

A SURVEY OF FAMILY SATISFACTION
WITH REGIONAL TREATMENT CENTERS AND COMMUNITY SERVICES
TO PERSONS WITH MENTAL RETARDATION IN MINNESOTA

with

EXECUTIVE SUMMARY

Welsch v. Gardebring Class Members

July 1988

Conroy & Feinstein Associates
2241 Wallace Street
Philadelphia, Pennsylvania 19130

Office of the Monitor
40 N. Milton St. - Rm. 106
St. Paul, Minnesota 55104

EXECUTIVE SUMMARY

This report presents the results of our survey of family satisfaction with services of certain Welsch class members. In June 1987, a 21-question survey was mailed to the families of 164 persons who had been discharged from a regional center to a community placement during 1985 and 1986. We received a very high response, with 110 families (69.6%) returning the completed survey. Highlights of the findings include:

-- On average, family satisfaction with the services provided to their relatives increased after the person moved from a regional treatment center to the community.

Illustrative of the results are the following:

(1) 88% stated they were somewhat or very satisfied with services in the community, while 61% had expressed the same levels of satisfaction with RTC services.

(2) This same high level of satisfaction with services in the community was expressed by family members of persons with severe multiple handicaps or behavior problems.

-- The majority of families (76%) agreed with the community placement decision; and of those who did not, almost all changed their minds following their relatives' discharge from the regional center -- now agreeing with community placement for their relatives.

-- Families are now making more frequent visits than when their relatives were living in a regional treatment center,

although the size of the community living arrangement appears to influence the number of visits with fewer visits the larger the facility In addition, families are now traveling about half the distance to visit relatives than when their relatives lived at a regional center.

FORWARD

As described in more detail in the text, this report describes the results of a satisfaction survey of parents and other family members of persons discharged from state regional treatment centers (formerly called state hospitals) in 1985 and 1986. Family members were sent questionnaires regarding their feelings and views on the community placement process, the services their family member is now receiving, as well as the services received previously at the regional treatment center. It was conducted by the Office of the Monitor between June through August 1987. Therefore, while most of the survey was performed while the *Welsch v. Gardebring* Consent Decree was still in effect, and prior to August 1987, the effective date of the Negotiated Settlement, Section VIII B (6) (e) of the Settlement comes into play. That provision authorizes the monitor to publish reports "provided that the provider or agency affected is afforded an opportunity to review the report ... and is afforded reasonable opportunity ... to submit a written response ... to be incorporated into the report" As the aforementioned satisfaction survey does constitute such a report, notice was given to the Department of Human Services. The Department's Director of the Policy Coordination Division, Jane Delage, by letter pointed out several minor errors in the draft and also cautioned that the results should not be understood to reflect the views of family members of current residents of regional treatment centers. Several changes were made to reflect these points. A copy of Ms. Delage's letter is attached as Appendix C.

The results were analyzed by Celia S. Feinstein, James A. Lemanowicz and James W. Conroy of Conroy and Feinstein Associates of Philadelphia, Pennsylvania, who submitted a report to Richard Cohen, Office of the Monitor, in May 1988. The following is the report with additional analyses and contributions from the Monitor's Office.

This joint effort included contributions of Elizabeth Carlson, Research Assistant, and Trudy Koroschetz, Office Manager, both of the Monitor's Office, in the design and content of the survey and the analyses and reporting of the survey results. Appreciation is also extended to Charles Lakin of the Minnesota University Affiliated Program for his feedback on the design of the survey and the preliminary results.

Richard A. Cohen
Monitor

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Introduction

This report presents results of a survey of families conducted by the Office of the Monitor in the case of Welsch v. Gardebring. One of the duties of the Monitor is to evaluate services to current and past residents of State Regional Centers; (formerly known as state hospitals). One of the ways to evaluate services delivered to individuals is to survey their families, who are often seen as "secondary" consumers of service. The report that follows presents the results of a survey of families of formerly institutionalized individuals.

Prior Research

Families have received little systematic attention in the policy making process in the field of developmental disabilities. Certain vocal and articulate families have always been accorded access to decision makers. But this type of political process is unsystematic in two important ways: (1) it practically assures that the only news that state officials will ever get from families; will be bad -- only the "problem cases" ever reach them, and (2) the families less gifted with assertiveness, verbal skill, and/or influence are never heard from. More broadly based surveys of the families of people with mental retardation are becoming a more frequently used and valued tool for assessing the

quality of services and for obtaining input for the policy making process (Conroy & Bradley, 1985; Covert, Hess, & Conroy, 1985; Bradley, et al., 1984).

Families of people in public institutions have been very satisfied with the facilities, and opposed to changes such as community placement. Surveys have been conducted in several states (Klaber, 1969, in Connecticut; Brockmeier, 1975, in Nebraska; Payne, 1976, in Texas; Wilier, Intagliata, & Atkinson, 1979, in New York; Meyer, 1980, in western Pennsylvania; Keating, Conroy, & Walker, 1980, in eastern Pennsylvania; Frohboese & Sales, 1980, again in Nebraska; Atthowe & Vitello, 1982, in New Jersey). Keating, Conroy, & Walker (1980), as part of the Pennhurst longitudinal study, found similar patterns in eastern Pennsylvania.

In addition to these local studies, Spreat, Telles, Conroy, Feinstein, & Colombatto (1984) reported on a national survey of the families of people living in public institutions. The same patterns of opposition to community placement were found in the national sample as in the local samples, including much stronger opposition among families of people perceived to be more seriously impaired.

