

Community Support Services for Persons with Serious Mental Illness in Iowa: Family Member Survey Results

Introduction

In rural states such as Iowa, community support services must be developed for a relatively small number of persons who have extensive service needs. These services are developed, funded, and administered in the context of limited financial and organizational resources. Provision of comprehensive community based services presents a particular challenge for states such as Iowa where the organization of community support services is primarily county based.

The purpose of this study is to describe community support service availability, access, and satisfaction of persons who have a family member(s) with serious mental illness. A similar survey of case managers and consumers was also performed and the results of these studies are reported separately (Rohland, 1996; Rohland, 1996).

Background

Definition of Serious Mental Illness. In Iowa, serious mental illness (SMI) in adults is defined by: 1) a psychiatric treatment more intensive than outpatient care more than once in a lifetime; or 2) a single episode of continuous, structured, supportive residential care other than hospitalization. In addition, individuals defined as having a serious mental illness are more likely to be unemployable in a competitive work force, require financial assistance for out of hospital maintenance, have a severe inability to establish or maintain a personal support system, require help in basic living skills or exhibit inappropriate social behavior which results in demand for intervention by the mental health or judicial system.

Organization of Services. Iowa is a rural state with 99 counties and nine Metropolitan Statistical Areas (MSAs). Systems of mental health service organization in Iowa are primarily county based. Although the state provides accreditation to mental health centers and mental health providers, each county is responsible for the limited provision of services for persons with serious mental illness who have residence in their county. However, there are 33 community support programs (CSPs) which are supported by state funding. All of the state funded CSP programs are affiliated with a community mental health center (CMHC), and most counties (93/99) have an affiliation with a CMHC. There are 36 CMHCs in Iowa, and each CMHC has a catchment area of one to nine counties.

County Funding for Mental Health Services. In an analysis of all counties (n=99), urban counties spend almost two dollars more per capita on mental health services than do rural counties (\$29.02 versus \$26.15). They also spend a higher proportion of their budget on persons with SMI (70% versus 61%). Among rural counties, counties with a CMHC in their county spend almost ten dollars more per capita than counties that have an out of county affiliation with a CMHC (\$32.29 versus \$22.63). Counties with no CMHC and no affiliation with a CMHC spend an amount of money which is intermediate

(\$27.01). The average proportion of the mental health budget that is spent on persons with serious mental illness is about the same for all rural counties regardless of whether a CMHC is present within the county or whether or not they have an affiliation with a CMHC, i.e., 58-64%.

Community Support Services. In 1977, the National Institute of Mental Health (NIMH) developed the concept of a community support system (CSS) as the basis for planning and organizing comprehensive, community based, services for persons with serious mental illness (Stroul, 1988). The NIMH model of community support has ten essential service components defined as necessary in order to provide a continuous, comprehensive system of care for persons with serious mental illness. Community support services are intended to be coordinated by case management, variably defined as a single person, team, or agency. In addition, case management was intended to monitor the adequacy and appropriateness of services.

The ten components of community support that were specified by the NIMH include:

1. Crisis Response Services (crisis telephone services, walk-in crisis services, mobile crisis outreach services, crisis residential service, inpatient services)
2. Mental Health Treatment (diagnostic evaluation, supportive counseling, medication management, substance abuse services)
3. Income Support and Entitlements
4. Protection and Advocacy
5. Physical Health and Dental Services
6. Housing (supportive housing, residential assistance for homeless mentally ill persons)
7. Psychosocial Rehabilitation (social and vocational)
8. Peer Support (self-help, consumer-operated services)
9. Identification and Outreach (client identification, outreach, transportation assistance)
10. Family and Community Support (support and assistance to families, support and education for the community)

Methods

Affiliate presidents of the Alliance for the Mentally Ill of Iowa (AMI) were contacted and asked to identify families who were willing to participate in this survey. In addition, AMI of Iowa sent county contacts in 65 counties a description of the project and included a form for interested participants to fill out and return in order to be included in this study. The AMI of Iowa newsletter, mailed to 4500 recipients, including 960 family units, also described the project and included a form for interested participants to fill out and return in order to be included in this study. A total of fifty-three family members living in the state of Iowa were identified by this method (28 responses from AMI of Iowa mailings, 22 responses from contact with AMI affiliate presidents, 3 responses unknown). Interested participants were sent a 15 page, 70 item survey to complete and return in a self addressed, stamped envelope between February 1, 1995, and August 15, 1995.

Family members, including spouses, were asked to evaluate the adequacy of case management and each of the 10 components of community support services available to their loved ones within their county of residence. The instrument used was adapted from an earlier, unpublished survey (Friedrich, R.M., 1994) and was reviewed by a multidisci-

iplinary team for content validity. The team consisted of nurses, psychiatrists, and representatives of the Alliance for the Mentally Ill (AMI), DHS, the Community Mental Health Centers Association, and case managers.

Results

Responses were obtained from 53 family members in 26 counties. Of the 26 counties represented 6 were urban and 20 were rural counties. There were 22 (42%) responses from urban counties and 31 (58%) responses from rural counties. The majority of family respondents lived in the same county as their ill family member (68%).

