



## The Technical Assistance Center for Lifespan Respite Fact Sheet Number 34, June 2012

### Respite for Caregivers of Children with Serious Emotional Disturbance

#### Introduction

In 1982, Jane Knitzer in her book, *Unclaimed Children*, noted that two million of the three million children and youth experiencing a serious emotional disturbance (SED) and their families in this country were not receiving adequate services.

During the early 1980s, local educational authorities joined child welfare in supporting children with various disabilities, yet children with serious emotional disturbances often remained unserved, underserved, or inappropriately served. In 1984, the National Institute of Mental Health, U.S. Department of Health and Human Services, initiated the Child and Adolescent Service System Program to help States plan for and design systems of care to address the mental health needs of children who were experiencing a serious emotional disturbance.

The systems of care approach was originally created in response to concerns that:

- Children in need of mental health treatment were not getting the services they needed
- Services were often provided in restrictive out-of-home settings
- Few community-based services were available
- Service providers did not work together
- Families were not adequately involved in their child's care
- Cultural differences were rarely taken into account (Stroul, 2002)

In 1992, Congress created the Children's Mental Health Initiative and began funding grants under the Comprehensive Community Mental Health

Services for Children and Their Families program. These grants have helped to create, and continue to expand, a system of care to improve access and expand the array of community-based, culturally and linguistically competent services and supports for children with SED and their families. However, in 2008 a follow-up to Knitzer's study (Cooper, et al) found that, while most States are attempting to address mental health issues, there are still many children and youth who remain under- or unserved. Authorities estimate that today about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need (SAMHSA, 2011).

Progress has been made in many States as systems of care have been developed. For young children who are able to access these services, both their own well-being and the lives of their families begin to improve within six months (SAMHSA, 2010a). In addition to treatments, therapies, and services directed to improving children's emotional health, systems of care may provide supports, including respite services, to families that help them manage the demands and stresses associated with children with SED. Respite, temporary relief for caregivers and families, should be provided as a regular component of family support services. Respite can be provided to families on either a planned or emergency basis. Respite provides many benefits to families, including: families are able to renew their energies and reduce stress; caregivers can take a break from caregiving; other children in the family may have an opportunity to interact with their parents; the child with SED may have a positive social experience outside the family; out-of-home placement may be avoided; and families are able to

continue caring for their children at home (Regional Research Institute for Human Services, 2002).

Since the writing of *Unclaimed Children*, research and training have continued to demonstrate that children and youth with SED have legitimate and long-ranging mental health needs. It behooves the service delivery system to acknowledge the needs of families with a child or youth experiencing SED and then work with them, and on their behalf, to provide individualized, flexible, family-driven services.

This fact sheet provides an overview of the population of children and youth with serious emotional disturbance, and discusses considerations that families, respite providers, and program administrators should take into account in

relation to accessing or providing respite to families of these children.

## Definition and Prevalence

Eligibility for services under the federal Comprehensive Community Mental Health Services for Children and their Families program includes “children and youth from birth to 21 years of age (with) an emotional, socio-emotional, behavioral or mental disorder diagnosable under the DSM-IV or its ICD-9-CM equivalents, or subsequent revisions. For children 3 years of age or younger, the Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood-Revised (DC: 0-3R) are used as the diagnostic tool. For children 4 years of age and older, the Diagnostic Interview Schedule for Children (DISC) may be used as an alternative to the DSM-IV. Further eligibility criteria require that the child or youth is unable to function in the family, school or community, or in a combination of these settings. Or, the level of functioning is such that the child or adolescent requires multi-agency intervention involving two or more community service agencies providing services in the areas of mental health, education, child welfare, juvenile justice, substance abuse, or primary health care. The identified disability must have been present for at least 1 year or, on the basis of diagnosis, severity or multi-agency intervention, is expected to last more than 1 year” (SAMHSA, 2011, pp. 6-7).

Children with SED may have a variety of diagnoses, including

## Systems of Care

Systems of Care are driven by six core values. The system of care should be

- **Family driven** – families have a primary decision-making role in the care of their children, as well as in the policies and procedures governing care for all children in their community, state, tribe, territory, and nation;
- **Youth guided** – youth are engaged as equal partners in creating systems change in policies and procedures at the individual, community, state, and national levels;
- **Culturally and linguistically competent** – agencies, programs, and services are responsive to the cultural, racial, and ethnic differences of the populations it serves;
- **Individualized and community based** – each child or adolescent served within a system of care should have an individualized care plan developed by the family team, with leadership from the child’s parents or legally responsible adult and the child or youth. Needed services and informal supports should be available within the community.
- **Evidence based** – practices are validated by documented scientific evidence.

From the Technical Assistance Partnership for Child and Family Mental Health <http://www.tapartnership.org/SOC/SOCvalues.php>

- anxiety disorders (high level of fear);
- bipolar disorder (swings in mood from very “high” to sad and hopeless);
- conduct disorders (trouble following rules, aggressiveness, lying, stealing);
- eating disorders (eating too much or too little, concern about body image);
- obsessive-compulsive disorder (recurring unwanted thoughts, repeating behaviors such as handwashing or counting); and
- psychotic disorders (not in touch with reality, hearing or seeing things that are not there, false beliefs).