The only study to date in which family feelings were assessed before and after community placement was the Pennhurst Longitudinal Study (Conroy & Bradley, 1985). From initial opposition, the families changed dramatically to overwhelming surprise and delight with the new community based arrangements. They felt that their relatives made stides that they thought impossible. They were pleased with staff and they perceived

their relatives to be happier in the community arrangements. They maintained, however, their serious concerns about the permanence of community programs and funding.

Methods

The sample for this study included the families of one half of the individuals who were discharged from Regional Treatment Centers (RTC) during 1985 and 1986 to a community placement. The sample did not include inter-institutional transfers nor individuals who were admitted for respite or a short term order (e.g., 3 days) and then discharged. From a list of all individuals who were discharged in 1985 and 1986, every other individual who was discharged (all even-numbered individuals on the Monitor's lists) was included in the sample. In addition, questionnaires were sent to the parents of children who had been discharged, and who were the subject of extension requests under paragraphs 17-20 of the Consent Decree. As with the rest of the sample, these were individuals who were discharged in 1985 and 1986, but who were not chosen during the random selection process. This added 4 individuals to the random sample, 3 of whom returned completed surveys. The survey and cover letter from the Monitor are included as Appendix A.

In early June questionnaires were sent to the selected parents/family members. Six were returned with incorrect addresses, leaving 158 surveys that could potentially be returned. By the second week in July, 88 were returned completed. Around the third week of July reminder postcards were sent to the remaining 67 families. Of those 67, 22 returned

completed surveys. When you add the 22 to the original 88 returned a total of 110 surveys were returned for a response rate of 69.6%. This response rate is quite high when compared to similar surveys performed in other states (e.g., Connecticut and Pennsylvania). Possible explanations for the increased response include the recency of the discharge of the individuals to community placements, and the follow-up postcards which increased the response rate considerably. Minnesota has a strong tradition of consumer involvement and awareness which may have also accounted for the difference.

Instruments

The 1987 survey form was designed by modifying and shortening the survey that was used for the Pennhurst Longitudinal Study (Conroy and Bradley, 1985). More detail was collected about family visits and the distance and time it took families to get to their relatives' homes both in terms of distance and time. The final form contained 21 items. The areas covered were satisfaction with services, demographics, frequency of visits, agreement with ideas such as deinstitutionalization, as well as a comparison of services at the RTC and in the community residence. The major difference between this survey and the survey used in the Pennhurst Study was in how they were administered. In the Pennhurst Study this survey was mailed to the families of all residents of Pennhurst Center in early 1980. As individuals left Pennhurst their relatives were resurveyed approximately 6 months post discharge. This is known as a pre-

post survey, where families were surveyed both before and after community placement occurred for their relatives.

In Minnesota surveys were sent to families only after their relatives had moved. Families were asked, retrospectively, how they felt about the services their relatives received while in the Regional Treatment Centers (RTCs). Families were also asked how they feel currently about the services their relatives are receiving.

Results

We received 110 completed forms. On the front page of the questionnaire the Office of the Monitor listed the class member's name, age, residence, day program, county, Regional Center discharged from and the date of discharge. In addition, as the surveys were returned, the Monitor entered on the front page, the size of the residential facility, and whether the individual experienced any overriding medical or behavioral challenges. The results indicated the average class member is 38 years old, with a range of from 9 to 86 years of age. The average class member lives in a site that serves 21 individuals, with a range of 2 persons to 165 persons. The average size may be misleading, however, as means are greatly affected by extreme values (i.e., there are only two class members living in settings with 165 individuals). Therefore, it may be useful to report the median which is less sensitive to extreme values. The median is that point above which 50% of the cases fall and below which 50% of the cases fall. For the size variable, the median is 12, which is smaller than the mean reported number of 21. Because there were

so many counties in which individuals live, for reporting purposes we collapsed the counties into their respective State Hospital Receiving Districts (SHRD). The SHRD broke out as follows:

TABLE 1

SHI D	Number of Persons	Percent
Fergus Falls	11	10
Willmar	11	10
St. Peter	13	12
Faribault	30	27
Cambridge	21	19
Brainerd	22	20
Moose Lake	2	2

The disposition of the sample in terms of the Regional Treatment Center (RTC) from which the individuals were discharged is as follows:

TABLE 2

RTC	Number of Persons	Percent
Fergus Falls	11	10
Willmar	11	10
St. Peter	10	9
Faribault	26	24
Cambridge	31	28
Brainerd	19	17
Moose Lake	2	2

The two tables show that most individuals were placed in the same geographic area in which the RTC is located.

Of the 110 individuals, 7 individuals experience challenging behaviors and 22 individuals experience physical disabilities (non-ambulatory and/or severe hearing and/or severe visual impairments).

