside of institutions was over-

whelming – and powerful enough to show public agencies that this is the best course of action for any reason.”

For updates on *Olmstead v. L.C. and E.W.*, connect to the Clearinghouse Web site at www.mhselfhelp.org or the Bazelon Center site at www.bazelon.org. ■

The brief argues the benefits of community support services.

Whatever we do, I want this positive feeling to continue.

....continued from p. 2
we'll get rid of all the psychiatric institutions tomorrow, we'll decide to educate people about the problems these institutions cause. We can move in increments without giving up our visions of the future.

A national consumer effort is crucial to realizing our visions, and it's my hope that the National Summit in August will lay groundwork toward this goal. To provide a setting where focused, grounded, and doable work can occur, the Clearinghouse has been disseminating information as we proceed with the planning.

With the help of our national Advisory Committee, we've provided a "model" agenda, with alternating general and working sessions. We've also provided a "model" of the issues that should be part of a national consumer/survivor platform. Prior to the summit, we hope to provide draft "position papers" on the major issues describing the background behind the issues, why they're important, how much con-

sensus we've built on the issues, and ideas for action with regard to each issue.

The Clearinghouse is disseminating all of this pre-work and stimulating this pre-discussion on our national listserv in hopes of preparing attendees ahead of time. Putting the summit together is proving to be a giving process – giving as much information as we can at all times and giving full attention to the feedback we receive. We want to know the real needs of the movement and, as a result, we hope for a significant attendance at the actual event.

Once we identify the major issues, we'll work on identifying the movement leaders who can best educate all of us on current successes, consensus, and action steps. These leaders will work throughout the summit as facilitators, helping us focus our energy and passion around the issues we care about.

After the summit, the Clearinghouse will continue its efforts to create a national platform

for consumer/survivors by continuing to work with the Facilitators' Committee, who will be charged with sharpening and implementing the action plans we develop in Portland. Again, the Clearinghouse will take an organizing role – convening the committee and reporting on its work.

As time goes on, I'm confident that an independent national organization governed by and for consumer/survivors will emerge. Thus far in the summit planning process, I have never seen as much support, with so little discord, for a discussion of national issues. Whatever we do, I want this positive feeling to continue. We must remember the necessity of our national voice. No one else can speak for us.

And we must also remember that we can work out differences and that disagreements need not get in the way of our ability to be heard. I expect that by the time of the summit in August, the momentum to proceed will be unstoppable. Let's go with it together in peace! ■

The goal of the summit is to develop action plans on the issues.

Summit Update....continued from front cover
determine the principle issues for the summit. The advisory committee is considering four main categories and then looking at the subjects that fall within each. The categories are Treatment and Treatment Alternatives, Advocacy and Organizing, Community Support Systems, and Issues Affecting Subgroups. Some of the specific subjects – from among more than 40 – include parity, recovery, consumer-run alternatives, involuntary commitment, consumer participation in research, system reform, employment, housing, forensic issues, and gay and lesbian concerns.

Reviewing the responses from the Call for Participation is a big part of the process for determining the planks. Not only will the "issues" be

Additionally, though, a workshop will be held the day before the summit sessions begin to teach group process and conflict resolution to

The summit is planned as a series of alternating meetings: "general" sessions and "working" sessions.

selected from these applications, but also the "individuals" to lead the discussions. The advisory council is especially interested in choosing those people with strong presentation and facilitation skills.

anyone interested.

The final issues will be determined in the next few weeks (and will be posted on the Clearinghouse Web site). Then, position papers will be drafted on these issues and

Summit Update....continued from p. 6
distributed to participants as they sign up to attend. By the time the summit begins, all registrants should have received the drafts so that everyone can be prepared for the discussions with a basic level of knowledge (though the papers will also be available on site).

The summit is planned as a series of alternating meetings: "general" sessions and "working" sessions. The event will begin with a general session, during which the participants can review the general issues for the planks. From there, attendees will choose what they want to work on and move on to the specific working sessions – the caucuses – where the issues will be discussed. At the end of each working session, reports will be made to the general session on areas of consensus. Points of consensus will imply a need for action and will thus be incorporated into final action plans.

The overall goal of the summit is to develop action plans for issues that can become the basis for the national platform of the collective voice of consumers and survivors. Once the summit concludes, the Clearinghouse, the Oregon Office of Consumer Technical Assistance, the Advisory Committee and a committee of the facilitators will compile the information that will become this national platform.

"This is an important opportunity for con-

sumers and survivors," said Joseph A. Rogers, executive director of the Clearinghouse. "And the response so far has been impressive – I think in part because technology has enabled us to communicate quickly and clearly. We want to keep people

informed and keep the process inclusive. Everyone involved in the process continues to welcome feedback as we go along."

