Report:

A STUDY OF "DUALLY DIAGNOSED" PSYCHIATRIC INPATIENTS:

Adults with developmental disabilities who were also psychiatric inpatients at state or community hospitals

OFFICE OF PLANNING,
EVALUATION AND
PROFESSIONAL DEVELOPMENT

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Adults with developmental disabilities who were
also psychiatric inpatients at state or community hospitals

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EXECUTIVE SUMMARY

A Study of "Dually Diagnosed" Hospitalized Persons

Each year, recently, about 170 of the 9,000 or so adult clients of the state's developmental disabilities community program (1 in 53) were also psychiatric inpatients at our state or community hospitals. The group generated about 239 psychiatric hospitalization episodes each year. Just under half of these were to the state hospitals.[1]

The hospitalizations most often resulted from recurring severe behavior problems. These behavior problems over time had exhausted community supports or tolerance. Most frequently mentioned were aggression towards others, also destroying property, temper tantrums, physical self-abuse, or attempting suicide. Just over half the admissions were at some point involuntary.

Are these admissions necessary? Are these persons mentally ill? Of the persons admitted to the state hospitals, 40 to 50 percent appear to have had a mental illness severe enough to warrant psychiatric hospitalization.

An additional 40 to 60 percent of the state hospital group did not have a severe mental illness but did need a closely supervised residence to manage and treat their recurring severe conduct. Some needed a secure residence as well, to protect others at the residence and persons at large. Two-thirds of this not severely mentally ill group had been involuntarily committed, and by law they required a facility certified able to supervise and treat involuntarily committed persons.

But should that facility have been a mental hospital? Under the 1984 agreement between the Division of Developmental Disabilities (DDD) and the Mental Health Division (MHD) the persons who were not severely mentally ill did not require psychiatric hospitalization. Their care and treatment was to be a DDD responsibility. But in actuality state and community psychiatric hospitals were about the only residences available that could provide the needed close behavioral supervision and, often, security and/or involuntary custody. Community residential options had been exhausted, and the state-run developmental disabilities institutions (the Residential Habilitation Centers) did not have the capacity to manage such persons in such numbers. The safety of others living at those RHCs is also a consideration.

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[1] There are many more "dually diagnosed" persons in Washington State than the 275 who were hospitalized and whom we studied. The Division of Developmental Disabilities (1987), using a survey of its field and institutional staff, recently estimated that 1,357 of its 9,000 or so adult clients (1 in 7) had a clinically diagnosed severe psychiatric condition, and 1906 (1 in 5) had a major behavior problem; 720 had both. These 2,543 "dually diagnosed" persons live in community settings or at DDD institutions, and only about 170 or so of them are psychiatrically hospitalized each year.

As to the persons who went only to community hospitals, we had no access to their hospital records and so we could not similarly review their needs. From what information we have it appears that half or more may well have needed behavioral supervision and treatment and some did need security and/or involuntary custody. Again the issue is one of available options.

Were hospital discharges delayed? Why? Of the persons admitted to the state hospitals, 39 percent left within 30 days, 67 percent left within 90 days. Virtually none stayed over a year. At community hospitals stays were much shorter: 86 percent left within 30 days.

Under the 1984 DD-MH Agreement, DDD is responsible for transferring these persons to community living (or to a DDD institution) within thirty days after the hospital recommends discharge. In actuality, just under half of the state hospital patients left there within the allowed 30 days. A third had to wait more than 60 days before they could leave their state hospital as recommended.

These delays for the most part were due to shortages of appropriate community services. Programs suited to these persons' special behavioral and mental health needs either did not exist where needed or did not have space available. In some cases a suitable program refused to take the person, or the person or family turned down the program.

What community supports were needed? Were they available? About three-quarters of the whole group on return to community living were provided some type of DSHS-supported residence. Almost all the rest lived with their families or at their own places; few if any were homeless. Almost all received federal income assistance and along with that medical assistance, which could pay for community health and mental health services.

Behavior problems, after hospital discharge, were reduced but still present to an appreciable extent. Half the total group was still behaving in difficult ways at least occasionally. Behavioral programming was much needed therefore. Some behavior management was now being provided through individualized treatment by specialized residential or day providers, but these services were not sufficiently available, according to the case managers.

Mental health services were being provided to 59 percent of the group after they returned to community living, up from 50 percent prior to hospitalization. Even so, 30 percent of the persons who had had a severe mental illness were reportedly receiving no post-hospital mental health care.

After hospitalization, 64 percent of the total group participated in day habilitation, most often DD-supported employment or mental health day treatment programs. This is an appreciable improvement from the 42 percent participation before hospitalization, yet a third of the total group still had no day programs or work. Day programs for these people must be specialized to address their behaviors, and more such programs are needed.

In summary, the community supports most needed are residences with adequate supervision and behavioral programming, outpatient mental health services and specialized adult day habilitation. This amounts to about $22,000 per person per year.

State cost. Over the two-year study period DSHS paid about $12 million to support these 275 persons: $9.8 million for community care, $2.1 million for state hospitalization, $0.28 million for psychiatric care in community hospitals. This amounts to about $22,000 per person per year.

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We enjoyed considerable cooperation from the Field Services staff of the Division of Developmental Disabilities and from the staffs at Eastern and Western State Hospitals. We were aware that our requests for help only added to these persons' already heavy workloads. Yet without their cooperation we could not have done the study.

INTRODUCTION

Over the two-year period, April 1986 through March 1988, about 275 different adults with developmental disabilities were at some point inpatients at Washington's two state mental hospitals or at the psychiatric units of community hospitals. Some were admitted more than once. Why were they so admitted? Were those admissions necessary? How long did they stay in those psychiatric units and were they delayed in returning to community living? What did this cost the state?

We did this study in response to concerns by many legislators and legislative staff, program officials and mental health and developmental disabilities advocates, that some persons with developmental disabilities are unnecessarily and inappropriately being sent to mental hospitals, and that once there they cannot return speedily to community living when ready to do so. If this is so then not only are some of these persons inappropriately served, but, also, the resources of our state and community hospitals could be put to better use. This study is intended to assist department planning for such "dually diagnosed" persons.

How This Study Was Done

For our starting point, we used information provided us by the state hospitals and DDD Field Services case managers to identify all DDD clients who had been inpatients at state hospitals or psychiatric units of community hospitals at any point between April 1, 1986 and March 31, 1988. We found 275 such persons: 142 had been admitted to state hospitals, 133 admitted only to community hospitals.

For samples totalling 175 of those 275 persons we then arranged interviews with their DDD case managers, to find out about the persons, and especially about their pre-hospital and post-hospital situations and the reasons for their hospitalizations.

For the sample 100 of the 142 state hospital patients we obtained additional information from their hospital records. (Our time limits precluded arranging similar access to patient records at community hospitals.) We especially wanted more information about the admissions and discharges. The hospital data were also used by our two-person clinical teams to diagnose presence or absence of a "major mental illness."

Service use and cost data were obtained for all 175 sampled cases from the case manager interviews, from DDD and MHD and from the department's Medicaid Management Information System.

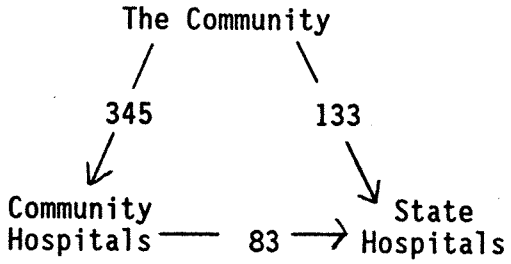
FINDINGS AND DISCUSSION

A. NUMBER OF ADMISSIONS

Over the two-year period April 1, 1986 through March 31, 1988 some 275 different adult clients of the department's developmental disabilities program were also inpatients at the state's two mental hospitals or at psychiatric units of community hospitals. Over those two years the group generated 478 hospitalization episodes, as some persons were hospitalized more than once. (We considered transfers from one hospital to another to be parts of the same hospitalization episode.) On average, about 170 different individuals were hospitalized each year.

The admissions paths are shown in Figure 1. Most (72 percent) of the admissions were to psychiatric units of community hospitals or to local Evaluation and Treatment Centers. There are 18 such Evaluation and Training Centers: State-contracted, they provide 24-hour inpatient care for civilly involuntarily detained persons. For this report we have combined the Evaluation and Training Centers with the community hospitals as both are locally situated and locally operated.

