Voices from the Front Line:
Patients' Perspectives of Restraint & Seclusion Use

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for the Mentally Disabled

Acknowledgments

The Commission would like to extend its appreciation to each person who participated in the survey. Those who took the time to answer the questions on the survey made an invaluable contribution to the Commission's ongoing examinations of the quality of treatment and services provided in New York. The Commission is especially appreciative of the many hundreds of individuals who wrote extensive comments on their survey forms describing their personal experiences and points of view.

The Commission would also like to acknowledge the contributions of the New York Association of Psychiatric Rehabilitation Services (NYAPRS) and Mental Health Association's Recipient Empowerment Project, the two recipient groups who assisted the Commission in the development and distribution.

The Commission would especially like to thank Ms. Susan Sleasman, who served as a consultant to the Commission on this study. Her assistance in helping us reach the large number of respondents, as well as her efforts to organize and analyze the narrative comments added immeasurably to the overall breadth and depth of the study report.

Preface

This report on the use of restraint and seclusion in psychiatric facilities in New York State describes the perspectives of over 1,000 former inpatients of these facilities who responded to a mail survey conducted by the Commission.

A companion report, *Restraint and Seclusion Practices in New York State Psychiatric Facilities*, reveals that the use of these restrictive interventions has increased dramatically in the last decade, during which 111 patient deaths associated with restraint or seclusion have been reported. At the same time, the Commission found wide variations in the frequency with which psychiatric facilities placed their patients in physical restraint or seclusion. While 16 percent of the 125 facilities surveyed made *no* use of these interventions during the period studied, another 9 percent made frequent use of them, and the rest fell somewhere in between. Neither the patients' demographic nor clinical characteristics could explain these wide variations. The Commission concluded that the attitudes and treatment philosophies of administrative and clinical leadership at individual facilities strongly influenced the frequency with which they used restraints and seclusion.

In this mail survey, the Commission sought to ascertain how former inpatients regarded their experience within psychiatric hospitals and, more specifically, their experience with being restrained or secluded. Given the wide variations in practice, the Commission believed that the voices of former inpatients, removed from the immediacy of the events, could be a valuable source for learning more about the use of restraints and seclusion and how they affect patients' perceptions about their care and treatment.

The responses from 1,040 former patients provide powerful testimony about the use of restraints and seclusion, about compliance with state placed in restraints or seclusion upon their attitudes towards hospitalization.

Slightly over half the patients (54%) reported having been placed in restraints or seclusion while hospitalized. Of these patients:

- 27 percent reported that the use of restraints or seclusion was appropriate given their condition;
- 94 percent had at least one complaint about its use or about their care and treatment:
  - 78 percent stated that their care and treatment while in restraints or seclusion did not comply with the requirements of the mental hygiene law or OMH regulations, specifically that:
    - they were not examined by a physician (46%);
    - they were not released and allowed to exercise every two hours (58%);
    - they were not allowed to use the bathroom hourly (46%);
    - they were not checked by staff every 30 minutes (38%); and
    - they were not allowed to eat or drink at mealtimes (34%);
  - 62 percent stated that they were not protected from harm when these interventions were used because staff:
    - had used unnecessary force (50%);
    - had psychologically abused, ridiculed or threatened them (40%);
    - had physically abused them (29%) or physically injured them (26%); or
    - had sexually abused them (10%).

The respondents were also asked 36 questions about their inpatient care and treatment. Generally, patients gave high marks to hospitals for respecting personal liberties like communication and visitation rights; custodial care services like clothing and personal hygiene; and protection from egregious physical or sexual abuse by staff. However, at least a third of the patients complained that they did not feel safe, could not exercise regularly, had their possessions stolen or taken away, could not go outdoors daily or that staff yelled at them or at other patients.