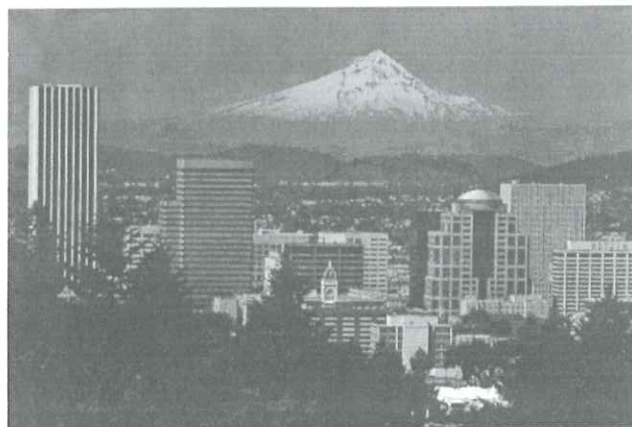
For continuous updates, access the Clearinghouse's Web site at www.mhselfhelp.org. ■

The National Summit of Mental Health Consumers and Survivors August 25-29, 1999 Portland, Oregon

The National Mental Health Consumers' Self-Help Clearinghouse is sponsoring a National Summit of Mental Health Consumers and Survivors to work toward a national consensus for action on issues building in the national arena.

The summit will be a forum for consumers and survivors to come together, discuss their concerns, and organize their ideas into a strong, collective voice that can influence debate on emerging issues.

The Clearinghouse urges interested consumers and survivors to participate with us in taking the next step toward building a united national advocacy initiative.



For more information contact:

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The death of Andrew McClain was not an isolated case.

...Restraints continued from front cover placing iron chains and shackles around their ankles and wrists.

But for people with mental illnesses, the story of McClain's death is a grim reminder

of a threat they still can face today. Although patients may no longer be shackled and chained, the use of restraints and seclusion remains intimidating.

"All restraints are abusive," said

Joseph A. Rogers, executive director of the National Mental Health Consumer's Self-Help Clearinghouse. "Anyone who tells you that you can 'lovingly' restrain someone has never been restrained."

To be sure, reforms that began in the 19th century have helped make psychiatric institutions much more humane than they once were. With appropriate training, staff members often can find ways to deescalate a potentially violent situation without using restraints at all. And some psychiatric institutions have successfully done away with their use altogether.

In addition, the advent of deinstitutionalization and the growth of community support programs in many parts of the country have meant that fewer and fewer people are even in a position to be threatened with restraint.

Even so, the death of Andrew McClain was not an isolated case. This became clear when the Hartford Courant reported on it as part of a five-day investigative series on the use of restraints and seclusion in psychiatric institutions that ran last October. The series concluded that inadequate training of staff, the lack of any policing of the healthcare industry, and the fact that there is no requirement that injuries or deaths that result from restraint use be reported and tracked, have all contributed to the problem.

The series, which uncovered 142 deaths — more than a quarter of them children — connected to the use of physical restraints in healthcare facilities, has triggered a national shock wave of concern, dismay, and anger.

Consumers and their families now know what they only once suspected — that death by restraint is much more common than they have been led to believe. A study by the Harvard Center for Risk Analysis, commissioned by the Hartford Courant, found that each year between 50 and 150 people — or one to three people each week — die in psychiatric facilities after being improperly bound in restraints. Countless others are injured.

Legislators and other decision makers both in Washington, D.C. and around

Restraints: Act on Your Convictions

Many consumers and their families feel strongly about the use of restraints and seclusion as a treatment option. But it is often hard to know how to put feelings into action.

Joseph A. Rogers, executive director of the Mental Health Consumers' Self-Help Clearinghouse, said consumers and others can begin work in their own communities.

"People who want to get involved should begin by asking questions, such as what is the policy in their state, or in their local hospitals," he said. "They should ask if there is any central repository in the state, or even in the hospitals, for information on the use of restraints."

If not, he said, consumers can begin by advocating for those things, either by writing letters or calling their state legislators and officials involved in behavioral health care.

Some states, such as Pennsylvania, are already committed to doing away with any use of seclusion or restraints in state hospitals.

"People should advocate for the use of restraints to become a major incident report, and that any use of restraints be reported to a central database," said Rogers.

At the national level, said Gary Gross of the National Association of Protection and Advocacy Systems (NAPAS), letters and phone calls can also be effective. In particular, if your congressman or senator is not co-sponsoring any of the proposed legislation now pending in Congress, write and urge him or her to do so.

