Findings Brief 5

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Family Experience of the Mental Health System

Helpfulness of Formal Services, Family Organizations and Informal Supports

Thirty families, over a period of two years, shared their experiences as they sought services, entered treatment, and remained in or terminated treatment. During those two years, the parents and other caregivers who participated in the FEMHS study were asked in thirteen separate interviews about the helpfulness of formal services and informal supports. The degree to which formal services were helpful to families in this study varied. Caregivers' perceptions of the degree to which services were beneficial was based on how well the service met an identified need, as well as the quality of the caregivers' interactions with specific agencies or individuals providing services. However, caregivers consistently identified the following aspects of services as critical variables as to whether services are beneficial:

- The quality of the relationship established between one's child and his or her therapist(s) or case manager(s);
- The accessibility and responsiveness of services and providers to the requests and needs of caregivers;
- The degree to which services were coordinated across providers; and,

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- The extended supports provided to the whole family (e.g., mentors, respite, transportation, family advocate, information and access to services).

The abilities of therapists to establish rapport with the children they served was predictive of caregivers' perceptions that therapy was beneficial, while changes in therapeutic personnel were almost always perceived as a negative aspect of services. Effective coordination of services was characterized by good communication across providers and the involvement of caregivers in identifying needs and making decisions concerning their children's care.

Services were not perceived as being beneficial when they did not address an identified need or there was no discernible difference in a child's behavior. Caregivers also became frustrated when appointments and assigned caseworkers or counselors were repeatedly changed and when services were not provided on a regular or frequent enough basis to generate change. Lack of recognition by a provider of a specific problem or need also resulted in frustration, as did providers making a decision to stop services.

Examples of Service and Service Provider Characteristics	
+ Helpful	**– Not Helpful**
+ Good relationship with child	– Service does not address need
+ Provider/agency responsive to request of caregiver	– Appointment times are changed
+ Provides support to entire family	– Provider is constantly changing
+ Services meet needs	– Service is not provided frequently enough
+ Positive interactions with provider/agency	– Lack of recognition of problem by provider
+ Coordinated services	– Lack of including caregiver in decisions to stop or change service
+ Good communication	– Lack of linguistically competent staff
+ Involvement of caregivers in identifying needs, planning and delivering services	

Of thirty families in the study, seven African American and eight Hispanic families participated. Their experiences with the helpfulness of services and supports varied depending on their ethnic/racial background, language proficiency, education, and immigration status and permanency. For Spanish-speaking families, lack of bilingual staff diminished the value and benefits of the services provided.

For most families who participated in the study, the mother was the primary care giver. However, African American and Hispanic families reported that they relied heavily on family members for help with childcare, extra income or emotional support.

"If nothing else, it gives me some sense of, if this makes sense to you, security. I know she's [psychologist] there…she is like the security thing to me."

"For TC to form those bonds with other people, [in this way] the therapist has been wonderful."

"We always have that open communication if we have a little problem going on or something, I alert them [provider]. I let them know what's going on before they get here and then we're able to monitor what is going on."

"The only time I was discontent was when the length of time between the therapist [visits]…if it could be a shorter period of time [weekly instead of monthly], so the children don't lose that confidence they have seeing them."

"Either they [OT with Independent Living] don't get in touch with me at all, somebody will call and say they can't come out, or they get the authorization so late that he only gets it [OT] for two weeks out of the month. I'm just really not happy with the service."

Among those who said they did not have family in the US, the caregiver herself was a source of support for family members abroad. The FEMHS study suggests that a holistic approach to care should include the role of extended families and their importance in identifying not only sources of support, but also sources of stress, such as the caregiver who provided support to family abroad.

Half the families in the study were in contact with a family support organization — the Federation of Families for Children's Mental Health was the organization most frequently mentioned. These families consistently reported how helpful the organizations were to them in providing information, support and opportunity to vent feelings. For many families, contact with other family members who were experiencing similar challenges gave them hope, understanding and respect, time to talk and explore options, and provided them a guide along a complex path and difficult journey to mental health services.

Many families also turned to friends, family, and spiritual connections for support and guidance. Some families often heard about services and supports through word of mouth or happenstance. For example, one family found out about a therapist and the eligibility requirements of the program from another parent while she was in the waiting room of a mental health center waiting for her child. Another mother found out about a service from another parent while they were at the playground with their children. These findings underscore the important roles family and advocacy organizations and informal supports play in a family's opportunity to learn about mental health services and feel supported in the process.

What the Research Says

For years, the behavioral and physical health literature has identified practitioner qualities and traits that patients see as important (Dinnebeil & Rule, 1994). For example, Darragh and associates (2001) identified three themes when interviewing 51 participants with brain injury:

1) Roles of the provider and their willingness to don a variety of roles (e.g., friend, mentor, team member, advocate);

2) Perceived helpfulness of services including relevance, meaningfulness, practical application, skill development and whether periodic feedback on progress was given; and,

3) Personal characteristics of the providers, including being a clear and honest communicator, supportive, respectful, good listener, and understanding.

