

ROLE OF THE FAMILY IN TREATMENT PROGRAMS

Over the past several years, the focus of mental health treatment and support for youth and families has increasingly been on evidence-based practices (National Alliance on Mental Illness [NAMI], 2007). Evidence-based practices are those that research has shown to be effective. However, although there is growing emphasis on evidence-based practices, it is equally important to emphasize the role of families as partners in the treatment process (NAMI).

To ensure successful treatment outcomes, it is crucial that family members are involved in child and adolescent services (Kutash & Rivera, 1995; Pfeifer & Strzelecki, 1990). Research has shown that the effectiveness of services hinges less on the particular type of treatment than on the family's participation in planning, implementing, and evaluating those services (Koren et al., 1997), as well as on their control over the child's treatment (Curtis & Singh, 1996; Thompson et al., 1997). Family participation promotes an increased focus on families, a provision of services in natural settings, a greater awareness of cultural sensitivity, and a community-based system of care. Research also confirms that family participation improves not only service delivery, but also treatment outcomes (Knitzer, Steinberg, & Fleisch, 1993).

There is a growing body of evidence indicating that children from vulnerable populations, children of single mothers, and children who live in poverty are more likely to exhibit the most serious problems. They are also the most likely to prematurely terminate treatment (Kadzin & Mazurick, 1994). Additional research is necessary to determine the factors that contribute to this early termination.

In recognition of this problem, it is important for mental health providers to ensure that families that have these characteristics are actively engaged in the services that their children receive in order to maximize the potential for successful outcomes. This goal is complicated by the fact that both families and providers may be confused and hesitant about the role that family members should play in treatment efforts. In addition, other barriers may preclude families from procuring high-quality mental health services for their children.

In an attempt to combat this problem, researchers have identified six broad roles that families should play in the treatment process (Friesen & Stephens, 1998). These roles are listed below:

Contributors to the Environment – Family members are a constant in the environment in which a child resides. Consequently, treatment providers often try to identify ways in which the behavior and interactions among family members influence the child's emotional and behavioral problems. With the assistance of the treatment provider, family members should consider ways to improve the home environment and the relationships within the family in order to provide the child with the most stable, supportive environment possible. In addition, family members should seek external support from their extended family and community to reduce the stress of raising a child with emotional or behavioral difficulties.

Recipients of Service – Family members are an important part of the therapeutic process. Service providers often focus on the family unit as a whole, creating interventions and strategies that target the health of the entire family. These interventions are intended to assess the strengths and weaknesses that exist within the family structure, to enhance the well-being of parents and other family members, and to help families locate support mechanisms in the community. The provider also assists family members in developing the skills necessary to support the special needs of the child. Services may include supportive counseling, parental training and education, development of coping

skills and stress management techniques, respite care, parental support groups, transportation, and financial assistance.

Partners in the Treatment Process – Family members serve as equal contributors in the problem-solving process. They should work with treatment providers to identify the goals of treatment and to plan realistic strategies to achieve these goals. Additionally, family members should play a key role in implementing these strategies to help ensure that treatment goals are met. When performing these functions, family members should not be afraid to ask questions and to voice their opinions and preferences. It is crucial that they are fully informed and that their preferences are considered in all treatment decisions.

Service Providers – The treatment process is incomplete unless family members also provide services to the child. Family members are responsible for providing information and emotional support to the child and to other family members, and for filling in the gaps in the services being received by the child. Furthermore, they often coordinate services by requesting and convening meetings and transporting the child to appointments. It is a crucial role, the importance of which cannot be overstated. Parents and caregivers need to remain vigilant and involved in all aspects of the child's treatment. This includes keeping all follow-up appointments, becoming knowledgeable about any prescribed medications, and keeping track of all treatments that have been unsuccessful.

Advocates – Family members often serve as their child's only voice in the mental health system. They should therefore actively advocate for the child to ensure that he or she receives appropriate services. They also must voice any concerns regarding undesirable practices and policies. There are several local, state, and national organizations that can assist parents and caregivers in these efforts, allowing them to serve as part of a larger voice in their communities.