Characteristics of Responding Family Members' Ill Relative

Relationship. The majority of family members who responded to the survey (39/53 or 74%) were parents of a child that is seriously mentally ill. Five responses were from spouses, 2 were from siblings, and 5 responses were from children of the ill family member.

Psychiatric Diagnosis. Respondents identified all psychiatric diagnosis that the ill family member had been given (average = 1.7 per family member) and the one diagnosis that was the main source of the person's disability. The diagnosis that was considered to be the main source of disability by the family member was schizophrenia (59%); bipolar disorder (27%); schizo-affective disorder (6%); depression (4%); and personality disorder (2%). Less than one-fourth of respondents (12/53) indicated that their family member had a co-occurring drug or alcohol problem.

Duration of Illness and History of Hospitalization. Family members reported their relative had been ill with a psychiatric illness for an average of 18.6 years. Over one-half of respondents (59%) indicated that their family member had been hospitalized for a cumulative period of more than 1 year for treatment of a psychiatric illness since the onset of their illness. Almost one third of respondents (15/51) indicated that their family member was on out patient commitment for treatment of their mental illness.

Demographic Characteristics (Age, Gender, Marital Status, Education, and Ethnicity). The average age of the ill family member was 40 years, with a range of 20-73 years of age. Of the family members described, 79% were male and 21% were female. The majority of the ill family members had never been married (70%) compared with 15% that were currently married and 15% that were either divorced or widowed. All but one respondent indicated that their family member had completed high school or higher level of education. Over one half of respondents (30/53) indicated that their family member had completed some college or junior college education. Five respondents indicated that their family member had completed a graduate or professional degree. All respondents described a family member who was white, not of Hispanic origin. Nearly all respondents indicated that their ill family member lived in their county of legal settlement (47/53).

Employment. Over one-half of the ill family members were not currently employed (59%). Of those that were employed (n=22), 46% worked less than 10 hours in the most recent week. Nearly one third of those employed had competitive employment (7/22); employment was transitional, supported, or in a sheltered workshop in 13 cases.

Housing. Family members reported that 49% of their ill relatives lived alone, 17% lived with a spouse or significant other, 17% lived with parents, 15% lived in a supervised group situation, and 2% were hospitalized at the mental health institute. The current housing arrangements for ill family members as indicated by respondents were living in own home or apartment without in-home staff visits (42%); own home or apartment with in-home staff visits (17%); and parental home without in-home staff visits (14%).

Family members were asked the type of housing they thought would be best for their ill family member, if available. The most frequent responses were an apartment building with individual units, 24 hour supervision and support services (12/40) and own home or apartment with in-home staff visits (11/40). The most common reason given by family members that their ill relative is not living in the housing they think is best was because the housing does not exist locally (56%).

Income Source. Family members indicated the main source of income for their family member was Social Security Disability Insurance (SSDI) (34%) and Supplemental Security Income (SSI) (32%). Other sources identified as main income sources were wages or salary from a job (11%) and money from family on a regular basis (11%). About 11% of respondents indicated that their family member received welfare benefits as a source of income, but none indicated that was the main source of income.

Mental Health Care Expenses. The main source of payment for mental health care expenses reported by family members was Medicaid (51%), Medicare (18%), and SSI/SSDI (11%). Only 3 respondents indicated that their family member's expenses were paid through private insurance (1 group insurance through employer, 1 individual health insurance, and 1 dependent coverage under family plan).

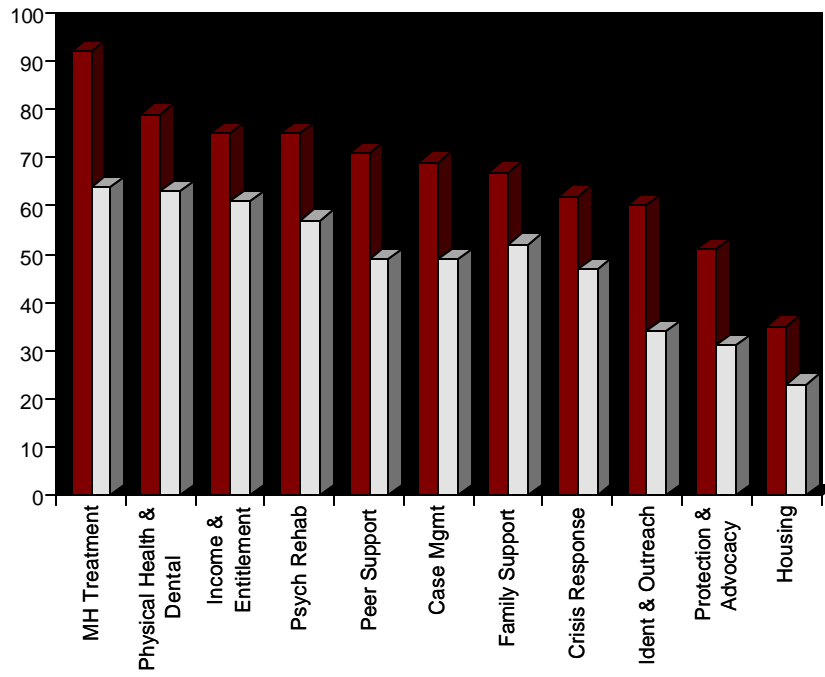
Service Component Satisfaction. Satisfaction of each of the ten components was assessed by asking family members how well the services (of each component) met the needs of their ill family member over the past one year period. They were asked to rate satisfaction by using a 4 point scale from 1 (very satisfied) to 4 (very dissatisfied). Family members could also indicate that the service was not used by their family member over the past year. Responses of "very satisfied" or "somewhat satisfied" were combined and compared to responses of "somewhat dissatisfied" or "very dissatisfied" to measure family member perception of service adequacy. Assessment of service satisfaction by family members for each service component is summarized in Table 1.