Figure 1. Admission Paths



Of the 345 community hospital admissions, 83 later transferred to state hospitals; the other 262 stayed only at community hospitals. The two state hospitals received 133 admissions directly from the community, plus 83 transfers from community hospitals (and seven transfers between state hospitals).

Is this figure of 478 psychiatric hospitalization episodes per two years for adults with developmental disabilities a comparatively high figure? A low figure? During our two-year study period, the state's developmental disabilities program supported about 12,500 adults and children in community settings. This suggests that the psychiatric hospitalization rate for DDD clients was at least 1.9 per hundred persons per year. We use the phrase

"at least" because we obtained data only on hospitalizations of adults. Any psychiatric hospitalizations of children or adolescents with developmental disabilities would increase the 1.9 per hundred estimate.

By comparison, the psychiatric inpatient admission rate for the entire U.S. civilian population (includes all ages) was 0.7 per hundred persons per year in 1983 (National Institute of Mental Health, 1987). This is the only comparison figure we could locate for incidence of psychiatric admission. Comparing the 1.9 and 0.7 figures suggests that the likelihood of psychiatric hospitalization for persons with developmental disabilities is at least twice as high, perhaps even three times as high, as for the general public.

B. SOME BACKGROUND INFORMATION ABOUT THE ENTIRE STUDY POPULATION

Sex and age data for all 275 persons in the study population are shown in Table 1 and Table 2, along with data for like groups. The data are not remarkable. There was some preponderance of men, but that is similarly so among the entire DD adult population and even more so among admissions generally to the two state hospitals. The preponderance of men is somewhat stronger (62 percent men) for the state hospital study group and weaker (only 51 percent men) for the community hospital group.

Table 1. Proportion Who Are Men

In the 275 person study population:	56 %
Among all 9614 adult DD clients:	55 %
Among all WHS and ESH study clients:	66 %

About three-quarters of the study group were younger adults, in their 20's or 30's. This age distribution is about the same as that for all adult DDD clients and all adults at the two state hospitals (Table 2).

Table 2. Age Distribution

	Percent in each age group							
Age group	18-19	20-24	25-29	30-34	35-39	40-44	45-49	50+
All 275 study persons	1	20	18	19	15	13	3	11
All adult DDD clients	6	17	19	16	12	10	6	14
All WSH and ESH adult clients	3	14	17	17	13	9	7	21

Ethnicity: About 15 percent of the 275 were members of ethnic minorities: Afro-Americans, Asians, Indians, Latinos.

NOTE: To simplify the data displays, throughout this report we will most often present the data of interest as a single figure for the entire 275-person study group, rather than showing separate figures for the community hospital study group, the Eastern State Hospital group, the Western State Hospital group. Wherever we show such a single combined figure we have examined the data for the three separate groups and found no notable differences. Where there is a notable difference between study subgroups we will show it or mention it in the text.

Geographic Distribution: The 275 persons we were studying originated somewhat disproportionately from Eastern Washington (Table 3). Thirty percent of the group had been living in Eastern Washington prior to hospitalization, though only 25 percent of the entire DDD adult (age 18+) non-institutional clientele lived there.

Table 3. Geographic Origin

Region of Origin	Percent of study population	Percent of state population	Percent of all adult developmental disabilities clients
Snohomish-King-Pierce Counties (Regions 3-4-5)	51 %	60 %	59 %
Eastern Washington (Regions 1-2)	30 %	23 %	25 %

The persons living in Eastern Washington were more likely to go to state hospitals, especially Eastern State Hospital (Table 4). This may reflect the relative unavailability of community hospital psychiatric inpatient services in Eastern Washington, and the Eastern State Hospital policy of accepting voluntary admissions; Western State Hospital will not.

Table 4. Use of State and Community Hospitals by Geographic Region

Region of origin	Percent using: The two state hospitals	Percent using: Community hospitals
Snohomish-Pierce-King Co. (Regions 3-4-5)	47 %	53 %
Eastern Washington (Regions 1-2)	71 %	29 %

Services and Supports Prior to Hospitalization

Community Residences. The great majority of these persons prior to hospitalization had been living with DSHS-provided supports of one sort or another or with their families (Table 5). Few were homeless or living in socially isolated ways, with no program supports. Sixty percent had been living in DSHS-paid or DSHS-assisted residences of one sort or another, and an additional 24 percent with their families. Further, DSHS had been paying special ("add-on") rates for 14 percent of the 83 persons living in the DD-specialized or generic DSHS-paid adult facilities.

Table 5. Living Arrangements Before Hospitalization

Living Arrangement	Used by percent of entire study group
At own place (often shared), with DSHS support person coming in part-time (tenant support or chore worker)	17 %
At own place (alone or shared), with no DSHS support person	5 %
With own family	24 %
At a DSHS-paid place with 24-hour staff	
a. MH-specialized facility	4 %
b. DD-specialized facility or apartment	20 %
c. DDD facility (Residential Hab. Center)	3 %
d. Other adult facility or family home	22 %
Elsewhere (includes jail, no known residence)	6 %
TOTAL	100 %

Income. The great majority of the group, some 93 percent, even before hospitalization was receiving federal income support for permanently disabled adults: Either through Supplemental Security Income or through the disability provisions of the Social Security program. Virtually none were receiving state General Assistance income grants. (The federal support level for a one-person household was $340 per month. These persons typically also received food stamps and Medicaid-paid health services, and sometimes housing and other assistance.)

Weekday Activities. Daytime programming was weak for many. Only a third reportedly participated in some DSHS-funded day program, and a few others were working on their own or were otherwise engaged regularly in weekday activities (Table 6). The majority reportedly did not have regular daytime programs.

Table 6. Participation in Day Programs Before Hospitalization

	Of entire study group
Employed without program assistance	2 %
Receiving DD vocational supports	26 %
In any other DD day treatment program	4 %
In a MH day treatment program	10 %
No day program identified	61 %

In some cases this non-participation in day programming may have been due to the person's behavioral or mental health problems. But the reverse could also be true: The lack of day programming in some cases may have aggravated the person's behavioral or mental health problems to the point where hospitalization was needed.

Use of Mental Health Services Before Hospitalization. Fifty percent of the total group reportedly was using mental health services of some sort directly before hospitalization (Table 7).

Table 7. Use of Mental Health Services Before Hospitalization

	Of entire study group
Using any mental health service	50 %
Medication management	28 %
Individual counseling	27 %
Group therapy	10 %
Day treatment	10 %

A quarter had been under medication management, and a quarter had used individual counseling. Some persons used both.

Arguably, perhaps not everyone in the group needed or could benefit from professional mental health services, but the use of such services would surely be indicated for persons who had a "major mental illness."

We will use the term "major mental illness" frequently in this report. The term "severe mental illness" is defined in the 1984 DD-MH Agreement, a level of dysfunctioning sufficiently serious to warrant psychiatric hospitalization. (See our summary of the 1984 DD-MH Agreement, on page 14.) For certain practical reasons the standard we could measure was slightly different from that in the 1984 Agreement. We will therefore use the term "major mental illness" in this report rather than "severe mental illness" to describe the mental statues of the study population. This technical differences is explained in the methods chapter.

For the persons admitted to state hospitals we did develop clinical judgments of whether the person had a "major mental illness" at the time of hospital admission. We estimate that 46 percent of the persons admitted to state hospitals did at that time have such "major mental illnesses." As discussed in the methods chapter, these clinical judgments enjoyed reasonable inter-team agreement, with disagreement tending possibly to somewhat underestimate the prevalence of major mental illness.

Table 8 estimates the number of state hospital patients with major mental illness and without who were and were not receiving mental health services prior to state hospitalization.

Table 8. Estimated Use of Mental Health Services Before State Hospitalization, by Persons Having or Not Having a Major Mental Illness

Mental health status	Percent using mental health services	Percent not using
66 persons having a major mental illness	61 %	39 %
76 persons not having a major mental illness	46 %	54 %
Total: 142 persons admitted to state hospitals	53 %	47 %

The data paint a mixed picture. On the positive side, community mental health services generally in short supply for the disabled and welfare-supported population were being provided to 61 percent of the persons who had a "major mental illness," as against to 46 percent of the persons who had no "major mental illness." On the other hand 39 percent of the persons with a "major mental illness" had not received mental health services prior to state hospitalization. We will return to this matter when later we examine the provision of mental health services after discharge from the state hospitals.

