

What Families and Friends Want and Need

Several studies have been conducted over the last 30 years about what families and friends want for their loved one with a severe and persistent mental illness (SPMI). Probably the broadest statement is that we want our loved one to be as *"healthy and independent as possible"*. We don't want to be the only caregiver in the case of children with serious emotional disturbances. We also don't want to be the primary caregiver in the case of adults with SPMI.

In an unpublished study conducted by Cunningham et al entitled "The Lonely Journey," the authors found that in a very practical way families who have a member with SPMI, compare their families and children to the "normal family life cycle." When a "normal" child can go to school everyday, we want our child to do the same. When a "normal" adult lives without psychiatric symptoms, we want ours to do the same. We want our loved one to contribute to society, to have friends, to travel and yes, when it's needed, to have access to an environment that protects them from their symptoms.

Research has shown the following to be key family wants and needs:

1. Assistance in understanding the symptoms of SPMI
2. Specific suggestions for coping with behavior that is strange or unpredictable
3. Opportunities to relate to people with similar experiences
4. Substitute care or respite, for the family
5. A living situation for the ill person, other than with parents

A survey conducted with 138 families, who were members of the National Alliance on Mental Illness, led to these findings of what families wanted from professionals:

1. Reduction of anxiety about the loved one
2. Understanding appropriate expectations
3. Learning to motivate the family member to do more
4. Learning about the nature of mental illness
5. Assistance during times of crisis

Caring for, and treating people with SPMI has a rather dismal history. At various times, these people were regarded as oracles from God, possessed, morally inferior, and mentally retarded. Treatment varied according to the operative theories: respect and worship for oracles from God, but far more often treatment involved punishment, ostracizing, contempt, imprisonment, and beatings.

Colonial America looked back to England and the Elizabethan Poor Laws of 1601. An important element of these laws, still with us today, was the categorizing of those with need. The "worthy" were cared for in poorhouses. Those deemed to be malingerers or ne'er-do-wells were often punished and locked in cellars. They were sometimes escorted out of the community.

In the late 1700s Philippe Pinel, who directed two hospitals in Paris, France, introduced the philosophy of "moral treatment" which included offering patients hope, guidance, support, and respect in small family-like institutions. During the 1840s, Dorothea Dix led an effort in the U.S. to encourage more humane treatment. After President Pierce vetoed federal legislation, Ms Dix turned her efforts to individual states. Although hospitals were established, they soon were overused, overcrowded, and dangerous. By 1955 there were 265 public institutions with a population of more than half a million.

By the 1970s the public hospitals themselves began to be viewed as the problem and "deinstitutionalization" became public policy. Those leading the community mental health movement meant to transfer care of the mentally ill to smaller community based settings. But what happened instead was that these community clinics increasingly served the "wounded well" while those requiring significant support and intervention were soon living on the fringes and ostracized. People with SPMI were once again living with their families who were largely on their own with the overwhelming burden of caring for their loved ones.

Programs offering supports to the ill loved one frequently haven't involved the family. There seems to be three main reasons for this exclusion:

1. The professional belief (on the part of some) that continues to assume that the family has caused the illness.
2. Overly strict compliance with confidentiality laws, and
3. Ignorance of the importance of building a partnership with the family for successful treatment and rehabilitation.

This Families In Action (FIA) program is intended to help families identify their needs and roles as partners in the care and treatment of their loved one. The FIA program assumes that a true partnership is needed to successfully promote health and independence.

Partnerships are easy to maintain when all parties agree, but when they do not, the partnership requires work, and it is within the conflict that both the family and the ill loved one can get lost and hurt. Some potential areas of conflict are:

Values: It is not uncommon for families to appear to value safety over independence while professionals seem to value independence and growth over safety and security. While it should be clear that both are important, specific situations and decisions may have to be made in one direction or the other. This conflict is often present when the family requests hospitalization, having seen the person at their worst, and the professionals, having seen them at their best, find this unnecessary.

Interpretation: Professionals and family members may see the same behavior differently. One may believe that the person needs hands on encouragement and assistance to maintain a neat and clean home. The other may believe that the person has the skills and knowledge necessary but simply chooses to live the way they do. One sees the issue as skill based; the other sees it as a problem with motivation.

Language: Perhaps all professions have developed exclusive language; mental health professionals certainly have. They often speak of "resistance, enmeshment, and denial." What the family experiences is feeling discounted and helpless when what they most need help with is information and skill development.

Confidentiality: Michigan's Mental Health Code prevents professionals from sharing information, without the ill person's permission, except in particular situations of perceived danger. This is a major frustration for families. Sometimes, when they most need information, and when their loved one seems to be in the most trouble, their loved one denies permission for the professionals to share information. And there are other times when families think they are being denied information when in fact, the professionals are not "in the know" either.

Treatment needs: Families and professionals may not agree on the treatment needs of their loved one and they may not agree on what resources are most important. The mental health code allows for services through community mental health to be provided only to those who are diagnosed as having a severe and persistent mental illness.

Resources: They are simply not sufficient to meet the needs of people with SPMI or their families. There isn't enough affordable housing; there are not enough employment opportunities. Case management service providers may have "too many" emergencies in a week to see everyone as much as is needed. And, very importantly, the right medication may not have yet been discovered. This too contributes to frustration of partners.

Only a serious and on-going commitment to working in partnership, for the benefit of the loved one, will offer the possibility that these barriers and others can be broken.

It is the intent of the FIA program to assist you in working with both your ill family member and the professionals involved in their lives as successfully as possible. The program's primary goal is this: to assist families to help their loved one to be as:

Healthy, happy, and independent as possible.