

Procedures to Share Treatment Information Among Mental Health Providers, Consumers, and Families

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Although practice guidelines for the treatment of persons with severe mental illness recommend involving family members in all phases of the treatment process, in many states unclear confidentiality statutes and regulations may present a barrier. This paper describes approaches used by a few locales to clarify confidentiality procedures for releasing information to families. It presents a model of steps that regional systems or local agencies may take to manage this barrier to provider-family collaboration. Policy guidelines must clearly state that release of information to family members requires client consent. A specific form for release of information to families indicating the types of information that may be released is then developed. Verbal release of information and a one-year time limit on release are recommended. The form, which should comply with state statutes and regulations, can then be integrated into routine clinical practice. Providers should be trained to discuss and explore issues about the release of information with both consumers and family members. (*Psychiatric Services* 50:1321-1325, 1999)

Significant evidence exists that providing information to families about their relatives' illness decreases the frequency of relapse and thereby reduces rehospitalization (1-3). Practice guidelines for the treatment of severe mental illness have integrated these findings and other evidence and now recommend involving families in all phases of routine care (4-6).

Although the guidelines call for families to be involved in a collaborative treatment process to the greatest extent possible, few strategies for implementing provider-family collaboration have been developed. As a result, many families are not involved in

the treatment process or given any information about their relatives' illness (7-13).

A number of factors have been examined as potential barriers to implementing provider-family collaboration (8-13). However, one potential barrier that has not been fully explored is unspecified or unclear statutes and regulations related to confidentiality (14-17). This paper discusses the dilemma faced by consumers, families, and mental health care providers in balancing consumers' right to confidentiality and families' need for information. Issues involved in clarifying confidentiality as it relates to the release of informa-

tion to families are outlined, and innovative approaches developed by two counties in response to these issues are presented. Finally, based on a review of the current approaches, a model for clarifying confidentiality is proposed.

The dilemma of consumers, families, and providers

Symptoms of mental illness such as confusion, cognitive deficits, isolation, and withdrawal make it difficult for consumers to recognize signs of relapse and to seek help. Consequently, families are frequently the first to recognize warning signs and symptoms (7). For this reason, families' role in their relatives' support network is often an integral component of effective treatment (18).

To fulfill this role, families must have, at a minimum, ongoing contact with providers and information about their relatives' diagnosis and treatment. Without such information, families may not be able to distinguish between warning signs of relapse and medication effects (14) or to support treatment goals and promote recovery (16,19). Without ongoing contact with providers, families may observe signs of relapse but have no means to share this information with providers who may intercede to prevent a crisis (20).

Providers are increasingly aware that families can be a vital resource in the treatment process, and providers recognize the need to share information with involved and supportive family members. However, in most states providers are presented with

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confidentiality statutes and regulations that do not mention the release of information to families. Therefore, under the letter of the law, providing even the most basic information about a client's condition without written consent, such as informing family members that their relative is improving, is technically a breach of confidentiality (Ulan H, Pennsylvania Department of Public Welfare, personal communication, Sept 1998).

A preliminary review of state statutes revealed that some states, such as New Hampshire, Iowa, Maine, New York, Maryland, Massachusetts, and Rhode Island, have included language about the release of information to families (21-27). Each of these states permits exceptions to obtaining client consent before release of information to families. According to the New Hampshire and Iowa statutes, for example, providers who receive written requests from a family are permitted to disclose specific information without the consumer's consent under certain conditions. First, the attending provider must verify that the family member is directly involved in providing care or monitoring the treatment of the ill relative. Second, the information disclosed must be necessary for the provision of care and monitoring of treatment. Although such exceptions to client consent are permitted, most state statutes strongly encourage obtaining consent whenever possible.

Requiring client consent is vital for a number of reasons. First, it safeguards consumers' trust, which is essential in the therapeutic relationship. Providers build trust by ensuring that information is not disclosed without clients' permission (14). Trust is a crucial component of successful treatment. Disclosing information, even to families, without explicit consent of the client is a violation of trust. Second, obtaining consent empowers consumers to develop their own support network, promoting both independence and the acceptance of mental illness as a chronic illness, like diabetes, that can be monitored and managed. Third, by discussing with clients the options for releasing information to families, providers communicate respect and validation of con-

sumers' ability to make decisions in their own best interest.

