

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). Families are coming to understand that evidence-based practices are those which have been shown through research to be effective. While there is growing emphasis on evidence-based practices, families must be educated to become partners in the process so they can select the treatment which best meets the needs of their child and family (NAMI).

The involvement of family members in child and adolescent services is crucial to ensure successful treatment outcomes (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 the services (Koren et al., 1997) and their control over the child's treatment (Curtis & Singh, 1996; Thompson et al., 1997). Family participation promotes an increased focus on families, 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, children who live in poverty, and minority children 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 which contribute to this early termination. In recognition of this problem, however, it is important for mental health providers to ensure that these families are actively recruited and engaged in the services that the child receives in order to maximize the potential for successful outcomes. This goal is complicated, however, 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, systemic barriers may preclude families from fully participating in the procurement of 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):

Contributors to the Environment – Family members are the key component of the environment in which a child resides. Consequently, treatment providers often try to identify ways in which the behavior and interactions between 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 in 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 members of the community in order to reduce the stress of raising a child with emotional or behavioral difficulties.

Recipients of Service – Family members are also 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 also 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 ensure that the treatment goals are

met. When performing these functions, caregivers 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 without the direct services provided to the child by family members. They are responsible for providing emotional support and information to the child and other family members, and for filling in the gaps in the services being received by the child. Furthermore, they often coordinate the services being received by the child by requesting and convening meetings, and transporting the child to appointments. It is a crucial role, the importance of which cannot be understated. 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 the child's only voice in the mental health system. They should therefore actively advocate for the child in order to ensure that he receives the appropriate services, and 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 the community.

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. While much of this research requires the involvement of the family for a significant length of time, the input of caregivers and other family members is extremely important.

Because families play important supporting roles in combating mental health disorders, it is important that family members assume each of these roles in order to provide the effective support network that is necessary for the child's continued improvement. Although the child is the most important focus of treatment, family members can help by offering support and encouragement, and by creating a favorable environment. Family members can help their child while they are receiving treatment by recognizing and praising small achievements, modifying expectations during stressful periods, measuring progress on the basis of the improvements made, and being flexible, while trying to maintain a normal routine (Psychiatry 24x7.com, 2005).

The following information is attributed to the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA, 2000). Families must recognize that, while 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 not worked in helping their child.

Families are ultimately responsible for determining what services and supports their children receive. Thus, families must communicate to service providers their children's strengths and weaknesses, as well as their priorities and expectations. Family members must also inform their service provider as soon as they realize treatment is not working so appropriate modifications can be made (SAMHSA, 2000). It is crucial to remember that children are different and their needs are also very diverse.

These recommendations also hold true for children who come in 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 families remain involved in order to provide information on the child's diagnosis and treatment history, use of medications, the families' ability to participate in treatment, special circumstances that affect their child, and their child's education history and status (including whether the child is enrolled in special education) (Osher & Hunt). Ideally, families should remain involved at each stage of the system so they can be involved in decision-making and treatment (Osher & Hunt). Families and juvenile justice officials must cooperate to ensure that all have mutual responsibility for the child's outcomes (Osher & Hunt).

Families must remain actively involved in all aspects of their child's mental health treatment. 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 specific recommendations, then they should consider a second opinion.

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

Supplementary Issues for Families

Continuous 24-hour news coverage of events, such as natural disasters, catastrophic events, and crime reports, may cause children to experience stress, anxiety, and fears (AACAP, 2002). According to the AACAP, children may be easily influenced and unable to distinguish the difference between reality and the fantasy presented on television (2001). As a result, children may be exposed to behaviors and attitudes that can be overwhelming and difficult to understand (AACAP, 2001). Caregivers should understand that violent media images may have a greater impact upon children with emotional and behavioral issues than might otherwise be the case (AACAP, 2006).

Questions that 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 which are available?
- What are the advantages and disadvantages of the recommended service or program?
- What will treatment cost, and how long will it take?
- 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 which commonly 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 and Family Involvement

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" (Stroul, 2002). It is not a program, but a philosophy. Information in this section is attributed to *Systems of Care: A Framework for System Reform in Children's Mental Health* (Stroul).

The primary values of the system of care philosophy are that 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:

1. choosing supports, services, and providers;
2. setting goals;
3. designing and implementing programs;
4. monitoring outcomes;
5. partnering in funding decisions; and
6. determining the effectiveness of all efforts to promote the mental health and well-being of children and youth.

Systems of care rely upon family and youth experiences and utilize families' expertise to steer decision-making in service and system design, operation, and evaluation. In recent years, studies have been designed to assess the impact of family partnerships upon child and family outcomes. The findings reveal that children who had families involved in their treatment experienced improved educational outcomes and well-being, as well as reduced length of stay in out-of-home placements and residential settings (Jivanjee, Friesen, Robinson & Pullman, 2002). Systems of care establish partnerships that work because the system is guided by the family.

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Organizations

American Association of Child & Adolescent Psychiatry (AACAP)

www.aacap.org

American Psychiatric Association (APA)

www.psych.org

American Psychological Association (APA)

www.apa.org

American Academy of Family Physicians

FamilyDoctor.org

<http://familydoctor.org/online/famdocen/home.html>

Center for Effective Collaboration and Practice

National Resource Network on Child and Family Mental Health Services

<http://cecp.air.org>

Florida Mental Health Institute

University of South Florida

<http://home.fmhi.usf.edu>

Medscape Today Resource Centers (from WebMD)

www.medscape.com

Mental Health America (MHA) (formerly National Mental Health Association)

<http://www.nmha.org>

National Alliance for the Mentally Ill (NAMI)

<http://www.nami.org>

National Technical Assistance Center for Children's Mental Health

<http://www.dml.georgetown.edu>

Research & Training Center on Family Support and Children's Mental Health

<http://www.rtc.pdx.edu>

U.S. Department of Education

Office of Special Education Programs

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

U.S. Department of Health and Human Services

Centers for Disease Control and Prevention (CDC)

www.cdc.gov

National Institutes of Health

Medline Plus

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

www.nlm.nih.gov/medlineplus

National Institute of Mental Health (NIMH)

<http://www.nimh.nih.gov/index.shtml>

Substance Abuse and Mental Health Services Administration (SAMHSA)

National Mental Health Information Center

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

<http://www.mentalhealth.samhsa.gov/child>

National Registry of Evidence-based Programs and Practices

<http://www.nrepp.samhsa.gov>

Virginia Resources

Children's Services System Transformation

801 East Main Street — Richmond, VA 23219

<http://vafamilyconnections.com>

Mental Health America of Virginia

<http://www.mhav.org>

National Alliance for the Mentally Ill Virginia (NAMI Virginia)

www.namivirginia.org

Virginia Department of Behavioral Health and Developmental Services (DBHDS)

P.O. Box 1797 — Richmond, VA 23218-1797

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

Virginia Office of Comprehensive Services

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

Voices for Virginia's Children

<http://www.vakids.org>

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