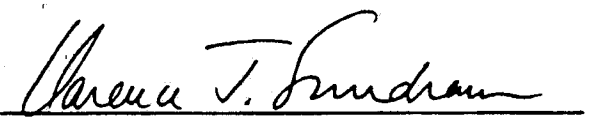
- 41 percent rated their overall care very positively, giving positive assessments on 80 percent or more of the survey items;
- 30 percent gave their overall care a failing grade, giving positive assessments on fewer than 60 percent of the survey items.

Notably, patients who had *not* been restrained or secluded were significantly more likely to assess their inpatient hospital treatment positively. Patients who had been restrained or secluded were twice as likely to have a negative overall assessment of their inpatient care. However, the efforts of staff to use less restrictive interventions before resorting to the use of restraint or seclusion seemed to have a significant effect in reducing the negative assessments of these patients.

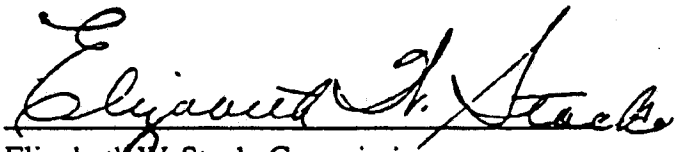
In this era of increased emphasis on consumer choices and consumer satisfaction with services, the voices of former inpatients reinforce the wisdom of legal requirements that restraints and seclusion be used only when less restrictive methods of intervention are not successful, that they not be used as punishment, as a substitute for program, or for the convenience of staff. Patients place a high value upon these safeguards.

There is a larger lesson here as well. The conclusion seems inescapable that there is a large measure of clinical discretion in the decision to place patients in physical restraints or seclusion. This discretion is also exercised with a high degree of variance among similarly situated facilities. The use of these interventions poses a risk of harm to both patients and staff, and plays a significant role in shaping a negative perception of the experience of inpatient hospitalization for the affected inpatients. Such perceptions can affect the willingness of patients to seek or voluntarily accept hospital care should their condition require it in the future.

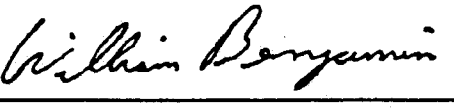
The voices of former patients reinforce what the statistical data from 125 psychiatric facilities suggest: there is substantial room for improvement in reducing the heavy reliance by many facilities on the use of physical restraints and seclusion. The Commission urges hospital administrators and clinical leaders to listen carefully.



Clarence J. Sundram, Chairman



Elizabeth W. Stack, Commissioner



William P. Benjamin, Commissioner

Table of Contents

List of Figures

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Chapter I
Introduction

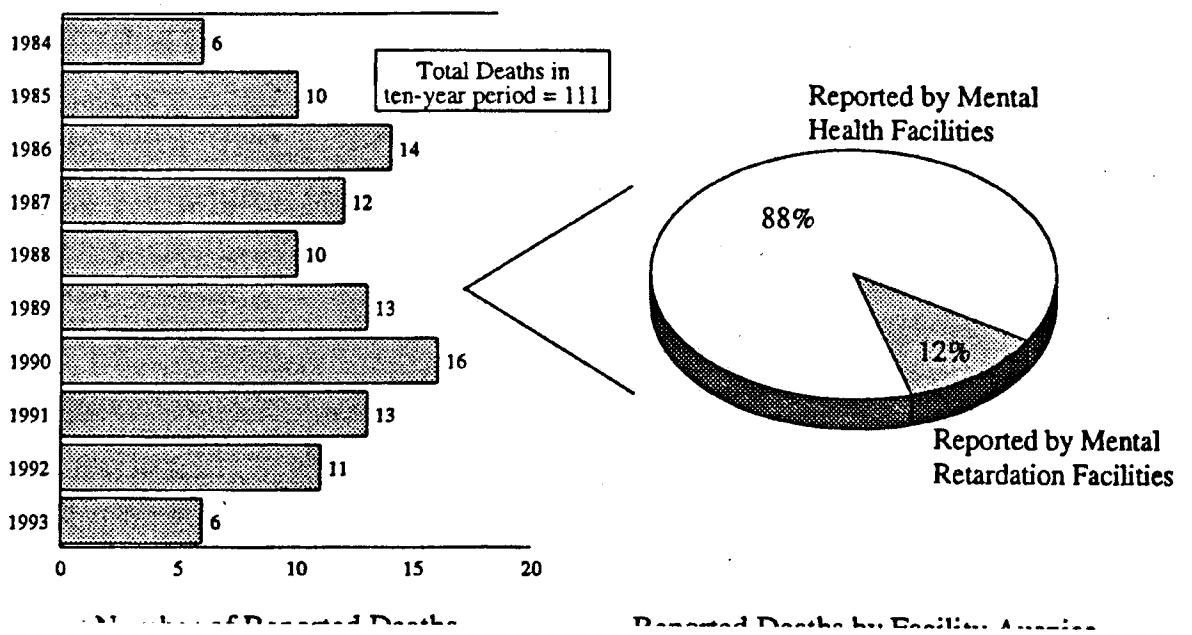
In Chapter 50 of the Laws of 1992, the State Legislature requested that the New York State Commission on Quality of Care conduct a review of the use of restraint and seclusion in the treatment of persons who are mentally disabled.