This second question on the survey form asks for the relationship of the respondent to the Welsch class members. The respondents were in the following categories:

TABLE 3

	Number of Persons	Percent
Mother	53	48
Father	18	16
Mother and Father	7	6
Other	32	29

In the first section of the questionnaire we asked the respondents to answer questions about both the distance and time it took to get to the RTC and the distance and time it takes to get to the place where their relatives currently reside. The average family member lived 55 miles from the RTC, and it took approximately one hour and 10 minutes to get there. Currently, the average family lives 20 miles from the place where their relatives live and it takes 30 minutes to get there. On the average, families are now travelling about half the distance that they were when their relatives were living in the institution. One of the goals of deinstitutionalization is to bring families closer together, making it easier for visits to occur and for relationships to build and strengthen. Clearly in Minnesota, for Welsch class members, efforts have been directed to bringing families closer together. There were four questions on the survey that tried to examine whether, as a result of deinstitutionalization, families are in closer touch with their relatives. The first two questions were, "How often did you visit your relative at the RTC during the last 5 years s/he lived there," and, "How often did your relative visit you at home from

the RTC:" The next two questions, were "How often have you visited your relative at the current community placement," and, "How often has your relative visited you at home from his/her community placement?" The responses are displayed in the following table.

TABLE 4

	Visit to RTC	Visit to Community Placement	Visit from RTC	Visit from Community Placement
Weekly	9%	18%	3%	7%
Monthly	34%	33%	16%	23%
3-4/year	26%	29%	20%	17%
Yearly	19%	8%	14%	11%
Less than Yearly	6%	4%	9%	4%
Never	5%	8%	38%	39%

Visits to the community home and visits to relatives from the community homes have increased on the average. At the RTC, 43% of the families visited monthly or more, and in the community that number has increased to 51%. At the RTC class members visited their families at least monthly for 19% of the class members, while in the community that number increased to 30%.

It appears, however, that the same number of families who visited infrequently or never at the RTC, visit infrequently or never to the community program. We also found a relationship between the size of the community living arrangement and the frequency of visits, with fewer visits to larger facilities. The results of the first two questions by RTC, and the second two questions, by Regional Service Specialist (RSS), are presented in the following tables. Regional Treatment Centers are abbreviated as follows:

Fergus Falls	FF
Willmar	Wil
St. Peter	St.P
Faribault	Fair
Cambridge	Cam
Brainerd	Bra
Moose Lake	ML

TABLE 5
VISITS TO RTC
N = 109

	Regional Treatment Center							
	FF	WIL	St.P	Fair	Cam	Bra	MT.	
Weekly	11%	10%	18%	4%	10%	9%	0%	9%
Monthly		40%	45%	38%	30%	9%	0%	34%
3-4 times/year	16%	27%	9%	23%	50%	36%	50%	26%
Once a year	37%	3%	27%	19%	10%	36%	0%	19%
Less than yearly	0%	13%	0%	8%	0%	9%	0%	6%
Never	5%	7%	0%	8%	0%	0%	50%	6%
Total number of people	19	30	11	26	10	11	2	109

TABLE 6
VISITS HOME FROM THE
RTC N = 109

	Regional Treatment Center							
	FF	WIL	St.P	Fair	Cam	Bra	ML	
Weekly	0%	7%	0%	0%	0%	9%	0%	3%
Monthly	21%	20%	9%	23%	10%	0%	0%	17%
3-4 times/year	16%	20%	36%	11%	50%	0%	50%	20%
Once a year	16%	10%	27%	15%	10%	9%	0%	14%
Less than yearly	16%	13%	9%	4%	10%	0%	0%	9%
Never	32%	30%	18%	46%	20%	82%	50%	38%
	19	30	11	26	10	11	2	109
Total number of people								

TABLE 7
 VISITS TO THE COMMUNITY LIVING ARRANGEMENT (Percent)
 N = 108

	Region											TOTAL
	1	2	3	4	5	6	7	8	9	10	11	
Weekly	0	0	14	17	0	14	33	0	20	25	14	17%
Monthly	40	0	29	50	75	14	28	25	10	50	33	33%
3-4 times/year	40	0	14	33	0	29	28	50	50	17	28	28%
Once a year	20	0	29	0	0	29	6	0	10	0	6	8%
Less than yearly	0	0	0	0	0	14	0	25	0	0	6	4%
Never	0	100	14	0	25	0	6	0	10	8	8	8%
Number of people	5	1	7	6	4	7	18	4	10	12	36	110

TABLE 8
 VISITS FROM THE COMMUNITY LIVING ARRANGEMENT TO FAMILY (Percent)
 N = 106

	Region											TOTAL
	1	2	3	4	5	6	7	8	9	10	11	
Weekly	0	0	0	17	0	0	0	0	10	17	3	6%
Monthly	20	0	29	0	50	0	11	0	10	17	39	22%
3-4 times/year	20	0	14	33	0	0	22	25	30	0	17	16%
Once a year	20	0	14	17	25	14	0	0	20	17	8	11%
Less than yearly	0	0	0	17	0	0	6	0	0	0	6	4%
Never	40	100	43	17	25	86	39	75	20	50	25	37%
Number of people	5	1	7	6	4	7	18	4	10	12	36	110

Question 6 asked families retrospectively, how satisfied they were with the services their relatives were receiving at the RTC. The responses could range from very satisfied (a score of 5) to very dissatisfied (a score of 1). The average score was 3.5, indicating that the average family was somewhere between neutral and somewhat satisfied.

The next question asked how families felt about their relatives' proposed discharge to the community. The average score was 3.8, indicating that families were somewhat in agreement with the decision. Twenty-two percent of the families (n=24),

however, reported having been in disagreement with the decision to move their relatives to the community. The responses to the two questions above are presented in Tables 9 and 10 by Regional Treatment Center (RTC). These results are somewhat different from those of the Pennhurst Longitudinal Study (Conr & Bradley, 1985). In that study the average family or a Pennhurst class member reported being very satisfied with services at the institution, and opposed to any decisions to move their relatives to the community. Seventy-two percent of the families in the baseline study said they would have disagreed with the decision to move their relatives to the community. However, once the move actually occurred, families reported being extremely satisfied with their relatives' placements. It seems that in Minnesota, families; were much more likely to be in agreement with the community placement from the beginning.

