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

Voices From the Front Line: Patients' Perspectives of Restraint and Seclusion Use

Clarence J. Sundram
CHAIRMAN

Elizabeth W. Stack
William P. Benjamin
COMMISSIONERS

September 1994

New York State Commission on Quality of Care
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 laws and regulations, and about the effects of being 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

Research Staff

Project Director

Nancy K. Ray, Ed.D.

Survey Coordinator

Karen J. Myers, M.H.S.A.

Statistical Analysis

Mark E. Rappaport, R.N., M.S.

Data Tabulation and Analysis

Jacqueline García, M.S.W.
Susan Sleasman
Rhonda Wallach

Production Staff

Gail P. Fetsko
Kathleen A. Runkle
Joyce A. Salazar

Chapter I
Introduction

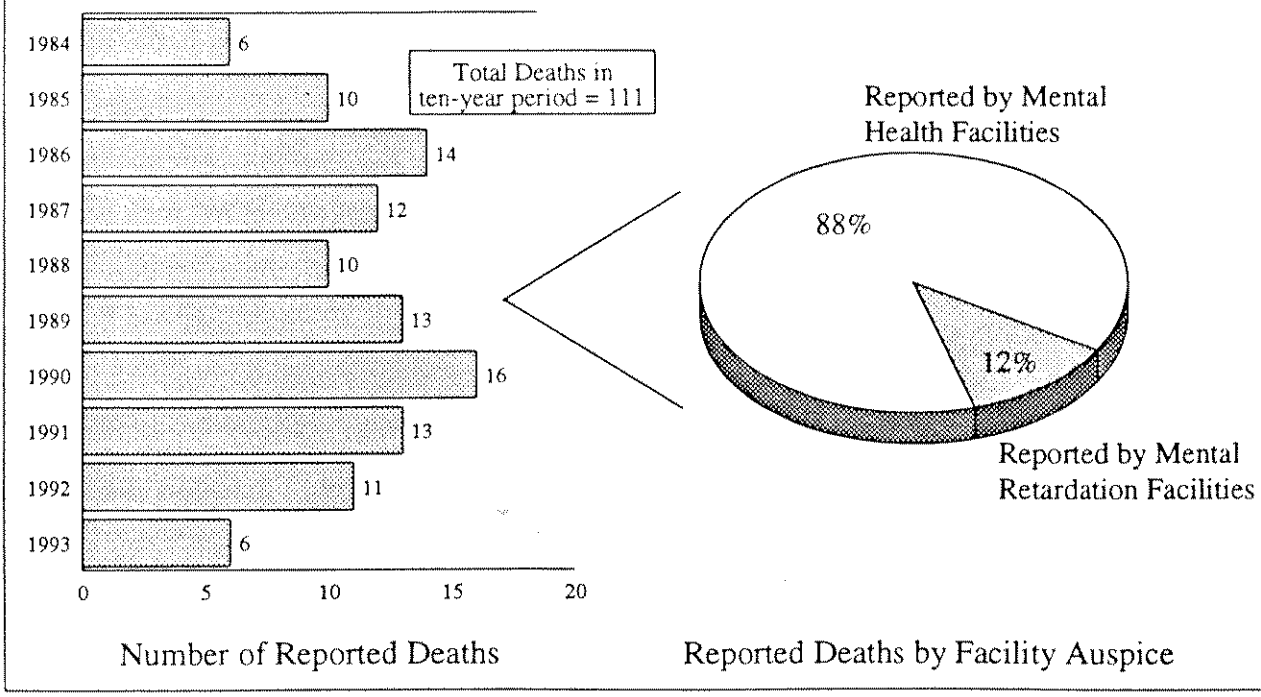
In Chapter 50 of the Laws of 1992, the State Legislature requested that the New York State Commission on Quality of Care conduct a review of the use of restraint and seclusion in the treatment of persons who are mentally disabled.

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 perspectives. 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

---

[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.

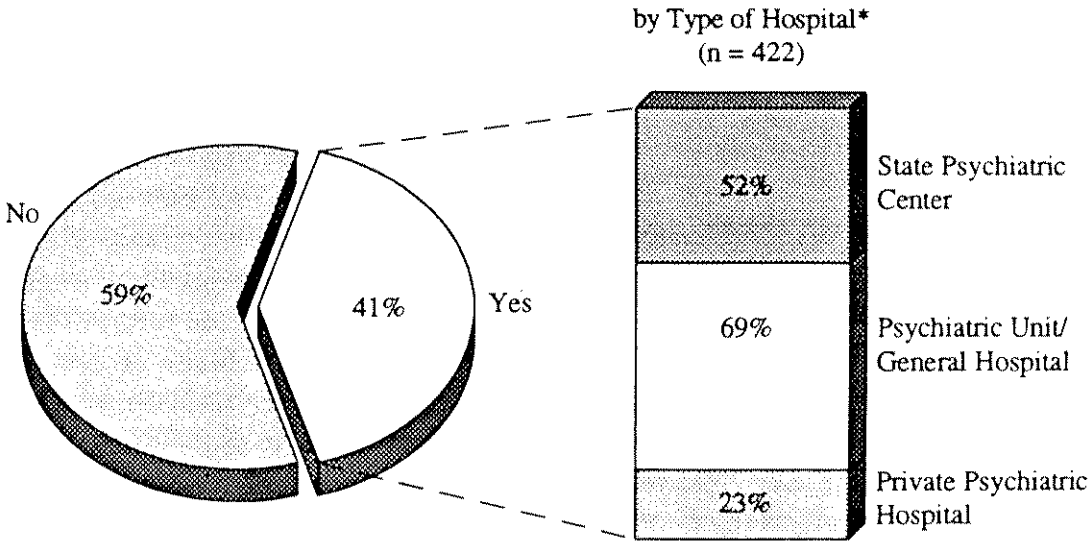
Half of the respondents (54%) stated that during at least one of their inpatient psychiatric hospital stays they had been restrained or secluded. Analyses also showed that respondents who had been hospitalized in the past two years for their psychiatric condition were significantly more likely to have 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]

---

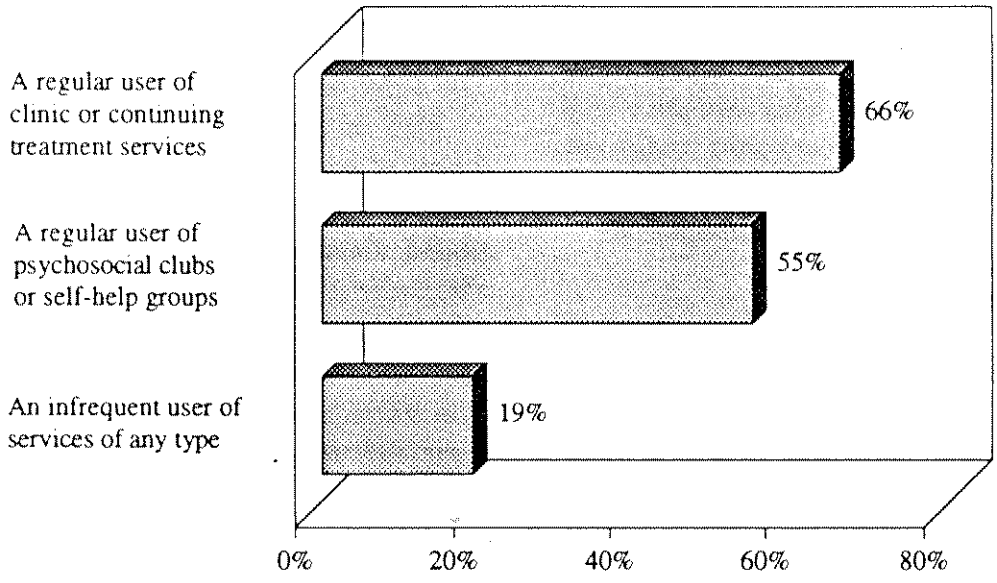
[2] This observation was consistent with the NYS Office of Mental Health's findings that the rate of restraint and seclusion use among state psychiatric centers had increased by 80% over the past eight years (*Report on the Task Force on Restraint and Seclusion*, NYS Office of Mental Health, 1994).