Evaluators and Researchers – It is important that families participate in research and evaluation activities so that their opinions can be heard regarding which treatments and services are most beneficial and convenient. The input of family members is crucial to ensure that all children receive services that are efficient and effective.

Because family members play important supporting roles in combating mental health disorders, it is important that they assume each of these roles in order to provide the effective support network that is necessary for the child's continued improvement. Family members who support and encourage their child and create a favorable environment for services will maximize the potential for successful outcomes.

The following information is attributed to the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA, 2000). Families must recognize that, although they are obtaining services for their child, they are the experts in understanding the following:

- How their child responds to different situations;
- Their child's strengths and needs;
- What their child likes and dislikes; and
- What has worked and has not worked in helping their child.

Families are ultimately responsible for determining what services and supports their children receive. Thus, family members must communicate to service providers their children's strengths and weaknesses, as well as their own priorities and expectations. They must also not hesitate to inform service providers if they believe treatment is not working so that appropriate modifications can be made (SAMHSA, 2000).

These recommendations also hold true for children who come into contact with the juvenile justice system. Family involvement is particularly critical for these youth to ensure positive outcomes (Osher & Hunt, 2002). It is imperative that family members provide information on the child's diagnosis and

treatment history, use of medications, education history and status (including whether the child is enrolled in special education), and any other special circumstances that affect the child (Osher & Hunt). It is also important that they communicate their ability to participate in treatment. Ideally, families should be involved in decision-making and treatment at each stage of service provision (Osher & Hunt). Families and juvenile justice officials must cooperate to ensure that all have mutual responsibility for the child's outcomes (Osher & Hunt).

Without family involvement, it is extremely difficult for service providers to ensure that the gains achieved by the child in treatment are maintained and solidified. Moreover, the combined efforts of service providers, family members, and advocates are necessary to ensure that the services provided in the community effectively meet the needs of all children and families. It is important that parents and caregivers understand the results of any evaluation, the child's diagnosis, and the full range of treatment options. If parents are not comfortable with a particular clinician or treatment option or are confused about a specific recommendation, they should consider seeking a second opinion.

If medication is suggested as a treatment option, families must be informed of all associated risks and benefits. In addition, children and adolescents who are taking psychotropic medications must be closely monitored and frequently evaluated by qualified mental health providers (NAMI). The decision about whether to medicate a child as part of a comprehensive treatment plan should be made only after parents carefully weigh these factors (NAMI, 2007). Figure 1 outlines questions parents should ask about treatment services.

Supplementary Issues for Families

Continuous news coverage of events such as natural disasters, catastrophic events, and violent crime may cause children to experience stress, anxiety, and fear (AACAP, 2002). In addition, some children may be unable to distinguish the difference between reality and the fantasy presented in the media (AACAP, 2001). As a result, children may be exposed to behaviors and attitudes that can be overwhelming or difficult to understand (AACAP, 2001). Caregivers should be made aware that violent media images can have a greater impact upon children with emotional and behavioral issues than might otherwise be the case (AACAP, 2015).

Systems of Care and Family Involvement

Unless otherwise cited, information in this section is attributed to *Systems of Care: A Framework for System Reform in Children's Mental Health* (Stroul, 2002). A system of care is defined as "a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families." It is not a program, but a philosophy. According to the primary values of the systems-of-care philosophy, services for children are:

- Community-based;
- Child-centered and family-focused; and
- Culturally competent.