It is difficult to identify the number of children in the United States with SED; estimates vary 5 to 26 percent (Brauner & Stephens, 2006). According to parental reports from the 2007 National Survey of Children’s Health, nearly 8 percent of children and adolescents ages 6–17 had ever been diagnosed with depression or anxiety, and 5.4 percent had ever been diagnosed with behavioral or conduct problems (Ghandour RM, et al, 2012).

SAMHSA estimates that 4.5 to 6.3 million children and youth in the United States suffer from a serious mental health condition (about 10%) and 20% have a diagnosable mental disorder; about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need (SAMSHA, 2011).

## Characteristics

The National Dissemination Center for Children with Disabilities has identified the following characteristics and behaviors as typical of children with emotional disturbances:

- Hyperactivity (can’t sit still very long, has problems paying attention, seems careless and disorganized, doesn’t finish projects and schoolwork);
- Aggression (has temper tantrums, picks fights, doesn’t cooperate);
- Self-injury (hurts him/herself);

- Withdrawal (failure to interact with others, retreat from exchanges or social interaction, excessive fear or anxiety);
- Immaturity (acts younger than his/her age, cries a lot, has temper tantrums, doesn’t cope well with change);
- Learning difficulties (doesn’t do well at his/her grade level at school). (NICHCY, 2010)

It is important to note that many children who do not have an emotional disturbance may display some of these behaviors at different points in their development. The fundamental difference is that for children who have a serious emotional disturbance these behaviors continue over a long period of time, demonstrating the child’s inability to cope with the environment or peers.

Some children and youth experience greater environmental risk of having mental health problems than the general population. This includes children in families receiving public assistance, those whose parents are unemployed, children of teenaged parents, children in military families, particularly during a parent’s deployment, and children in the foster care or juvenile justice systems (Stagman & Cooper, 2010).

Recognition and acceptance of a child’s behaviors that may be indicative of emotional disturbance can vary in some cultural communities. Immigrants for whom language is a barrier to information and services may have difficulty accessing help for their children, may be distrustful of systems that are unfamiliar to them, or concerned that their status may be compromised by seeking assistance. One of the core values of the system of care is that of cultural and linguistic competence, with agencies, programs and services that are responsive to the cultural, racial, and ethnic differences of the populations being served.

## Respite Considerations for Family Caregivers of Children with Mental Health Conditions

### Family Stress

Families of children and youth experiencing a serious emotional disturbance are subject to high levels of stress caused by the difficulty of caring for and managing their children's behaviors at home, at school, and in the community. In addition, they are often blamed and held responsible for behaviors that may be viewed as "bratty" or irritating. As children get older, they may be seen as unruly, delinquent, out of control, mean, and even dangerous. The perceived cause may be that they have not been taught or "made" to "mind," show respect, or learn responsibility. Because of this tendency to blame families for behaviors that are a symptom of the child's illness, caregivers often do not trust the systems designed to help their children and, as a result, may not be perceived as cooperative and caring.

Families of children with SED experience a variety of stresses and challenges in addition to the obvious strain of dealing with their child's behaviors, which may include:

- Child may not follow predictable developmental stages, disrupting the normal path of family life and growth;
- Families experience a sense of a loss of their hopes and expectations for their child;
- Families may have to plan for long-term support of a child beyond adulthood;
- Siblings may feel depressed or isolated, compete for family resources, or experience higher expectations from their parents;
- Families must adjust their roles, structure, time, attention, and plans to accommodate the needs of the child with SED (Modrcin & Robison, 1991; Wright, Anderson, Kelley & Kooreman, 2007).

These families need a variety of services and supports to navigate these challenges; without them, families may feel forced to turn to institutionalization for their child or to the juvenile justice system to handle problematic behaviors. The availability of respite care in the package of available supports provides opportunities to both get a break from the daily care of their child with SED and to experience normative individual and family-related activities with other children and relatives.

*"I...wish I had had more support before my son and I reached a crisis point. I needed respite and in-home care so I wouldn't have felt so exhausted and overwhelmed. I believe my son would be home with me today if I was given respite care when I asked for it." (Burks, 2011).*

### Obstacles to Care

Families face many obstacles in accessing appropriate treatments and services for their children with SED. As noted above, behaviors may be seen as merely troublesome or the result of poor parenting; young children's mental health conditions may not be identified or diagnosed until behaviors cause serious problems in school or the community. Even after diagnosis, families may have to navigate a patchwork of service and payment systems, dealing with health and mental health care professionals, schools, public and private insurance, and perhaps child welfare and juvenile justice systems. Sometimes children are referred out-of-home or even out of state for services, which can pose additional hardships for them and their families. Inadequate family support and transition services can make this process even more difficult when returning home (National Alliance on Mental Illness, 2009).

Stigma attached to having a child with SED can also keep a family isolated and fearful of seeking help. These obstacles can result in families' mistrust of

the mental health system overall, making them less likely to trust an offer of respite.