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)

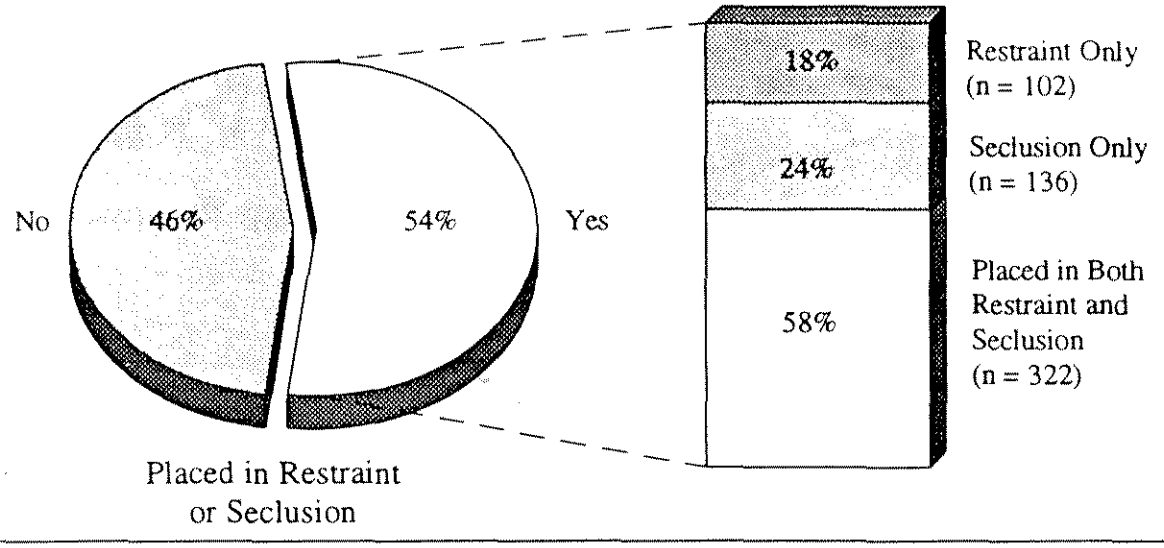
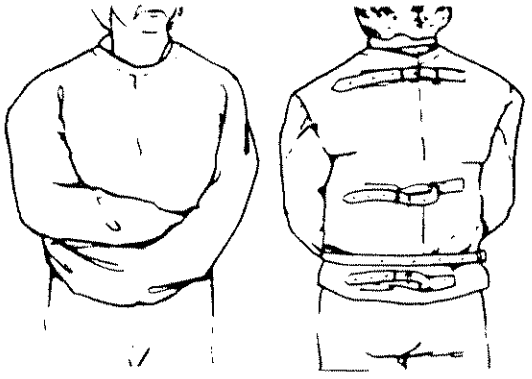
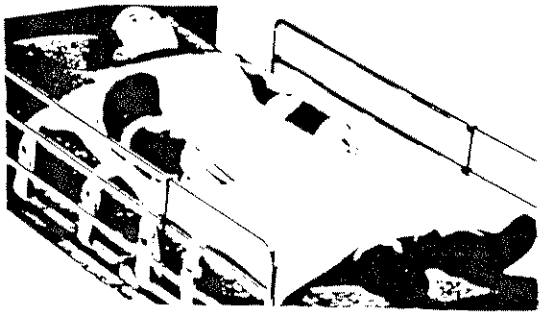


Figure 4
Commonly Used Mechanical Restraints



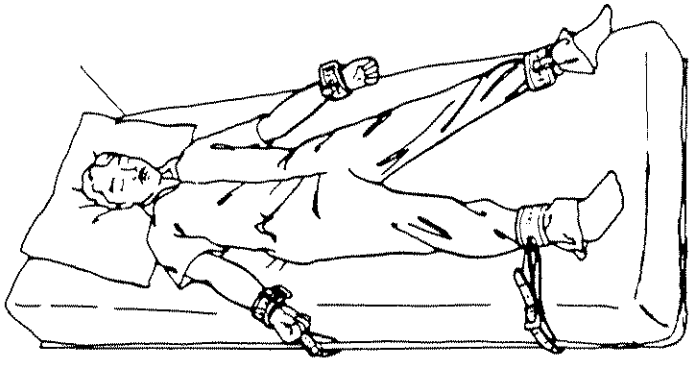
Camisole

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."

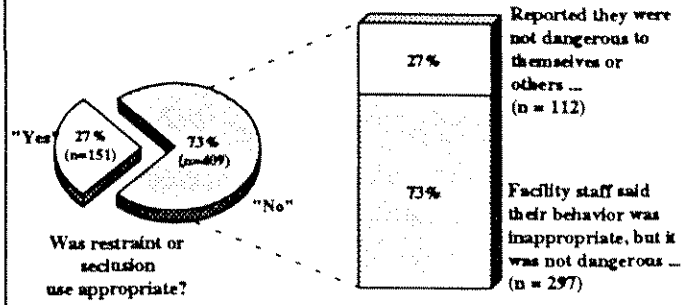
"Sometimes, a person needs to be tied down. Being restrained helps me stay alive."

"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

Complaints Regarding Use of Restraints and Seclusion

"Staff is quick to restrain people just to get them out of the way."

"Seclusion and restraint were used to intimidate and frighten and not for protection of patients and others."

"I was not told why or given an opportunity to object verbally [to restraint/seclusion] . . . it was out of my hands."

"I was, I still feel unfairly, put into restraints. I said I 'felt' like killing a staff person because of her terribly abusive treatment of me. Anyone would have 'felt' like killing her I believe."

"I wish people would have talked to me instead of restraining me."

"Locked in a room for 12 hours a day. Just sat and slept."

"The staff would pick fights with me because I was small and couldn't fight back and when I tried they would knock me down, and tie me up in a jacket."

"Treated cruelly and inappropriately -- locked in seclusion for no reason."

"[I] watched a doctor demand a patient to take meds and when she refused, he pushed her and when she fought back, he yelled to staff that she was becoming violent. Staff pushed her to the floor, injected her, and put her in seclusion."

"I was put in seclusion for no good reason. The staff would manipulate and provoke me to lock me up. I never bothered with anyone.

"I was put in seclusion for having a polite disagreement with staff."

"Told by staff if I didn't attend activities they chose for me, I would be put into seclusion."

"I was put in restraints without being told why."

"When I could not sleep, I was put in restraints and given a needle."

"At one point of my detention, I was restrained for asking for a cigarette."

or seclusion when they were upset or acting inappropriately. Others stated that restraints and seclusion were used as "punishment" for their refusal to take medications or to follow other staff directives.

Poor Monitoring of Patients' Conditions and Well-Being

The survey respondents who had been restrained or secluded were also generally critical of their treatment and care while they were subjected to these interventions. Over three-fourths of these 560 respondents (78%) reported that their care and treatment while being restrained or secluded was not compliant with at least one standard specified in NYS mental hygiene law or regulations. (Figure 6). Forty-six (46) percent reported that they were not examined by a physician; 58% said that they were not released and allowed to exercise every two hours; 46% said that they were not allowed to use the bathroom hourly; 38% said that they were not checked by staff every 30 minutes; and 34% said that they were not allowed to drink or eat at mealtimes. (See pages 18, 20, and 21 for a discussion of the influence of restraint and seclusion use and respondents' opinions of their overall hospital experiences.)

