

A Word About Confidentiality.....

Federal confidentiality regulations (HIPAA) and State law protect the confidentiality of patient information, and are often seen as a barrier to family involvement in treatment. Under HIPAA, persons have the right to "agree or object" to disclosures to family members or persons involved in their care. Under the New York State Mental Hygiene Law, patient "consent" is generally needed before disclosures to family members can be made, but the form the "consent" must take is not specified. Therefore, as a general rule, an adult patient must give permission before families can be provided with information about them.

When done in such a manner as to not compromise or reveal information that should be kept between therapist and patient, family involvement can be accomplished without obtaining the express permission of the patient and without violating confidentiality. For example, staff could discuss the programs that are available for the patient, privileges, family visits, legal status, and plans for discharge. Also, if not clinically contraindicated and appropriate, staff could share information provided by the family with the patient, such as relaying messages of support. Confidentiality laws protect the disclosure of information; they do not prevent providers from receiving information about persons under their care, such as background information, insights and observations from family members.

It is also important to remember what is protected under State and federal confidentiality laws. In general, "confidential information" means clinical information about patients, as well as information that would tend to identify a person as having a mental health condition, either at the current time or in the past. General information about serious mental illness that is available to the public, such as diagnoses, prognoses, symptoms, medication, treatment modalities, and information about community resources is not confidential information, and can be tremendously helpful to family members.

This pamphlet was written to encourage professionals to include families in the mental health care of their loved ones. The New York State Office of Mental Health and the American Psychiatric Association are among

those organizations supporting family inclusion, and excerpts from their publications are included in this document.

FAMILY MEMBERS

The laws, regulations, and policies governing mental health care include you. Firmly assert your right to be involved in your loved one's treatment and discharge planning. Tell your family member's provider about your experiences with your loved one's illness, and seek to participate in his/her care and treatment.

PROVIDERS

When family members are involved in mental health treatment, everyone can benefit. Make services available to families that acknowledge their contributions and help them be active participants in effective treatment. Make information and education available to family members about mental illness, treatment, coping skills, and ongoing support, and refer families to NAMI to help them find additional educational and supportive services. Form a working alliance with family members to empower them as important members of their loved one's treatment team.

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***Make the
Mental Health System
Work for You***

**When families
join the
mental health
care team
everyone
benefits!**

Mental health treatment outcomes can be dramatically improved when families are active partners in mental health treatment. The unique strengths and knowledge that family members can contribute to the treatment process can benefit everyone—the patient, the practitioner, and the family members themselves!

What do families need to know when:

A FAMILY MEMBER IS HOSPITALIZED? When a member of your family is hospitalized, you need to obtain education about his/her illness and how it affects him/her. You should also ask questions about hospital programs, services, policies, staffing, the public mental health system, medications, contact information, and where you can obtain additional information about other resources that might be helpful to you.

"A guiding principle is that the patient's family members should be involved and engaged in a collaborative treatment process to the greatest extent possible. Family members generally contribute to the patient's care and require education, guidance and support, as well as training to help them optimize their caretaking role and to improve their own wellbeing. The acute phase or times of crisis may be the best time to engage the family." (*American Psychiatric Association, Practice Guidelines for the Treatment of Patients with Schizophrenia, second ed., 2004, pp. 70, 106*).

"Each facility's written plan must provide for the development and implementation of orientation programs and written materials for families of patients [to address the following:] ...the

role of family and professional staff ...pertinent information related to mental illness ...facility programs and services and other state and local programs and services; policies and procedures ...concerning communications ...names and telephone numbers of key staff and administrators; ...names of Mental Hygiene Legal Service attorneys; Hotline number; establishment of regularly scheduled hours when families may make telephone contact or meet with specific staff." *OMH Official Policy Manual, (applicable to NYS OMH operated facilities) OMH Official Policy PC-1050 (D) (1) (c)*.

A TREATMENT PLAN IS DEVELOPED? The treatment plan outlines treatment goals, what programs or therapies will be undertaken to achieve these goals, and a timetable for assessing progress. Under New York State law, parents of minors in OMH operated facilities must be involved in the development of a treatment plan, (unless the minor is over 16 years of age and objects to such participation, and a clinician determines it is not clinically appropriate to involve them). If an adult patient in an OMH operated facilities requests that a family member be involved in the development of his/her treatment plan, that person must be included in its development (NYS Mental Hygiene Law §29.13)

"Patients and, when appropriate, their families," (must be) "informed about the outcomes of care, treatment, and services." "The Joint Commission, Comprehensive Accreditation Manual for Hospitals (*CAMH*), 2006, §RI.2.90, second ed., 2004.

DISCHARGE PLANNING BEGINS? It is important to remember that discharge planning begins on the first day of admission. With patient consent, family members should be informed about, and included in, all aspects of discharge planning. This is especially important for family members who are caregivers, who must be involved in decisions that will directly affect them.

"The discharge ...of all clients ...shall be in accordance with a written service plan prepared by staff... [in consultation with] an authorized representative of the patient to include the parent or parents if the patient is a minor, unless such minor sixteen years of age or older objects to the participation of the parent or parents and there has been clinical determination by a physician that it is not clinically appropriate." (*NYS Mental Hygiene Law Mental Hygiene Law §29.15 (f)*).

"The written service plan shall include: a statement of patient's need ...for supervision, medication, aftercare services, and assistance in finding employment; recommendation of type of residence and services available; listing of organizations and individuals to provide services in accordance with identified patient needs, notification of appropriate school district and special education for patient under twenty-one; evaluation of patient's need and potential eligibility for public benefits, including public assistance, Medicaid, and supplemental security income." *Mental Hygiene Law §29.15 (g)*.

"Planning for transfer or discharge involves the patient and all appropriate licensed independent practitioners, staff and family members involved in the patient's care, treatment and services." (*The Joint Commission, CAMH, 2006, PC §15.20*).

THE FAMILY NEEDS SUPPORT? Families of persons with mental illness often have their own critical needs. Not only do they need to learn how to effectively help their relative in his/her recovery, but families often experience stress that arises from having a family member with a serious illness. Families need information about mental illness and its treatment, the mental health system, providing care to their family member, community resources, and how to cope with, and adapt to, their relative's needs and circumstances. It is important to make these needs known to your family member's provider so that support can be provided.

"Interventions for families include education, problem solving and communication to reduce symptom relapse and contribute to improved patient functioning and family well-being. Family education ...can markedly diminish relapses and improve quality of life for patients.... It is helpful to retain strong ties with persons who interact with the patient frequently, who would be most likely to notice any resurgence of symptoms." (*American Psychiatric Association Practice Guidelines for the Treatment of Patients with Schizophrenia, second ed., 2004, pp. 20, 34, 105*).

"Each facility's written plan must provide for an ongoing family support program to ...to provide educational and informational opportunities to families as partners in treatment. Such programs should be made available on a regularly scheduled basis and must accommodate work and other schedules of families and be provided in locations accessible to families." *OMH Official Policy Manual (applicable to OMH operated facilities), PC-1050.D(2)*.