In addition, respite programs which accept and are prepared to handle children with SED may be particularly difficult to locate and access. Families seeking such services should ensure that providers are trained to handle their child's needs, and that programs meet acceptable standards of liability and confidentiality as discussed below.

### ***When and How to Seek Referrals***

Every parent needs a break from caring for their children. For most families, hiring a babysitter or asking a relative or neighbor may be sufficient. For families with children with a serious emotional disturbance, relief from caregiving may be a much more complicated issue. Children's behaviors may range from difficult to potentially dangerous, and those who provide temporary care, whether for a few hours or an extended period, must be prepared to deal with situations that may pose serious challenges. Families who find that their child's behaviors cannot be handled without special instruction should seek referral for respite care to ensure that their child will receive the care and supervision needed to keep both the child and the temporary caregiver comfortable and safe.

Many families may feel they can only turn to their closest friends or churches, synagogues or mosques to find individuals they can trust to provide respite. Over time, however, they may feel they have "used up" the help they can glean from these sources, especially if their child has difficult behaviors. Referrals to appropriate respite programs may be available through the State Lifespan Respite Program, State Respite Coalition, child's school, health care, or mental health care provider, case manager, or your community mental health association. The ARCH National Respite Network and Resource Center maintains an online respite locator at <http://www.archrespite.org/respitelocator>.

### **Definition of Family Driven**

According to the National Federation of Families for Children's Mental Health, family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation.

This includes:

- Choosing culturally and linguistically competent supports, services, and providers;
- Setting goals;
- Designing, implementing and evaluating programs;
- Monitoring outcomes; and
- Partnering in funding decisions.

### ***Family-Driven Care***

It is critical that families of children and youth with SED be included in the development of services. Family participation can range from the development of their own child's service plan as an equal partner on their child's treatment team, to service delivery and service system assessment activities, to membership on statewide policy and planning groups. One of the core principles of the system of care philosophy is that services are family driven, with families having the primary decision-making role in the care of their children. Families accessing respite for their child with SED should be active participants in the development and implementation of those services.

### **Considerations for Respite Providers/Programs**

Respite care providers should receive training that provides them a set of knowledge, skills, and values that can enable them to effectively care for children with an SED and interact with their families.

- **Knowledge:** Providers should have an overview of the characteristics and behaviors typical of children with SED, as well as specific information about the child for whom they will be providing respite. They should have an understanding of any relevant culturally congruent practices for the population they serve, and be able to communicate in the language the child and family speaks. They should be familiar with liability and confidentiality issues, and have resources to help them with any issues in those areas. They should also know how to reduce their own stress and prevent burnout as they work with children and families under difficult conditions.
- **Skills:** Providers should be competent in the skills listed below under Considerations for Respite Program Administrators.
- **Values:** Providers should understand challenges faced by families, including bias against them, the prejudgment families often face, and the reluctance some providers and systems have historically demonstrated to serve children with difficult behaviors and their families. Because having a child with SED is often blamed on the style of parenting a child receives, a family may feel they are under the microscope of the personnel and agencies from which they receive services. Having a respite provider come into a family's home can feel intrusive and family members may feel violated. It is important for respite providers to remember that things they see or hear in a family's home should not be shared with anyone (with the exception of issues of abuse or neglect). Establishing a level of trust between child, family, and respite provider will enhance the care the child receives and insure a trusting and meaningful relationship.

In addition, the role of respite providers is to provide a break for the family while establishing good relationships with the children. The role of respite providers is not to "fix" what they perceive as deficient or wrong with the family. For example, if a family maintains a standard of living that does not feel appropriate or comfortable to the respite

provider, it is not his or her role to try to enhance or change that standard. That is an intrusion of the family and beyond the boundary of delivering respite. Of all respite issues, those of boundaries and confidentiality are violated most often.

## Considerations for Respite Program Administrators

Respite programs should be integrated into a System of Care that provides an adequate array of services which follow System of Care values and principles (Giliberti, 2001). Specific considerations for respite program administrators include the following:

**Referrals:** Respite programs should receive referrals for respite from all participants in the local service delivery system: mental health, social and rehabilitation services, medical services, public schools, and families.

**Intake and screening:** Some programs may want to use an interagency team, consisting of representatives of all referring parties, to screen referrals for appropriateness and then triage for delivery of respite. In addition to specific screening to determine diagnostic and financial eligibility for the program, administrators may want to consider questions such as the following in order to determine if the respite available (as well as other supports and services offered) are appropriate to the child and family:

- Where is the child/youth currently living?
- Is he/she eligible for respite or other services from other programs?
- If he/she is already receiving services, what are they and who is delivering them?
- Is the child/youth in imminent risk of removal from the home or placement in an institution?

**Recruitment, preparation and ongoing support (retention) of respite providers:** Program administrators should ensure that respite providers are adequately screened, prepared, and trained to meet the needs of the children and families they serve.

Training needs specific to children and youth with SED include (SAMHSA, 2010b):

- CPR and first aid certification
- management of children and youth with mental health issues/SED
- client rights
- confidentiality
- safety management
- individual dignity and choice.

Providers should receive both initial training to prepare them for their role and regular in-service training to keep knowledge and skills up to date.