Figure 6
Percent of Respondents Citing Care and Treatment Complaints While in Restraint or Seclusion
(N = 560)

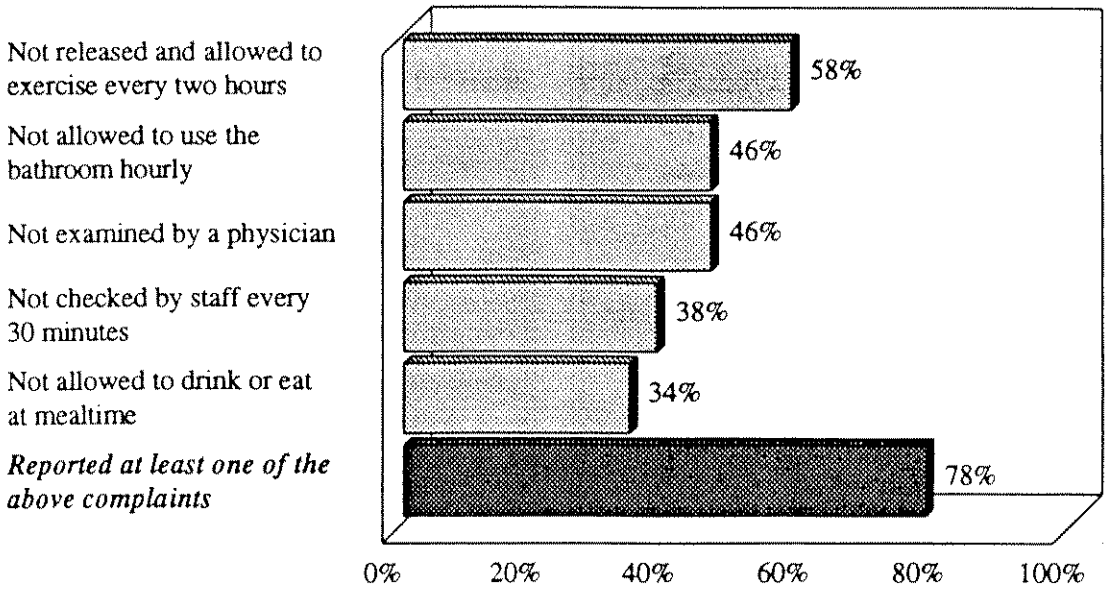
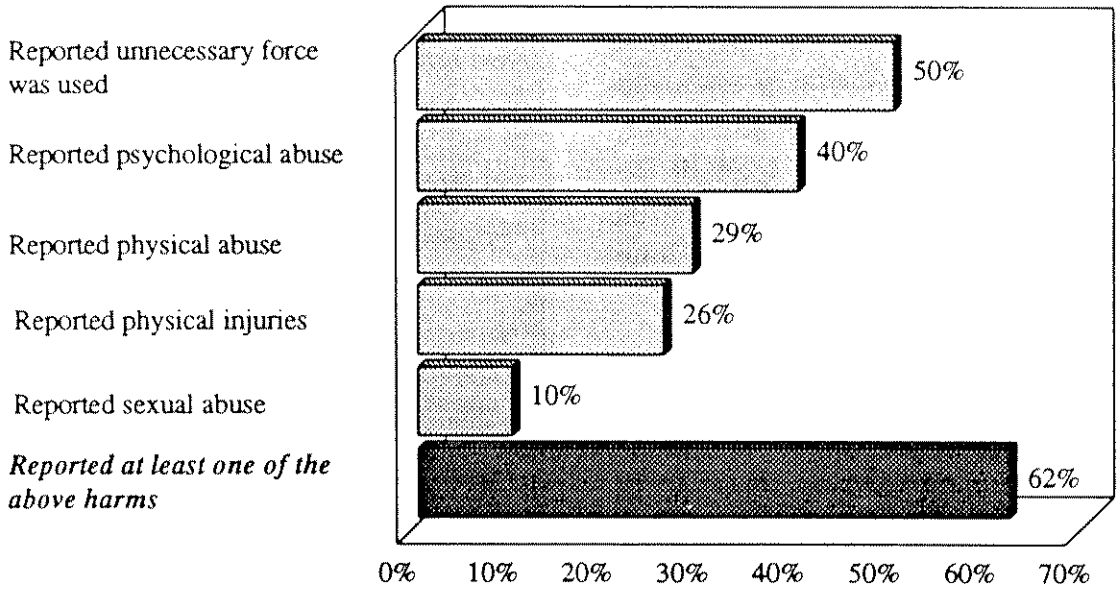


Figure 7
Percent of Respondents Alleging Abuse or Injury While in Restraint or Seclusion
(N = 560)



Improper Care While in Restraints and Seclusion

"I was placed in seclusion with only a mattress and no heat."

"Left in full sheet restraint for hours; no help for hours after request."

"No one checked on me [while I was in seclusion] and when I asked to go to the bathroom, I was told by staff they'll let me know when I can go."

"When I was in restraints and had to go to the bathroom, the staff would tell me that I couldn't go."

"When I was placed in seclusion I only had a mattress and the room had no heat."

"Put in restraints for 12 hours with only one time to go to the bathroom."

Again, the respondents' narrative comments gave a fuller picture. Many respondents complained of simply being ignored while they were in restraints or seclusion; others made specific complaints about not being periodically released from tight restraints or of not being allowed to go to the bathroom; some made specific mention of uncomfortably cold conditions in seclusion rooms. Many comments related to the duration of time the respondents spent in restraints or seclusion and their belief that the interventions had been employed for too long.

Allegations of Abuse and Mistreatment

The most serious respondent comments related to allegations of abuse and injury during the time spent in restraints and seclusion. In total, 62% of the 560 respondents who reported having been restrained or secluded stated that they were not protected from harm when these interventions were used (Figure 7). Half (50%) *alleged* that unnecessary force had been used by staff in placing them in restraints or seclusion; 40% *alleged* that they had been psychologically abused, ridiculed, or threatened; 29% *alleged* physical abuse; 26% *alleged* physical inju-

Allegations of Undue Force and Abuse

"While being in seclusion, the female nurse showed my breast to the male staff."

"In four points restraints the ties were so tight and painful that it cut off my circulation. I was left like this for 12 hours."

"Staff put a bag over my head during restraint/seclusion -- I passed out and went to sleep."

"I was brutally treated, had to sit in a corner up against the wall on a chair -- and not allowed to go to the bathroom. Lost consciousness while in a jacket and was gagging on my own saliva."

"Once when I was in restraints, a staff member was unnecessarily sadistic . . . I think he had no concept of restraints as being a medical tool. I would like to see staff taught that acting out is sometimes part of sickness and not necessarily 'being bad.'"

"Stripped naked and placed in seclusion room."

"A huge male nurse and two female aides grabbed me and manhandled me. I was called a 'piece of shit' and 'white bitch' . . . it was below 32 degrees in that room."

"I was put in observation and a staff member abused me."

Figure 8
Influence of Less Restrictive Interventions on Perceptions of Restraint/Seclusion Use
(n = 499)*

	Respondents Reporting:	
	Use of Less Restrictive Interventions (n = 236)	***No Use of Less Restrictive Interventions (n = 263)***
Reported 4 or more complaints about restraint/seclusion use	49%	92%
Reported physical abuse while restrained or secluded	20%	41%
Reported psychological abuse while restrained or secluded	26%	58%
Reported physical injuries	20%	35%

*Eleven (11) percent of respondents reporting restraint and/or seclusion use did not respond to the item related to less restrictive interventions.

ries; and 10% *alleged* sexual abuse. Written statements by respondents detailed their specific complaints. Many respondents wrote at length about what had happened to them, their fear for their safety, and their distressing memories about their experiences.

As is true for the other respondent comments on the survey, these allegations have neither been investigated nor sustained by the Commission — thus, they reflect only the respondents' perspective of what happened, not necessarily what actually happened. Notwithstanding this limitation, however, it is noteworthy that so many individuals who responded to the Commission's survey had negative recollections of their restraint and seclusion experiences and that they took the time to discuss these perceptions in some detail on their completed surveys.

Affirmation of the Importance of Less Restrictive Interventions

The Commission also asked respondents to comment on their perceptions of whether less restrictive interventions had been tried prior to the use of restraint and seclusion. This item was phrased, "Before hospital staff put me in restraints or seclusion, someone tried to calm me down or resolve my problem." Of the 560 respondents who had been restrained or secluded, 47% reported that this statement was false, while 42% reported that this state-

Negative Remembrances of Restraint and Seclusion

"[I had] numerous experiences with restraints, most of which I believe were unnecessary and far too long in duration. It is painful to even write about this experience."