Investigations of restraint- and seclusion-related deaths have been an ongoing priority of the Commission's Mental Hygiene Medical Review Board, and in total, over the ten-year period 1984 – 1993, 111 deaths associated with restraint and seclusion use have been reported, investigated, and reviewed by the Board (Figure 1). These individual death reviews, as well as other advocacy complaints and abuse investigations conducted by the Commission, have reinforced the need for all treatment facilities using restraint and seclusion to do so with extreme caution and diligent quality assurance review.

Although patient deaths directly related to restraint and seclusion have been relatively infrequent, each year the Commission has investigated cases involving preventable injuries and deaths, and has identified problems and deficiencies which have contributed to their occurrence. These problems and deficiencies have included:

- use of restraint and seclusion without adequate efforts to calm the patient or

Figure 1
Restraint and Seclusion Related Deaths
Reported by Mental Hygiene Facilities
(1984-1993)



resolve the problem using less restrictive interventions;

- use of restraint and seclusion by staff who had not been adequately trained, and who thereby misused techniques and sometimes used excessive force, which compromised the safety and well-being of the patient, leading to serious injury or death;
- failure of professional staff to comply substantively with the state's statutory and regulatory requirements governing the use of restraint and seclusion, which often left patients' comfort and safety seriously compromised for long periods of time, contributing to the serious harm and sometimes the death of patients;
- use of restraint and seclusion without adequate attention to the proper size and condition of the restraining device or environmental hazards, including excessive heat, poorly ventilated rooms, and suicidal hazards, which contributed to serious harm to patients and sometimes death; and
- failure of facilities to recognize medical emergencies that are sometimes associated with restraint and seclusion use and to ensure that emergency medical equipment was promptly accessible and that staff were well-trained in emergency medical procedures, including cardiopulmonary resuscitation.[1]

The Review

Based on its experience reviewing the use of restraint and seclusion in psychiatric treatment facilities, the Commission recognized that its response to the Legislature's requested study would require a number of different research activities which incorporated data collection from many sources and perspectiyes. In accordance with this recognition, the Commission has responded to the Legislature's request with the preparation of two reports.

(1) The first report, *Restraint and Seclusion Practices in NYS Psychiatric Facilities* (September 1994), details the highly variable rates of restraint and seclusion use among NYS psychiatric facilities and reports the Commission's findings that these variations appeared to be independent of differences in the patient populations served and of most facility characteristics. The report also provides other findings that suggest that low restraint and seclusion use by a psychiatric facility does tend to be associated with specific treatment and custodial practices, including better assurances of patients' personal liberties, including off-ward privileges, better environmental conditions, and more patient participation in programming.