**Matching families and respite providers:** To insure the continuity of care, the matching of respite providers and families is critical. An effective matching process may take as many as three stages.

- The first stage is to make a match on paper. The strengths, interests, and values of the child and family are matched to the respite provider pool.
- In the second stage, the match is made in the home on a trial basis. This provides an opportunity for the child, family, and respite provider to gain familiarity and security with each other. It also begins a dialogue between the family and respite provider and follow-up dialogue with the respite coordinator. Perhaps most importantly, it allows the respite provider to be trained by the family in their own environment.
- The third stage concludes with a final match. Based on the information gathered from the application(s) and the success of the trial match, the final match is made between respite provider, child, and family. It is important that family members feel comfortable with the provision of care and the respite provider feels comfortable and capable of managing the child's behavior. If either the family or the respite provider is uncomfortable, it is best for all concerned to match a different provider with the family.

### Tennessee Respite Initiatives for Families Whose Children Have SED

The Tennessee Department of Mental Health and Substance Abuse Services (TDMHSAS) provides planned respite services to families of children identified as seriously emotionally disturbed, or dually-diagnosed with SED and intellectual disabilities who are ages 2 through 17, through a Planned Respite Model and through a consumer directed voucher program.

**Planned Respite** is provided by respite consultants in 8 sites across the state (Memphis, Jackson, Nashville, Murfreesboro, Crossville, Chattanooga, Knoxville/OakRidge, and the Tri-Cities area). Individualized Family Respite Plans (IFRP) are developed with the family. The IFRP may include short-term direct respite care by staff, identification of possible respite resources, and determination of child learning characteristics and behavior patterns that interfere with the family's ability to secure respite. Services are provided at no cost to parents. Service duration is three months. Families may access this service one time. For more information, contact Louise Barnes, Ph.D., Mental Health Program Planner, Office of Children and Youth, Division of Mental Health Services, Tennessee Department of Mental Health and Substance Abuse Services, Louise.Barnes@tn.gov, or 615- 532-6727.

**Respite Voucher Program** provides respite vouchers for families with children with SED or Autism. Parents enroll in the Respite Voucher Program, which is administered by the TN Respite Coalition, and must pay the provider first and then turn in their respite voucher for payment by the program. The program can serve up to 150 families with children with SED or Autism per year. For more information, contact the Tennessee Respite Helpline at 1-888-579-3754 or visit [www.tnerespite.org](http://www.tnerespite.org)

**Consumer direction:** It is important for respite programs to incorporate family perspectives during the training of respite providers. While potential respite providers may have had some experience working with children and youth experiencing a serious emotional disturbance, it is rare that their experience has taken them into a family's home over an extended period of time. It is a different dynamic when the service is delivered on the "family's turf." There are fears and expectations held by both the family and respite provider. While it may be the respite provider's first time in that home, it may be one of a dozen times the family has had an outsider intrude on their privacy.

To address some of these anxieties, it is recommended that a team approach be used in the training of respite providers. A mental health professional and a family member can co-facilitate the training and use service providers, siblings, and other family members as needed. As part of the team, the mental health or behavioral specialist could exchange ongoing consultation with the respite provider, with the goal of incorporating respite within the overall treatment or care plan.

As respite providers are assigned to particular families, it will be important for the family to provide information that is specific to their child's behavioral needs.

An ongoing discussion regarding confidentiality and boundary issues between family and respite provider needs to be woven throughout the training of respite providers.

**Liability:** Due to the intense needs of children and youth experiencing SED, liability concerns may be high for both families and respite providers, particularly around behavioral issues. Respite programs may want to consider the following strategies regarding this issue:

- Decide if respite providers are to be employees of the agency or independent contractors. Agency employees will be covered under the umbrella of the agency's liability policy.

- Regular supervision by a respite coordinator will help to minimize crises, as well as reduce provider burnout and turnover.
- The agency may want to obtain release from liability forms signed by the family. While a waiver of liability is unlikely to provide protection in a court of law, it does give families and administrators an opportunity to discuss the potential for accidents to occur during the provision of respite services.
- The respite coordinator should inquire about liability coverage under the family's insurance policy.
- The respite program should provide on-call emergency backup providers.
- Respite providers should undergo criminal and child abuse background checks.

## Funding for Respite Services and Programs

A range of possible state and federal funding sources may be available to help pay for respite services. States with a State Lifespan Respite Program or State Respite Coalition should be able to provide links to existing funding sources or assist with possible funding sources that may be unique to the state.

Much of the funding for treatment and services comes from Federal and State dollars, mainly from Medicaid and education funding. The majority of children receiving care are doing so through school systems, which are mandated to provide special education services under the Individuals with Disabilities Education Act (IDEA). Those who qualify can receive both intensive classroom assistance and a range of free services, including therapies, day treatment, and residential care, outside the classroom. However, schools are only required to provide services that are essential for learning, and therefore families are unable to access services such as therapy and respite care. The majority of children with SED are not receiving intensive special education services, usually because they are misidentified, sometimes purposely so that schools

can avoid paying for expensive services or in order to avoid stigmatizing the child (Koppelman, 2004).