Most family members expressed satisfaction with service components when indicating that the service was used. However, for many service components, a large proportion of family members indicated that services were not used over the past year (see Figure 1). For example, although two-thirds of respondents who used housing services expressed satisfaction with services, over one-half of respondents (28/43) indicated that they did not use housing services over the past 12 month period. Therefore, one cannot conclude from this data that satisfaction with services necessarily implies satisfaction with that component e.g., the service may not have been available. The proportion of respondents who indicated that they had used and were satisfied with each service component is illustrated in Figure 1.

Table 1: Assessment of Service Component Satisfaction by Family Members

Service Component	Assessment of Satisfaction			
	number responding	service not used over past one year	percent reporting use and satisfaction	satisfaction and use
I. Crisis Response	47	38% (18/47)	76% (22/29)	47%
II. Mental Health Treatment	50	8% (4/50)	70% (32/46)	64%
III. Income and Entitlement	48	25% (12/48)	81% (29/36)	61%
IV. Protection and Advocacy	45	49% (22/45)	61% (14/23)	31%
V. Physical Health and Dental	44	21% (9/44)	80% (28/35)	63%
VI. Housing	43	65% (28/43)	67% (10/15)	23%
VII. Psychosocial Rehabilitation	49	25% (12/49)	76% (28/37)	57%
VIII. Peer Support	49	29% (14/49)	69% (24/35)	49%
IX. Identification and Outreach	47	40% (19/47)	57% (16/28)	34%
X. Family Support	45	33% (15/45)	77% (23/30)	52%
XI. Case Management	45	31% (14/45)	71% (22/31)	49%

Figure 1: Proportion of Respondents Reporting Use and Satisfaction for Each Service Component (percent)



used service



satisfied



Most Helpful Resource. For each service component, family members were asked to identify the most helpful resource for their ill family member. Choices given included no one, family, friends/peers, mental health professional, family doctor, law enforcement officer, don't know, or other (specify). The results are summarized in Table 2. Mental health professionals were most frequently identified as the most helpful resource for crisis response and mental health treatment. For all other service components (with the exception of psychosocial rehabilitation) family was most frequently identified as the most helpful resource to ill family members. "Other" was identified as the most helpful resource for psychosocial rehabilitation and this included a variety of resources e.g, CSALA staff, Goodwill Industries staff, staff at residence, conservator.

Table 2: Most Helpful Resource to Family Member for Each Service Component

Service Component	Service Not Needed	Most Helpful Resource (percent)
Crisis Response	20/51 (39%)	mental health professional (38%)
Mental Health Treatment	0/53 (0%)	mental health professional (58%)
Income and Entitlement	2/52 (4%)	family (40%)
Protection and Advocacy	11/49 (22%)	family (53%)
Physical Health and Dental	1/50 (2%)	family (39%)
Housing	11/49 (22%)	family (55%)
Psychosocial Rehabilitation	5/52 (10%)	other (34%)
Peer Support	5/53 (9%)	family (33%)
Identification and Outreach	2/49 (4%)	family (45%)
Family Support	4/49 (8%)	AMI support groups and educational programs (36%)
Case Management	2/48 (4%)	family (37%)

Service Access. For several types of services within each service component, family members were asked if a family member needed help over the past year period, and if help was received (when needed). This proportion was used as an estimator of access to services. These results are summarized in Tables 3-13 in the section that follows.

I. Crisis Response. Emergency services (walk-in crisis support, outpatient psychiatric clinic emergency services, and emergency visits to the family doctor) were reported to be needed by 30% or more of respondents. Phone contact with counselor was the service with the highest reported need (60%). Services that were most often reported as being received when needed were phone contact with a counselor (25/32; 78%); emergency visit to a family doctor (14/16; 88%); short term residential services (6/8; 75%); and hospital emergency room visit (13/14; 93%).