As providers attempt to fulfill the statutory requirement to obtain client consent, they often discover that forms and procedures specifically for releasing information to families do not exist. Instead, the only option available is to use general agency release forms. Because these general forms are typically created for interagency use, the release is often limited to 30, 60, or 90 days, or the form specifies that the information may be released one time only. Because mental illnesses are chronic and recurrent, these restrictions make the forms cumbersome and impractical to use for families who need to receive information on an ongoing, long-term basis. In addition, the short time limit is difficult to keep updated and often impedes communication at times when it is most needed, such as during a crisis.

The lack of specific forms and procedures creates a real dilemma for providers, and this dilemma is further complicated by unclear definitions of confidential and nonconfidential information. Nonconfidential information includes basic information about mental illnesses, including etiology, warning signs and symptoms, general prognoses, and basic treatment options. In reality, much of the information families seek may be disclosed in a manner that does not breach confidentiality (12,15).

For example, consumers often tell family members their diagnosis and where they are receiving treatment. Families may call the agency requesting information with the sole purpose of learning more about the illness to provide more effective support to their ill relative. Providers may believe that responding to the request is a breach of confidentiality when, in fact, many of the questions may be answered without disclosing any identifying (confidential) information. However, in the face of legal and ethical obligations, providers often respond cautiously and may mistakenly withhold even general information from families (15,16).

Zipple and colleagues (15) outlined methods of providing general information to families without violating

client confidentiality. For example, providers may simply state that they cannot verify whether the individual receives services at the agency, but that they can share basic information about mental illnesses, the services provided by the agency, and other community resources. When contacted, providers may also listen to families and receive information about clients without breaching confidentiality. General information and contact with providers is crucial for families attempting to understand and support their ill relative (15).

Innovative local approaches

Local efforts have been directed at filling in gaps when confidentiality statutes are not specific and developing clear procedures to guide the disclosure of information to families. The first issue involved in establishing procedures is deciding who is responsible for initiating the consent process. Many agencies require that consumers or families request information. Two counties, Riverside County, California, and Allegheny County, Pennsylvania, have taken a proactive stance by developing procedures that place the responsibility for initiating the consent process in the hands of providers (28; Holder B, Alliance for the Mentally Ill of Southwestern Pennsylvania, personal communication, 1998).

This approach is reasonable and effective for a variety of reasons. First, substantial evidence about consumers' and families' experience with mental illness suggests that leaving the responsibility to consumers or families is likely to be extremely burdensome. One reason is that both consumers and families battle with the stigma and shame of mental illness (29-32). It is natural for both consumers and families to minimize or doubt symptoms, blame themselves, and become isolated from friends and other supports. Consequently, requesting information and initiating the consent process may be difficult for them.

Furthermore, current practice guidelines recommend that providers involve families in the treatment process. Providers' initiation of the consent process is a concrete strategy

for fulfilling this recommendation. Moreover, it affords a means to engage consumers in a dialogue about the benefits of involving their family in the treatment process.

Not designating providers as initiators of the consent process has some potentially negative effects. For example, families and consumers who do not understand that information from the clinical record is confidential may attribute providers' silence to a belief that mental illness is shameful. When providers fail to raise the issue of releasing information to families, outdated beliefs that mental illness should not be discussed are reinforced. By initiating honest discussions with consumers about disclosing information about their illness to their families, providers are taking the first step in breaking the secrecy that maintains the shame and stigma of mental illness.

Riverside County's procedures also contain several elements integral to promoting collaboration. The procedures raise awareness of the importance of support networks and encourage a team approach with an open dialogue between providers, consumers, and families. Providers are responsible for discussing with clients options such as releasing limited or specific information to a designated family member. Once a client chooses to sign such a release form, providers are responsible for encouraging the family member to become involved. For family members who are hesitant to participate in the treatment process, providers are instructed to respectfully explore the reasons for their reluctance.