For services not provided by schools, parents often turn to private health insurance coverage, but many plans have historically limited access to mental health treatments. A Government Accounting Office study in 2003 reinforced long-standing concerns that some parents had to relinquish custody of their children solely to obtain treatment for their children's behavioral or emotional problems. Prompted by this finding, federal and state policies have begun to address mental health care financing for children (Ireys, 2006). These include:

- The Mental Health Parity Act of 1996 (MHPA) was the first federal law to ensure that group health plans could not impose annual or lifetime limits on mental health benefits which were stricter than those imposed on medical surgical benefits.
- The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), which supplemented MHPA, requires (with some exceptions) that group health plans may not impose less favorable annual or lifetime dollar limits on mental health benefits than they do on medical surgical benefits, or require higher copayments for mental health services than for other health care. However, the law does not require private plans to offer coverage for mental health substance abuse disorders. Only group plans covering 50 or more employees are regulated by the law. Medicaid-managed care and SCHIP plans are covered. For details of MHPAEA, see the Centers for Medicare & Medicaid Services website at [https://www.cms.gov/healthinsreformforconsume/04\\_theMentalHealthParityAct.asp](https://www.cms.gov/healthinsreformforconsume/04_theMentalHealthParityAct.asp)
- The Patient Protection and Affordable Care Act of 2010 establishes state-based health insurance exchanges to help individuals and small businesses purchase health insurance; these plans must include mental health and substance abuse disorder services at parity. Insurers may not set lifetime limits on mental health coverage; beginning in 2014 they may not set annual

limits. Plans may not deny coverage for a pre-existing conditions, including mental illness, for individuals under age 19 (extending to all plans beginning in 2014) (Bazelon Center for Mental Health Law, 2010).

- Many states also regulate mental health insurance coverage through parity laws. For a listing of state laws regulating mental health benefits, see the National Conference of State Legislatures website at <http://www.ncsl.org/issues-research/health/mental-health-benefits-state-laws-mandating-or-re.aspx>

## Federal Funding

**Medicaid and State Children's Health Insurance Program.** Low-income children who are eligible for Medicaid should be receiving medically necessary services under either the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit. Other low income children can access mental health services through the State Children's Health Insurance Program (SCHIP).

**Medicaid Section 1915(c) Home and Community-Based Services Waivers.** Generally, every state offers some respite assistance through various home and community-based Medicaid Waivers. These waivers have helped reduce the rate at which families were forced to relinquish custody to the child welfare or juvenile justice systems (NAMI, 2009). Each state's eligibility criteria and funding for waivers is different. To see if a state has a Medicaid waiver that serves this population, see the ARCH National Respite Locator Service at [www.respitelocator.org](http://www.respitelocator.org) by clicking on an individual state or see ARCH's Compendium of Home and Community-Based Medicaid Waivers that Pay for Respite at <http://archrespite.org/productspublications/products-and-publications#Waivers>.

States have been reluctant to apply for Medicaid waivers to pay for home and community based services for this population because of the requirement that children served must require a hospital level of care. Many states no longer

have children in psychiatric hospitals; instead, they are being served in less expensive residential treatment facilities, so states believe that they cannot apply for the waiver because they cannot show cost neutrality. The Alternatives to Psychiatric Residential Treatment Facilities Demonstration Project (discussed below) was designed to address this issue.

### **CMS Community Alternatives to Psychiatric Residential Treatment Facilities Demonstration Project.**

A five-year demonstration project was established by the Deficit Reduction Act of 2005 (DRA) to test the feasibility and cost-effectiveness of home- and community-based waivers (1915(c)) for children who would otherwise be placed in psychiatric residential treatment facilities (PRTF). The demonstration is funding nine states (Alaska, Georgia, Indiana, Kansas, Maryland, Mississippi, Montana, South Carolina, and Virginia) from 2007 to 2012. All of the funded states are providing in-home and out-of-home respite. Across all States, the services provided are short-term, offered both inside the home and in community settings, reimbursed at an hourly or daily rate, and accessed in routine or crisis situations. The only notable difference among the States is that Mississippi allows respite to take place in PRTFs for up to 29 days, while Montana explicitly prohibits the provision of respite in PRTFs. At the end of the demonstration project, states may continue to provide home and community-based alternative services to participants in the program (IMPAQ, 2010). States have enrolled close to 3000 children and youth as of March 1, 2011. It is estimated that approximately 6,000 children and youth will be served by the end of the demonstration (Centers for Medicare & Medicaid Services, 2010). At the conclusion of these demonstrations, states will have the option of continuing to provide home and community-based care alternatives for demonstration participants under a 1915(c) waiver.