Table 3: Service Component I. Crisis Response

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	24 hour crisis telephone service	14/53 (26%)	21/53 (40%)	2/53 (4%)	6/14 (43%)	7/14 (50%)	0/14 (0%)
b.	walk-in crisis support services at a community mental health center	17/53 (32%)	21/53 (40%)	2/53 (4%)	8/17 (47%)	6/17 (35%)	1/17 (6%)
c.	phone contact with counselor during the week	32/53 (60%)	8/53 (15%)	1/53 (2%)	25/32 (78%)	4/32 (13%)	0/0 (0%)
d.	mobile crisis unit that comes to your home	5/53 (9%)	25/53 (47%)	4/53 (8%)	0/5 (0%)	5/5 (100%)	0/0 (0%)
e.	short term crisis residential services	8/53 (15%)	27/53 (51%)	2/53 (4%)	6/8 (75%)	2/8 (25%)	0/0 (0%)
f.	outpatient psychiatric clinic emergency services	17/53 (32%)	20/53 (38%)	2/53 (4%)	10/17 (59%)	5/17 (29%)	0/0 (0%)
g.	hospital emergency room	14/53 (26%)	19/53 (36%)	2/53 (4%)	13/14 (93%)	0/14 (0%)	0/0 (0%)
h.	police department services	6/53 (11%)	27/53 (51%)	2/53 (4%)	4/6 (67%)	1/6 (17%)	0/0 (0%)
i.	emergency visit to family doctor	16/53 (30%)	20/53 (38%)	1/53 (2%)	14/16 (88%)	2/16 (13%)	0/0 (0%)

II. Mental Health Treatment. The majority of respondents reported needing all types of mental health treatment services except for family therapy which was reported to be needed by only 9/53 (28%) of respondents. Approximately one-third or more of respondents that indicated a need for some kind of education and in-home staff visits did not receive the services.

Table 4: Service Component II. Mental Health Treatment

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	help with medication problems (for example, side effects)	34/53 (64%)	12/53 (23%)	1/53 (2%)	29/34 (85%)	2/34 (6%)	0/34 (0%)
b.	help with taking medication as directed	21/53 (51%)	19/53 (46%)	1/53 (2%)	15/21 (71%)	4/21 (19%)	0/21 (0%)
c.	individual counseling	42/53 (89%)	5/53 (11%)	0/53 (0%)	35/42 (83%)	5/42 (12%)	0/42 (0%)
d.	group therapy	22/53 (60%)	15/53 (41%)	0/53 (0%)	18/22 (82%)	3/22 (14%)	1/22 (5%)
e.	family therapy	9/53 (28%)	23/53 (72%)	0/53 (0%)	4/9 (44%)	5/9 (56%)	0/9 (0%)
f.	monitor symptoms of mental illness	24/53 (62%)	14/53 (36%)	1/53 (3%)	18/24 (75%)	3/24 (13%)	2/24 (8%)
g.	education in coping skills	23/53 (59%)	14/53 (36%)	2/53 (5%)	13/23 (57%)	8/23 (35%)	2/23 (9%)
h.	education regarding signs of relapse	20/53 (53%)	16/53 (42%)	2/53 (5%)	11/20 (55%)	7/20 (35%)	2/20 (10%)
i.	education concerning mental illness	21/53 (54%)	16/53 (41%)	2/53 (5%)	12/21 (57%)	7/21 (33%)	1/21 (5%)
j.	frequent in-home staff visits	17/53 (46%)	19/53 (51%)	1/53 (3%)	9/17 (53%)	7/17 (41%)	0/17 (0%)
k.	in-home staff visits (for example, Visiting Nurse Association)	17/53 (49%)	17/53 (49%)	1/53 (3%)	11/17 (65%)	6/17 (35%)	0/17 (0%)

III. Income Support and Entitlements. Although only about one third of family members reported needing these services, most who needed them reported that they had received them. About two thirds of the respondents indicated that they had received assistance with obtaining health care financing when they needed it.

Table 5: Service Component III. Income Support and Entitlements

	Service Component	Was this type of service needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	assistance with obtaining income supports (for example, SSI, SSDI)	15/53 (28%)	27/53 (51%)	1/53 (2%)	11/15 (73%)	4/15 (27%)	0/15 (0%)
b.	assistance with obtaining health care financing (for example, Medicaid, Medicare, private health insurance)	19/53 (36%)	25/53 (47%)	1/53 (2%)	13/19 (68%)	4/19 (21%)	0/19 (0%)
c.	assistance with obtaining welfare benefits (for example, food stamps, Aid to Families with Dependent Children, etc.)	15/53 (28%)	26/53 (49%)	2/53 (4%)	15/15 (100%)	0/15 (0%)	0/15 (0%)
d.	housing assistance	18/53 (34%)	24/53 (45%)	0/53 (0%)	14/18 (78%)	4/18 (22%)	0/18 (0.0%)

IV. Protection and Advocacy. Few family members indicated that they needed protection and advocacy services over the past year. Only one half of families who needed assistance with the commitment process received such help.

Table 6: Service Component IV. Protection and Advocacy

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	information about legal rights	10/53 (19%)	34/53 (64%)	1/53 (2%)	7/10 (70%)	1/10 (10%)	2/10 (20%)
b.	assistance with commitment process	8/53 (15%)	35/53 (66%)	1/53 (2%)	4/8 (50%)	3/8 (38%)	1/8 (13%)
c.	assistance in contacting agencies about questions or complaints	19/53 (36%)	26/53 (49%)	2/53 (4%)	12/19 (63%)	5/19 (26%)	0/19 (0%)

V. Physical Health and Dental Services. Most respondents 32/53 (60%) indicated that their ill family member had medical problems in addition to their psychiatric illness. The physical health and dental services with the highest reported need by respondents were assistance obtaining dental services (47%); assistance with weight control (40%); and assistance obtaining medical treatment for illnesses other than mental illness (38%). Most persons needing to obtain medical treatment (85%) and dental treatment (72%) received it. However, only 29% of persons whose family member needed help with weight control received it.