In general, the "The Patient Freedom From Restraint Act of 1999," sponsored by Representatives Diana DeGette (D-CO), Rosa DeLauro (D-CT) and Pete Stark (D-CA), is the strongest of three bills recently introduced into Congress.

The bill sponsored by Sen. Joseph Lieberman (D-CT) is compatible, although it allows a facility to determine for itself whether a death or injury constitutes an "unexpected occurrence" that requires it to be reported. His bill is called the "Freedom From Restraint Act of 1999." A bill sponsored by Sen. Christopher Dodd (D-CT) would amend the "Protection and Advocacy for Mentally Ill Individuals Act" (PAMI), to require the reporting of restraints-and seclusion-related deaths within seven days. The Dodd bill is called the "Compassionate Care Act." Lieberman and Dodd are co-sponsors of each other's bills, which complement each other.

To contact any of the sponsors of this legislation or any of your own Senators or Representatives by phone call 202-224-3121 and ask for their office. They can be contacted by writing them at the U.S. Senate or the U.S. House of Representatives, Washington, D.C. 20510.

— Cece Lentini

The bills set guidelines for the use of restraints and seclusion.

the country have been appalled by the incidents highlighted in the series. Many have begun receiving calls from constituents who now feel freer to call, complain, and even relate horror stories of their own.

And various interest groups, ranging from psychiatrists to the commission that accredits health care providers, have begun reviewing their positions on the issue.

Most notably, on March 25, three pieces of legislation were introduced in Congress. The strongest of the three, introduced into the House of Representatives, would limit the conditions under which restraint and seclusion may be used with patients in psychiatric treatment facilities, facilities for the developmentally disabled, residential treatment facilities for children and similar facilities that receive Medicare, Medicaid, or both.

At a press conference that day, Sen. Joseph Lieberman, (D-Conn.), who is sponsoring a Senate version of the bill, said he only learned the scope of the problem from reading the Hartford Courant series.

"We have been taken (by this series) into the dark corners of psychiatric institutions, too often invisible to most of us unless we have family there," he said.

Referring to a table full of different types of leg, arm, and body restraints, he added that they looked like something that "would only be used on animals. . . and perhaps not appropriately on (them)."

Rep. Diana DeGette (D-Colo.), a co-sponsor of the House bill, said her colleagues in the House of Representatives have been "amazed" when she has talked to them about the issue.

"They thought this problem was taken care of more than 10 years ago when Congress passed legislation regarding the use of restraints in nursing homes," she said. "It will take time

to educate them about this issue. The problem is that in psychiatric facilities, this gets swept under the rug."

Together, the bills establish guidelines for the appropriate use of restraints and seclusion, similar to the guidelines from the Omnibus Budget Reconciliation Act of 1987 (OBRA), which covered their use in nursing homes. That law mandates that

restraints and seclusion are only to be used to ensure the immediate physical safety of the patient or others, and are only to be used upon the written order of a physician.

Provisions in the bills would also make information about the use of restraints and seclusion more accessible by setting up a number of reporting requirements for institutions that treat people with severe and persistent mental illnesses or children with emo-

tional and behavioral problems. Among the strongest provisions contained in the bills are those that would:

1. Limit the use of restraints to situations where the safety of the consumer or the staff is at stake;
2. Establish minimum guidelines for the appropriate use of restraints and seclusion;
3. Require facilities to keep records on the use of restraints;
4. Require facilities to open those records to Protection and Advocacy (P&A) agencies upon request;
5. Report any deaths that result from the use of restraints to P&A agencies;
6. Establish a process for compiling and reporting on the frequency of restraint use and the number of deaths that result from their use through the Department of Health and Human Services;
7. Require facilities to establish a regular training program for patient care staff on the appropriate use of restraints, as well as on techniques for addressing problems without using restraints;

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**On March 25,
three pieces
of legislation
were
introduced.**

DON'T FORGET!

**THE 1999 CLIFFORD W. BEERS NATIONAL MENTAL HEALTH CONFERENCE
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- **HOTEL COSTS:
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Joseph Rogers testified that restraints are overutilized.

8. Impose financial penalties and loss of federal dollars on facilities that fail to comply with the legislation.

Rep. Rose DeLauro (D-Conn.), a co-sponsor of the House bill, said she believed that the proposed legislation is a good start for giving consumers and their families a way to find help.

"This affects the most vulnerable people in our society, during some of the most difficult circumstances in their lives," she said. "These people should not have to fear for their lives when checking into a hospital."

