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Families' Perceptions of the Mental Health System

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Abstract

This study was carried out with the assistance of Supporting Families in Mental Illness (SF) Nelson/Marlborough, to provide insight into families' perceptions of their current involvement in the mental health system when a family member was being treated for mental illness. The survey collected information about gender, age, relationship to client, mental health diagnosis and the participants' rating of their satisfaction with the services provided by the mental health system when their family member was receiving treatment for a mental illness. Participants were asked to describe what they wanted from the mental health system for their family member. The majority considered their family member had a severe mental illness and were more dissatisfied by the system than those whose relative had a less severe illness. The findings are discussed and suggestions made for the improvement of support to families provided by mental health services.

Introduction

The serious mental illness of a close relative is a catastrophic event for families. In the words of one family member, "this terrible illness colours everything – a family cannot escape" (Marsh & Johnson, 1997, p. 229).

Mental health difficulties do not occur to individuals in isolation, but in the context of family, social networks, and the greater community. Over the past decade there has been an increasing call for practitioners to include families and caregivers in the assessment, treatment and recovery of clients who exhibit mental health problems. This research was designed to find out how recent changes in mental health policy in New Zealand were becoming apparent in practice.

The Blueprint for Mental Health Services (Mental Health Commission, 1998, p. 9) states:

> *People with serious mental illness are not ill in isolation. Their families, extended whanau, and significant others, whatever they think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are*

> *inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them. Beyond the immediate family are other relatives, friends, neighbours and workmates who may have a role in the life of the person and need, therefore, to be part of the healing or maintenance programme.*

Families experience a range of emotions when a severe mental illness strikes one of their members. They feel the loss of the person who is ill, who may become a "different person". Families mourn the loss of the family member's potential, and often experience intense grief reactions. Siblings and children are often greatly affected by this experience. According to Hatfield (1990), parents whose children have schizophrenia endure difficulties with self-image where feelings of embarrassment, shame, guilt and blame persist, and because of stigmatisation they are often isolated from the community. Concerns arise about the dangerousness of the unwell relative, both to family members and to the wider community, and family members may be apprehensive about their own loss of control in the face of constant stress.

The demands of living with a relative who has a serious mental illness have been described in many recent publications (Lefley & Johnson, 1990; Marsh, 1992). Reactions to loss of control and constant stress are often not recognised by mental health professionals, despite the increasing body of literature by family workers (Alexander, 1991; Backlar, 1994; Torrey, 1995). International reports call for education and training for families to reduce the burden and the levels of stress, and for more support to help them care for their mentally ill relatives in positive ways (World Schizophrenia Fellowship, 1998). It has become increasingly obvious that professionals working with the mentally ill need to increase their recognition of the strength of families and the great burden that they have to cope with on a daily basis (Peternelj-Taylor & Hartley, 1993).

Whiteside and Steinberg (2003), writing for a New Zealand audience and using the findings of an extensive international literature, demonstrate the effectiveness of inclusion rather than exclusion of families in the treatment of schizophrenia and other mental illnesses. Falloon (1999) argues that the use of family and community systems significantly diminishes the rates of relapse of clients with mental health illness and the provision of support services to caregivers in families in New Zealand can considerably reduce their stress levels. Thus there is considerable support in the literature for the benefits of involving families in management of the mental illness of a relative.

The evolution of the family-professional relationship, which is the current philosophy behind the practice, can be understood in terms of three eras.

Institutional care

Until recently, the need to control people with mental disorders was perceived as more important than individuals' need for treatment, hence people were institutionalised (Lefley, 1996). Prior to World War II, during the institutional era, patients with mental illness were sent to state hospitals and isolated from their families. While in these institutions, the patients' families had very little contact with them or with the professionals caring for them. Families were generally ignored. They were therefore denied any knowledge of the diagnosis or treatment of their family member and were unable to provide any effective support or care. Before deinstitutionalisation, it has been reported that some families were told at the hospital doors to "pretend that their children were already dead" (Marlatt, 1988, p. 7).