However, similar to the Pennhurst study is the turn around on the part of the families who disagreed with the decision. Of the 24 families who fall into this group, the vast majority of them now express agreement with the decision. In fact 18 (75%) now report agreement with the community placement, 2 indicate neutral feelings, and only 3 families (13%), report continuing disagreement, with one family not answering this item.

These responses are also consistent with the families' answers to questions concerning their current overall satisfaction level with their relative's community placement. The average score here was 4.5, indicating that families are currently satisfied with the placements, and are even more satisfied than

they were initially. As show in Table 11, 90% of all the respondents indicated they were very or somewhat satisfied with their relatives' community placement.

Table 11 presents the responses to this question by region, while Table 9 shows the results on family satisfaction with services at the RTC and the extent of their agreement with the decision to place their family member in the community. It should be noted that the survey did not attempt to ascertain the respondents' knowledge of their relative's legal rights to various services or the respondents' knowledge of service options at the RTC's or in the community.

As concern is often expressed about the community's capacity to serve persons with severe physical or sensory impairments or challenging behavior problems, we analyzed the responses of the family (numbers of persons in those groups. We found no significant difference between their level of satisfaction with the community living arrangements in which their family members were placed. Their respective levels of satisfaction were also high and with ratings almost identical to the sample as a whole.

TABLE 9 SATISFACTION WITH SERVICES
AT THE RTC

	Regional Treatment Center							TOTAL
	FF	Wil	St.P	Fair	Cam	Bra	ML	
Very satisfied	46%	40%	29%	38%	29%	24%	0%	32%
Somewhat satisfied	36%	20%	14%	21%	29%	47%	50%	29%
Neutral	9%	30%	14%	25%	11%	12%	0%	16%
Somewhat dissatisfied	9%	0%	43%	8%	18%	18%	50%	15%
Very dissatisfied	0%	10%	0%	8%	14%	0%	0%	7%
Total number of people	11	10	7	24	28	17	2	99

TABLE 10
 AGREEMENT WITH DECISION TO MOVE RELATIVE TO
 COMMUNITY LIVING ARRANGEMENT

Regional Treatment Center

	FF	Will	St.P	Fair	Cam	Bra ML	TOTAL
Agreed Strongly	47%	29%	36%	50%	70%	27%	43%
Agreed Somewhat	26%	35%	36%	15%	10%	18%	25%
Neutral	11%	10%	9%	8%	10%	18%	10%
Disagreed Somewhat	10%	19%	0%	23%	10%	27%	16%
Disagreed Strongly	5%	6%	18%	0%	0%	9%	6%
Total number of people	19	31	11	26%	10	11	110

TABLE 11
 CURRENT SATISFACTION WITH THE COMMUNITY LIVING ARRANGEMENT
 Region

	1	2	3	4	5	7	8	9	10	11	TOTAL	
Very Satisfied	50	0	86	67	50	86	78	75	90	83	64	72%
Somewhat Satis.	25	0	14	0	50	0	22	0	0	8	25	16%
Neutral Somewhat	0	100	0	17	0	14	0	25	10	0	3	6%
Dissatis.	0	0	0	17	0	0	0	0	0	8	6	4%
Very Dissatis.	25	0	0	0	0	0	0	0	0	0	0	1%
Number of people	5	1	7	6	4	7	18	4	10	12	36	110

In the next section, families were asked about satisfaction with residential services, day program services, and case management services in the community. The results were as follows:

TABLE 12

	Residential	Day	Case Management
Very Satisfied	73%	68%	67%
Somewhat. Satisfied	17%	18%	20%
Neutral	6%	11%	9%
Somewhat; Dissatisfied	4%	3%	3%
Very Dissatisfied	1%	0%	1%

As the table shows, most families are satisfied with each of the types of services their relatives are receiving in the community. The Monitor has notified the families who expressed dissatisfaction with the services advising them as to who to contact to get their concerns addressed. In the few cases (approximately 6 out of 11) in which families expressed consistent or serious concerns with their relative's placement, in all or virtually all of the cases, the residence was also under scrutiny by authorities, this Office, or advocacy groups.

The next question asked families to compare services at the RTC with services at the community program in which individuals live. The areas which this question is asked about include: opportunities to learn new skills, opportunities to experience or participate in interesting or enjoyable activities, opportunities to make friends or acquaintances, opportunities to experience a variety of places in the community with no more than one or two other people, appearance, food, physical appearance and comfort of the residence, and an overall rating. For data analysis purposes, we combined the responses to these items into a scale which we call relative satisfaction. The scores on the scale range from a 0, indicating that the RTC did a better job of providing the services, to a score of 100, indicating that the community now provides better services in each of the areas. Actual scores for the families who responded consistently (N=80), ranged from 20 to 100, producing an average score of 80, indicating a feeling that in general family members clearly felt that community programs were doing a better job.