"They locked me up to the point that I felt like suicide."

"I did not like being tied up. I felt like an animal."

"It was very scary to be in restraints."

"When admitted to the hospital, I felt unsafe at first, because of the method of restraint and lack of concern for my body. I felt it was not necessary."

"I was only 9 years old and I was never scared of adults (before this)."

ment was true. Eleven (11) percent did not respond to this survey item.

Further analysis revealed that respondents' answers to this single item were strongly predictive of their responses to the other restraint and seclusion items on the survey. It appeared that, although respondents who had been restrained or secluded usually had some negative memories of the experience, those who believed that staff had made some earnest efforts to deal with their behavior or distress in a less restrictive manner felt significantly more positive about the experience (Figure 8). On all but *one* of the restraint- and seclusion-related items on the survey, these respondents offered more positive overall assessments than the respondents who did not report that less restrictive interventions had been attempted by staff. Other statistically significant differences were also noted between these two groups of respondents.

- While virtually all respondents (94%) reported at least one complaint about their placement in restraints or seclusion, respondents who reported that staff had attempted less restrictive interventions were significantly *less likely* than other respondents to have expressed four or more complaints (49% versus 92%; $X^2 = 152.28$, df = 2, $p < .001$).
- These respondents were also significantly *less likely* than other respondents (who did not report that less restrictive interventions had been tried) to have reported the most egregious complaints about their experiences being restrained or secluded, including physical abuse (20% versus 41%; $X^2 = 27.28$, df = 2, $p < .001$), psychological abuse (26% versus 58%; $X^2 = 50.83$, df = 2, $p < .001$), or physical injuries (20% versus 35%; $X^2 = 14.50$, df = 2, $p < .001$).

Chapter III
Patient Comments on Inpatient Treatment

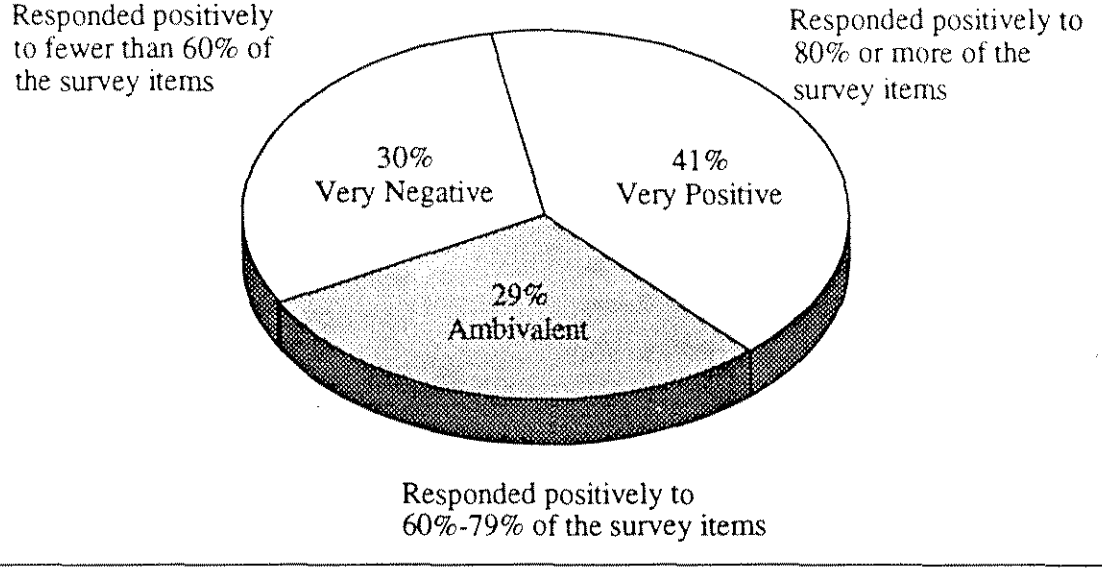
All 1,040 respondents — those who had and those who had not experienced restraint or seclusion — responded to the 36 true/false survey items assessing their opinions of their overall inpatient care and treatment. These 36 items covered a wide range of issues about the respondents' psychiatric hospitalizations. Items related to basic custodial care services (e.g., food, clothing, personal hygiene), assurance of basic rights (e.g., access to mail services, telephone, religious services, outdoors, legal advocates), protection from harm issues, and the extent to which individuals had been informed about and involved in their treatment and discharge planning.

Overall Findings

Forty-one (41) percent of the respondents gave very positive overall assessments, answering positively to at least 80% of the survey items assessing their inpatient care and treatment (Figure 9). Many of these respondents commented about their positive experiences at specific psychiatric facilities, and most related the positive qualities of their treatment to the caring and respect of individual staff members.

In contrast, slightly less than one-third of the respondents (30%) gave a failing grade to their treatment in inpatient settings, answering posi-

Figure 9
Respondents' Overall Ratings of Inpatient Psychiatric Treatment
(N = 1,040)



tively to fewer than 60% or fewer of the items. Comments on these survey forms varied, but there was a constancy to the respondents' concerns about their safety and well-being, their feelings that staff did not care about them and ignored their concerns, and their allegations that their basic dignity and privacy had been violated.

Areas with More Positive Responses

Further analyses of the respondents' ratings indicated that they tended to give the most positive assessments to items assessing certain personal liberties (e.g., communication and visitation rights), custodial care services (e.g., provision of personal hygiene supplies and clothing), and protection from the most egregious staff abuse (e.g., sexual and physical abuse). For example, more than three of every four respondents indicated on the survey that:

- they could make and receive telephone calls (87% and 82%, respectively);
- they could have visitors (84%);
- staff did not read their mail (78%);
- they had appropriate bathroom supplies and personal clothing (85% and 79%, respectively); and
- staff did not hit them or ask them or others for sexual favors (79% and 85%, respectively).

Areas With More Negative Responses

In contrast, at least one of every three respondents answered negatively to other items related to these basic personal liberties and safety, stating that:

- they did not feel safe (35%);
- they could not exercise three times a week (37%);
- their things were stolen or taken away (39%);
- staff yelled at them or other patients (43%); and
- they could not go outdoors daily (46%).

As a group, however, the respondents gave the most negative responses to items which related their assessment of treatment activities and their involvement and role in treatment planning, medication decisions, and discharge planning. At least one-fourth of the respondents answered negatively (false) to each of the 11 true/false survey items related to these issues, and one-third to one-half of the respondents answered negatively to 6 of these 11 items (Figure 10).

Further analysis indicated that, in this treatment arena, the respondents were most likely to be positive about the treatment itself. Seventy (70) percent of the respondents stated that inpatient staff helped them with problems or questions about their treatment, and 67% reported that the activities and groups on the inpatient unit helped them to get better.

In contrast, when offering negative comments the respondents were the most likely to be negative about their involvement in treatment planning. Respondents tended to be the most critical of their exclusion from decision-making and information related to psychotropic medications.

- 34% of the respondents stated that staff did not listen to their concerns, if they objected to their treatment;
- 35% of the respondents stated that they were not given choices about the activities they attended;
- 36% stated that staff had not explained reasons for treatment and medication changes to them;

For Many the Hospital Experience Was a Good One

"Staff were friendly, dedicated, excellent, professional."

"Hospital was good; helps us get well."

"State hospital was open to my thoughts at all times and all of my requests were met."

"I received a lot of attention and I needed it at the time. In retrospect, and even at the time, I know they were trying to help me."

"The care I received at Four Winds (Saratoga) was a welcoming change after spending time in both state and general [hospital] psychiatric units. I was treated with respect and left with my dignity."

"Nurses were excellent."

"Staff gave me a chance to understand my condition."

"I feel my stay at Strong Memorial was excellent and needed. It did a world of good. The staff was very good to me. I also think it is a good place for long-term care. I was there for 12 days."

"I was not in good enough shape to participate in activities but they were available to me. I had excellent care, a good doctor, and a successful stay. I was well enough to go home in a week."

"What really helped during my stay was a group session with Dr. _____. It helped me realize that I could function more than I thought I could."

"I was treated very well during my stay at Central Islip Hospital."