(2) This second report, *Voices From the Front Line: The Patients' Perspectives of Restraint and Seclusion Use*, reports the

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1 NYS Commission on Quality of Care, *Christopher Dugan - A Patient at South Beach Psychiatric Center*, January 1985; *Mia Martine - A Patient at Mid-Hudson Psychiatric Center*, December 1982; *Pedro Montez - A Patient at Manhattan Psychiatric Center*, December 1982; *Alex Zolla - A Patient at South Beach Psychiatric Center*, May 1982; *Janice Sherman - A Patient at South Beach Psychiatric Center*, February 1982; *Fred Zimmer - A Patient at Kingsboro Psychiatric Center*, June 1981; *Alphonse Rio - A Patient at South Beach Psychiatric Center*, March 1981; *Peter Breen - A Patient at St. Lawrence Psychiatric Center*, February 1981; *Allen S. - A Patient at Manhattan Psychiatric Center*, November 1979.

findings of the Commission's mail survey to individuals who had been inpatients of New York psychiatric facilities. Summarizing the responses of over 1,000 former inpatients, the report provides both a clear statement of patient concerns regarding restraint and seclusion use and a better understanding of specific restraint and seclusion practices which most substantially influence patients' negative versus positive opinions.

Methods

In obtaining the opinions of individuals who had been inpatients in New York psychiatric facilities regarding restraint and seclusion, the Commission worked with two recipient advocacy groups, the New York Association of Psychiatric Rehabilitation Services and the Recipient Empowerment Project of the NYS Mental Health Association. Representatives of both of these organizations assisted the Commission in developing the mail survey. The recipient advocacy groups also assisted the Commission in the distribution of the mail survey to approximately 285 organizations, including self-help groups, clubhouses, psychosocial clubs, and recipient advocacy organizations, and 950 individuals on their mailing lists.

In total, approximately 3,000 surveys were distributed. No stipend or other incentive was offered to recipients who responded to the survey. Over 1,000 surveys (N = 1,040) were completed and returned to the Commission.

The Surveys

In accordance with the advice from recipient advocates, the Commission's survey was a brief two pages, and all items were constructed to be easy to read and respond to. The survey included 36 *true/false* items related to the individual's overall assessment of his/her inpatient treatment, 21 *true/false* items related to restraint and seclusion use, and 7 *yes/no* items asking about the types of mental health inpatient and outpatient services the former inpatients had used. (See Appendix A for a copy of the survey.) The survey also requested respondents to add their narrative comments, which many did.

The survey instrument recognized that many respondents would have been treated in inpatient psychiatric settings more than once in the past and that their responses would represent a recollective perspective related to these admissions which may have involved multiple facilities. Thus, readers are cautioned to keep in mind that negative experiences at one psychiatric facility or during one admission may have overshadowed positive experiences at another, or vice versa, for some respondents.

The Respondents

The 1,040 respondents to the survey represented individuals who had attended a variety of different types of inpatient and outpatient service programs (Figure 2). While all of the individuals had been treated in an inpatient psychiatric facility sometime in the past, 41% reported that they had received inpatient treatment in the past two years in one or more psychiatric facilities.

Half of the respondents (54%) stated that during at least one of their inpatient psychiatric hospital stays they had been restrained or secluded. Analyses also showed that respondents who had been hospitalized in the past two years for their psychiatric condition were significantly more likely to have reported that they had been treated with restraints and seclusion than other respondents (62% versus 48%, $X^2 = 20.53$, df = 1, $p < .001$).[2]