This apparent non-provision of mental health services to 39 percent of the group who were later hospitalized with a "major mental illness" suggests a clear shortcoming in community services. For most of these persons their mental health condition had surfaced earlier and were known, though those conditions may not yet have reached levels requiring hospitalization. Pre-hospitalization mental health services should therefore have been provided in view of these persons' manifest conditions, and regardless of whether hospitalization could have been averted.

Some Illustrative Cases

(#9) Elaine, age 24 and developmentally disabled, with a prior history of psychiatric hospitalization, had been living with her sister for one year. She was being financially exploited and sexually abused by a family friend. She experienced auditory hallucinations and was moved to a congregate care facility. There she refused medications or to follow house rules and was feeling suicidal, and so, after one week, was involuntarily committed to Western State Hospital where she spent five months. She refused all post-hospital placement attempts and went back to her family. There she stayed two months, then left. All contact with her is lost.

(#21) Brian, age 33 and developmentally disabled, with no prior history of psychiatric hospitalization (prior assaultive history unknown), had been living at a congregate care facility for one year. In 1986 he was charged with second-degree murder, found incompetent to stand trial, and involuntarily committed to Western State Hospital, where he still lives.

(#102) George, age 33 and developmentally disabled, with no prior history of psychiatric hospitalization, for eight years had been living in his own apartment with DDD residential services (tenant support). He and his girlfriend decided to live together after dating for two and one-half years. The girlfriend's sister came to the apartment, verbally abused the man and took the girlfriend away. The man then attempted suicide and was involuntarily committed to Eastern State Hospital for four days. He has cerebral palsy and experiences depression concerning his limitations. After the hospitalization, he returned to his apartment, but soon after moved to his parents' home in Idaho.

(#184) Stuart, age 34 and developmentally disabled, with no prior history of psychiatric hospitalization, had been living for one month in his own apartment with DSHS-paid chore services. It was decided that he was not physically or mentally able to live on his own because of suppressed emotional trauma; earlier he had been stabbed and left for dead on the way home from church. He became increasingly depressed and several times tried to commit suicide. Voluntarily admitted to a community hospital he stayed for one month. He then returned to his apartment as a participant in the Crime Victim Assistance Program, and still resides there. He receives mental health services at a community mental health center.

C. THE EVENTS PRECEDING THE PSYCHIATRIC ADMISSIONS

The case managers described for us the events preceding each admission. The circumstances were diverse, and not always fully known to the case managers. On the facing page we summarize typical cases.

The precipitating events very often involved recurring problematic behaviors: Behaviors recurring to the point where they exhausted local supports or tolerance. Additionally, these behavior often posed unacceptable risks of harm to others, sometimes to the person. Key events before hospitalization are shown in Table 9.

Table 9. Key Events Before Hospitalization

	Percent experiencing this event among persons admitted to state hospitals	Percent experiencing this event among persons admitted only to community hospitals
Person was behaving in a difficult way	91 %	88 %
Violence during precipitating incident	79 %	72 %
- Violence to others	60 %	37 %
- to self	20 %	30 %
- to property	29 %	33 %
Police called in	55 %	39 %
Criminal court involved	18 %	6 %
Detention under Involuntary Treatment Act at some point	74 %	36 %

The nature of these behavior problems is further explained in Table 10. These data, too, were provided by the case managers.

From Tables 9 and 10 one can see that violence of some sort was involved in fully three-quarters of the situations precipitating admissions. Violence to others was most common, having been reported by DDD case managers for three-fifths of the persons admitted eventually to the state hospitals, and for over a third of those going strictly to community hospitals. Violence to self and violence to property were each reported in a fifth to a third of all state and community hospital admission.

Some More Illustrative Cases

(#109) Fred, age 21 and developmentally disabled, with prior history of psychiatric hospitalization, had been living at a Residential Habilitation Center for two and one-half years. He was involuntarily committed to Eastern State Hospital to determine competency to stand trial on the charge of forcible rape of a female resident at the RHC. There had been several similar incidents, also a charge of physical assault of an RHC resident. He stayed in the hospital for three months, then was jailed for two months. He now lives at a private residence, independent of all MHD or DDD services.

(#213) Stanley, age 49, alcoholic and developmentally disabled, with no prior history of psychiatric hospitalization, had been living in his own apartment with DDD-paid occasional residential supports (alternative living). Four months prior to hospitalization, he discontinued his medication. He was arrested on misdemeanor charges for screaming, yelling, threatening people at his apartment building, irrational behavior and resisting arrest. He was also involved with a young man who may be a heroin addict. He refused to return to community mental health for counseling and treatment, and was involuntarily committed to Western State Hospital for ten days. He returned to his residence when he promised that he would pay for damages. He was also issued a notice threatening his eviction were there any more disruptive or destructive behavior. He was uncooperative with mental health services, and four months later was re-hospitalized, this time in a community hospital.

(#267) Joan, age 29 and developmentally disabled, with prior history of psychiatric hospitalization, for three years had been living in her own apartment with DDD-paid residential support (tenant support). She was also receiving mental health services. Over a two-week period she stopped taking her medication, began auditory and visual hallucinations, became disoriented and refused to eat. She was voluntarily admitted to a community hospital where she stayed for several days. She then returned to her residence where she still resides, but she refuses all mental health services including medication. She continues to have hallucinations.

Table 10. Behavior Problems Before Hospitalization

	Percent behaving this way among persons admitted to state hospitals	Percent behaving this way among persons admitted only to community hospitals
Poses Actual or Possible Danger to Others		
Aggressive toward others	73 %	57 %
Steals	20 %	13 %
Sexually molests others	8 %	12 %
Poses Actual or Possible Danger to Self		
Physically self-abusive, self-destructive	21 %	32 %
Attempts suicide	17 %	25 %
Other Problem Behaviors		
Destroys property	51 %	45 %
Has temper tantrums	40 %	49 %
Completely withdraws or is severely depressed	27 %	20 %
Severely hyperactive	20 %	17 %
Acts unacceptably (e.g., undresses frequently, masturbates in public)	18 %	21 %
Repeats unusual behavior (e.g., stereotyped, non-adaptive...)	16 %	21 %
Wanders	19 %	16 %

Involuntary detention and treatment authorities reportedly were used with 36 percent of all persons admitted strictly to community hospitals and 74 percent of all those admitted directly or eventually to the state hospitals. At Western State Hospital, 80 percent of the admissions were at some point involuntary, according to the case managers; likewise, 64 percent of the admissions to Eastern State Hospital. Police were called in 48 percent of all cases.

Severe behavior problems are generally more prevalent among adults with developmental disabilities than among other adults of like age. Bruininks, Hill and Morreau, in their recent authoritative and comprehensive review of the research literature on the prevalence of maladaptive behavior and mental illness among persons with developmental disabilities conclude:

> At considerable risk of oversimplification, it would appear that 20 to 40 percent of mentally retarded people in various samples and service programs consistently exhibit behavior problems that are perceived by others in their environment as serious problems. Rates for such behavior problems generally run higher among those in licensed residential facilities and among clinically referred samples than among more randomly distributed people in community settings. (1988, p.8)

The 1984 DD-MH Agreement

In 1984 the Division of Developmental Disabilities (DDD) and Division of Mental Health (MHD) agreed on how the two divisions would share the responsibilities for evaluating and serving persons who have both developmental disabilities and mental health needs. Below we summarize those elements of the 1984 Agreement most relevant for the persons in this study. Under the 1984 Agreement:

1. DDD is responsible for determining eligibility for DDD services.

2. MHD has primary responsibility for DDD clients if and while they have a "severe mental illness." (See definition below.) Primary responsibility means responsibility for residential programming and for coordinating all other services.

3. DDD has primary responsibility for DDD clients who have mental health needs but do not have a "severe mental illness."