Psychiatric drugs

In New Zealand, psychiatric drugs began to be used around the late 1950s. These medications were effective in curbing bizarre distortion of perception, thoughts and feelings, and provided the opportunity for more humane care for people with severe mental illnesses like schizophrenia. At this time the government policy in New Zealand supported this, and change occurred which resulted in institutionalised mental health clients being discharged into what was known as integrated community care. The goals of this model were to transfer residents of psychiatric hospitals into the community and to avoid the need for residential care through early treatment.

At this point contact between families and professional mental health workers increased, but because of the widespread belief that mental illness resulted from a dysfunctional family environment families often found themselves being held accountable for the illness of their family member. Describing this earlier era, Keith (1997) states, "... families were four times punished, blamed for causing the illness, forced to watch deterioration of their loved one, excluded from treatment plans and required to pay for such treatment".

Deinstitutionalisation became the focus of mental health policy and has remained in controversial favour ever since. Concerns have been raised, such as lack of appropriate and sufficient community support and rehabilitation facilities, lack of trained professional staff to manage the care of clients in the community, and lack of resources to provide information, education and support for families who then had the task of caring for their family members as well as dealing with the stigma of social perceptions about mental illness. Thus during the early years of deinstitutionalisation the family-professional relationship was distant (Brookes & Thompson, 2001).

Community integration

The philosophy currently being promoted is distinguished by increasing community integration and participation by people with mental illness. This has promoted a shift towards a more constructive family-professional relationship. The intention of this model is to be collaborative and to build on the strengths and contributions of both groups. Involvement of family members is considered to be vital from the onset of an individual's illness. The World Schizophrenia Fellowship (1998) suggests that alliances need to be made between family carers, clinicians and those with major mental illness. A philosophy needs to be adopted which promotes mutual respect, trust and understanding among all parties, and which values family expertise.

The present situation in New Zealand

It is claimed that one in five people in New Zealand will experience a mental illness at some stage in their lives (Oakley-Browne et al., 1989). According to the Mental Health Commission, a crown entity which reports on the implementation of the National Mental Health Strategy, there are 60,000 New Zealanders who have ongoing mental illness (Coddington, 2001). This suggests that there are at least this many family members who are significantly involved in these people's lives.

When people with mental illnesses were institutionalised there was a perception in the community that they were dangerous, but very little opportunity was provided for the community to understand the differing nature of mental illness and its effect on individual lives. With deinstitutionalisation there have been cases where community supports have been inadequate and medication regimes have not been followed. Media reporting of crimes and suicides that have involved seriously disturbed mental health clients and increasingly intolerant levels of family distress has led to family involvement being considered a necessity when clients are involved with the mental health service.

As a consequence of these incidents, a report was commissioned (Mason Report, 1996) and this led to the establishment of the Mental Health Commission. An amendment to the Mental Health Act was introduced by the National government in the wake of the Raurimu massacre (as it has become known), requiring clinicians to consult families during assessment and treatment of the mentally disordered. This amendment was passed by the Labour-Alliance government in March 2000, along with an announcement that there would be a significant increase in funding for mental health.

Following the Mason Report, the National Mental Health Standards were established in June 1997 (Ministry of Health, 1997a). These were intended to apply to all mental health providers across New Zealand, and were used to complement existing standards and to inform consumers, their families and the New Zealand community what to expect from a mental health service. Standard 10 of the National Mental Health Standards clearly stated that families and carers were to be involved in the planning, implementation and evaluation of the mental health service. Standard 10.3 specifically states that the mental health service will assist with education and support for families, carers and staff to maximise family and carer participation in the service.

Following these standards, the document *Moving Forward* was produced in July 1997 (Ministry of Health, 1997b) as a plan to outline goals and strategic directions for the development of mental health services over the next ten years. With regard to families and caregivers, the main objective was to improve the responsiveness of mental health services.

In 2001 the Ministry of Health and the Health Funding Authority jointly conducted a review of the National Mental Health Standards. This review produced what are known as the Health and Disability Sector Standards. The aims of the revised standards were: (a) to achieve better mental health services, and (b) to ensure consistency in the delivery of mental health treatment and support for every New Zealander who needs to use mental health services. Under Sector Standard 10.3, it is stated that the mental health service encourages family/whanau to provide feedback and contribute to the collective views. This includes: (a) the mental health service assisting with education and support for families/whanau to maximise their participation in the service; (b) training for staff in working with families/whanau as advisors; (c) the use of satisfaction surveys, and (d) advisors liaising with family/whanau groups or networks (Ministry of Health, 2001a).