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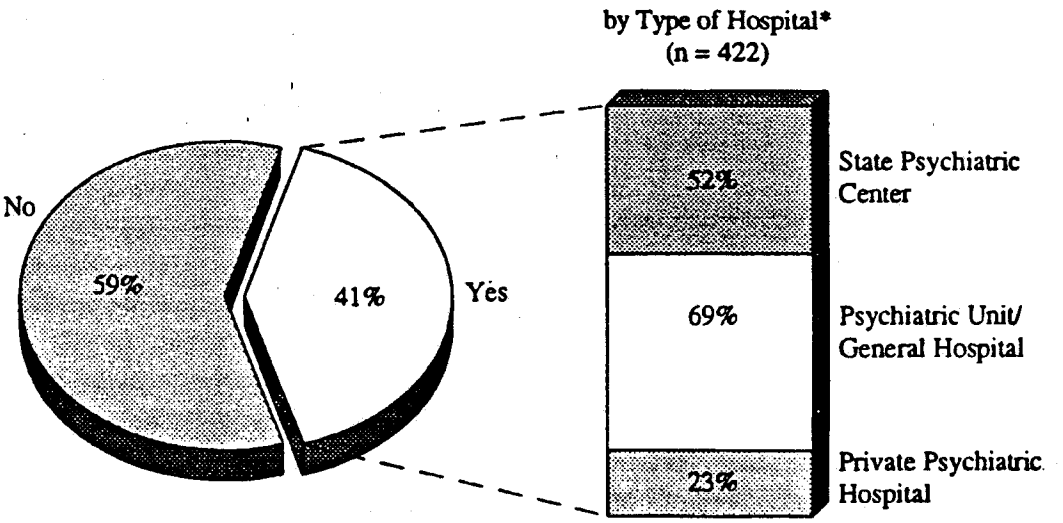
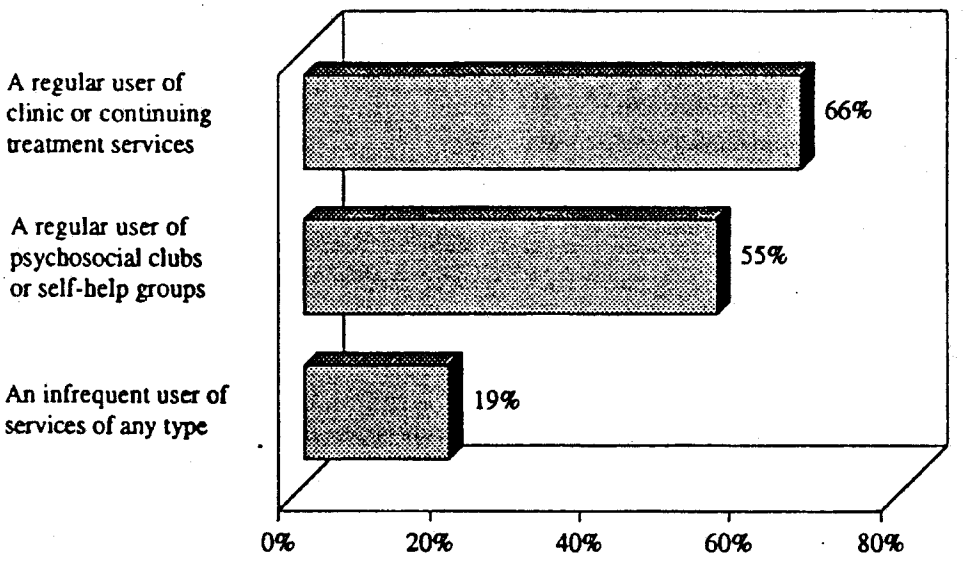
[2] This observation was consistent with the NYS Office of Mental Health's findings that the rate of restraint and seclusion use among state psychiatric centers had increased by 80% over the past eight years (*Report on the Task Force on Restraint and Seclusion*, NYS Office of Mental Health, 1994)

Figure 2
Profile of Respondents
(N = 1,040)

Hospitalized for a Psychiatric Condition in the Past Two Years



Types of Outpatient Services Used*



*Not mutually exclusive.

More than 80% of the respondents indicated that they were currently using some form of mental health outpatient or support group service, and 42% reported that they were regular users of at least two types of services. Two-thirds (66%) reported that they were regular users of mental health clinics or continuing day treatment programs; 55% reported that they were regular users of psychosocial clubs or support groups. Only 19% of the respondents reported that they were not currently using any mental health outpatient service.

In short, although survey respondents did not reflect a random sample, they did represent a large group of former patients with varied treatment backgrounds in assorted New York State inpatient psychiatric facilities. The 1,040 respondents also represented individuals currently using both traditional and nontraditional mental health outpatient services.