4. A "severe mental illness" is one which (i) involves hallucinations, delusions, thought disorder, affective (mood) disorder or anxiety, (ii) to such an extent that the person's customary functioning is extremely disturbed in any of the following areas: eating, sleeping, personal hygiene, speech, social interaction, work or recreation. **Note:** (i) identifies a major mental illness; (ii) identifies a severe episode of that major mental illness.

5. Determination of whether a DDD client has a "severe mental illness" is to be made jointly by DDD and MHD liaison staff. Disagreements are to be decided by a DDD-MHD resolution committee.

6. MHD is responsible for providing community mental health services for all DDD clients needing mental health services, including clients for whom MHD has only secondary responsibility, that is, clients who have no "severe mental illness." DDD is responsible for providing developmental supports, including adult work or day programs, for all DDD clients, including those for whom it has only secondary responsibility, that is, clients who do have a "severe mental illness."

7. DDD is to take primary responsibility once a hospitalized client is no longer "severely mentally ill. DDD is then to arrange a community residence and transfer the client there within 30 calendar days of being informed that that person no longer has a "severe mental illness" (within five working days if the client can return to her prior residence). If such a transfer is not accomplished within the set time, DDD is to immediately transfer the client to one of the DDD institutions (Residential Habilitation Centers), unless the state hospital or community hospital agrees to the person staying there.

D. WERE THESE HOSPITALIZATIONS NECESSARY?

This is one of the more difficult issues we set out to examine. The issue consists actually of four separate questions that we can explore with our data:

i. Were these people mentally ill, severely enough to warrant psychiatric hospitalization?

ii. Was an institution appropriate for other reasons?

iii. But should that institution have been a mental hospital?

iv. Couldn't community arrangements have been used instead?

i. Were these people mentally ill, severely enough to warrant psychiatric hospitalization?

Our two-clinician review teams, using the information in state hospital records, assessed the mental health status of a sample 100 of the 142 state hospital patients. Forty-six percent were judged by the clinical teams as having had a "major mental illness" at hospital admission. Under the 1984 DD-MH Agreement (see facing page) only persons with such a "major mental illness" require psychiatric hospitalization. (The Agreement uses the term "severe mental illness," but that is materially the same as "major mental illness." See Study Methods chapter.)

By this "major mental illness" criterion, psychiatric hospitalization was appropriate for 46 percent or just under half the total state hospital group. (We could not similarly diagnose the community hospital group as we had no access to their community hospital records.)

This finding is generally consistent with other, published, research. Bruininks, Hill and Morreau (1988), reviewing the literature, estimated the prevalence of mental illness among a general population of persons with developmental disabilities at between 5 and 13 percent. Lewis and MacLean (1982), in an earlier review article, concluded:

> "The available studies lead to the inescapable conclusion that emotional disorders are much more common among mentally retarded persons than in the general population. This conclusion is based on investigations using very different patient samples and very different methodologies." (p.7)

These two reviews indicate that persons with developmental disabilities can also have a mental illness; indeed, that mental illness is likely more prevalent among developmentally disabled persons than among non-disabled persons. In consequence, when planning service systems for persons with developmental disabilities one should anticipate some need for mental health services, including inpatient psychiatric care.

ii. Was an institution appropriate for other reasons?

Assignment to an institution may also be appropriate for persons who, while they have no "major mental illness", persist in dangerous or otherwise unacceptable conduct to the point where community tolerance and options are exhausted. Often these persons will have to be involuntary detained, but not necessarily so.

Thirty-four percent of our total state hospital group were involuntarily detained yet had no "major mental illness." For these persons some sort of well-supervised institution or other residential facility, which provided behavior management and security as needed, and was certified or designated for involuntarily committed persons would seem appropriate.

Such a well-supervised facility would also be appropriate for at least some of the remaining 20 percent of the entire state hospital group. The remaining 20 percent had had no "major mental illness" and were not involuntarily detained, but according to their case managers some at least had histories of violent, dangerous or otherwise unacceptable conduct. In summary somewhere between 34 and 34+20=54 percent of the state hospital group, while they had no "major mental illness," by their behavior and involuntary commitments appeared to be suitable candidates for a well supervised residential program, in some cases a secure program.

iii. But should that institution have been a mental hospital?

It is arguable whether a mental hospital should have been used for these persons who may have needed a well supervised residence, even a secure residence, but evidenced no "major mental illness". The state hospitals are staffed and programmatically prepared to serve people who have substantial mental health dysfunctions; yet the above group did not have such symptoms. And, under the 1984 DD-MH Agreement, MHD is not given primary responsibility for persons if they do not have a "major mental illness;" for these persons primary responsibility is assigned rather to DDD.

Viewed from this programmatic vantage point the state hospitals (or psychiatric units of community hospitals) were not appropriate. However, from another point of view, the state hospitals can provide the close supervision (and security, in some cases) these people require, and the hospitals are designated and prepared to manage involuntarily committed persons.

In summary, the state hospitals (or community psychiatric facilities) are appropriate in some respects for these persons but not in other respects: They can provide the needed supervision and security where indicated, and they can manage involuntarily committed persons, but their programmatic (mental health) capabilities are not appropriate, for persons who do not have a "major mental illnesses."

Psychiatric hospitalization is used here in good measure because other options are scarce. Under the DD-MH Agreement DDD is support to provide residential programming for persons not having a "major mental illness." But DD to this day does not have available in any quantity residential resources to provide the needed close supervision, security and administration of involuntary commitment. In consequence, the unavoidable obligation to provide residential programming when all community supports have been exhausted defaults to the state hospitals and community hospitals. Considering the absence of options, the hospitals are not entirely inappropriate: They can provide the needed supervision, security where indicated, they can administer involun-tarily committed persons, and they do function as facilities of last resort: They do accept these persons when all other options are exhausted or unavailable.

iv. Couldn't community arrangements have been used instead?

There is some opinion especially among client advocates that many of these hospitalizations would not have been necessary were proper community supports adequately available. This is a difficult issue to examine factually because such a situation -- abundant community resources -- does not exist. On the other hand it is true that for almost every one of the 275 persons in our study group, giving funding, one could devise some sort of staff-intensive program that would have allowed the person to continue to live in the community.

The real issue here is not a lack of technology, or even community tolerance, but rather the scarcity of resources and, even more important, the competing needs of others who have fewer problematic behaviors, who enjoy more community tolerance, and who could be supported at lower cost. In effect, the question of community alternatives is more a policy issue and a planning topic than a research question.

To get a sense of whether the psychiatric hospitalizations were preferable to community options, we asked each DDD case manager for her views as to what community supports then available might realistically have prevented the hospitalization, and whether the hospitalization was still the preferred option, even were those other supports available.

The DDD case managers' replies regarding services that might have prevented the hospitalizations were often speculative rather than precise and confident. They frequently suggested more mental health services or better access, and more, more specialized and more tolerant residential and day programs; also mentioned were counseling for the client and family, and better prepared staff. Several case managers indicated that needed supports had been available, but the client was not cooperating.

In actuality those wanted additional community resources were not available and, to some degree, the case managers further acknowledged that those desired options would likely have limited value for "dually diagnosed" persons such as we are studying. Asked whether hospitalization, even briefly would still have been their preferred option, even had those additional supports been available, 74 percent of the DDD case

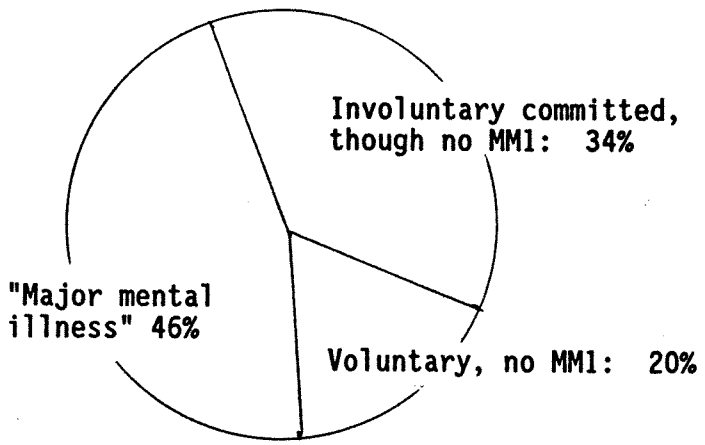
managers for state hospital clients and 57 percent of the case managers for strictly community hospital clients answered that in their views hospitalization would still have been preferred. Also, in 41 of 175 interviewed cases, the case managers replied or suggested that in their views no additional supports might realistically have prevented the hospitalizations. In conclusion, the DDD case managers judged that upwards of 75 percent of the state hospital admissions and upwards of 63 percent of the community hospital admissions were appropriate given the circumstances of those individual cases and the options then actually available.