Table 7: Service Component V. Physical Health and Dental Services

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	assistance obtaining medical treatment for illnesses other than mental illness	20/53 (38%)	24/53 (45%)	1/53 (2%)	17/20 (85%)	2/20 (10%)	0/20 (0%)
b.	assistance obtaining dental services	25/53 (47%)	23/53 (43%)	0/53 (0%)	18/25 (72%)	3/25 (12%)	1/25 (4%)
c.	assistance maintaining physical fitness	18/53 (34%)	21/53 (40%)	2/53 (4%)	5/18 (28%)	10/18 (56%)	2/18 (11%)
d.	assistance with weight control	21/53 (40%)	18/53 (34%)	2/53 (4%)	6/21 (29%)	13/21 (62%)	1/21 (5%)
e.	assistance with stopping the use of alcohol and/or drugs	7/53 (13%)	33/53 (62%)	1/53 (2%)	3/7 (43%)	2/7 (29%)	1/7 (14%)
f.	assistance with pregnancy prevention	2/53 (4%)	34/53 (64%)	1/53 (2%)	1/2 (50%)	1/2 (50%)	0/2 (0%)
g.	assistance controlling smoking	11/53 (21%)	28/53 (53%)	1/53 (2%)	4/11 (36%)	6/11 (55%)	0/11 (0%)
h.	assistance with prevention of sexually transmitted diseases and AIDS	2/53 (4%)	33/53 (62%)	5/53 (9%)	0/2 (0%)	0/2 (0%)	2/2 (100%)

VI. Housing. About 20% of families indicated that they needed help with housing services. When needed, services were received about one half of the time.

Table 8: Service Component VI. Housing

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	help finding housing that has services needed by ill family member	11/53 (21%)	38/53 (72%)	0/53 (0%)	7/11 (64%)	4/11 (36%)	0/11 (0%)
b.	help finding long-term, stable housing	10/53 (19%)	37/53 (70%)	0/53 (0%)	5/10 (50%)	3/10 (3%)	1/10 (10%)
c.	help finding affordable housing	10/53 (19%)	35/53 (66%)	0/53 (0%)	6/10 (60%)	3/10 (30%)	0/10 (0%)
d.	help finding emergency housing	5/53 (9%)	40/53 (76%)	1/53 (2%)	2/5 (40%)	2/5 (40%)	0/5 (0%)

VII. Psychosocial Rehabilitation. Psychosocial services least likely reported as needed were help with completing education 7/53 (13%) and help with the use of public transportation 4/53 (8%). However, when needed, these services were most likely to be received (71% and 100%, respectively). The service that was least likely to be received, when needed, was help in finding volunteer work (38%). Family members were also asked how their ill family member spent most of his/her time during a usual week. The responses were “does nothing much” (54%), “works at a job for pay” (23%), “goes to school” (15%), and “goes to a structured daytime program” (8%).

Table 9: Service Component VII. Psychosocial Rehabilitation

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	help with finding a job	24/53 (45%)	20/53 (38%)	2/53 (4%)	13/24 (54%)	9/24 (38%)	0/24 (4%)
b.	help with keeping a job	19/53 (36%)	22/53 (42%)	3/53 (6%)	12/19 (63%)	7/19 (37%)	0/19 (0%)
c.	help with job training	16/53 (30%)	24/53 (45%)	2/53 (4%)	10/16 (63%)	6/16 (38%)	0/16 (0%)
d.	help with completing education	7/53 (13%)	32/53 (60%)	1/53 (2%)	5/7 (71%)	2/7 (29%)	0/7 (0.0%)
e.	help with finding volunteer work	13/53 (25%)	28/53 (53%)	2/53 (4%)	5/13 (38%)	8/13 (62%)	0/13 (0%)
f.	help with tasks of everyday living (for example, laundry, housecleaning, preparing meals, shopping for groceries, etc.)	22/53 (42%)	25/53 (47%)	0/53 (0%)	12/22 (55%)	7/22 (32%)	1/22 (5%)
g.	help with the use of public transportation	4/53 (8%)	38/53 (72%)	0/53 (0%)	4/4 (100%)	0/4 (0%)	0/4 (0%)
h.	supervision or help with managing money	26/53 (49%)	22/53 (42%)	0/53 (0%)	15/26 (58%)	8/26 (33%)	0/26 (0%)
i.	assistance in maintaining personal hygiene (for example, bathing, dressing, grooming)	12/53 (23%)	31/53 (59%)	1/53 (2%)	7/12 (58%)	4/12 (33%)	0/12 (0%)

VIII. Peer Support. Services reported to be needed most often by family members were help with making friends (53%) and help with day to day social interaction (59%). Family members were asked which programs or organizations that their ill family member currently uses as a means of contact with others. Responses were church (21%), work or volunteer setting (20%), self-help/support groups (16%), drop-in center (10%), agency planned recreational programs (9%), restaurants/bars (9%), housing arrangements (6%), consumer/client run business (5%), and clubhouse program (5%). Help with making and getting along with friends was received about 20% of the time when it was needed.