Chapter II
Patient Comments on Restraint and Seclusion Use

Of the 1,040 respondents to the Commission's survey, 560 or 54% reported that they had been restrained or secluded during an inpatient psychiatric hospital stay (Figure 3). Of these 560 respondents, 322 or 58% indicated that they had been *both* restrained and secluded; 136 or 24% indicated that they had only been secluded; and 102 or 18% indicated that they had only been restrained.

Of the respondents who stated they had been restrained (n = 424), most reported that they had been subject to one or more of four types of restraint: camisole (57%); vest, chair, or bed restraint (55%); 4-point restraint (49%); and/or full-sheet restraint (44%). Figure 4, on page 8, provides sketches of these various types of restraining devices, which are the most commonly used in New York psychiatric facilities.

Some Patients Valued Restraints and Seclusion

While almost all respondents (94%) who stated that they had been subjected to restraint or seclusion cited at least one complaint about its use or their care and treatment, it was noteworthy that a small percentage of respondents offered positive narrative comments

Figure 3
Percent of Respondents Placed in Restraint or Seclusion
(N = 1,040)

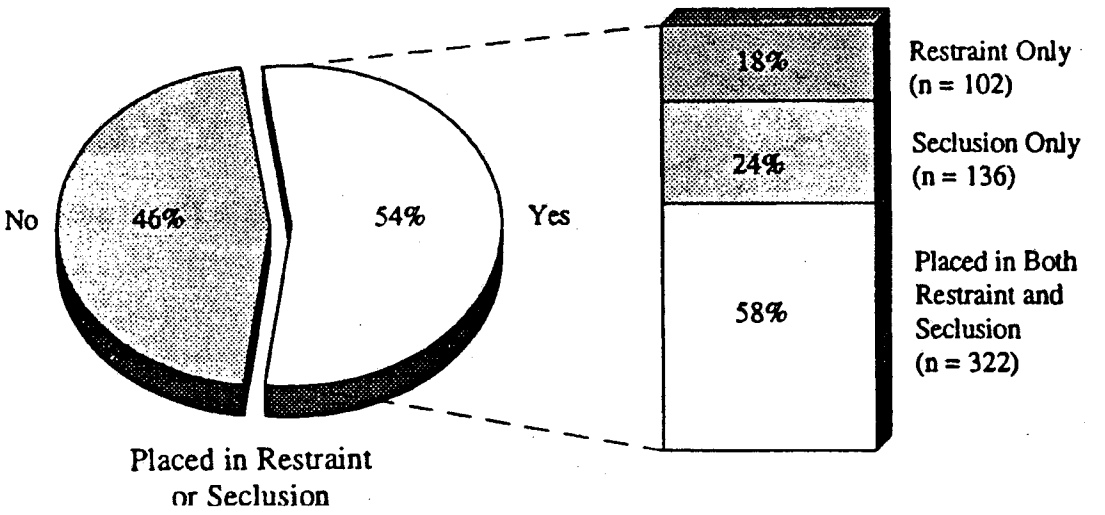
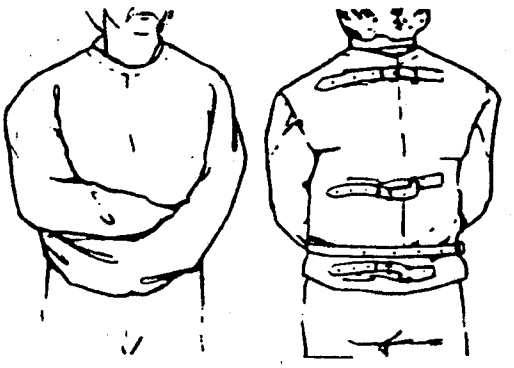
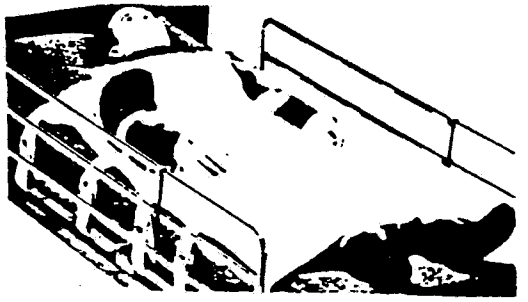