The case managers were not necessarily concurring with the use of psychiatric facilities. Rather, given these clients' behavior histories and the exhaustion of ordinary community resources, the managers seemed to be saying that some sort of closely supervised residential facility was appropriate. Many case managers might have preferred a community-situated, closely supervised facility, or even a developmentally oriented state facility but these are not often real options and we did not ask the question.

E. SUMMARY: WERE THESE HOSPITALIZATIONS NECESSARY?

Just under half of the state hospital group had a "major mental illness" at hospital admission, according to the diagnosis by our project's clinical review teams. (See Figure 2.) For these persons psychiatric hospitalization is appropriate.

Figure 2. Mental Health Status at Admission of Persons Admitted to the Two State Hospitals



For those without a "major mental illness," some sort of well-supervised institution or other residential facility prepared to manage difficult behavior and authorized to administer involuntary committed persons, providing security as needed, would also be appropriate for the 34 percent of state hospital patients who were involuntarily committed and for some of the remaining 20 percent who were admitted voluntarily.

But this facility need not be a psychiatric hospital: These persons did not appear to have a "major mental illness" at admission, and under the 1984 DD-MH Agreement should not have gone to a mental hospital.

In summary, perhaps 40-50 percent of the state hospital group did need a psychiatric facility and an additional perhaps 40-50 percent for any of several reasons needed some other well supervised facility, though not a psychiatric hospital.

For the community hospital group we can make only very general estimates as we had no diagnostic data. A third were involuntarily committed and presumably required suitable supervision, therefore. Among the other two-thirds, all voluntary admissions, many had severe behavior problems: aggressive, assaultive, destructive, etc., and they too may have needed supervision and behavior management moreso than psychiatric services.

Some Additional Observations

1. The term "major mental illness" as we use it here means a mental illness severe enough to warrant psychiatric hospitalization. Of people who do not have a "major mental illness" many may have lesser though still significant mental health needs, and they may well need community outpatient mental health services, even if they do not need inpatient psychiatric services.

2. One should keep in mind that the case managers whose opinions we have relied on were developmental disabilities professionals. Many did not have extensive formal training or experience in psychological assessment. In interpreting their clients' presenting conditions they may have seen more mental illness than mental health professionals would have.

3. The mental health and developmental disabilities clinicians on the study's two diagnostic teams tended to agree in their diagnoses. The two types of diagnostician agreed in 16 of 21 cases where we deliberately obtained diagnoses from both groups. In all five disagreements the developmentally-oriented professionals diagnosed a "major mental illness" whereas the mental health professionals did not.

   The two developmentally-oriented clinicians who participated in our project did have appreciable formal training and experience in psychological or psychiatric assessment. This preparation may have provided the common ground for agreement between the two types of clinicians. We note parenthetically that developmental disabilities professionals often do not have psychometric or psychiatric diagnostic experience, which fact may help explain the alleged diagnostic disagreements between mental health and developmental disabilities professionals.

   Our (very limited) data suggest that with proper diagnostic preparation clinicians of both camps can come to diagnostic agreement in most cases.

F. LENGTH OF STAY AT THE HOSPITALS

Of the 142 persons admitted to the state hospitals 38 percent left within one month and 58 percent within two months of admission (Table 11). Some 26 percent stayed longer than four months; 15 in 100 stayed for six months or longer; 4 in 100 stayed for 12 months or longer.

Table 11. Length of Stay

Stay	For persons admitted to state hospitals	For persons admitted only to community hospitals
1-7 days	13 %	39 %
8-14 days	9 %	24 %
15-30 days	16 %	23 %
1-2 months	20 %	4 %
2-3 months	9 %	4 %
3-4 months	7 %	1 %
Over 4 months	26 %	2 %
TOTAL	100 %	100 %

Note: The lengths of stay analyses exclude persons already hospitalized on Day-One of the study.

For state hospital clients we studied all discharges through October 31, 1988. This late date, six months after the March 31, 1988, end of the study proper allows us to observe six months of discharge experience for every person in the state hospital group, even someone admitted on March 31, the last day of the study period.

Not every person moved on, however. In our study group we found four persons who had been living at one or the other state hospital for over two years, one having been there 20 years. These are atypical cases: They are the few patients remaining of probably a thousand or more persons with developmental disabilities who had come to the state hospitals over the last decade or longer. This is not to say that such long-staying persons may be ignored. But the data do indicate that 38 percent of an admitted group leave again within 30 days, 58 percent within 60 days.

We could not directly determine the lengths of stay of our community hospital group as we had no access to these persons' hospital records. The case managers' length of stay reports for community hospital clients were imprecise, and the lengths of stay we derived (see Table 11) are likewise undertain. Even so, these data strongly suggest that the stays at community hospitals are much shorter than at state hospitals. According to the case manager reports, 86 percent of the persons admitted strictly to community hospitals left there within one month.

We next compare the lengths of stay at state hospitals of persons with and without "major mental illness." For this analysis we use the sample of 100 state hospital clients for whom our clinical teams had provided us with assessments for "major mental illness." Their lengths of stay are shown in Table 12.

Table 12. Length of Stay for State Hospital Clients Who Had or Did Not Have a Major Mental Illness

Stay	MMI	No MMI
1-7 days	11 %	14 %
8-14 days	8 %	9 %
15-30 days	11 %	20 %
1-2 months	6 %	30 %
2-3 months	11 %	8 %
3-4 months	13 %	5 %
Over 4 months	40 %	14 %
TOTAL	100 %	100 %

Persons with "major mental illness" remain at the state hospitals longer. Only 30 percent left within 30 days (or compared with 43 percent of those not having a "major mentally illness") and 40 percent stayed over four months (or compared with 14 percent of those not having a "major mentally illness").

Length of Stay After Discharge is Recommended

Regarding the state hospitals clients there is a suspicion that a fair number are delayed in returning to community living after their discharges are recommended by the hospital. Under 1984 DD-MH Agreement DDD is to transfer the person out of the state hospital within 30 days after discharge is recommended.

Actual waiting times after "referral" (the point at which discharge is recommended) are shown in Table 13. Forty-four percent of the group did leave within the agreed-on 30 days after referral for discharge, 22 percent stayed for one additional month or less, but 34 percent stayed even longer. The situation appeared better at Eastern State Hospital, where 76 percent left within 30 days after referral. But at Western State Hospital only 42 percent left within that 30-day period.

The delayed discharges consumed 192 bed-months over the two-year study period. Accelerating the discharges of the delayed persons to the point where half of those now delayed left no later than 30 days after referral, according to these data, would free up 96 patient bed-months per biennium (4 beds) at the state hospitals.

Factors contributing to these discharges delays will be mentioned in the next section.

Table 13. Length of Stay After Discharge From State Hospital was Recommended

Stay	
1-7 days	23 %
8-14 days	8 %
15-30 days	14 %
1-2 months	22 %
2-3 months	4 %
3-4 months	11 %
Over 4 months	18 %
TOTAL	100 %

G. COMMUNITY LIVING AFTER HOSPITALIZATION

Almost all the persons we were following did in time return to community living, but half did not return to their previous residences (Table 14).

Table 14. Numbers of People Returning to Previous Community Residences, and Reasons

Percent who did return to their previous residences:	51 %
Percent who did not:	49 %

Reasons for not returning:

No space available	4 %
They wouldn't take him/her	53 %
The client wouldn't go there	11 %
Other	32 %

Thus half of these persons when returning to community living had to face the practical problems and stresses of a new residence, a new neighborhood, and new other persons.

Though the actual residences changed often, the mix of residences that the entire study group was using overall remained largely the same as the mix they had used before hospitalization (Table 15). Even so, there was substantial drop in the proportion living with their own families (from 24 percent of the total group before hospitalization to 14 percent after), and there was a substantial increase in use of state-run DDD facilities: The Residential Habilitation Centers (formerly known as the state schools for the mentally retarded.)