Table 10: Service Component VIII. Peer Support

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	help getting along with family	19/53 (36%)	28/53 (53%)	0/53 (0%)	11/19 (58%)	8/19 (42%)	0/19 (0%)
b.	assistance with recreation and leisure activities	24/53 (45%)	17/53 (32%)	3/53 (6%)	13/24 (54%)	10/24 (42%)	0/24 (0%)
c.	help with making friends	28/53 (53%)	13/53 (25%)	2/53 (4%)	6/28 (21%)	20/28 (71%)	1/28 (4%)
d.	help getting along with friends	18/53 (34%)	24/53 (45%)	1/53 (1%)	4/18 (22%)	12/18 (67%)	1/18 (6%)
e.	help with spouse or girlfriend or boyfriend relationships	13/53 (25%)	25/53 (47%)	2/53 (4%)	7/13 (54%)	4/13 (31%)	1/13 (8%)
f.	help with day to day social interactions	31/53 (59%)	17/53 (32%)	0/53 (0%)	12/31 (39%)	11/31 (36%)	6/31 (19%)

IX. Identification and Outreach. The service most frequently cited as being needed was “information about services available” (51% of respondents). Outreach services to individuals who decline a formal treatment program were indicated as needed by 26% of respondents. However, when they were needed, 71% of respondents indicated that they were not received.

Table 11: Service Component IX. Identification and Outreach

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	information about services available	27/53 (51%)	16/53 (30%)	1/53 (2%)	15/27 (56%)	8/27 (30%)	1/27 (4%)
b.	referral to agencies for services	23/53 (43%)	17/53 (32%)	1/53 (2%)	14/23 (61%)	6/23 (26%)	1/23 (4%)
c.	coordination of community services	19/53 (36%)	19/53 (36%)	1/53 (2%)	9/19 (47%)	8/19 (42%)	1/19 (5%)
d.	transportation to the services	16/53 (30%)	26/53 (49%)	2/53 (4%)	13/16 (81%)	3/16 (19%)	0/16 (0%)
e.	outreach services to clients who miss appointments or discontinue medication	7/53 (13%)	30/53 (57%)	2/53 (4%)	3/7 (43%)	4/7 (57%)	0/7 (0%)
f.	home visits for clients on a downhill turn	12/53 (23%)	23/53 (43%)	3/53 (6%)	5/12 (42%)	5/12 (42%)	1/12 (8%)
g.	outreach services to individuals who decline a formal treatment program	14/53 (26%)	23/53 (43%)	1/53 (2%)	4/14 (29%)	10/14 (71%)	0/14 (0%)

X. Family Support. Identification of temporary caregivers so the family can get away was the least likely service reported to be needed (13%), but, when needed, also the least likely service received (14%).

Table 12: Service Component X. Family Support

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	identification of temporary caregivers so your family could get away	7/53 (13%)	35/53 (66%)	0/53 (0%)	1/7 (14%)	6/7 (86%)	0/7 (0%)
b.	referral to family support groups (for example, Alliance for the Mentally Ill (AMI))	19/53 (36%)	30/53 (57%)	0/53 (0%)	16/19 (84%)	2/19 (11%)	0/19 (0%)
c.	referral to family therapy groups	8/53 (15%)	34/53 (64%)	0/53 (0%)	3/8 (37%)	3/8 (38%)	0/8 (0%)
d.	education about the illness and medications	20/53 (38%)	25/53 (45%)	1/53 (2%)	12/20 (60%)	5/20 (25%)	0/20 (0%)
e.	assistance with handling daily problems related to psychiatric illness	20/53 (38%)	23/53 (43%)	0/53 (0%)	10/20 (50%)	9/20 (45%)	0/20 (0%)
f.	involvement of family in treatment planning	23/53 (43%)	20/53 (38%)	1/53 (2%)	13/23 (57%)	9/23 (39%)	0/23 (0%)

XI. Case Management. Family members were asked if their ill relative currently had a case manager (a person other than a therapist who is responsible for monitoring their condition and linking them to services). Family members response was 43% “yes”; 44% “no”, and 13% “don’t know”. Family members were asked the frequency with which their ill relative met with or talked to their case manager. Most family members reported that their ill relative met with or talked to their case manager once a month or less (15/21 or 71%).

Case management services that were said to be needed by about 50% or more of family members were: to arrange for individualized services (49%); develop comprehensive treatment care plans (49%); and monitor ill family member’s condition e.g., change in symptoms, mood (60%).