### **Comprehensive Community Mental Health Services for Children and Their Families Program.**

SAMHSA funds this program, also known as the Child Mental Health Initiative, which provides

grants to develop and expand community-based systems of care (SOC) for children with SED. These local systems of care communities, which have produced positive clinical and functional outcomes over time, serve a few thousand children and youth per year. Grantees are required to implement an array of mental health and support services which must include respite care, although care coordinators have reported that they have had the most difficulty meeting the need for respite services and therapeutic foster care (Macro International, 2005). To access information about individual grantees by state, see the SAMHSA Grant Awards – State Summaries at <http://www.samhsa.gov/Statesummaries/index.aspx>;

**The Community Mental Health Services Block Grant** program supports the delivery of a broad range of community-based systems of care for individuals with serious mental illnesses, including children with SED, as an alternative to hospitalization. All states and territories are eligible for the grant program, which is administered by the Center for Mental Health Services (CMHS) within SAMHSA. The grants are based on a state's demographic and economic factors. They offer flexible funding that states can use not only to support mental health services not covered by other sources but also to pay for mental health treatment for uninsured individuals.

### **Additional Funding Sources**

Some states have developed **state-funded systems of care for children with mental health conditions**. State agencies responsible for children's mental health may provide funding through regional, county or local community mental health organizations. These approaches may include the various Medicaid coverage options, integrated funds from the numerous agencies that serve children, designated care management entities (CMEs) for high-risk populations, time-limited demonstration projects funded by the Substance Abuse and Mental Health Services Administration SAMHSA, and other Medicaid waivers (such as Section 1115 Research and Demonstration Project waivers – see <http://>

[www.cms.gov/MedicaidStWaivProgDemoPGI/03\\_Research&DemonstrationProjects-Section1115.asp](http://www.cms.gov/MedicaidStWaivProgDemoPGI/03_Research&DemonstrationProjects-Section1115.asp) for more information on this waiver program) (Ireys, 2006).

Children with mental health issues are at increased risk for child abuse and neglect, as well as for placement in the child welfare or juvenile justice systems in order to access services unavailable to their families otherwise. **Community-Based Grants for the Prevention of Child Abuse and Neglect** (CBCAP) provide funds for planned and crisis respite services to provide relief to families whose children are at such risk. CBCAP funds can be used to help existing respite agencies and programs expand services and reduce waiting lists and build new capacity and programming to service underserved populations (FRIENDS, 2007). However, only a handful of states use this option to fund respite. For information on how states use Title II CBCAP funds, see <http://www.friendsnrc.org/state-resources/state-reports>.

For more information, see Children's Mental Health section in the ARCH's Federal Funding and Opportunities for Respite (2012). [http://www.lifespanrespite.memberlodge.org/Resources/Documents/Child%20Education\\_Health\\_Mental%20Health.pdf](http://www.lifespanrespite.memberlodge.org/Resources/Documents/Child%20Education_Health_Mental%20Health.pdf)

## State Administration

State Lifespan Respite Programs and/or State Respite Coalitions in collaboration with other agencies, may want to consider convening a state planning committee working to insure the continuation of respite for children and youth experiencing a serious emotional disturbance and their families. The planning committee should be comprised of representatives of those agencies that serve children and youth experiencing SED and their families (mental health, social and rehabilitation services, medical services, public schools, and family members). The committee should receive, analyze, and disseminate evaluation information collected by local respite programs. It should also develop a long-range strategic plan for the continued funding

and delivery of respite based on the results of the evaluation.

## Evaluation

As is the case for all types of respite programs, evaluation is a critical component when providing service to children and youth experiencing a serious emotional disturbance. As mentioned above, this population has been under-identified and under-served. Longitudinal data needs to be developed to support the importance of respite for children with SED, and the benefit to their families. For example, retrospective analysis of data from 45 system of care communities initially funded in 1997 through 2000 showed that at least one-third of caregivers whose children participated in system of care services indicated that their level of strain was significantly reduced (Macro International, 2011).

Public and private funding for programs is increasingly being tied to those which are able to demonstrate evidence of success. Evaluation efforts must be undertaken regularly to build a solid base of evidence that respite works to support and sustain families and contributes to positive behavioral outcomes for children and youth with SED. For more on respite program evaluation strategies, see *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Care Program Managers*, available from <http://www.archrespite.org/program-evaluation>.

## Recommended Strategies

Expanding respite options and improving respite access, appropriateness, acceptance and cultural relevance for those caring for children with mental health issues will take the work and expertise of mental health professionals, government agencies, community providers and many others diligently working in partnership with family caregivers. There are steps that Lifespan Respite Programs, state organizations and respite coalitions, respite providers and even family caregivers can take to improve the situation. For more detail, see "Respite Considerations" above.

### ***For State Lifespan Respite Programs:***

1. Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts together to develop public awareness and education materials that focus on the special needs of children with mental health issues.
2. While conducting needs assessments in your states to identify service gaps, include questions to determine the specific barriers to respite for this distinct population and work toward strategies to overcome these barriers.
3. In developing training materials to recruit and train respite providers and volunteers, seek expertise from the mental health professional community and family caregivers, to develop training modules that will result in more respite providers able to serve this population. Specifically, train providers and caseworkers to respect the dignity of the client and their family. Include family caregivers as part of the training team for professionals.
4. Offer participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.
5. Train family caregivers to recognize the warning signs of burnout and how to recognize when their child may be in need of additional care.
6. Develop training programs for peer mentors to assist other family caregivers. They understand what others coping with mental illness are experiencing.