In one of the last questions on the survey, respondents were asked to rate the adequacy of a list of services that were potentially delivered to their relatives. Respondents were asked to score this question either:

- 1 = Service is adequate
- 2 = Service is provided, but not adequate
- 3 = Service is not provided, but needed
- 4 = Service not needed
- 9 = Don't know

The services rated included: behavioral/psychological, medical, vision, dental, physical/occupational therapy, speech or communication, self-care, independent living, work and/or work training, leisure, advocacy, and case management or social work. All responses that were rated 1, 2, 3 were summed into a scale. The range of values on the scale was from 0 to 100. Actual scores ranged from 60 to 100, with an average score of 96, indicating that most families believe that their relatives are receiving adequate services.

The last question on this survey asked families to make any comments regarding their feelings about their relatives' discharge from the State Regional Center to the community placement. Because these were open ended, verbatim comments, we decided not to do any formal analysis, but rather to present them verbatim as Appendix B to this report.

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APPENDIX A

SURVEY FORM AND COVER LETTER

OFFICE OF THE MONITOR

EVALUATING THE QUALITY OF SERVICES
TO PERSONS WITH MENTAL RETARDATION

LEGAL EDUCATION CENTER, ROOM 106

40 NORTH MILTON STREET

SAINT PAUL, MINNESOTA 55104

TELEPHONE: (612) 224-3647

November 19, 1987

Dear Parent/Family Member:

Thank you for responding to the Questionnaire to Parent/Relative of Welsch Class Members that we sent you last summer. We are in the process of tabulating the results.

In your response to the questionnaire, you indicated dissatisfaction with one or more services that your relative needs. If you would like help to obtain or improve that needed service, you can call or write to **the** following persons:

COUNTY CASE MANAGER

OFFICE OF OMBUDSMAN FOR MENTAL HEALTH AND MENTAL RETARDATION
4th Floor Centennial Office Building
St. Paul, Minnesota 55155
Telephone: 296-5687 (metro)
1-800-652-9747 (statewide toll free)

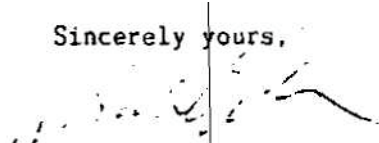
LEGAL ADVOCACY FOR DEVELOPMENTALLY DISABLED PERSONS IN MINNESOTA
222 Grain Exchange Building
323 Fourth Avenue South
Minneapolis, Minnesota 55415
Telephone: 332-7301 (metro)
1-800-292-4150 (statewide toll free)

DEVELOPMENTAL DISABILITIES DIVISION
Department of Human Services
444 Lafayette Road
St. Paul, Minnesota 55155
Telephone: 296-2160

If your relative is under state guardianship, you can also contact: OFFICE OF PUBLIC GUARDIANSHIP 4th Floor Centennial Building St Paul, Minnesota 55155 Telephone: 296-2168

Thanks again for participating in the survey.

Sincerely yours,

A handwritten signature in dark ink, appearing to read "Richard A. Cohen", is written over a vertical line. The signature is somewhat stylized and includes a long horizontal flourish extending to the right.

Richard A. Cohen
Monitor

Chrono 87-269

QUESTIONNAIRE TO PARENT/RELATIVE OF WELSCH CLASS MEMBERS

This questionnaire is part of a survey of families of persons discharged from the State Regional Centers in the past two years. We are doing this survey to help see how satisfied or dissatisfied relatives are with placements and services. This office, the Office of Court Monitor, has been in existence since 1980. One of our duties is to evaluate programs and services to current and past residents of the State Regional Centers (formerly known as state hospitals).

You may feel you cannot give an exact answer to every question, or you may be unsure of how you felt when recalling past events. In such cases, please give us your best estimate and then go on to the next question.

Even if there are some questions you cannot answer, please return the questionnaire in the enclosed postage-paid envelope. Your name and the name of your relative will be kept confidential.

Please answer by filling in the blank, or by putting an "X" in the blank that best fits your answer.

Name of Class Member _____ Age _____

Residence/Town _____

Day Program/Town _____

County _____

Regional Ctr. Discharged From _____ Date of Discharge _____

PLEASE PRINT.

If you know that any of the above information is not correct or is not current, please fill in the correct information.

PLEASE PRINT.

1. What is your name? _____ Today's date? _____, 1987
2. What is your relationship to the above Welsch class member? (Check one)
Father ___ Mother ___ Other (please specify) _____
3. About how many miles was your home from the State Regional Center your family member resided at? _____ miles. About how long a drive was it to the Regional Center? _____
4. About how many miles is your home from the residence your family member now resides at? _____ miles. About how long a drive is it to his/her current residence? _____
5. If your relative was admitted to another Regional Center (formerly state hospital) prior to the one identified above, please state the age he was first admitted and the facility.
Facility _____ Age _____
6. Overall, how satisfied were you with the services your relative was receiving at the state regional center? (Check one)
Very satisfied ___ Neutral ___ Somewhat dissatisfied ___
Somewhat satisfied ___ Very dissatisfied ___
7. Please describe how you felt about your relative's proposed discharge to the present community placement when you heard about it. (Check one)
Agreed strongly ___ Neutral ___ Disagreed somewhat ___
Agreed somewhat ___ Disagreed strongly ___
8. Please describe how you now feel about your relative's present community placement. (Check one)
Agreed strongly ___ Neutral ___ Disagreed somewhat ___
Agreed somewhat ___ Disagreed strongly ___
9. Overall, how satisfied are you with the residential services your relative is now receiving in the community? (Check one)
Very satisfied ___ Neutral ___ Somewhat dissatisfied ___
Somewhat satisfied ___ Very dissatisfied ___
10. Overall, how satisfied are you with the day program, educational, or vocational services your relative is now receiving? (Check one)
Very satisfied ___ Neutral ___ Somewhat dissatisfied ___
Somewhat satisfied ___ Very dissatisfied ___
11. Overall, how satisfied are you with the case management or social work services your relative is now receiving in the community? (Check one)
Very satisfied ___ Neutral ___ Somewhat dissatisfied ___
Somewhat satisfied ___ Very dissatisfied ___
12. Please indicate what type of protective arrangement presently exists for your relative.
___ Private conservatorship ___ Public guardianship ___ Private guardianship ___ None
13. How often did you visit your relative at the State Regional Center during the last 5 years he/she lived there? At least:
___ weekly ___ 3-4 times a year ___ less than once a year
___ monthly ___ once a year ___ never
14. How often did your relative visit you at home from the state regional center? At least:
___ weekly ___ 3-4 times a year ___ less than once a year
___ monthly ___ once a year ___ never