Families are designated partners in the design of effective mental health services and supports. Families have a primary decision-making role in the care of their own children, as well as in the policies and procedures governing care for all children in their communities. This includes:

- Choosing supports, services, and providers
- Setting goals
- Designing and implementing programs
- Monitoring outcomes

- Partnering in funding decisions
- Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth (AACAP, 2009)

Figure 1
Questions Parents or Caregivers Should Ask About Treatment Services

Before a child begins treatment, parents should ask the following:

- Does my child need additional assessment and/or testing (medical, psychological, etc.)?
- What are the recommended treatment options for my child?
- Why do you believe treatment in this program is indicated for my child? How does it compare to other programs or services that are available?
- What are the advantages and disadvantages of the recommended service or program?
- How long will treatment take?
- What will treatment cost, and how much of the cost is covered by insurance or public funding? Will we reach our insurance limit before treatment is completed?
- How will my child continue education while in treatment?
- Does my child need medication? If so, what is the name of the medication that will be prescribed? How will it help my child? How long before I see improvement? What are the side effects that occur with this medication?
- What are the credentials and experience of the members of the treatment team?
- How frequently will the treatment sessions occur?
- Will the treatment sessions occur with just my child or the entire family?
- How will I be involved with my child's treatment?
- How will we know if the treatment is working? What are some of the results I can expect to see?
- How long should it take before I see improvement?
- What should I do if the problems get worse?
- What are the arrangements if I need to reach you after-hours or in an emergency?
- As my child's problem improves, does this program provide less intensive/step-down treatment services?
- How will the decision be made to discharge my child from treatment?
- Once my child is discharged, how will it be decided what types of ongoing treatment will be necessary, how often, and for how long?

Source: American Academy of Child & Adolescent Psychiatry (AACAP), 2000.

Systems of care establish partnerships that work because the system is guided by the family. They use the family's expertise to steer decision-making in service and system design, operation, and evaluation. In recent years, studies have found that children whose families were involved in their treatment experienced improved educational outcomes and well-being. They also spent less time in out-of-home placements and residential settings (Jivanjee et al., 2002).

While families must take care to ensure that their child is properly treated, they must also understand that the family may also require support. Family members often experience considerable stress physically, emotionally, socially, and spiritually due to both the child's health problems and the stress of interacting with medical professionals. Ensuring that the family is also well supported can empower the family to support the child's treatment (SAMHSA, n.d.).

Resources and Organizations

American Academy of Family Physicians

<https://www.aafp.org>

American Association of Child & Adolescent Psychiatry (AACAP)

<http://www.aacap.org/>

American Psychiatric Association (APA)

<http://www.psych.org>

American Psychological Association (APA)

<http://www.apa.org/>

Familydoctor.org

<https://familydoctor.org/>

Medscape Today Resource Centers (from WebMD)

<https://www.medscape.com/internalmedicine>

Mental Health America (MHA)

<http://www.mentalhealthamerica.net/>

National Alliance for the Mentally Ill (NAMI)

<https://www.nami.org/>

National Mental Health Information Center

Child, Adolescent and Family Branch, Center for Mental Health Services

<https://www.samhsa.gov/children>

National Technical Assistance Center for Children's Mental Health

<https://gucchdtacenter.georgetown.edu/>

U.S. Department of Education

Office of Special Education and Rehabilitative Services

<https://www2.ed.gov/about/offices/list/osers/index.html?src=mr>

U.S. Department of Health and Human Services

<https://www.hhs.gov/>

U.S. National Library of Medicine and the National Institutes of Health (NIH)

Medline Plus

<https://medlineplus.gov/>

Substance Abuse and Mental Health Services Administration (SAMHSA)

National Registry of Evidence-based Programs and Practices

<https://www.nrepp.samhsa.gov/landing.aspx>

Virginia Resources and Organizations

Mental Health America of Virginia

<https://mhav.org/>

National Alliance for the Mentally Ill Virginia (NAMI Virginia)

<https://namivirginia.org/>

Virginia Department of Behavioral Health and Developmental Services (DBHDS)

<http://www.dbhds.virginia.gov/>

Virginia Office of Children's Services

<http://www.csa.virginia.gov/>

Voices for Virginia's Children

<https://vakids.org/>

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DISCLOSURE STATEMENT

The information contained herein is strictly for informational and educational purposes only and is not designed to replace the advice and counsel of a physician, mental health provider, or other medical professional. If you require such advice or counsel, you should seek the services of a licensed mental health provider, physician, or other medical professional. The Commission on Youth is not rendering professional advice and makes no representations regarding the suitability of the information contained herein for any purpose.