### ***For Respite Programs, Community Agencies, and Health Care Providers:***

1. When looking for volunteers to assist in respite service delivery, consider reaching out to university or community college students who are pursuing careers in the mental health field or look to state professional associations to find volunteers with mental health experience.

2. Develop and use training modules that educate the respite workforce in the special needs of children with mental health concerns and offer additional supports to encourage respite workers to engage with this population.
3. Include family caregivers as a member of the consumer's support team and encourage their input in the development of individual service plans.

### ***For State Mental Health Agencies or State Respite Coalitions:***

1. Provide information sessions for family members focused on particular mental conditions affecting children and adolescents, what to expect, and how to seek support.
2. Engage your state chapter of the Federation of Families for Children's Mental Health for guidance and oversight.
3. Encourage State affiliates of mental health related organizations, such as the National Alliance on Mental Illness (NAMI) or Mental Health America (MHA), to co-sponsor educational events that allow for caregiver/care recipient feedback and input.

### ***For Family Caregivers***

1. Become involved with your state Respite Coalition and/or your State Lifespan Respite Program to share input regarding your specific respite needs.
2. Seek support and information from your state chapter of the Federation of Families for Children's Mental Health.
3. If your state programs are already working on these issues, stay involved to offer your expertise and input as new respite services are developed and new providers are trained and recruited.
4. Seek support and use respite early and as often as appropriate!

## Conclusion

Children and youth experiencing a serious emotional disturbance and their families have long been under identified and under served. Some parents of children with SED have been forced to give up custody of their children in order to obtain needed services, and in some states, residential placements may be a great distance from the child's home – sometimes out of the state.

Because these children and youth often do not look “different”, expectations from service providers and the community at large may not match the child's level of functioning in educational or social situations. When children do not meet expectations, blame may be inappropriately placed on their families, who experience a high level of stress. Respite can prevent a child or youth from being institutionalized and separated from his/her family and community. Respite needs to be flexible, fluid, creative, and unconditional. In addition, families need to play an integral part in designing and implementing respite programs.

## Resources

The following resources may be helpful to Lifespan Respite Programs, respite providers, mental health consumers and their family caregivers.

### American Psychological Association (APA)

APA is a scientific and professional organization representing 154,000 psychologists in the United States. It offers information services on its website and provides a Psychologist Locator to help individuals find practicing psychologists locally.

*American Psychological Association  
750 First Street, NE  
Washington, DC 20002-4242  
Phone: 800-374-2721/ 202-336-5500  
TDD/TTY: 202-336-6123  
Website: <http://apa.org>*

### Bazelon Center for Mental Health Law

The Bazelon Center is a nonprofit organization devoted to improving the lives of people with mental disabilities through changes in policy and law. Legislative news, fact sheets, and reports about coordinating systems of care for children and adolescents with emotional, behavioral, and mental health challenges that support families and enable children to become successful adults. The center works to advance and preserve the rights of people with mental health challenges and developmental disabilities.

*Bazelon Center for Mental Health Law  
1101 15th Street, NW, Suite 1212  
Washington, DC 20005  
Phone: 202-467-5730  
TDD: 202-467-4232  
Website: <http://www.bazelon.org>*

### Maternal & Child Health Library at Georgetown University

The library offers an extensive Knowledge Path on Emotional, Behavioral, and Mental Health Challenges in Children and Adolescence that contains resources from the fields of health, education, social services, and juvenile justice for families, schools, health professionals, program administrators, policymakers, and community advocates.

*[http://www.mchlibrary.info/KnowledgePaths/kp\\_Mental\\_Conditions.html](http://www.mchlibrary.info/KnowledgePaths/kp_Mental_Conditions.html)*

### National Alliance on Mental Illness (NAMI)

NAMI is the nation's largest grassroots mental health organization dedicated to improving the lives of individuals and families affected by mental illness. NAMI has over 1,100 affiliates in communities across the country who engage in advocacy, research, support, and education.

Members of NAMI are families, friends, and people living with mental illness such as major depression, schizophrenia, bipolar disorder, obsessive-compulsive disorder (OCD), panic disorder, post-

traumatic stress disorder (PTSD), and borderline personality disorder.

*National Alliance on Mental Illness*  
Phone: (703) 524-7600 or (800) 950-NAMI (6264)  
Website: [www.nami.org](http://www.nami.org)

### **National Federation of Families for Children's Mental Health**

The National Federation of Families for Children's Mental Health is a family-run national organization that advocates for the rights of children and youth with emotional, behavioral and mental health challenges and their families. They provide leadership and technical assistance to a network of family-run organizations.

*National Federation of Families for Children's Mental Health*  
9605 Medical Center Drive  
Rockville, MD 20850  
Phone: 240-403-1901  
Fax: 240-403-1909  
Email: [ffcmh@ffcmh.org](mailto:ffcmh@ffcmh.org)  
Website: <http://ffcmh.org>

### **National Technical Assistance Center for Children's Mental Health (TA Center)**

The TA Center is located within the Georgetown University Center for Child and Human Development in Washington, DC. Since 1984, the Technical Assistance Center has been dedicated to working in partnership with families and many other leaders across the country to transform systems and services for children, adolescents, and young adults who have, or are at risk for, mental health problems and their families.