In November 2000, the Community Liaison Committee of the Royal Australian and New Zealand College of Psychiatrists prepared the document *Involving Families: Guidance Notes: Guidance for involving families and whanau of mental health consumers/tangata whai ora in care, assessment and treatment processes.* These guidance notes were a result of extensive consultation throughout the mental health sector during 1999. They set out some ways in which families can be involved in the delivery of mental health services to their family members as well as ways that mental health services can more effectively work with families. They suggest ways in which people working in the mental health area can ensure that families can access information, education and support in culturally appropriate ways. A more recent document, which reiterates the importance of family involvement in the care of mentally ill clients, is the Health and Disability Act 2001 (Ministry of Health, 2001b). This standard states the importance of consumer rights and providers' obligations.

Processes currently in place for monitoring of National Mental Health Standards have been in operation throughout New Zealand over the last two years. These include self-audits, reporting as specified in contracts with health funders, and independent audit and review.

From the point of view of the general public there has been a proliferation over several years of government reports and coroners' findings emphasising the necessity of including families in mental health assessment, treatment and care. The claim that there is a need to involve families has gained support from the much publicised cases of Mark Burton, Lachlan Jones and their families. Despite the present climate in mental health, where it seems that services are making genuine attempts to involve families in the support of clients, public debate continues as to whether the professional-family relationship is really collaborative as is suggested and intended. The present study is motivated by the desire to find out whether the policy changes in the mental health system are perceived by the families of people with mental illnesses to be producing the services that are needed.

Methodology

This study was carried out with the assistance of the organisation Supporting Families in Mental Illness (SF). The Nelson and Blenheim branches agreed to distribute the approved survey forms to members. Once approval was obtained from the Massey University Human Ethics Committee, 50 questionnaires were posted to the branches of SF, and 36 were returned.

Each questionnaire was accompanied by an information sheet which explained the purpose of the research and pointed out that no names, addresses or any other identifying information was sought. Questionnaires were to be returned by way of a self-addressed envelope.

The questionnaire included three sections. Section 1 sought information about gender, age, relationship to client and mental health diagnosis. Section 2 asked participants to rate their satisfaction with the services provided by the mental health system when their family member was receiving treatment for a mental illness. The rating scale ranged from one (very satisfactory) to four (very unsatisfactory) and five (not relevant). Section 3 was qualitative and asked participants, "What do you want from the Mental Health System when your family member is receiving treatment for their mental illness?" Responses to Sections 1 and 2 were tabled (see Tables 1, 2 and 3).

Data from the two centres were combined. Section 3 information was summarised and participants' "wants" were extracted from each questionnaire. Common identified themes were then derived, and the individual wants of each respondent were categorised on the basis of these identified themes.

Results

Of the 50 questionnaires that were distributed, 36 (72%) were completed. Table 1 shows information regarding respondents' gender, age and relationship to the mental health client, and the mental health diagnosis of the client. These results show that a large percentage (81%) of the respondents were female, with 65% of these over the age of 50 years. Eighty-one percent also described themselves as parents of the family member with mental illness. Sixty-two percent of the respondents regarded their family member's illness as severe, 32% moderate and only 5% mild. The majority of family members (73%) were reported as being diagnosed with schizophrenia. Of those who completed the questionnaire a total of 65% did not fully agree that treatment received through the mental health system had improved the mental health of their family member. This included 54% who stated that they partially agreed and 11% who disagreed.

Table 1: Results of Section 1 of the questionnaire

		Total responses	% of respondents
Respondent gender	Male	7	19
	Female	30	81
Respondent age group	<20	0	0
	20–30	1	3
	30–50	12	32
	50–60	15	41
	60>	9	24
Relationship to client	Parent	30	81
	Partner	4	11
	Sibling	1	3
	Other	2	5
Mental health diagnosis	Schizophrenia	27	73
	Depression	5	14
	Bi polar	5	14
Regard family member illness as	Mild	2	5
	Moderate	12	32
	Severe	23	62
Treatment received through mental health system has improved the mental health of your family member	Disagree	4	11
	Partially Agree	20	54
	Agree	13	35

The results show considerable dissatisfaction with the mental health services. Table 2 shows that 62% of the total number of respondents were unsatisfied/very unsatisfied with the amount of information provided about the mental illness of a family member. With regard to information provided about medications and their side effects, 57% of respondents reported that they were unsatisfied/very unsatisfied. Fifty-four percent of the respondents reported that skills/strategies provided by health professionals to cope with their family members' illness were unsatisfactory/very unsatisfactory.