Table 13: Service Component XI. Case Management

	Service Component	Was this type of help needed in the past year?			Of respondents that indicated help was needed was this type of help received in past year?		
		Yes	No	Don't know	Yes	No	Don't know
a.	arrange for individualized services	26/53 (49%)	16/53 (30%)	3/53 (6%)	15/26 (58%)	9/26 (35%)	1/26 (4%)
b.	make referrals to agencies (for example, Visiting Nurse Association)	12/53 (23%)	25/53 (47%)	3/53 (6%)	6/12 (50%)	6/12 (50%)	0/12 (0%)
c.	advocate on behalf of the client to programs and agencies	22/53 (42%)	16/53 (30%)	5/53 (9%)	14/22 (64%)	7/22 (32%)	1/22 (5%)
d.	develop comprehensive treatment care plans	26/53 (49%)	16/53 (30%)	4/53 (8%)	15/26 (58%)	9/26 (35%)	0/26 (0%)
e.	monitor ill family member's condition (for example, change in symptoms, mood)	32/53 (60%)	12/53 (23%)	4/53 (8%)	14/32 (44%)	13/32 (41%)	3/32 (9%)

Comments by Family Members

Thirty respondents provided open-ended comments that generally fell into three categories: 1) comments about present medication management; 2) personal experiences with treatment; and 3) comments about the organization and availability of support services.

Three respondents specifically addressed the benefits that their family member has derived from Clozaril, e.g., “Thank God for Clozaril...(my family member) would have had to stay in Cherokee state hospital or died on the street”.

One respondent specifically addressed concerns regarding Medicaid managed mental health care: “...we are only one shot away from the hell of mental illness. If MEDCO screws with her access, they’d better get bullet-proof vests, ‘cause I’m tired of going to court (in 2 states) for commitments”.

Some comments addressed the overall organization of support services: “The weakest links in the mental health system over the past 13 years have been case management,

family information, and adequate safe living options. Untrained, low paid group home personnel are also a problem in providing a stable, caring, comfortable living environment". At least one comment was positive: "Our county services have become quite good and we are in constant communication and when there are problems they have been dealt with; communications are good -- staff on all levels are humane and caring; not always highly trained, but caring". Representative comments about specific community support services are listed below.

Crisis Response.

- None specific.

Mental Health Treatment.

- "something needs to be done with the system...(my family member) never gets more than 10 minutes with a psychiatrist. They keep changing her medications, over-prescribing, making her go with no medication. It's a frustrating life for her and us. The only way anyone can get help is for her to be admitted so the doctors can get more payment from her insurance."

Income and Entitlement.

- "...My biggest concern is that SSI payments and \$50 a month in food stamps are grossly inadequate. She would not be able to live independently, progress on her own merits, look for a job, etc., without family assistance."
- "...Without Medicaid, (our family member) would be unable to receive (Clozaril) and psychiatric help."

Protection and Advocacy.

- "...Iowa Protection and Advocacy represented (our family member) when her housing was threatened due to her poor housekeeping. Her managers at the apartment felt threatened when P & A told them she had a right not to clean....We were unhappy with P & A (because they) addressed the problem from a legal viewpoint, not from a mental health view...Since their intervention, (agency x that provided supported living assistance) has backed off and our daughter is living in a pit that she refuses to clean."
- "...Persons with mental illness did not ask for their problems, and cannot speak out for themselves--we need to do a better job for them."

Physical Health and Dental.

- "It is very difficult to find out just who accepts Title XIX. Most specialists don't and if they do most do just a mediocre job of attending to the patient. We are fortunate to have a fine dentist and also eye specialist but to find a gynecologist to just give a check-up it is almost impossible..."

Housing.

- "...there is a shortage of affordable housing."
- "If there was a long term care residence here staffed by all mental health professionals that's were I'd like to see her...."
- "...after calling 84 telephone numbers and not finding anyone who would rent to a person with schizophrenia, we were able to secure a landlord willing to agree to Low Rent Housing and rent to a person with schizophrenia. It has been satisfactory to both parties for over five years."

Psychosocial Rehabilitation.

- "We would like to see more programs for the mentally ill dealing with training and work..."
- "I would like to see more direct assistance in the obtaining of jobs. Too much is left to the client who has been "out of the mainstream."
- "As parents, we are disappointed that our daughter's residence has no requirements to work, volunteer or day treatment. Little is expected of her and more structure would help her with responsibly issues and contacts outside of her housing."

Peer Support.

- None specific.

Identification and Outreach.

- "The government and the public need to be better informed about mental illness..."

Family Support.

- "If I were dead--this would all be a different story--and I can't begin to guess what kind of story."
- "...parents still have considerable responsibility..."
- "...family therapy seems to be non-existent."
- "She has no case manager, no help at all but family."

Case Management.

- "....case managers and staff, social worker, etc. are fine but when the consumer can fire them at will it sometimes doesn't work very well...it doesn't make anyone happy."
- "The problem with case management is that it operates as a gatekeeper in some cases. It coordinates only an incomplete, fragmented system of service providers and services available."

Study Limitations

This survey provides an assessment of community service support services by family members of persons who have a serious mental illness and who live in Iowa. Limitations of the present study should be considered in its interpretation and application. There were only 53 respondents and their perceptions may not be representative of all family members in all parts of Iowa. Family members who responded to the survey may have been different from non-respondents by a non-random self-selected process. Also, they are describing ill family members with different needs who live in different counties.

Summary of Survey Findings

Service Component Use and Satisfaction. Service satisfaction ranged from 57% for Identification and Outreach to 81% for Income and Entitlement among those respondents who reported that their family member had used the service component over the past one year period. However, service use varied widely across components. The service most likely to be reported as being used over the past one year period was mental health treatment (92%) whereas only 35% of respondents reported use for housing services. When the proportion of persons who reported using a service was multiplied by the proportion who were satisfied with the service, the component with the highest use/satisfaction score was mental health treatment (64%) and the lowest was housing (23%).