Table 15. Living Arrangements Before and Immediately After Hospitalization

	Percent of entire study group using this living arrangement	
	Before hospital	After hospital
At own place (along or shared), with DSHS support persons coming in part-time (tenant support or chore worker)	17 %	17 %
At own place (alone or shared), with no DSHS support person	5 %	4 %
With own family	24 %	14 %
At a DSHS-paid place with 24-hour staff		
a. MH-specialized facility	4 %	6 %
b. DD-specialized facility or apt.	20 %	16 %
c. DDD facility (RHC)	3 %	11 %
d. Other facility or home for adults	22 %	25 %
Elsewhere (includes jails, no known residence)	6 %	6 %
TOTAL	100 %	100 %

Behavior problems decreased considerably after return to community living (Table 16). There were appreciable reductions in aggression, stealing, physical self-abuse and attempted suicide, and destruction of property. Similar decreases, through of lesser magnitude, are seen in every behavior category, and for both state and community hospital clients.

Even after these decreases, however, the persons who returned to community living continued to exhibit appreciable levels of problem behavior: see the "After" columns in Table 16. Close to half these persons reportedly were still behaving at least occasionally in ways that could pose danger to others or to themselves. As we will discuss later, behavioral programming was still much needed, therefore.

Table 16. Problem Behavior Before and After Hospitalization

	Percent showing that behavior among state hospital patients		among community hospital patients	
Actual or possible danger to others	Before H	After H	Before H	After H
a. Aggressive towards others	73 %	30 %	57 %	43 %
b. Steals	20 %	9 %	62 %	8 %
c. Sexually molests others	7 %	6 %	12 %	7 %
Actual or possible danger to self				
d. Physically self-abusive, self-destructive	21 %	7 %	32 %	21 %
e. Attempts suicide	16 %	4 %	25 %	13 %
Other problems behaviors				
f. Destroys property	51 %	18 %	45 %	37 %
g. Has temper tantrums	40 %	24 %	49 %	41 %
h. Completely withdraws or is severely depressed	28 %	17 %	20 %	16 %
i. Severely hyperactive	20 %	7 %	17 %	11 %
j. Acts unacceptably (e.g., undresses frequently, masturbates in public)	18 %	10 %	21 %	15 %
k. Repeats unusual behavior, e.g., stereotyped, non-adaptive)	16 %	11 %	21 %	13 %
l. Wanders	19 %	11 %	16 %	13 %

One should not credit the reductions in problem behaviors entirely to the programs at the hospitals. The hospitals may well have contributed, but in there is also a natural tendency for extreme behaviors of any sort to fall back toward average levels when observed again later. Also, the case managers may inadvertently have exaggerated for us the before and after behavioral situations. Absent a non-hospital comparison group we have no basis for attributing these behavioral improvements to the hospital stay, to time alone or to any other factor.

Whatever the reasons, the data in Table 16 strongly suggest that problematic behavior did drop substantially during the hospital stays. This suggests that the hospitals may be functioning successfully as places where persons with developmental disabilities and severe socially disturbing conduct may go for care and treatment during the acute phase of such behavioral episodes.

The use of community mental health services increased somewhat after return from the hospital (Table 17). These increases are pervasive though not generally substantial in size. For example, the use of community mental health services overall increased only from 50 percent before hospitalization to 55 percent after discharge. (One should keep in mind that these increases in use of mental health services are occurring even as persons behavioral problems are decreasing.)

Table 17. Use of Mental Health Services Before and After Hospitalization

	Before hosp	After hosp
Using some mental health service	50 %	59 %
- Medication management	28 %	32 %
- Individual counseling	27 %	36 %
- Group therapy	10 %	12 %
- Day treatment	10 %	17 %

While there is this improvement we are also left with the fact that 45 percent of the total group were reportedly not connected with mental health services even after return from their mental hospitals.

As a refinement, Table 18 shows the use of mental health services before and after hospitalization for the group of state hospital clients for whom our clinical teams evaluated presence or absence of "major mental illness." Keep in mind, however, that persons without "major mental illness" may still require outpatient mental health services. Bruininks, Hill and Morreau, (1988), reviewing the literature, estimated the prevalence of mental illness among persons with developmental disabilities at between 5 and 13 percent. Lewis and MacLean, in an earlier review article (1982), concluded: "The available studies lead to the inescapable conclusion that emotional disorders are much more common among mentally retarded persons than in the general population. This conclusion is based on investigations using very different patient samples and very different methodologies." (p.7)

Table 18. Use of Mental Health Services Before and After Hospitalization, by Persons Having or Not Having a "Major Mental Illness"

	Use by persons with a "major mental illness"		Use by persons without a "major mental illness"	
	Before H	After H	Before H	After H
Using some mental health service	60 %	71 %	45 %	54 %
- Medication Management	33 %	38 %	22 %	24 %
- Individual counseling	17 %	19 %	22 %	29 %
- Group therapy	14 %	10 %	7 %	6 %
- Day treatment	17 %	26 %	5 %	2 %

Mental health services of some sort were being provided even before hospitalization to 60 percent of the group assessed as having a "major mental illness," as against 45 percent of those without "major mental illness." And after hospital discharge use of mental health services increased for both groups: from 60 to 71 percent for the group with "major mental illness," from 45 to 54 percent of the group with no "major mental illness."

The post-hospital picture, while it reflects an improvement, is far for ideal. It appears that 29 percent of the persons with "major mental illnesses" return to community living without being connected with mental health services, which services we may presume are necessary for every one of these persons.

The use of adult habilitation and behavioral interventions is appropriate for everyone in the study group as all are clients of the developmental disabilities program and as many still have some severe problematic behaviors. Participation of the study group in employment or other adult habilitation is shown in Table 19.

Table 19. Participation in Employment or other Adult Habilitation Before and After Hospitalization

	Percent of entire study group participating in weekday programs	
	Before hospital	After hospital
Employed on their own	2 %	4 %
Receiving DD vocational supports	26 %	32 %
In any other DD day program	4 %	8 %
In a mental health day treatment program	10 %	20 %
None of the above	58 %	36 %

Although there has been some improvement over the pre-hospital situation, even after return to community living 36 percent of these persons reportedly are not participating in work or other day habilitation.

H. SERVICES AND SUPPORTS STILL NEEDED

We did not contact the clients or ourselves assess the supports they were using. This is an exceptionally difficult group to contact and study in person, and doing so fell beyond the time and resource scope of this project. Thus this report does not directly estimate clients' aggregate support needs and the portions met and unmet.

Even so, from our data, we can make some observations about unmet needs and the reasons for those. Two areas where needs are only partially met can be seen in the data we just examined on post-hospital mental health and habilitation services.

Mental health services of any sort were reportedly not being provided to 29 percent of those with "major mental illness."

Employment or other adult habilitation was reportedly not available to 65 percent of the entire study group.

Additionally, there is some indication from the case managers that suitable residences were in short supply. The case managers, asked what problems they encountered in returning the client from the hospital, principally noted that suitable programs were not readily available (Table 20).

Table 20. Problems Encountered in Returning Persons To Community Living (As Reported by Case Managers)

For 64 persons discharged later than 30 days after referral

	Percent mentioning this problem
Appropriate services not available	33 %
Provider refused	30 %
Client or family refused	16 %
Procedural problems	5 %
Arrangements proved inappropriate	4 %
Other	7 %

Such shortages are especially noted for persons whose discharges took more than 30 days from date of referral; the delays apparently resulted from having to wait for a suitable residence to come available.

There may also be a need for additional behavioral programming, in view of the continued prevalence of difficult behaviors (Table 16). The data do not indicates how important this need may be or how this behavioral programming should be provided: at the residence by special staff, by general care staff, by day programs, through counseling, etc. The claimed shortage of appropriate residences may reflect a need for residences specially able to handle these persons' difficult behaviors.

For more information about unmet needs we asked each case manager what additional community supports the manager would have liked to provide the client (Table 21). The data provide some indication of what services and supports are needed most. The principal requests from the case managers are for mental health services (or counseling) for the client and/or their family and vocational or other day programs.