15. How often have you visited your relative at the current community placement? At least:
 ___ weekly ___ 3-4 times a year ___ less than once a year
 ___ monthly ___ once a year ___ never

16. How often has your relative visited you at here from his/her community placement? At least:
 ___ weekly ___ 3-4 times a year ___ less than once a year
 ___ monthly ___ once a year ___ never

Please indicate how strongly you agree or disagree with the following statements.

	Agree Strongly	Agree Somewhat	Neutral	Disagree Somewhat	Disagree Strongly
17. I believe that all services needed by my relative were available to him/her in the state regional center.	___	___	___	___	___
18. I believe that all services needed by my relative are available to him/her in the community.	___	___	___	___	___

19. This question asks you to compare services at the Regional Treatment Center (RTC) with the community programs your family member is now in. Check only one for each item.

	Much Better at RTC	Somewhat Better at RTC	Same in Both Places	Somewhat Better Now	Much Better Now	Don't Know
a. Opportunities to learn new skills	___	___	___	___	___	___
b. Opportunities to experience or participate in interesting or enjoyable activities	___	___	___	___	___	___
c. Opportunities to make friends. acquaintances	___	___	___	___	___	___
d. Opportunities to experience a variety of places in the community with no more than one or two other people	___	___	___	___	___	___
e. Appearance, dress	___	___	___	___	___	___
f. Food, nutrition	___	___	___	___	___	___
g. Physical appearance and comfort of residence	___	___	___	___	___	___
h. Overall for my family member the programs and services were:	___	___	___	___	___	___

20. Please rate the following services on behalf of your relative.

	Service is adequate	Service is provided, but not adequate	Service is not provided, but needed	Service not	Don't Know needed
a. Behavioral/psychological (assessment, behavior modification, eliminating problem behaviors)	_____	_____	_____	_____	_____
b. Medical (check-ups, exams, treatment, nursing)	_____	_____	_____	_____	_____
c. Vision (check-ups, glasses)	_____	_____	_____	_____	_____
d. Dental (check-ups, treatment, dentures)	_____	_____	_____	_____	_____
e. Physical/occupational therapy (evaluation, therapy, training)	_____	_____	_____	_____	_____
f. Speech or communication	_____	_____	_____	_____	_____
g. Self-care (grooming, hygiene, dressing)	_____	_____	_____	_____	_____
h. Independent living (cooking, budgeting, public transportation)	_____	_____	_____	_____	_____
i. Work and/or work training	_____	_____	_____	_____	_____
j. Leisure (hobbies, sports, trips)	_____	_____	_____	_____	_____
k. Advocacy (citizen, volunteer, or legal)	_____	_____	_____	_____	_____
l. Case management or social work	_____	_____	_____	_____	_____
m. Other (indicate): _____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

21. Please make any contents regarding your feelings about your relative's discharge from the State Regional Center to the community placement. (Use additional pages, if necessary.)

JUL 20 1988
RECEIVED



STATE OF MINNESOTA
DEPARTMENT OF HUMAN SERVICES
Human Services Building
444 Lafayette Road
St. Paul, Minnesota 55155-38 _

July 15, 1988

Richard Cohen
Monitor
Office of the Monitor
Legal Education Center
Room 106
40 North Milton Street
St. Paul, Minnesota 55104

Dear Mr. Cohen:

Thank you for the opportunity to review and comment on your report titled "A Survey (if Family Satisfaction with the Regional Treatment Centers and Community Services to Persons with Mental Retardation)". The information presented was very interesting.

In reviewing the report, we discovered a few areas in which we believe the data from Moose Lake and Faribault were inadvertently transposed. You may want to recheck the tables to see if that is what happened. We also found the discussion of the data on the placement of persons in the Cambridge region (on page 7) to be somewhat confusing. Do you mean that more of the people in the sample live in the Cambridge area than were discharged from the Cambridge RTC?

The only other concern we had related to how the results are to be interpreted. We believe that the results should not be interpreted as mirroring or reflecting the satisfaction level of the families of all RTC clients. Since the survey was completed only by families whose family member had recently been placed in community services, the comments on their satisfaction with RTC services might not be representative of the larger group of families who are current and past users of RTC services.

I appreciate the work that went into this report and the opportunity to review the results. The Department agrees that this type of survey is an important means of assessing the services provided to persons with mental retardation and has included a family survey as part of the field reviews the Department staff are completing under the terms of the Welsch Negotiated Settlement.