"Staff at Mercy Care were great."

"The staff concern for me was for my own safety and to soon get well and get a job."

"The best encouragement of the hospital approximately six years ago was a workshop I attended on the grounds."

"I liked being hospitalized at Rochester General."

"I found the staff at both Benjamin Psychiatric Recovery Center and Clifton Springs Hospital very understanding and helpful."

"Unlike people I know, my experience was hopeful and helpful."

"Upstate Hospital in Syracuse is very good."

"I was treated very well and felt safe in the hospital."

"The staff were supportive. I got every chance to exercise."

"Direct care staff were caring and hard-working."

"Stay was good (St. Vincent's)."

"Activities were excellent."

"I feel the staff and the doctors were perfect."

"Staff talked to me about problems; gave me correct medication care."

"The last hospitalization in 1990 was excellent . . . not like the other hospitals."

"During my stay on the unit, I gained weight and felt pretty safe."

"The staff were really supportive."

"I was fairly treated."

"Treated well -- not kept too long; not discharged too soon."

Figure 10
Respondents' Assessments of Treatment and Their Involvement in Treatment Decisions*
(N = 1,040)

False		*True*
25%	Medications were not used as punishment	71%
26%	Staff helped with problem or question about treatment	70%
26%	Staff explained why and how privileges could be regained, if lost	62%
29%	I was told what I needed to do to leave the hospital	66%
30%	I felt the activities/groups helped me get better	67%
34%	If I objected to my treatment, staff listened to my concerns	58%
35%	I was given choices about the activities I attended	62%
36%	Staff explained reasons for treatment or medication changes	59%
39%	The purpose and side effects of my medications were explained to me	57%
42%	I helped choose my treatment goals	53%
51%	I could say "no" to medications and staff would respect my decisions	44%

*The sum of true and false responses does not equal 100%, as some respondents did not answer all items.

- 39% of the respondents stated that purpose and side effects of their medications were not explained to them;
- 42% of the respondents stated that they had not helped in choosing their treatment goals; and
- 51% stated that if they said "no" to medications, staff would not respect their decisions.

Influence of Restraint and Seclusion Experiences

Further analysis showed that respondents who had *not* been restrained or secluded were significantly more likely to offer very positive assessments about their inpatient psychiatric treatment than other respondents who had been restrained or secluded. Over half (53%) of the respondents who had *not* been restrained or secluded gave positive responses to at least 80% of the 36 items assessing their care and treatment (Figure 11). In contrast, slightly fewer than one-third (32%) of the respondents who had been restrained or secluded offered such positive overall assessments ($X^2 = 51.32$, df = 2, $p < .001$).

The analysis also showed that respondents who had been restrained or secluded were also twice as likely as other respondents to have given a very negative overall assessment of their inpatient care. As shown in Figure 11, 40% of these respondents answered positively to fewer than 60% of the survey items, compared to only 19% of other respondents who had not been restrained or secluded ($X^2 = 59.63$, df = 2, $p < .001$).

In short, restraint and seclusion use was associated both with less likelihood that respondents remembered their inpatient treatment as an overall positive experience *and with greater likelihood that they remembered it as a distinctly negative experience.*

Respondents Complaints About Hospital Stays

Being Ignored Can Be Bad Enough

"While I experienced staff as non-abusive and reasonably respectful, they were very much detached and I had no personal contact of any meaningful kind with them. I was scared and would have liked someone to take the time to talk with me about what was happening."

"Staff didn't tell you things that they certainly should know and could have told you."

"Very depressed when I left the hospital, they acted like they wanted me to go whether I felt safe or not."

"You could never find a doctor or someone to talk to when you needed to. The staff was usually behind the desk doing paperwork. I found that I get better treatment in the clinic."

"The therapy aides watched TV or read ... very little positive interaction with patients."

Privacy Violations

"They made me do a strip search, naked."

"Can't be alone in the bathroom."

"Anyone on the ward can look at you in the shower."

"[I] didn't need to be nude to be inspected. I felt like I was in jail and did something wrong."

"It was difficult to have privacy with visitors, because there wasn't sufficient space available."

"After restraints were removed, I was put in seclusion. My clothes were taken away ... what purpose does that serve?"

"[My] privacy was invaded."

"My person [body] and possessions were searched several times in an abusive manner."

"Visitors do not have privacy."

Complaints of Boredom and Being Kept Inside

"No outdoor activities at any time."

". . . Psychiatric Center had no activities except in the summer."

"No outside walks for clients."

"They never let me outside to exercise and to get fresh air."

"There were almost no activities in the hospital."

"Funding too low; can't hire enough staff to take patients on walks or recreation."

"Felt like I was in jail -- could not go outside."

"Did not go outside from day of admission to day of discharge."

Staff Ridicule & Verbal Abuse Alleged

"During my time of stress and anxiety, no one would see me to talk. They yelled at me and provoked escalation."

"I was yelled at for crying. I was depressed and I cried"

"Patients were often laughed at, teased, made fun of .... I could not find out what I needed to do to leave."

"A therapy aide told the patients that they were 'scum of the earth.' I never felt so degraded."

"Staff laughed at me and ridiculed me alot. When that happened I started thinking about how I couldn't wait to get out so I could commit suicide."

"A nurse told me I was not wanted because I was retarded and if I wanted to kill myself I should and [she] showed me where I could cut myself with a razor .

Figure 11
Influence of Restraint and Seclusion on Respondents' Overall Assessments of Inpatient Psychiatric Treatment
(N = 1,040)

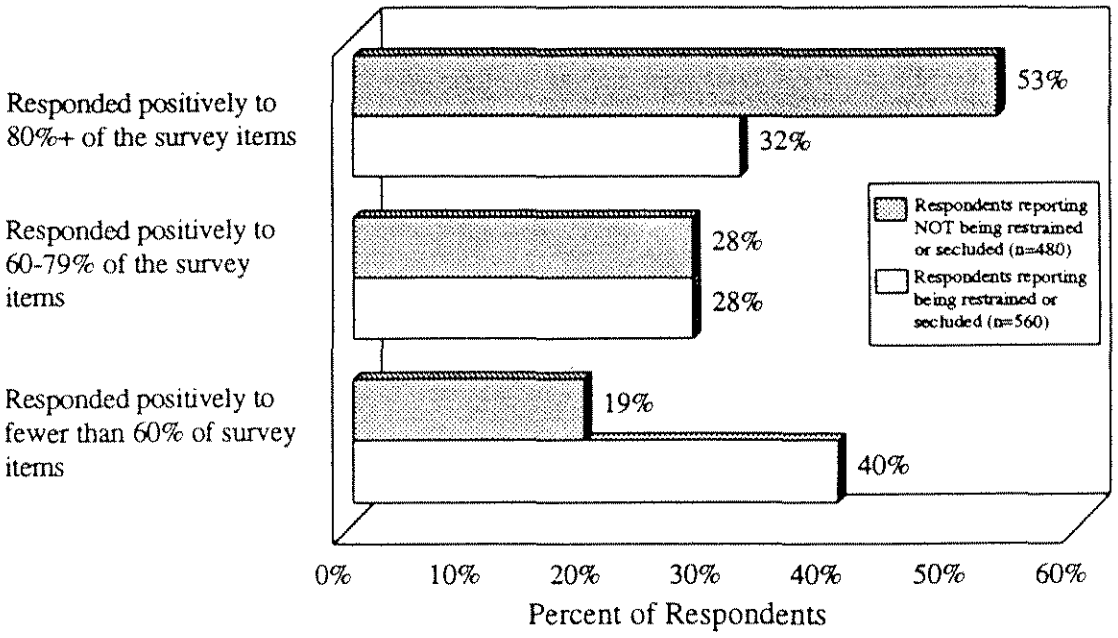
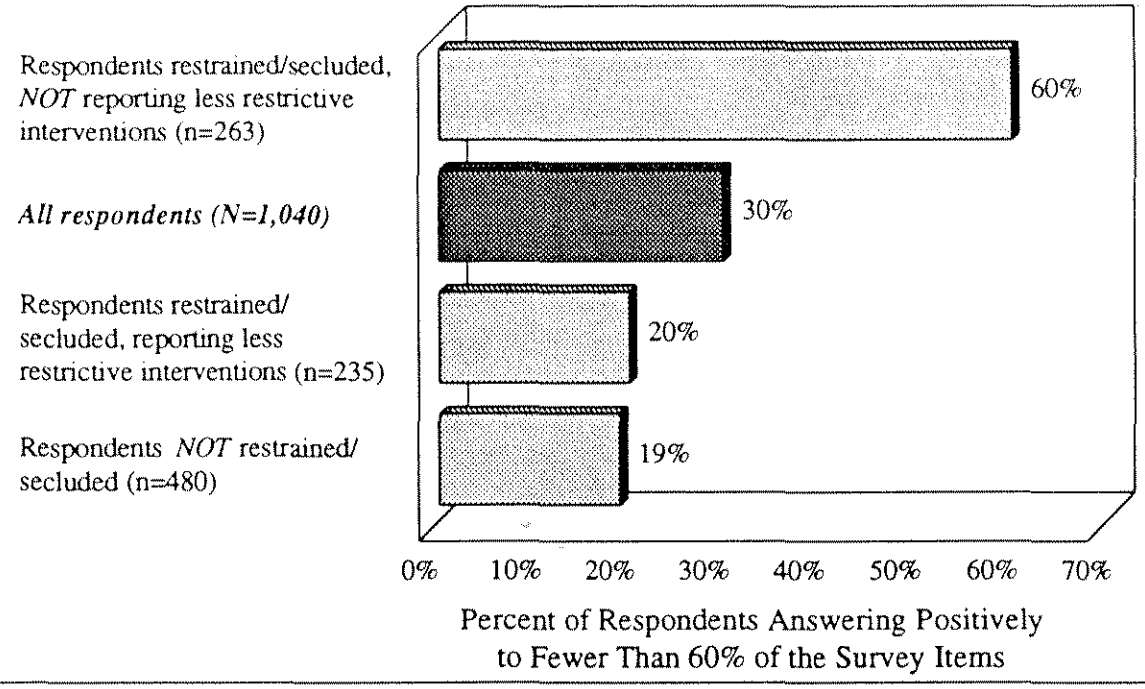