In spite of the deficiencies highlighted by the survey, the majority of respondents (70%) reported that they were very satisfied/satisfied with the respect shown to them

Table 2: Levels of satisfaction/dissatisfaction of total group of respondents in relation to support, partnership, information and education. Percentages do not add up to 100 because of "Not relevant" responses or missing data

	No. very satisfied/ satisfied (%)	No. unsatisfied/ very unsatisfied (%)
Support and partnership		
The respect shown to me by health professionals	26 (70)	9 (24)
The acknowledgement given to my opinions by health professionals	16 (43)	19 (51)
Encouragement given to be involved in sessions	19 (51)	17 (46)
Attention to my cultural needs	13 (35)	5 (14)
Frequency of contact with health professionals	18 (49)	19 (51)
Overall support provided to me by the mental health system	17 (46)	17 (46)
Information and education		
The amount of information provided about my family member's mental illness	12 (32)	23 (62)
Information given about management of mental illness	15 (41)	19 (51)
Information provided about medications and their side effects	14 (38)	21 (57)
Information provided about privacy/confidentiality	21 (57)	12 (32)
Skills/strategies provided by health professionals to cope with my family member's illness	14 (38)	20 (54)
Information provided about community services	14 (38)	14 (38)
Assistance/response provided by health professionals during crisis	23 (62)	13 (35)

by health professionals. The responses were similar regarding information provided about privacy/confidentiality (57%) and with regard to assistance/response provided by health professionals during crisis (62%).

With regard to opinions about the overall support provided to them by the mental health system, 46% reported that they were very satisfied/satisfied, and 46% reported that they were unsatisfied/very unsatisfied.

Table 3 shows the respondents' level of satisfaction/dissatisfaction according to the severity of their family members' mental illness. When data were analysed according to severity of illness, a distinct pattern emerged. Higher rates of dissatisfaction and lower rates of satisfaction for most questions were reported by respondents who described their family members as having a severe mental illness. In particular these included: acknowledgement given to respondents' opinions by health professionals; overall support provided by the mental health system; the amount of information provided about the family member's illness; management of the illness; medication and side effects, and skills/strategies to cope with the family member's illness.

Table 3: Respondents' levels of satisfaction/dissatisfaction according to the severity of the family members' mental illness (mild/moderate to severe)

SUPPORT AND PARTNERSHIP	Severe (n = 22)		Mild/moderate (n = 14)	
	No. very unsatisfied/ satisfied (%)	No. very unsatisfied/ unsatisfied (%)	No. very satisfied/ satisfied (%)	No. very unsatisfied/ unsatisfied (%)
The respect shown to me by health professionals	14 (64)	8 (36)	13 (93)	1 (7)
The acknowledgement given to my opinions by health professionals	7 (32)	15 (68)	10 (71)	4 (28)
Encouragement given to be involved in sessions	11 (50)	11 (50)	9 (64)	5 (36)
Attention to my cultural needs[1, 2]	6 (27)	5 (23)	8 (57)	1 (7)
Frequency of contact with health professionals	11 (50)	11 (50)	8 (57)	6 (43)
Overall support provided to me by the mental health system	8 (36)	14 (64)	10 (71)	4 (28)

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Table 3 continued

INFORMATION AND EDUCATION	**Severe (n = 22)**		**Mild/moderate (n = 14)**	
	No. very unsatisfied/ satisfied (%)	No. very unsatisfied/ unsatisfied (%)	No. very satisfied/ satisfied (%)	No. very unsatisfied/ unsatisfied (%)
The amount of information provided about my family member's mental illness	8 (36)	14 (64)	6 (43)	8 (57)
Information given about management of mental illness[3]	8 (36)	13 (59)	11 (78)	3 (21)
Information provided about medications and their side effects	8 (36)	14 (64)	8 (57)	6 (43)
Information provided about privacy/confidentiality[4]	10 (45)	10 (45)	12 (86)	2 (14)
Skills/strategies provided by health professionals to cope with my family member's illness	8 (36)	14 (64)	9 (64)	5 (36)
Information provided about community services	9 (40)	13 (59)	8 (57)	6 (43)
Assistance/response provided by health professionals during crisis	11 (50)	11 (50)	12 (86)	2 (14)

Notes

1. Eleven respondents in the severe category rated this question not relevant.
2. Five respondents in the mild/moderate category rated this question not relevant.
3. One respondent in the severe category rated this question not relevant.
4. Two respondents in the severe category rated this question not relevant.