AN EQUAL OPPORTUNITY EMPLOYER

The innovative home in Kasson has kept us well informed as to his needs and progress. We have no way of evaluating his care except when we do visit he is clean and appears to be well cared for. When I placed xxx in Faribault at the age of two I was told he would be placed in a community of his own. That he would be much happier than at home and that I had to place him for his sake. It was very hard to do. Now with closing of state institutions these long lost children are being placed and replaced from home to home which I'm sure must be very hard for them to adjust to each time. I will be 70 yrs. old. Too old and physically unable to resume his care. I hope you will be able to find a place for xxx where his care and needs will be fulfilled.

50. At the time the group home was being developed we had some doubts. But since opening we cannot find any problems. I wish more children could be placed in homes like the Brown House. We feel the staff go out of their way to make sure their residents are comfortable and happy. We have seen a change in xxx since being there. He is much more alert and happy which is important to us.

APPENDIX B

VERBATIM COMMENTS

2. Concerning #4- I did live 25 miles (40 Years) from xxx's present residence until Aug. 1986 when I moved to Upland, CA. I was very happy to have xxx placed in the community - with fewer residents he received more 1 on 1 care and rehabilitation. Although he is blind & severely retarded, through the staff and employees' patience and support he has learned to do many things. I would never have thought possible. Living now in California, I have kept in touch with his progress and well being by correspondence with the staff. They have been wonderful. With xxj: in his present residence, he is also closer to my married children and their families making it easier for them to visit him. I will be visiting xxx again in August when I return for a visit with other relatives. Thank you. xxx's Mother.

3. We are pleased to have xxx out of SRC. We hope that he will make some necessary adjustments in his social habits and we will also hope that his mental attitude will change. We feel that his leisure time is not well occupied. His counselors and public servants and us feel that he should partake of more social activities with his own peer group, whenever these activities are provided.

4. RTC had the tunnel system which was a great asset in the winter. The community house is air conditioned and seems to be a better environment in the summer.

6. Very little communication in her transfer from Brainerd St. Hospital to Starbuck (a matter of a few days). If a move was to be made why not St. Cloud (area) instead of Starbuck. Our daughter is assigned to a home in Starbuck but is shuffled to different homes in Alexandria on weekends, leaving her with a feeling of not belonging anywhere and is difficult because she is non-verbal. A, very unhappy attitude is apparent which was not the case when she was in Brainerd St. Hospital.

7. I think xxx is doing fine where is right now Charis House and Paul Bungan PAC. I would like to have him stay there.

8. She seems to be coming along fine now. Has some upset times. But they say she's beginning to show a big improvement. Still likes her home visits and we love having her home. I hope she continues to get to come home for visits. As if she stays away for a 2 mo. period she seems to get a little upset. Home sick I believe.. But if she gets to come home in 1 mo, to 1 1/2 mo. she's not too disappointed. I am well satisfied with her placement.

10. The reason we don't bring her home often is because she has become too heavy for Dad to lift her into the car. Her

Dad is 78 years old. I had 2 heart attacks 1 1/2 years ago. We were satisfied with her in the state hospital.

11. I am happy for him. He doing great at Fernwood. He is more alert and happy.

12. xxx appears to be much happier and her hair and teeth are better cared for. Her general appearance is so much better. She is positioned many times a day at Rem Inc. and is hardly ever in her wheel chair unless being wheeled to and from activities, etc.

13. I think it was the best move ever made for our son. He is happier and more content.

14. My knowledge of what really happens to xxx is through the written reports sent to me by the staff. I was assured that she would receive the same level of care at Northome that she had at Brainerd.

15. I was satisfied with all the services xxx was receiving from the RTC but I felt he needed to be with peers he could communicate and relate to. I guess my biggest concern now is that there hasn't been enough communication between prior and present medical personnel on what kinds of medication and dosages needed to control his seizures.

16. The only negative feeling we have is that the Prairie View Community Center is 3 times farther away from our home than when our daughter was housed at the Regional Treatment Center in Brainerd. We are very happy with her treatment at Slayton but because of distance find it difficult to visit her more than once a year. Now that we are retired and have the time to visit we find the distance prohibitive.

17. The move to St. Camillus Shelter in Little Falls was an excellent one. My sister xxx is in a very happy home and supportive community. Brainerd RTC was a vast improvement over Riofield, S.D. but as time went on and changes in population, etc. occurred, the move to St. C. was a wise one. xxx is very happy, and her family is extremely pleased.

18. We believe that he is being taken care of better at the community placement.

19. I was very happy with Brainerd while she was there. The last time I visited her there I was beginning to worry because there were more people in her unit that were able to get around. (She is in need of total care.) This move to St.. Cloud pleases me all the way around. Yours Truly.

21. xxx is getting one on one care at the Kimbal Home. This for her is necessary and beneficial..

22. She gets more attention now, which is very good, because of a smaller place.

23. I thought she could not adjust but she has. She is happier at Avernon and Residential Alternatives.

24. She was much more adjusted at Cambridge. She held a job at Cambridge and made more money for her upkeep than she has at the DAC. She had less aggressive behavior at Cambridge.

25. We believe that the group home is a better environment but do believe when problem arise the social worker should either write or call us about it. We now know of a problem that we should have been told about in the group home. We think he is a happier person when we go visit him now.