Figure 12
Percent of Respondents Offering Overall Negative Ratings of Inpatient Psychiatric Treatment



More Affirmation of Less Restrictive Interventions

As the Commission studied the surveys of respondents who had been restrained and secluded more carefully, an additional finding surfaced which provided support of the importance of the use of less restrictive interventions prior to the use of restraint and seclusion. Analyses showed that the negative halo effect of restraint and seclusion use on respondents' overall recollections of their psychiatric hospitalization was almost fully attributable to respondents *who also reported no staff efforts to calm them down or resolve their problems prior to the use of restraint or seclusion* (Figure 12).

In total, 42% of the respondents reported that less restrictive interventions had been tried prior to their placement in restraints or seclusion, while 47% responded that they had not been. Sixty (60) percent of the individuals reporting *no use* of less restrictive interventions prior to restraint or seclusion gave a failing grade regarding their care or treatment on inpatient psychiatric units. In contrast, only 20% of the individuals who had been restrained and secluded *but who reported staff use of less restrictive interventions* — gave such a failing grade. Notably, almost the same percentage of respondents who were not restrained or secluded — 19% — gave a similar rating.

Thus, while it appeared that restraint and seclusion use adversely influenced respondents' overall assessments of their inpatient care and treatment, it also seemed that the negative influence of restraint and seclusion was markedly less for respondents who believed staff had tried less restrictive interventions to calm them down or solve their problems prior to the use of these interventions. This finding adds further empirical confirmation of the importance of hospital staff's explicit use of less restrictive interventions prior to resorting to restraint and seclusion.

Complaints About Medications...

"I was given medication and no explanation was given to me about why or what it was for."

"If I said no to medication, they would have threatened me with an injection."

"Doctors only have time to work on meds and meds don't work for everybody."

"I was forced to take the medication. The medication gave me lots of side effects. I repeatedly asked the doctor to take me off the medication, but he continued to refuse."

"[I] was not told side effects of meds."

"My backside was completely abscessed from injections."

"[I was] medicated over objection; [my] right to refuse medication was not respected."

"If you refused to take medication you were restrained to the bed or put in a straight jacket till they figured you were ready to be released."

"[I] was not told why I was on prescribed meds."

"They didn't give you any freedom of choice in choosing medication."

"Couldn't object to medication or [you were] put in restraint or seclusion."

"If I tried to refuse my medications, I knew they would not let me out of the hospital."

"Meds were used (once) as a disciplinary measure."

Chapter IV
Conclusions and Recommendations

Research reports documenting the perspectives of former psychiatric patients have not received great credence in the psychiatric literature. Nowhere is this observation more prevalent than in research on restraint and seclusion. Although clinical researchers have devoted volumes to these subjects, surveys of former or current patients' perspectives are few.

As the Commission has informally shared its survey findings, it has also heard reservations about their reliability. Some have questioned the ability of the respondents, due to their mental illness, to report accurately; others have doubted their good intentions to report honestly.

As governmental services are increasingly attempting to incorporate "customer satisfaction" into their processes for evaluating quality of services, we cannot simply dismiss as irrelevant, ignorant, or invalid the opinions of over 1,000 "customers" of psychiatric hospitals.

The Commission concurs that one cannot assume that all that was reported on the returned surveys is accurate or that the respondents' answers and comments necessarily reflect a complete portrayal of what actually occurred during their hospitalizations. At the same time, however, the Commission does believe that as governmental services are increasingly attempting to incorporate "customer satisfaction" into their processes for evaluating quality of services, we cannot simply dismiss as irrelevant, ignorant, or invalid the opinions of over 1000 "customers" of psychiatric hospitals.

For all of us, our memories are not perfect reflections of our experiences, but they are what stay with us, and they do shape our future perspectives, beliefs, and behaviors.

For all of us, our memories are not perfect reflections of our experiences, but they are what stay with us, and they do shape our future perspectives, beliefs, and behaviors. As such, these opinions of former patients are, in fact, very important to hospital administrators and staff as they seek to better meet the needs of their patients in the future.

The response of 1,040 respondents to this survey told us much about what a large sample of persons with serious mental illness think about their psychiatric hospital stays and the care and treatment that they received.

Many Respondents Offered Positive Comments

First and foremost, the findings dispelled the myth that most persons with serious mental illness have very negative belief sets regarding the value and quality of their inpatient hospitalizations. To the contrary, 41% of the respondents offered very positive overall assessments of their hospital experiences. Additionally, the respondents offering positive perceptions of their

hospital stays well-documented that their positive recollections could be directly attributed to hospital staff's concern, help, protection, and respect for them as individuals. None of these respondents attributed the positive assessments of their hospitalizations to miracle cures; they seemed to acknowledge the limitations of current treatments for serious mental illness. What they deeply appreciated was the caring and responsive environment that the hospital staff offered them to recover from their acute symptoms.

None of the respondents attributed the positive assessments of their hospitalizations to miracle cures. What they deeply appreciated was the caring and responsive environment that the hospital staff offered them.

The Respondents Were Discriminating Critics

The range of the responses to the different survey items also suggested that former patients of psychiatric facilities are discriminating raters of the care and treatment that they received. In this regard, the survey findings offered insights to the aspects of inpatient psychiatric treatment which respondents generally regarded positively and those which they generally regarded negatively.

Three-fourths of the respondents indicated that most aspects of their basic custodial care in the hospital was good, that they were afforded personal liberties such as use of the telephone and the mail, and that they were not subjected to physical or sexual assaults by staff. Simultaneously, however, at least one-third of the respondents were critical of other aspects of their daily care and protection while in the hospital, stating that:

- they did not feel safe (35%);
- they could not exercise three times a week (37%);
- their things were stolen or taken away (39%);
- staff yelled at them or other patients (43%); and
- they could not go outside daily (46%).

Three-fourths of the respondents indicated that most aspects of their basic custodial care in the hospital was good, that they were afforded personal liberties, and that they were not subjected to physical or sexual assaults by staff.