Response rates for satisfaction and dissatisfaction were similar with regard to involvement in sessions, frequency of contact with health professionals, and information provided about privacy and confidentiality. Those respondents who reported their family member as having a mild or moderate mental illness were much more satisfied with the mental health system, except for the amount of information provided about the family member's illness, where 57% were unsatisfied/very unsatisfied.

Table 4 presents the common themes from the answers to open-ended questions asked of respondents regarding what they wanted from the mental health system

Table 4: Common themes expressed by respondents regarding what family members want from the mental health system

	% of respondents
1. Communication with family/carers: involvement of family in diagnosis, treatment and management	72
2. Education on medication, medication side effects, the mental illness including early crisis warning signs and coping strategies. Also cover legal rights and support agencies available	56
3. Opinion/knowledge/confidentiality of family member acknowledged	42
4. Post discharge monitoring	17
5. Post discharge supervised accommodation and support	14
6. Meaningful and organised activities	14
7. Drop-in centres	8
8. More attention by health professionals to drug side effects	8
9. Professional counselling available as parallel treatment to medication	8
10. Improved in-patient facilities	8
11. Consistent contact with health professionals	8
12. Respite care facilities	6
13. Increased number of appropriately trained health professionals	6
14. Holistic approach to treatment vs clinical	6
15. Family/carer consultation prior to discharge	6
16. Careful use of the Privacy Act with the aim being overall well-being of client	3
17. Transport assistance	3
18. Put into contact with other families in a similar situation	3
19. Non-fragmentation of mental health care	3
20. Increased funding for medication	3
21. Education of general public re mental illness	3
Total number of respondents	**36**

when their family member was receiving treatment for their mental illness. A high number of respondents (72%) indicated a need for communication/involvement of family with regard to the treatment and management of their family member. Fifty-six percent of respondents wanted education, skills and strategies to cope with their family member, for example, in the management of their mental illness including early crisis warning signs, medication and side effects, education on their legal rights, and which support agencies were available to them. Forty-two percent of respondents also wanted acknowledgement of their opinions, their knowledge valued, and a commitment to confidentiality by health professionals. Overall this section has produced a considerable list of suggestions for ways in which the family can be assisted in their responsibilities when caring for their family member who has a mental illness.

Discussion

This study was conducted with families who were currently involved within the Nelson-Marlborough Mental Health System when their family member was being treated for mental illness and assisted by SF in this area. Although it is a small sample (36), the number of participants probably represented more than half the relevant family population in that area. Nevertheless, because of the size of this sample and the manner in which participants were selected, information obtained from this survey should be considered in relationship to the sample studied and cannot be representative of the general population of families whose member is experiencing mental illness.

Since policy documents have been pressing for the involvement of families for some years, this research was sought to investigate whether families were finding this to be happening. Key findings of this survey suggest that further support, information and skills/strategies are needed by families in coping with the impact that mental illness has on their family member.

It was the group of respondents who reported that their family member had a severe mental illness, mainly schizophrenia, who felt more dissatisfied than those who rated the mental illness as moderate. This finding highlights the importance of the need for increased supports for families when one of their members has a severe mental illness. Over the past 20 years, people with schizophrenia have spent considerably less time in hospital and much more time at home (Weidermann et al., 1994). Families of people with a severe mental illness usually have a great deal of personal investment in caring during the advent and hospitalisation phases of the illness (Hanson, 1989). Often they have sustained that investment with the return of their mentally ill family member to the community (Hatfield, 1994). Frequently the family have been the primary carers for the client in the community, acting as de facto case managers for their relative with mental illness (Doll, 1976). Against this background, increasingly acknowledged has been a considerable degree of burden on relatives (MacCarthy et al., 1989), necessitating the development of mental health services that meet the needs of clients and their relatives (Smith & Birchwood, 1987).