Table 21. Additional Supports Case Managers Would Have Liked to Provide

	Percent mentioning this support
Mental health services, counseling	34 %
Vocational or other day programs	28 %
Mental health - specialized residence or better prepared staff	8 %
Social experience	8 %
Behavior management services	8 %
More DD-funded residences	6 %
No additional supports; none available	10 %

Note: Percentages based on 120 replies from managers of 175 cases.

We then asked each case manager why these needed services and supports were not being provided, particularly if those services were available in the community at large. The reasons are shown in Table 22.

Table 22. Reasons Why Needed Supports Are Not Being Provided (From Case Managers)

	Percent mentioning this reason
Insufficient capacity or funding	38 %
Person will not accept or cooperate	21 %
Mental health provider will not serve	13 %

Note: Percentages based on 103 replies from managers of 175 cases.

We also asked case managers to indicate the functional levels of their clients. This gives us some information to help guide the design of support programs. In particular, in 66 of the cases the case managers indicate that the client need frequent or constant help in community survival, and in 72 percent of the cases that the client needed frequent or constant help in employment.

I. STATE COSTS

Over the two-year study period we estimate by combining various DSHS records that DSHS paid about $12 million to support these 275 persons. On average, this comes to about $22,000 per person per year. The cost components are shown in Table 23.

Table 23. Estimated DSHS Costs To Support These 275 Persons Over The Two-Year Study Period

A.	Community residential care and related:	
	DDD-paid residences and supplemental svs.	$ 2.96 million
	Residential habilitation centers	4.55
	MHD-paid residences	0.15
	Other DSHS-paid residences	0.66
	TOTAL, residential care	$ 8.33 million
B.	Adult day program:	
	DDD-paid vocational supports	0.62 million
	MHD-paid day programs	0.10
	TOTAL, adult day programs	$ 0.72 million
C.	Community mental health and behavior therapy services	$ 0.23 million
D.	Community medical care	$ 0.48 million
A-D.	TOTAL for community care and supports	$ 9.76 million
E.	State hospital care	$ 2.09 million
F.	Community psychiatric inpatient care	$ 0.28 million
A-F.	GRAND TOTAL, all costs	$12.13 million

Our estimating methods are described in the Study Methods chapter. To be able to use available data we relied on several estimating methods, rather than a single consistent cost accounting scheme. These figures cannot be used to estimate the additional state costs (or savings) of a new initiative (or program reduction).

Community care and supports as a group accounted for 80 percent of total expenditures, and residential care was by far the largest community expense. Costs for adult day programs and community mental health services were low in part because many persons were not getting those supports (Tables 17, 19). Also, the community mental health expenditure figure does not include DDD expenditures for outpatient mental health services for clients who do not meet community mental health centers' eligibility priorities.

The $280,000 two-year state expenditure for psychiatric care at community hospitals is considerably smaller than the $2.09 million figure for state hospital care. This difference is partly due to lower use of the community hospitals; stays there were considerably shorter (Table 11). We estimate that the 275-person group used about 6,200 community hospital days over those two years, and 16,300 state hospital days. (The latter figure includes 2920 days for four persons who lived at the state hospitals contnuously over the two-year study period.)

Also, the community hospital cost figure represents the state's actual payments for services to these persons, whereas the state hospital figure is based on hospital days used times average (billable) cost per day. This cost per day figure, estimated by cost accounting, is not the same as payments actually made. The state payments figure is lower as it does not take into account services provided by the community hospitals and paid by others, in particular by third-party insurers or Medicare, or charges disallowed by the state.

STUDY METHODS

Overview

We set out to study adult DD clients who had recently been psychiatric inpatients, specifically within the last two years. We identified these people from two sources: state hospital records and DD case managers. Any individuals admitted to both state and community hospitals in the study period were included in the state hospital group, as we were primarily interested in use of state resources.

Our population includes 275 individuals:

132 were admitted only to community hospitals,
87 were admitted only to state hospitals,
56 were admitted to both state and community hospitals.

We then proceeded to find out about these individuals, particularly about the events surrounding their psychiatric hospitalizations: their situation before hospitalization, the precipitating incident, the situation after hospitalization. If the individual had more than one hospitalization in the two-year period, we focused on their most recent state hospitalization.

Our information about pre and post-hospital situations was obtained by interviewing the client's DDD case manager, using a 12-page schedule of questions, distributed in advance. Data about the hospitalization itself were obtained from hospital records, including the psychiatric summary and the social status report at admission, annual reviews, and discharge summaries. Hospital records could be reviewed only for state hospitals, as we did not have access to community hospital records.

Resource limits required we use stratified sampling. We studied 100 state hospital cases, which is a little over two-thirds of all the 142 clients in the state hospital group. The 100 cases to be studied were allocated proportionally between Eastern State Hospital and Western State Hospital. Then the clients at each hospital were ranked by the length of time they had spent in the hospital during the study period. The clients with the most hospital time were selected for study, until half of the study openings at each hospital were filled. The remaining slots in each group were selected by random selection among the remaining cases at each hospital.

One of our two-person clinical teams reviewed the hospital records of each person in the state sample and decided whether the client had a "major mental illness", as defined by the 1984 DD-MH Agreement.

Data on costs of services were obtained from DDD, MHD and the Division of Medical Assistance. For each person, DMA provided data on actual expenditures over the study period. DDD and MHD provided average costs for its service types, and we multiplied these by the service quantity information we had gotten from the case managers for our sample of 175 persons.

Delineation of Study Period

We wanted a time period recent enough to show current administrative practices; we wanted in far enough in the past for most of the clients to have been discharged from the hospital; we did not want it so far in the past that memory of the incident would have been lost by the DD caseworkers who would be providing us much of the information we would need. Finally, the time period had been long enough to be unaffected by seasonal fluctuations or temporary idiosyncracies, and to include a sufficient number and reasonable cross-section of cases.

On the basis of preliminary data and discussions, we decided that a two-year span would be long enough to provide the data we were interested in and be buffered from short term fluctuations. The ending date of the time period was placed as close to the start of data collection as feasible. This put the study period running from April 1, 1986 through March 31, 1988.

Definition of Population

To be considered a member of the population, an individual had to meet two criteria:

1) He or she had to have been determined eligible for DDD services. We ourselves, did not identify and screen potentially eligible individuals.

2) He or she had to have been a psychiatric inpatient in Washington state at some time in the two-year study period.

Enumeration of Population

We decided to enumerate the population as two study groups:

(1) Those who had been admitted to either of the two Washington state psychiatric hospitals, (state hospital study group) and

(2) Those who had been admitted only to a psychiatric unit at a community hospital, (community hospital study group) .

An individual with admissions to both community and state hospitals was included in the state hospital study group and not in the community hospital group. Data on all hospitalizations were collected later, so that members of the two study groups could be identified. This division into two study groups using the rule above, was made in the interests of enumerating non-overlapping sampling frames.

The state hospital group was identified from records maintained by the hospital liaison personnel. The liaison staff are expected and required to maintain contact between the hospital and the DDD. Their duties include contacting DDD and arranging for outplacement when a developmentally disabled client is ready for discharge, and referring hospital patients who appear to be developmentally disabled to DDD for determination of eligibility.

We believe the records maintained by the liaison offices were substantially complete. It is possible, however that a few DD-eligible persons at the state hospitals may not have been identified to the liaison officer.

The community hospital study group was enumerated by asking DDD Field Services caseworkers to list all DDD clients who were known to have been admitted to a community hospital psychiatric unit in the study period. These names were returned to us and checked for duplications between offices and with the state hospital group. A list was compiled of those admitted to community hospitals, but not to either state hospital, was compiled.

Our estimates of state hospital admissions are probably fairly accurate as we identified these from the state hospitals' own records, supplementing this information with our DDD case manager interviews. The community hospital admissions figures may be underestimates as we obtained these data only from the case managers, not from community hospital records. Securing psychiatric admissions data from the state's many community hospitals was beyond the resources of this project, and would have been complicated as confidential hospital records could be accessed by the state only after approval by each hospital's administration and institutional review board.

The case managers whom we interviewed did not always know every client's every psychiatric admission, and in some cases their memories (or records) of dates were imprecise. Sometimes the case managers had not had these particular individuals assigned to them at the times of hospitalization. And in some instances the case managers were not informed of a client's hospitalization till later, if at all. Such psychiatric admissions, particularly to community hospitals, will more often involve the county designated mental health professional and the residential provider and family.