Many Respondents Felt Excluded From Treatment Decision-Making

The most negative assessments overall were given to items related to the individual's assessment of his/her clinical treatment and his/her involvement in treatment decision-making, especially treatment decisions related to medications. It was clear, both from the respondents' ratings of these survey items and from their narrative comments, that many individuals who had received treatment in New York's psychiatric facilities were dissatisfied with their limited participation in the treatment process.

The negative comments related to these survey items indicated that hospital staff's responsiveness to patients' concerns, fears, questions, and preferences was a critical factor in the respondents' overall assessments of their hospital care and treatment. These findings suggest

that psychiatric facilities should focus more on staff attitudes and behaviors which reflect patient-centered values. Specifically, encouraging staff to show empathy for patients' feelings, to provide time to listen to their concerns, and to demonstrate a willingness to be flexible and responsive in addressing patient concerns may do more toward motivating individuals with serious mental illness to accept treatment that they may need than any number of changes in mental health law on involuntary treatment.

It was clear that many individuals who had received treatment in New York's psychiatric facilities were dissatisfied with their limited participation in the treatment process.

Negative Perceptions of Restraint and Seclusion

The analyses also showed that the vast majority of respondents who had been restrained or secluded during a psychiatric hospitalization were critical of the use of these interventions — with 94% raising at least one complaint about the use of these interventions or their monitoring while subjected to them. In total, approximately three-fourths of the respondents who had been restrained or secluded believed that the use of these interventions was not justified and/or that they had not been appropriately monitored while in restraint and seclusion. Most seriously, 62% believed that they had not been protected from harm while placed in restraints or seclusion.

Further analysis indicated that respondents who had been restrained or secluded during their psychiatric hospital stay were significantly more likely than other respondents to provide negative assessments of their inpatient care and treatment. Twice as many of these respondents (40% versus 19%) gave very negative overall assessments of their inpatient care and treatment.

These assessments of restraint and seclusion use, together with their apparent influence on the individual's overall assessment of their hospital experience, suggest that use of these interventions warrant very careful evaluation and attention by psychiatric facility administrators and staff. Although the survey respondents were not a random sample, the sheer number of these former patients reporting negative opinions of practices regarding restraint and seclusion is a cause for concern. Despite the safeguards put in place by the Legislature and the Office of Mental Health, the fact that the respondents nevertheless report in large numbers the misuse of restraints and seclusion, as well as some abusive practices, should prompt a reexamination of the standards and practices.

Hospital staff's responsiveness to patients was a critical factor in the respondents' overall assessments of their hospital care and treatment.

Endorsement of the Use of Less Restrictive Interventions

Beyond these findings was the unexpected affirmation of the clinical importance of staff's use of less restrictive interventions in mitigating patients' more negative perceptions of restraint and seclusion experiences. Although most respondents clearly had negative remembrances of their restraint and seclusion experiences, respondents who believed that staff had first tried to calm them down or to resolve their problem in another manner *before using restraint or seclusion* — were much more positive about these experiences, and more likely to agree that such interventions were necessary.

Respondents who believed that staff had first tried to calm them down or to resolve their problem in another manner before using restraint or seclusion—were much more positive about their experiences, and more likely to agree with staff's assessment that such interventions were necessary.

While virtually all respondents (94%) indicated at least one complaint about restraint or seclusion use, respondents who reported that staff had attempted less restrictive interventions were significantly *less likely* than other respondents to offer as many or as serious complaints and allegations regarding restraint and seclusion use. Additionally, while the Commission found that restraint and seclusion use tended to be associated with more negative overall assessments of inpatient care and treatment by the respondents, it also found that this finding was largely attributable to the assessments of respondents who believed restraints and seclusion had been employed *without staff first trying these less restrictive interventions.*

Recommendations

The voices of the individuals who have used psychiatric services raised in this report have important implications for the ongoing administration and quality assurance activities of psychiatric services and facilities and the NYS Office of Mental Health.

First, the respondents' answers and comments clearly identify those aspects of inpatient psychiatric treatment settings with which consumers are most often satisfied and most often dissatisfied. While these aggregate findings do not reflect conditions and services on all psychiatric services, they do provide a useful framework for psychiatric administrators in tailoring quality assurance activities for their own programs. Additionally, sharing this survey's findings with program staff may serve as a helpful reinforcement of management's insistence on a patient-centered focus to inpatient treatment and pursuit of customer satisfaction.

Second, the survey's findings confirm that former patients are a rich source of information about the care and treatment offered by inpatient psychiatric treatment settings, and they support the importance of efforts by psychiatric facilities in surveying their consumers' satisfaction. In these efforts, the Commission recommends that administrators work more closely with consumer advocacy groups. These groups provided the Commission invaluable advice. For example, they strongly advised against any surveying of individuals while they were still patients or even at the point of their discharge; they recommended that the survey form collect minimal demographic information as many individuals are uncomfortable with these questions; and they correctly focused us on basic and concrete aspects of care and treatment (e.g., physical safety, personal respect, basic liberties, informed consent and involvement in treatment decision-making, medication practices, and restraint and seclusion use).

The survey's findings confirm that former patients are a rich source of information about the care and treatment offered by inpatient psychiatric treatment settings, and they support the importance of efforts by psychiatric facilities in surveying their customers' satisfaction.

Third, and most central to the primary purpose of the survey, the respondents' comments

Very few of the respondents reported positive perceptions of these interventions. Indeed, the major difference among survey respondents was not in how they viewed restraint and seclusion, but in how negatively they viewed them.

strongly support quality assurance efforts by individual psychiatric facilities and services and the NYS Office of Mental Health to reduce the unnecessary use of restraint and seclusion in inpatient psychiatric care. Clearly, for most individuals, placement in restraint and seclusion while on an inpatient psychiatric unit is viewed negatively, sometimes as harsh punishment and sometimes as overt staff abuse. Very few of the respondents reported positive perceptions of these interventions as protective or therapeutic. Indeed, the major difference among survey respondents was not in how they viewed restraint and seclusion, but in *how negatively* they viewed them.

These findings take on special meaning as one recognizes that usage rates for restraint and seclusion among inpatient psychiatric settings in New York vary dramatically -- from many facilities which do not use them at all to many facilities which use them relatively frequently. Approximately 40% of the 125 inpatient psychiatric treatment settings in New York made no use of seclusion during the one-month period studied by the Commission; and approximately one-fourth (27%) made no use of restraint during this same period. These facilities contrasted with 36% of the facilities with combined order rates of restraint and seclusion which exceeded 31 orders to every 100 patients in the average daily census.

As noted in the Commission's report, *Restraint and Seclusion Practices in NYS Psychiatric Facilities*, there was no apparent explanation for the variation noted based on differences in the patient populations served by the different hospitals. Indeed, based on a more limited case study of 12 psychiatric facilities, it appeared that restraint and seclusion usage rates were primarily influenced by more subjective aspects of the psychiatric service or facility, including the degree to which the administrators spoke clearly against the frequent use of these interventions, the provision of other personal liberties to patients, and the likelihood that patients would be engaged in at least a minimal weekly schedule of activities. The findings of this survey lend further credence to these findings and suggest that psychiatric services and facilities which make low or no use of restraint and seclusion may also be more sensitive to issues of customer satisfaction.

The voices of the more than 1,000 consumers responding to the survey lend a strong endorsement of the need for the Office of Mental Health to assure greater accountability for critical aspects of patient-centered care and treatment in its regulation and oversight of these programs.

Finally, the survey's findings are also relevant to the NYS Office of Mental Health's oversight and certification activities related to state-operated and -licensed inpatient psychiatric facilities. As noted, the Commission did not investigate or verify the many complaints and serious allegations raised by the consumers responding to the survey. Nonetheless, the sheer number of these complaints and their consistency across respondents suggest that conditions complained of warrant closer examination in the Office of Mental Health's ongoing supervision of inpatient psychiatric programs.