Figure 4
Commonly Used Mechanical Restraints



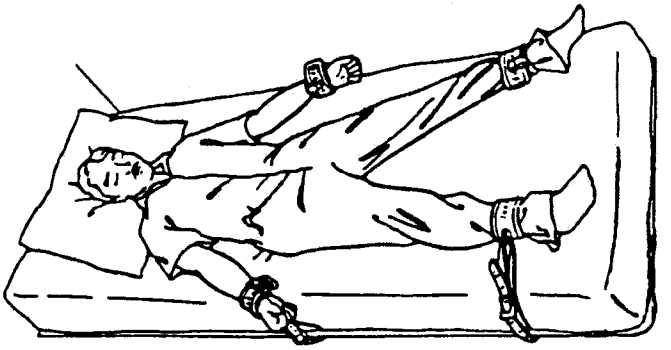
Camisole

Waist/Vest Restraint



Full Restraint Sheet

Chair Restraint



Four-Point Restraint

about their placement in restraints and seclusion. Although these respondents expressed their viewpoints differently, common themes in their remarks were that their behavior was dangerous, that they had been treated fairly, and that they benefited from the use of the interventions.

Positive Experiences with *Restraint and Seclusion*

"The restraints used afforded me safety from self-destructive behaviors and were applied with my comfort in mind."

"Most effective seclusion was at Marcy Psychiatric Center in 1984. Was offered voluntary seclusion with no locked door. The room was nicely painted and furnished. The therapy aide was attentive and kind."

"I felt that overall, I was treated fairly when I was put in restraints."

"When I [was] placed in seclusion, it was my own choice because I needed to feel safe."

"I was threatening others; out-of-control; I was not hurt; it helped me think about what I needed to do."

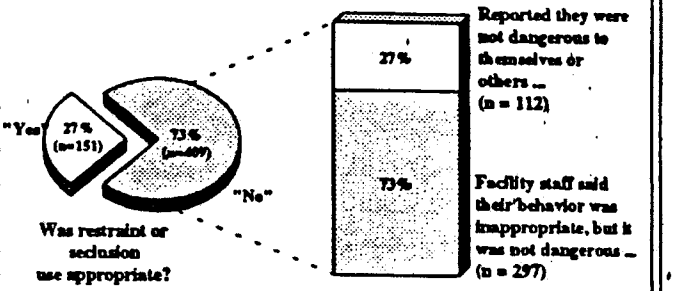
"Sometimes, a person needs to be tied down. Being restrained helps me stay alive."

"I appreciated it [seclusion] . . . I needed it to help me cope and relax myself."

Inappropriate Use of Restraint and Seclusion

The vast majority of the respondents, however, rated their restraint and seclusion experience negatively. And, negative narrative comments on respondents' restraint and seclusion experiences outnumbered positive comments by more than ten to one.

Figure 5
Percent of Respondents Stating Restraint/Seclusion Used Inappropriately
(N = 560)



Among the most prevalent comments of the respondents was that the reason they had been placed in restraint or seclusion was not compliant with NYS mental hygiene law and regulations, which specify that these interventions may only be used when an individual is dangerous to himself/herself or others. (Figure 5). Approximately three-fourths of the respondents (73%) stated that at the time the restraint or seclusion was instituted, they were not dangerous to themselves or others. Of these 409 respondents, 297 or 73%, reported that facility staff had said their behavior was inappropriate, but that their behavior was not dangerous. The remaining 112 respondents who reported that the use of restraint or seclusion was inappropriate simply self-reported that they were not dangerous at the time.

Narrative comments on the respondents' survey forms clarified that many believed that staff had acted precipitously in using restraints