Worthington and associates (2001) reviewed several studies and found several of the same qualities perceived by caregivers as helpful in mental health providers — knowledge in the field; good

I don't think he'll (brother) let me lose the house, you know. I know he'll give me some money."

communication skills, both listening and responding; a family centered approach; supportiveness to families; positive personality traits; positive outlook; sensitivity; sharing information and building parent's confidence; and, clarifying team members' expectations. The literature also validates the importance and relevance of a parent's view about the helpfulness of a provider, their services and the treatment they provide (Tarico et al., 1989).

Studies have found informal helpers to be major sources of support, even though some support is inconsistently provided due to limitations of emotional, financial and physical resources of family, friends and community supports (Lazear & Worthington, 2002). Increasingly, research supports the helpfulness of the types of services and supports that informal helpers can provide. For example, findings from studies looking at respite services found respite did help families who received it (Burns & Burchard, 2000), and helped to sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect (ARCH National Respite Network and Resource Center, 2002).

Research also validates the perspective of the parents and caregivers in the study who identified extended supports provided to the whole family as helpful. For example, Dellve and associates (2000) examined the coping processes of siblings whose brother or sister had an emotional or behavioral challenge. Their findings lead to the conclusion that a better understanding by siblings of their brothers' or sisters' disability is associated with more empathetic attitudes. Thus, they concluded, it is important that siblings' voices be included in the design and delivery of services.

A growing body of literature supports the critical role family organizations play in providing peer support to other families (Clausen et al., 1998; Bryant-Comstock et al.,1996; Koroloff et al., 1996) and ensuring families have access to needed quality services (Anderson et al., 2002; Kamradt, 2000; Nash et al., 1992; Worthington, et al., 2001).

Studies are assessing the public's recognition of emotional and behavioral disorders and their beliefs about the effectiveness of various treatments. Jorm and associates (1997) refer to this public recognition as "mental health literacy." Their research concludes that, "If mental disorders are to be recognized early in the community and appropriate intervention sought, the level of mental health literacy needs to be raised. Further, public understanding of psychiatric treatments can be considerably improved" (pg.1).

As more formal and informal helpers are being called upon to identify and provide supports and services to youth with emotional or behavioral challenges and their families, greater attention must be paid to broadening the mental health knowledge base of the community. Stiffman and associates (2000) found that professionals

who come into contact with youth (e.g., physicians, social workers, teachers, police officers, etc.) are most likely to refer youth for mental health services when they feel capable of making a mental health assessment of the child and when they are familiar with the mental health services available in the community for that child.

System of Care Checklist: Helpfulness of Formal Organizations and Informal Supports

Service can be more helpful to families if…

- ☐ The family is treated with respect and is seen as the lead in planning services for their child.
- ☐ The family is given all the information necessary to partner in treatment decisions and make decisions from a position of strength.
- ☐ Services are coordinated across providers.
- ☐ Communication among providers and between families and providers is effective and efficient.
- ☐ Families receive accurate information about what services offer and the eligibility criteria to receive those services.
- ☐ There is a positive relationship between the service provider and the child and between the parent and the service provider.
- ☐ Families feel confident in the skills of their child's service provider and have information available to them about the skills and experiences of specific providers.
- ☐ The service provider is accessible and responsive to the requests and needs of caregivers.
- ☐ Supports and services (i.e., mentors, sibling counseling, respite) are extended to the whole family.
- ☐ The care manager works in partnership with the family to examine all life domains and how to support each, as necessary (e.g., transportation, food, housing).
- ☐ Families receive regular contact from providers about their child's progress.
- ☐ Families do not have to wait an unreasonable amount of time for an appointment or sit in the waiting room an unreasonable amount of time for a scheduled appointment.
- ☐ Therapist, care mangers or other direct service personnel remain relatively constant while the child is in service.
- ☐ Families feel that the service addresses the need.
- ☐ All aspects of service provision are conducted in a culturally competent manner, including meetings with the family about the youth, or his or her services and treatment (e.g., conducted in the primary language of the caregiver).
- ☐ The approach to care is holistic and family-centered, and includes examining the role of extended family as a source of support as well as a source of stress.

- ☐ Families are aware of and have access to family advocacy and support organizations in their community.
- ☐ Families and treatment team members are clear about their roles and tasks.
- ☐ Agencies and service providers are flexible to meet the needs of the family, such as time of appointments and locations.
- ☐ Policies are in place whose main objectives are to raise the mental health literacy of the community.

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