Of note, 79% of the individuals responding to the survey registered at least one of following serious complaints: they were not involved or informed about medication and other treatment decisions; they did not feel safe; their belongings were not protected from theft; staff yelled at patients; and/or they were not allowed to go outside. And, in regard to restraint and seclusion use, with the exception of a small minority of respondents, almost all complained that these interventions were used contrary to state law and regulation.

The voices of the more than 1,000 consumers responding to the survey lend a strong endorsement of the need for the Office of Mental Health to assure greater accountability for critical aspects of patient-centered care and treatment in its regulation and oversight of these programs.

Appendix A

Consumer Mail Survey

Restraint and Seclusion Study
Consumer Mail Survey

When I was most recently in the hospital for psychiatric treatment . . .
(Circle "true" or "false")

T F I felt safe.

T F Staff were usually kind and caring to patients.

T F Staff did not yell at patients.

T F Staff did not hit me or other patients.

T F Staff did not call patients names or speak to them in ways that were insulting.

T F Staff never asked me or other patients for sexual favors.

T F Food was good to eat.

T F I had appropriate personal clothing to wear.

T F My clothes were not lost or given to another patient.

T F I was allowed access to my personal possessions.

T F My personal possessions were not stolen or taken away from me.

T F I had a toothbrush, toothpaste and toilet paper.

T F I could have visitors of my choice.

T F I was allowed to have some private time.

T F I was given privacy when receiving visitors.

T F I was allowed to make phone calls.

T F I was allowed to receive phone calls.

T F If I did not have any money, staff gave me money to use the telephone.

T F Staff did not read my mail.

T F I had the opportunity to attend activities or groups at least 3 hours per day.

T F I was given choices about the activities I attended.

T F I felt the activities/groups helped me get better.

T F I was able to go outdoors every day for at least one hour (weather permitting).

T F I was able to physically exercise three times per week.

T F If I had a problem or a question about my treatment, staff helped me.

T F I helped choose my treatment goals.

T F If my treatment or medications changed, a staff person explained the reasons to me.

T F Staff did not talk about my treatment in front of other patients.

T F I could say "no" to medications, and staff would respect my decision.

T F The purpose and side effects of my medications were explained to me.

T F Medications were not used as punishment.

T F If I objected to my treatment, staff listened to my concern.

T F If I was placed on restriction, someone explained why and how I could get my privileges back.

T F I was told what I needed to do to leave the hospital.

T F I was aware of the availability of Mental Health Legal Services to assist with my legal rights.

T F I could attend religious services or meet with clergy of my choice.

Please comment about any of these issues. (Please also use the back of this page to write any comments if needed.)

Comments:

During a hospital stay for psychiatric care, have you ever been ....
(Circle "yes" or "no")

Y N Placed in seclusion?

Y N Placed in a camisole?

Y N Placed in a full sheet restraint?

Y N Placed in four-point restraint?

Y N Placed in a vest, chair, or bed restraint?

Y N Other restraint? _____

If yes to any of the above, before hospital staff put me in restraints or seclusion . . .
(Circle "true" or "false")

T F I was acting in a manner that could have been dangerous to myself or others.

T F Someone tried to calm me down or resolve my problem.

T F I was examined by a physician.

T F The reasons why I was restrained or secluded were explained to me.

T F Staff said my behavior was inappropriate, however my behavior was not dangerous.

T F I was given medication.

While in restraint or seclusion . . .
(Circle "true" or "false")

T F I was allowed to take a drink of water and/or eat at mealtime.

T F I was released every two hours and given an opportunity to move about and exercise.

T F Hospital staff checked on me every 30 minutes to see if I was okay.

T F I was allowed to use the bathroom at least every hour.

T F Unnecessary force was used.

T F I was physically injured.

T F I was physically abused.

T F I was sexually abused.

T F I was psychologically abused, ridiculed, or threatened.

Comments: (Please feel free to add any comments, concerns, or complaints regarding your episode[s] of restraint or seclusion, here, or on the back of the page.)

_____

_____

_____

As an individual who has used mental health services, would you describe yourself as . . .
(Check all that apply)

☐ a regular user of clinic or continuing day treatment services?

☐ a regular user of psychosocial clubs or self-help groups?

☐ an infrequent user of formal services of any type?

☐ having been hospitalized in the past two years for psychiatric treatment?

If yes . . .

☐ were you hospitalized in a state psychiatric center?

☐ were you hospitalized in a psychiatric unit of a general hospital?

☐ were you hospitalized in a private psychiatric hospital?

Comments:

Appendix B

Respondents' Answers to Survey Items

Ratings of Psychiatric Treatment*
(N = 1,040)

False		*True*
11%	I was allowed to make a phone call	87%
12%	Staff never asked me or other patients for sexual favors	85%
13%	I had a toothbrush, toothpaste and toilet paper	85%
13%	I could have visitors of my choice	84%
14%	I was allowed to receive phone calls	82%
16%	Staff did not read my mail	78%
18%	I had appropriate personal clothing to wear	79%
19%	Staff did not hit me or other patients	79%
20%	Staff did not talk about my treatment in front of other patients	75%
24%	I was given privacy when receiving visitors	71%
25%	Medications were not used as punishment	71%
24%	I could attend religious services or meet with clergy of my choice	71%
25%	I was allowed access to my personal possessions	72%
25%	I was allowed to have some private time	72%
25%	I had the opportunity to attend activities or groups at least 3 hours per day	71%
25%	I was aware of the availability of Mental Health Legal Services to assist with my legal rights	71%
26%	If I had a problem or a question about my treatment, staff helped me	70%
26%	If I was placed on restriction, someone explained why and how I could get my privileges back	62%
27%	Staff were usually kind and caring to patients	70%
29%	My clothes were not lost or given to another patient	69%
29%	I was told what I needed to do to leave the hospital	66%
30%	Staff did not call patients names or speak to them in ways that were insulting	68%
30%	I felt the activities/groups helped me get better	67%
32%	Food was good to eat	66%
34%	If I objected to my treatment, staff listened to my concerns	58%
35%	I felt safe	63%
35%	I was given choices about the activities I attended	62%
36%	If my treatment or medications changed, a staff person explained the reasons to me	59%
37%	I was able to exercise three times per week	59%
39%	My personal possessions were not stolen or taken away from me	59%
39%	The purpose and side effects of my medications were explained to me	57%
42%	I helped choose my treatment goals	53%
43%	Staff did not yell at patients	56%
46%	I was able to go outdoors every day for at least one hour (weather permitting)	51%
51%	I could say "no" to medications, and staff would respect my decision	44%
69%	If I did not have any money, staff gave me money to use the telephone	23%

*True and false percentages do not always total 100% due to some respondents not answering all questions.

Ratings of Restraint/Seclusion Use

(n = 560)

Before Being Put in Restraint/Seclusion

False		*True*
20%	I was given medication	69%
32%	Staff said my behavior was inappropriate; however my behavior was not dangerous	53%
46%	I was not examined by a physician	44%
43%	I was not acting in a manner that could have been dangerous to myself or others	46%
42%	No one tried to calm me down or resolve my problem	47%
40%	The reasons why I was restrained or secluded were not explained to me	49%

While in Restraint/Seclusion

False		*True*
56%	I was not allowed to take a drink of water and/or eat at mealtime	34%
53%	Hospital staff did not check on me every 30 minutes to see if I was okay	38%
41%	Unnecessary force was used	50%
41%	I was not allowed to use the bathroom at least every hour	46%
50%	I was psychologically abused, ridiculed, or threatened	40%
30%	I was not released every two hours and given an opportunity to move about and exercise	58%
61%	I was physically abused	29%
64%	I was physically injured	26%
79%	I was sexually abused	10%

Copies of this report are available in large print, braille, or voice tape. Please call the Commission for assistance in obtaining such copies at 518-473-7538.

The Commission on Quality of Care for the Mentally Disabled is an independent agency responsible for oversight in New York State's mental hygiene system. The Commission also investigates complaints and responds to requests concerning patient/resident care and treatment which cannot be resolved with mental hygiene facilities.

The Commission's statewide toll-free number is for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.

Toll-free Number: 1-800-624-4143 (Voice/TDD)