Structure of the Sample

A total of 85 clients with Western State Hospital admissions and 57 with Eastern State Hospital admissions in the study period were identified. Of these, 6 had admissions to both hospitals. All of these had started at Western and been transferred to or readmitted at Eastern. Individuals were assigned to their most recent hospital for purposes of drawing a sample.

Within each study group, clients were ranked by duration of hospitalization within the study period. We were most interested in a complete description of individuals with extended hospitalizations, so we decided on a stratified sampling scheme that would study all the clients with the longest hospitalizations, and a random selection of the others. Our resources were sufficient to study a total of 100 state hospital clients. We apportioned these 100 openings between the two state hospitals. Then we started down the list of clients at each hospital, selecting clients with the most hospital time, until we had half the needed cases at each hospital. The samples were then filled by randomly selecting among the remaining clients. The initial sample sizes are: 30 longer term and 31 shorter term clients for Western, and 19 longer term and 20 shorter term clients for Eastern.

A replacement case was drawn for one client when it looked like we would not be able to get pre-hospitalization data. Data on the original case was ultimately collected, so a total of 101 cases were reviewed. The estimates given in the Findings chapter are all population estimates extrapolated from the sample cases.

The original strictly community hospital study group list included 161 names, nominated by case managers. We wanted a sample of 75 from this list. It turned out we had to draw 91 to get the 75. In 16 cases, the hospital episode recalled by the case worker turned out either not to have resulted in admission or to have occurred before the study period. Assuming that there is no systematic difference between the sample cases reviewed and the others on the original list of nominees, we conclude that 16/91 = 17.6 percent of the nominees do not really belong on the list. This gives us an adjusted estimate of 133 clients in the study community hospital study group.

Data Collection Procedures

Clinical Reviews

Hospital records were examined for the 101 selected hospital clients. Copies were made of the admission papers, annual updates, and discharge summaries. These were made available to two clinical review teams.

Each clinical review team was made up of a psychiatrist and a masters level social worker or psychologist. They were asked to review the hospital records and indicate whether they thought that the patient showed a "major mental illness" at the time of admission. (Note that both DD professionals had psychometric or psychiatric diagnostic training or experience.)

Our use of the concept of "major mental illness" follows the 1984 DD-MH Agreement. For details of the agreement, see page 15.

The review teams scanned the documents provided, looking for evidence of the symptoms of a "major mental illness." Decisions were made primarily on the basis of this information. But as the documents rarely included information about the client's ordinary level of functioning, the criterion of perturbations from normal could not be addressed.

One review team, with primary affiliations at Western State Hospital, reviewed the cases from Eastern State Hospital. Both members of this team were Mental Health Division staff. One was a psychiatrist and the other a social worker. The second review team was composed of DDD staff. One member worked in a DDD field office in Eastern Washington, and dealt with clients who would be treated at Eastern State Hospital. The second member was a psychiatrist who split his time between a DDD Residential Habilitation Center, a community hospital, and a private practice. He had little contact with either state hospital. This second team reviewed the cases from Western State Hospital.

Ten cases from Eastern State Hospital and eleven from Western State Hospital were randomly selected. These cases were reviewed by both teams, as an inter-rater reliability check. We found that in 76 percent of the cases the review teams agreed (Table 24). And, whenever the Mental Health review team diagnosed a major mental illness, so did the Developmental Disabilities team.

Table 24. Percent Interteam Agreement on Is there a "Major Mental Illness?"

		DD reviewers decided: YES	NO	All 21 cases
MH reviewers decided:	YES	8/21= 38 %	0/21= 0 %	38 %
	NO	5/21= 24 %	8/21= 38 %	62 %
All 21 cases		62 %	38 %	100 %

The latter observation -- that the disagreements all involve cases where the MH team failed to find a major mental illness and the DD team did -- suggests that the individuals in the MH team were more stringent in the level of evidence they demanded.

It appears that DD workers are more liberal in seeing mental illness than are mental health workers. From the point of view of DD workers, this is perhaps a failure on the part of the mental health workers: they are focusing on the developmental disability -- about which there is no disagreement -- and allowing it to "overshadow" the evidence of an underlying mental illness. From the point of view of the mental health workers, they are making accurate diagnoses, but they are doing it in the face of factors that cloud the evidence. Indeed, they argue (and have argued directly to the researchers writing this report) that individuals with developmental disabilities may learn to act as if they had a major mental illness after they are involuntarily admitted to a mental health hospital. They are therefore willing to discount some of the evidence of mental illness as learned, imitative behavior.

Case Worker Interview

Each client's DDD case worker was identified, with the cooperation of the DDD field office supervisors, and asked to fill out a questionnaire about the client. The questionnaires were distributed by mail and the case workers visited and interviewed one or two weeks later. The intent of the questionnaire was to gather data on the services being offered to the client before and after hospitalization, and data on the incident precipitating hospitalization. We wanted to be able to address the issue of the relationship between DDD and MHD at two junctures: As the need to hospitalization arose and some measures to address a crisis had to be undertaken, and as the patient neared discharge and was referred to DDD for outplacement. The questionnaire itself is attached.

By persistent follow up, and the fact that replying to the survey was defined as part of the case manager's job, we were able to obtain data on all our ultimately selected cases. Still, some individual item are missing. Case managers were not always personally familiar with the incidents, often because the client had become part of the case worker's load after the hospitalization. In some cases there were multiple hospitalizations, and incidents had telescoped in the case worker's mind. Finally, there may be some incidents, especially community hospitalizations, that were simply unknown to the case managers.

Cost Estimates

To take advantage of available data we used a variety of cost estimating methods rather than a single consistent cost-accounting scheme.

To estimate costs of community health and mental health services, and psychiatric inpatient care at community hospitals we determined actual payments made by the Medical Assistance program on behalf of each of the 175 individuals in our sample. These payments are made through the Medicaid Management Information System (MMIS), which is the source of these data.

The estimate of community hospital costs includes all MMIS payments for psychiatric inpatient care, also psychiatric physician services provided during a hospitalization, also involuntary treatment services, also all inpatient hospital care, physician care and diagnostic-related group charges, the latter three categories only if there was a psychiatric diagnostic code.

To estimate community mental health and behavior therapy service costs we included all MMIS payments for outpatient psychiatric services, also psychiatric physician services provided outside dates of hospitalization, also all drugs, also any other mental health services except mental health day program. Also included here were any DDD payments for professional and therapeutic/training services.

To estimate costs of community residential care, day programs and state hospital care, from our interviews with case managers we determined the approximate dates and duration of each service, and then multiplied the hospital days by unit prices (such a cost per person-day or person-month) which we obtained from program staff. For the state hospitals we used each hospital's standard billing rate for the programs these persons typically used. The community residential costs also include any DDD payments for additional staff or attendant care and skill training.

The community residential cost estimates are uncertain for several reasons. (a) The dates the case managers told us were approximate and subject to memory distortion. In some cases the case managers might not have known all the services provided or dates.

(b) The unit price estimates were averages for that service category, and did not take into account that services for these typically more difficult clients might be more expensive.

(c) In some cases the state had already prepaid for services in bulk as it were, and actual ("marginal," to the economist) state payments for the particular client were low or non-existent. This is especially so for state hospitals, Residential Habilitation Centers, community evaluation and treatment centers and some community mental health services. In all but the latter we used average per-person-day figures, based on total annual expenditures divided by total person-days. For practical reasons we could not easily do this for community mental health centers, and there we include only services actually paid through Medical Assistance.

Also excluded for the same reason is the cost of the case management services provided by DDD Field Services staff and in some cases by DDD institution-based Habilitation Program Administrators. The persons in our study were often provided very considerable case management assistance, but the amounts are not easily estimated and, in any case, this service too is prepaid and provided at no charge.

(d) Because of practical difficulties in tracking individual clients and department accounting arrangements we did not estimate state and federal cost shares. Doing so would be especially difficult for community mental health services as the centers use their state block funds as the match to recover federal share of Medical Assistance charges.

Because our cost estimates include fixed and variable cost components these figures cannot be used to estimate the true additional costs of new initiatives.

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