As debate begins on the proposed legislation, hearings were held on April 13 before the Appropriations Subcommittee on Labor, Health, Human Services and Education. Consumers heard that day included Rogers, who spoke in part about the



Joseph A. Rogers, executive director of the Clearinghouse, offered compelling testimony about his personal experiences with restraints at the April 13 Senate hearing.

experience in Pennsylvania, where the state is working toward the goal of eliminating all use of restraints.

"My experience is that in places where they are allowed, they are highly overutilized," he said. "It is amazingly easy to get restrained. And if you are an inpatient, there isn't too much opportunity to protest."

Meanwhile, a number of groups have come out with position statements on the use of restraints and seclusion, as well as on various pieces of the proposed legislation.

Among the staunchest supporters of the bill introduced into the House is the National Association of Protection and Advocacy Systems (NAPAS), which would have expanded powers and play a critical role in monitoring and investigating the use of restraints and seclusion if the bill becomes law.

In a statement, Curtis L. Decker, executive director of NAPAS, noted that in New York, state laws have long given the Protection and Advocacy System the type of powers included in the proposed federal legislation.

As a result, he said, in New York not only has the use of restraints and seclusion declined significantly, but also emergency medical care has improved and the suicide rate has dropped.

"This legislation will provide P&As with an invaluable tool — routine reporting of potential restraint-related death," he said. "Once the P&A receives these reports, their trained investigators and legal staff can determine which deaths may be due to the misuse of restraints, and can take appropriate corrective actions to ensure that the abuses do not occur in the future."

Other groups that have issued statements in favor of the proposed legislation include the National Mental Health Association (NMHA) and the National Alliance for the Mentally Ill (NAMI).

Some organizations, however, are not as happy with the legislation.

The American Psychiatric Association (APA), which has 40,000 physician members, said in a prepared statement that the legislation might have a "chilling effect on treatment and hospital safety within a healthcare environment." It also said "inappropriately placing restrictions on health care professionals' use of interventions that help guarantee their safety as well as the safety of patients in their care is unwise."

The APA went on to say that it also is unhappy with the proposed legislation because while it "rightly" cites better

The Key

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Many disagree that restraints have a place in psychiatric treatment.

training and adequate staffing as basic necessities, none of the bills discuss how this would be paid for.

The National Association of Psychiatric Health Systems (NAPHS), which has about 100 members that operate more than 400 hospitals and other treatment centers, has issued a statement called "Guiding Principles on Restraint and Seclusion for Behavioral Health Services." The principles, based on existing policies, were released in conjunction with the powerful American Hospital Association.

Carol Szpak, NAPHS' director of communications, said the association favors a system that encourages voluntary reporting of deaths and injuries related to the use of restraints.

"One of our biggest concerns is that mandatory reporting requirements might actually hinder and not help patient safety efforts," she said. "We're concerned that some requirements could actually discourage medical personnel from coming forward with mistakes or errors. We think a voluntary policy has been shown to work."

Szpak said NAPHS' other concern has to do with patient confidentiality. "Patients or family members may not want to have that kind of sensitive information publicly disclosed," she said. "These bills could increase the likelihood of private information becoming public."

NAPHS also wants to work closely with the Joint Commission for Accreditation of Healthcare Organizations, said Szpak.

The commission also held public hearings in March and April on the issue. It was seeking feedback "to improve the detection of the use and misuse of physical restraint and therapeutic holding and to identify best practices when the use of restraint is necessary," according to a statement.

At the end of March the commission also issued a statement in support of mandatory reporting and public disclosure of deaths related to the use of restraints. It said it favored Sen. Joseph

Lieberman's proposed legislation because it outlines a method for doing this that protects privacy.

The ongoing debate, as well as the three pieces of proposed legislation, all begin with the assumption that restraints and seclusion have a place in psychiatric institutions. Some, however disagree.

Clearinghouse executive director Joseph A. Rogers addressed that position during his testimony in Washington in April.

He talked about his own personal experiences with restraint, and his belief that the use of restraints reflects a failure of the system to manage the people in it. At the very least, he said, their use needs to be reported systematically to a central database, and should only be used when they are

authorized by the most senior person at the institution. Institutions, he said, should also have policy statements that say restraints are abusive and harmful.

But he said he also talked about his belief that the issue really goes toward the idea that people need to move out of hospitals and into community placements.

"Restraints should be viewed as abusive, and not as part of the normal therapeutic practice," he said. "Whenever federal dollars are spent on the mental health system, this should be the accepted view. But the issue goes beyond restraints. One way to prevent the use of restraints is simply not to have people locked up in an inpatient setting." ■

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