Access to Service Components. The proportion of respondents who reported that their family member both needed and used a service component was calculated in order to estimate access to a service component. Service accessibility ranged from 27% for housing to 85% for mental health treatment.

Most Helpful Resource. Mental health professionals were identified as being the most helpful resource for crisis response by 38% of respondents and for mental health treatment by 58% of respondents. Family members were identified as being the most helpful resource for all other services except for psychosocial rehabilitation. Over one half of family members indicated that they were their ill family member's most helpful resource for protection and advocacy services (53%) and for housing (55%).

Access to Services within each Service Component. Respondents were asked to indicate whether they had needed, and, if needed, used specific types of services within each service component. Results for each service component are summarized below.

I. Crisis Response. The service with the highest reported need was phone contact with counselor (60%); the service with the lowest reported need was police department services (11%). The service with the highest reported rate of access (e.g., when needed, it was received) was hospital emergency room (93%); the service with the lowest reported access was mobile crisis unit (0%). Access to 24 hour crisis telephone service was reported by less than one half of respondents (43%).

II. Mental Health Treatment. The service with the highest reported need was individual counseling (89%). The service with the lowest reported need was family therapy (28%) which was also the service with the lowest reported access (44%). The service with the highest reported rate of access (e.g., when needed, it was received) was help with medication problems (85%).

III. Income Support and Entitlements. Although only about one third of family members reported needing these services, most who needed them reported that they had received them.

IV. Protection and Advocacy. About one third of respondents indicated that they had needed assistance in contacting agencies about questions or complaints, and 63% were able to receive help. Eight families reported needed assistance with the commitment process, and only one half reported receiving such help.

V. Physical Health and Dental Services. Most respondents 32/53 (60%) indicated that their ill family member had medical problems in addition to their psychiatric illness but less than one half of respondents indicated that they had needed help in obtaining services. Of respondents indicating that they needed assistance obtaining medical treatment for their family member, most (85%) indicated that they had received it. One half or less of persons who indicated that their family member needed help in abstaining from alcohol and/or drug abuse, pregnancy prevention, or assistance controlling smoking reported that they had received these services.

VI. Housing. About 20% of families indicated that they needed help with finding housing. When needed, it was received about one half of the time. Only 5 families reported that they needed help finding emergency housing and 2 of those families reported that they were able to find it.

VII. Psychosocial Rehabilitation. Psychosocial services of any type were reported to be needed by less than 50% of respondents and least likely reported as needed were help with completing education 7/53 (13%) and help with the use of public transportation 4/53 (8%). When needed, help with completing education and help with the use of public transportation were most likely to be received (71% and 100%, respectively). The service with the greatest reported need was help with money management (49%). The service that was least likely to be received, when needed, was help in finding volunteer work (38%). Help with finding a job was reported by 54% of the respondents who indicated that their family member had needed it.

VIII. Peer Support. Services reported to be needed most often by family members were help with making friends (53%) and help with day to day social interaction (59%). These services were reported to be received, when needed, by 21% and 39% of respondents, respectively. However, 19% of respondents indicated that they did not know if their family member had received help with day to day social interactions.

IX. Identification and Outreach. The service most frequently cited as being needed was information about services available (needed by 51% of respondents and received by 56%, when needed); the service least likely to be reported as needed was outreach service to clients who miss appointments or discontinue medication (13%). Transportation to services was indicated as needed by 30% of respondents and received by 81% who needed it. Outreach services to individuals who decline a formal treatment program, indicated as needed by 26% of respondents, was only received by 29% of respondents who needed it.

X. Family Support. Identification of temporary caregivers so the family can get away was the least likely service reported to be needed (13%), but, when needed, also the least likely service received (14%). Less than one half (43%) of respondents indicated that they had needed involvement in treatment planning; of those, 57% indicated that this was received.

XI. Case Management. Responses were nearly equally divided between respondents who said they did (43%) and did not (44%) have a case manager. Thirteen of respondents didn't know. Most family members reported that their ill relative met with or talked to their case manager once a month or less (15/21 or 71%). The service with the highest reported need was for the case manager to monitor the ill family member's psychiatric symptoms (60%), however, less than half of the respondents said that this occurred (44%) with 9% indicating that they didn't know. About one half of respondents indicated that their family member's case manager needed to arrange for individualized services and develop comprehensive treatment care plans over the past year. However, only 58% said that their family member received such services when needed.

References

Rohland, B. M. (1996). Community support services for persons with serious mental illness in Iowa: Case manager survey results. Iowa City, Iowa: University of Iowa, Iowa Consortium for Mental Health Services Training and Research.

Rohland, B. M. (1996). Community support services for persons with serious mental illness in Iowa: Consumer survey results. Iowa City, Iowa: University of Iowa, Iowa Consortium for Mental Health Services Training and Research.

Stroul, B. (1988). Community support systems for persons with long-term mental illness. Rockville, MD: National Institute of Mental Health, Community Support Program.

Friedrich, R.M. (1994). [Community support services for the seriously mentally ill.] Unpublished instrument.