26. xxx is in a very good place, is well taken care of, treated real good. We go see him quite often. He does real good. He is blind and can't hear. He couldn't be in a better place. It is just great for him there. He is doing fine .

28. We were very satisfied with the services our daughter receive at Cambridge and were reluctant to have her moved. We feel she is more content at her present location and we are really pleased with her present placement.

29. This is a good step; we at first thought it might not work out; but if this didn't happen we would not have known what he was capable of doing. Yes, he has come a long way and this is nice for him and us. Like in any special service centers there are probably people who are not concerned; they should not be in it. It takes "Special"- "Caring" People with concern to handle the situation that arise .

30. We feel that our prayers have been answered for our son by being in the group home, instead of the St. Hosp. There is no comparison. He is like a different person. His behavior has changed dramatically for the better. We know he was abused at Cambridge but try and do anything about it was impossible. There should be some way that the staff can report it and kept confidential, because they are afraid to report anything. There should be some one outside of State Hospitals that they can report to, as most times when it is reported nothing is done about it anyway. Staff at group homes have that opportunity. It seems in our prisons, the inmates are treated better than our mentally retarded in State Hospitals. They fan voice what is going on, our retarded cannot. Someone has to do it for them. Thank you for the opportunity to let us share our feelings and what we believe We believe in group homes versus St. Hosp. 100 %.

There should be more group homes in smaller towns, so parents and family can be closer to their loved ones. Thank you again.

32. I'm very pleased with xxx' s care at Woodvale. The extra time, they can work with her and a lot of one on one, has made a good change, in her in all areas.

34. I like it that she is nearby. It seems to me she likes it here too.

35. She very much needs to be in a smaller group home for many reasons. Is deaf and severely retarded, needs constant supervision and help. Now they keep changing staff which causes some of her frustrations and it takes a long time for her to adjust to changes. We are enclosing xxx's 1986 Team meeting annual report, which describes her behaviors and problems.

36. At first I questioned if it was in xxx's best interest to place him in another facility, Stearns Co. Social Services, had wanted to place him in a Kimball Home to which I objected strongly because I felt it would not meet his needs. In Jan. 1985 he was placed in the Mother Terese Home in Cold Spring. That home was too advanced for xxx' s capabilities and he was sent back to Cambridge. But I have found that REM and DAC are trying to help xxx develop as much as possible. He is very hyper and difficult to handle at times but the staff is very patient with him.

38. I am very pleased that xxx was placed in a group home - He has improved greatly.

41 . We are very pleased with the Brown house. It is a small group home, 3 residents, 1 respite care. The home like setting is very nice for xxx. The one on one she gets is great . The children are the same age and the home will be made an adult home when they reach 18. This is a very good feature. xxx is happy and comfortable. We think it is the best place for her.

42. Please see the attached letter. Kindly give some consideration to the two final paragraphs. When committed to Cambridge at age 5 in approx. 1948 xxx spoke clearly, used ample vocabulary, walked and ran freely. Following measles and chickenpox he developed petit-mal seizures. Dr. xxx in charge of Cambridge ran a complete farm-type work program with milk pasteurization plant, bakery and complete food processing. This fresh food was used in a nutrition program which achieved some success in treating seizure activity. To save money, the farm activities were discarded, patients were kept heavily sedated and warehoused. Parents paid dues, held raffles and raised money for antiseptic soap the institution was unable to provide, an occasional TV or other

recreational item, etc. About 6 years ago more capable people began constructive work with patients - often on a one to one basis. Inappropriate behavior previously taught and sanctioned was laboriously corrected - as best possible after some thirty years. Two transitional prototypes of community homes on the Cambridge grounds eased the transition to the community where those in charge are intelligent and caring. The real problem has always been the doctors in charge who think in terms of multiple drugs for supression of brain function - overlooking that this is self-perpetuating the condition. We had xxx in our home overnight on Memorial Day. We were shocked that he had more seizures than when he went in 40 years ago. Control has not been achieved and his severe locomotor ataxia has undoubtedly been actually caused by these drugs. Please note the attached copy of a case history. Employment of physicians with knowledge of biochemistry and nutrition and the considerable body of reports on these subjects as found in the Journals would free these unfortunate patients from physician caused drug dependence.

43. So far it is hard to know what to say. No one talks to us of what xxx is doing (work - help with clothes). We just hope the workers know what they are doing - much more that we can do. xxx is always happy when she makes a different family situation - but later on when she gets used to it, it is a different story. My husband and I are both 84. Our girls - xxx and xxx both married with families of their own. It is not always easy for them. They take her out to eat, buy clothes for her and sometimes take her to the movies.

44. I guess it was a good move but we were satisfied with the state hospital. We been to visit her twice and it looks like she has good care.

45. I think my son is more happy where he is now as he is more relaxed in a more quiet home and has adjusted very well at New Beginnings.

47. xxX's first community experience was not a pleasant experience for xxx. It is difficult for parents to tell community placement residence leaders that your son doesn't like them. There appeared to be little or no compassion displayed at his first community placement. He seems to be happy in his new home.

48. Dear Sir, We started to fill out this questionnaire (and then) we received a phone call, from xxx, xxx's social worker telling us xxx would be transferred in the fall of this year. That Kassan, his present, residence will be closing - so I need not answer the questionnaire. We are sorry for the delay. xxx's level of I.Q. is profound. He does not speak and has no way of communicating with others.