The fact that only a small percentage of males completed the questionnaire indicates that females may be more likely to take on the primary role of caregivers for a family member with a mental illness. That caregivers are most likely to be older women suggests that mothers more readily take on this role, or sisters when mothers get too old for the task. The caregiver role is explored in studies such as those by Ascher-Svanum and Sobel (1989) and Anderson and Elfert (1989). The difficulties faced by siblings, spouses or children of individuals with mental illness may in fact be quite different from those faced by parents. Family concerns may also vary according to the stage of the illness or other factors such as the age or gender of the family member with mental illness.

A perception that there is a lack of information and education for families by mental health professionals emerged as a particular area of concern in this study. This is not an unusual finding in research of this type over recent years in New Zealand and elsewhere. Families require information and education such as understanding the mental illness, knowledge of medications and their side effects, and information on skills and strategies to cope with their family member's mental illness (Biegel & Yamatani, 1986; Hatfield et al., 1982). The impact of living with a relative with schizophrenia has been the focus of a number of studies (Baker, 1989; Smith, 1991; Whitfield & Virgo, 1989). Heywood-Jones (1987) and Laffey (1978) outlined the problems caregivers face, and identified the common need for both more support and more information (Wheeler, 1994). The replies to Section 3 of the questionnaire indicate that much more needs to be done by mental health professionals for family members in this local area if the policies of the service are to be achieved in practice.

The question needs to be raised as to why health professionals are not providing what is so clearly documented as needed by families and what the barriers are that prevent implementation of family education, training and support programmes. Consideration may need to be given to historical factors such as the way in which families were viewed negatively, educational and social treatments not being seen as important, and the level of funding provided for family psycho-education programmes. Other factors may also include inadequate training of professional mental health workers, inappropriate use of the Privacy Act, the mental health systems' inability to manage current resources, and finally, mental health clients being treated as individuals rather than collectively as part of a family (Whiteside & Steinberg, 2003; World Schizophrenia Fellowship, 1998).

The need to include families in the treatment of family members with mental illness has been well recognised in New Zealand and strategies continue to be implemented, evaluated and developed to encourage appropriate family and carer participation and involvement. Findings from the present study, however, indicate that for this sample of families a gap remains between expected and actual delivery of family involvement, suggesting that this needs to be an ongoing process that should be systematically reviewed.

This study calls for the ongoing development of a strategy for the training and education of mental health professionals with regard to involving families. Of significance is the acknowledgement of each individual member's needs for support within a family. Individuals will experience a variety of needs and concerns depending upon their life stage and roles in relationships, such as parent, spouse, sibling or child. A model is needed that enhances partnership and collaboration between both the family/individual family member and mental health professionals. It is essential that the model draws on the knowledge and experience of both parties and also shows respect for the needs, desires, concerns and priorities of families. The model should have a mechanism by which families are actively supported in their involvement in the decisions that affect them and in establishing mutually acceptable goals for their family members' treatment and rehabilitation.

In this current era, families often serve as the cornerstone of their relative's support system, and they fulfil valuable roles as primary caregivers (Marsh, 1998). Considering all this, much more of a collaborative approach is required of mental health professionals in order to provide a range of family-focused services. This can occur if mental health professionals are trained to offer these services.

Conclusion

The present study used a questionnaire to find out how families with a member being treated for a mental illness in a small, mostly rural, area of New Zealand perceived their involvement with the mental health system. Key findings of this survey suggest that further support, information and skills/strategies are needed by family members in coping with the impact that mental illness has on a member of the family, and especially when that is a severe mental illness. This study could therefore be seen to be a baseline study which could easily be replicated in later years to see whether mental health policies have been followed up by appropriate actions.

This study calls for the development and implementation of a strategy for the training and education of mental health professionals to promote the involvement of families, and suggests a model that enhances partnership and collaboration between the family and mental health professionals. The knowledge and experience of both parties needs to be embraced, and respect shown for the needs, desires, concerns and priorities of families. Families need to be actively supported in being involved in the decisions that affect them, including the establishment of mutual goals for their family member's treatment and rehabilitation.

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