Riverside County's procedures are an important first step in alleviating misunderstandings between families, consumers, and providers about confidentiality, but the impact of the county's educational effort has been limited. Riverside County has relied on brochures to educate both providers and families about the procedures. Although the brochures were widely distributed, many providers are unaware of the procedures, which were developed in 1997. Moreover, the lack of countywide training for providers has resulted in inconsistent implementation of the procedures. Therefore, the

potential effectiveness of the effort has been reduced (Callahan C, County of Riverside Mental Health Department, personal communication, Sept 1998).

Riverside County's procedures clarify confidentiality on the provider level, whereas Allegheny County implemented a systemwide policy clarification. Allegheny County's efforts began about eight years ago when public mental health officials, families, consumers, and county legal staff convened and, over a period of two years, introduced a form specifically for releasing information to families. They also developed procedures for disclosing information to families and implemented systemwide provider training.

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The release form developed by Allegheny County includes several key components that address issues arising from the use of general consent forms. First, consumers choose the family member or significant other to whom information will be verbally released. Verbal release of information promotes flexible communication by allowing providers to update families with a brief phone call rather than requiring formal written correspondence. In addition, verbal release can protect clients from the chance of written correspondence ending up in the wrong hands.

Second, consumers choose the types of information they wish to release, such as the provider's name, the

name of the treatment program, the treatment plan, medications, and the dates of scheduled appointments. General forms often require the categorical release of all information in the clients' medical record. Consumers who refuse to sign a categorical release may be willing to release specific types of information. Therefore, these provisions enhance the likelihood that consumers will benefit from family involvement and support.

A third key component in the Allegheny County approach is that clients who are physically unable to give written consent may verbally authorize release of information with the signature of two witnesses. Fourth, Allegheny County addressed the problematic issues associated with short time limits on information release by adopting a non-time-limited form and allowing clients to revoke the release form at any time by submitting a written request.

Besides the creation of a specific release form, procedures were established to integrate the release form into routine clinical practice. The form is presented to clients at intake into the county mental health system. The medical records department of the central intake agency in each of Allegheny County's catchment areas is responsible for retaining the original release form, notifying all involved agencies, and maintaining records of which agencies are notified. A notice is also sent to the designated family member to inform him or her of the type of confidential information that may be released on an ongoing basis. The centralized process ensures that the information that consumers and families receive is uniform across all agencies.

All staff in Allegheny County's mental health system, including intake workers, psychiatric nurses, therapists, and receptionists, were required to attend a training session to help providers integrate the form into routine clinical practice. Allegheny County's experience has indicated that given the option of releasing specific information to families, 90 percent of clients agreed to sign the form (31). If a consumer chooses not to sign the form, it is the treating therapist's responsibility to discuss the pol-

Steps for developing a policy and a form to release information to clients' families

1. Clearly state in the policy guidelines that release of information from the client's clinical record to family members requires client consent
2. Develop a form specifically for the release of information to family members
 - Create categories for the types of information that may be released that are applicable to the local agency or system
 - Consider an appropriate time limit for the release form
 - Indicate how information will be released (a verbal or a written release, or both)
 - Review state statutes and regulations to ensure that the form is in compliance with the law
3. Establish procedures for the form to be integrated into routine clinical practice
 - Present the release form to clients at intake to the agency or mental health system
 - If a client is too ill to provide consent, determine the procedure for reintroducing the release form once the client is stabilized
 - Develop procedures for updating the release form (if applicable)
4. Develop training for providers
 - Train providers in ways to discuss and explore issues about the release of information with both consumers and family members
 - Include information about the release of general information to family members when consent is not provided
 - Develop procedures for integrating training into the orientation for new employees

icy with the client. Treating therapists are instructed to keep in mind clients' right to refuse while exploring their hesitations. If a client is too ill to provide consent, then the treating therapist is instructed to reintroduce the form when the client is stabilized. The mandatory training helped providers in Allegheny County discuss these issues as well as procedures for implementing the policy consistently across agencies.

Although no formal evaluation of the implementation of these procedures has been conducted, anecdotal information suggests that the efforts have been quite successful. According to members of the local Alliance for the Mentally Ill, it has been many years since complaints have been received from families feeling disengaged from the treatment process (Holder B, Alliance for the Mentally Ill of Southwestern Pennsylvania, personal communication, 1998).

Steps for clarifying confidentiality at the local level

Although guidelines for clarifying confidentiality policies may be developed on the federal, state, or local

levels, the model proposed here integrates the strengths of current approaches and outlines steps that may be taken by regional mental health systems or local agencies (see box).

Step 1: clarifying the need for client consent

The proposed model places a high priority on the protection of clients' rights by requiring consent for the release of any confidential information to families. Therefore, the proposed model is in accord with the most conservative interpretations of confidentiality statutes and may feasibly be implemented in any state.

Step 2: developing a release form

Several factors need to be considered when developing a form specifically for releasing information to families. The first consideration concerns the categories of information that may be released. Although the categories developed in Allegheny County may be used as a model, they may need to be adjusted to meet local needs or to accurately describe services. If the form is to be used systemwide, the categories on the form should represent

all types of information that may be released from the various agencies in the system.

The second factor to consider is the use of a time limit. For mental health systems or agencies that decide to institute a time-limited form, a one-year limit is recommended. Selection of this time frame is based on balancing tradeoffs between the extreme options of release forms with very short time limits to those with no time limits.

Although forms with no time limits ensure that continuity is not disrupted by the formality of updating forms, the inclusion of a reasonable time limit offers important protections for the consumer. For example, when properly implemented, time limits compel providers to update the form, thereby accommodating changes in consumers' social networks. Updating the form reminds both providers and consumers of the importance of involving families in the treatment process. Moreover, the inclusion of a time limit fulfills statutory requirements for states that require beginning and end dates on all release forms.

A third factor to consider in developing a release form is the manner in which the information will be released. Based on the advantages discussed above, the proposed model recommends a verbal release of information.

Step 3: integrating the release form into routine clinical practice

In the proposed model, providers are responsible for initiating the consent process. The release form may be presented to clients at intake into the agency or mental health system. If the client is too ill to consent at that time, a designated provider may reintroduce the form once the client is stabilized. The designated provider should be selected from the client's treatment team and offered training on how to discuss and explore the options for releasing information with the client. The designated provider is the likely choice for being responsible for updating the release form if the form includes a time limit.

If the release form is integrated systemwide, the coordinating procedures

used in Allegheny County offer a feasible model. In this model, the original forms are stored in a central location, and copies are dispersed to all appropriate mental health agencies. The designated provider forwards all updates to the central record-keeping location, which then notifies all appropriate agencies and the designated family member of updates about the status of the release form.

In mental health systems in which efforts cannot be feasibly coordinated on a systemwide basis, agencies may independently integrate the release form into routine clinical practice. The agency would then be responsible for notifying designated family members that the release has been signed. Furthermore, families would need to be informed that the form is specific to one agency only and that a new release form must be signed in order to receive information from any other agency.

Step 4: developing training for providers

The proposed model recommends mandatory training for all providers. The purpose of the training is to review the newly developed procedures and offer providers skills for addressing issues about the release of information to families. Procedures developed in Riverside and Allegheny Counties offer a model for others to adopt. The training should emphasize that families are entitled to receive general information, regardless of whether they have been designated by their ill relative to receive confidential information.

To maintain consistency across agencies in the implementation of the confidentiality policy, it is necessary to develop procedures for training incoming staff after the initial implementation training. Mental health systems may consider integrating the training into orientations for new employees. Other options include developing a manual for new employees or designating trainers within each agency.

Conclusions

The intent of confidentiality statutes and regulations is to provide clients with the choice of releasing informa-

tion from their clinical record to individuals they deem appropriate and trustworthy. However, procedures to make this choice a reality are frequently not available. With significant evidence mounting about the benefits of involving families in the treatment process, it is vital for local mental health systems to reconsider current procedures for releasing information to families. The model outlined here can help bridge the gap between recommended standards for working with persons with severe mental illness and the current mode of routine clinical practice. ♦

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