*National Technical Assistance Center for Children's Mental Health*  
Georgetown University Center for Child and Human Development  
Phone: 202-687-5000  
Fax: 202-687-1954  
Email: [childrensmh@georgetown.edu](mailto:childrensmh@georgetown.edu)  
Website: <http://gucchdtacenter.georgetown.edu/in>

## **References**

ARCH National Respite Network and Resource Center. (2011). *Fact sheet 2: Building blocks for lifespan respite: Federal funding for adult's and children's respite*. Chapel Hill, NC: Author.

ARCH National Respite Network and Resource Center. (2002). *Fact sheet 44: Recruiting and retaining respite providers*. <http://www.archrespite.org/productspublications/arch-fact-sheets>

Bazon Center for Mental Health Law. (2010). *Insurance market reforms in the Patient Protection & Affordable Care Act and the Health Care & Education Reconciliation Act*. Washington, DC: Author.

Brauner, C.B., & Stephens, C.B. (2006). Estimating the prevalence of early childhood serious emotional/behavioral disorders: Challenges and recommendations. *Public Health Reports, 121*(3). 303-310.

Burks, C. (2011). *Sick and tired*. *Rise, 18*, 1-3. <http://www.risemagazine.org>

Centers for Medicaid and Medicare Services. (2010). *Community alternatives to psychiatric residential treatment facilities for children*. [http://www.cms.gov/CommunityServices/25\\_PRTF.asp](http://www.cms.gov/CommunityServices/25_PRTF.asp)

Cooper, J.L., Aratani, Y., Knitzer, J., Douglas-Hall, A., Masi, R., Banghart, P., & Dababnah, S. (2008). *Unclaimed children revisited: The status of children's mental health policy in the United States*. New York: National Center for Children in Poverty. Retrieved July 2011 from [http://www.nccp.org/publications/pub\\_853.html](http://www.nccp.org/publications/pub_853.html)

FRIENDS National Resource Center for Community-Based Child Prevention. (2007). *Respite and crisis care, Fact Sheet #14*. <http://www.friendsnrc.org/print-materials#respite>

Ghandour RM, Kogan MD, Blumberg SJ, et al. (2012) Mental health conditions among school-aged children: Geographic and sociodemographic patterns in prevalence and treatment. *Journal of*

*Developmental and Behavioral Pediatrics* 33(1):42-54.

Giliberti, M. (2001). *Merging system of care principles with civil rights law: Olmstead planning for children with serious emotional disturbance*. Washington, DC: Bazelon Center for Mental Health Law.

IMPAQ International & Westat, Inc., (2010). *National evaluation of Medicaid demonstration: Home- and community-based alternatives to psychiatric residential treatment facilities Year 2 implementation status report*. Columbia, MD: Author. [https://www.cms.gov/CommunityServices/Downloads/CBA\\_Implementation\\_Status\\_Report\\_2009.pdf](https://www.cms.gov/CommunityServices/Downloads/CBA_Implementation_Status_Report_2009.pdf)

Ireys, H.T, Pires, S., & Lee, M. (2006). *Public financing of home and community services for children and youth with serious emotional disturbances: Selected state strategies*. Washington, DC: Mathematica Policy Research, Inc. [http://www.chcs.org/publications3960/publications\\_show.htm?doc\\_id=392747](http://www.chcs.org/publications3960/publications_show.htm?doc_id=392747)

Knitzer, J. (1982). *Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services*. Washington, DC: Children's Defense Fund.

Koppelman, J. (2004). *Children with mental disorders: Making sense of their needs and the systems that help them*. Washington, DC: National Health Policy Forum. [http://www.regionsix.com/ResourceLibrary/Mental%20Health/IB799\\_ChildMentalHealth.pdf](http://www.regionsix.com/ResourceLibrary/Mental%20Health/IB799_ChildMentalHealth.pdf)

Macro International. (2005). *Comprehensive Community Mental Health Services for Children and Their Families Program: Evaluation findings: Annual report to Congress 2005*. Washington, DC: Substance Abuse and Mental Health Services Administration. <http://store.samhsa.gov/product/The-Comprehensive-Community-Mental-Health-Services-for-Children-and-Their-Families-Program-Evaluation-Findings/SMA10-4536>

Modrcin, M.J., & Robison, J. (1991). Parents of children with emotional disorders: Issues for consideration and practice. *Community Mental Health Journal*, 27(4), 281-292.

National Alliance on Mental Illness (NAMI). (2009). *Reinvesting in the community: A family guide to expanding home and community-based mental health services and supports*. Arlington, VA: Author.

National Dissemination Center for Children with Disabilities (NICHCY). (2010). *Emotional disturbance*. NICHCY Disability Fact Sheet #5. Washington, DC: Author.

National Federation of Families for Children's Mental Health. (2010). *Family-driven – defined*. <http://ffcmh.org/r2/publications2/family-driven-defined>

Regional Research Institute for Human Services. (2002). Respite for children with serious emotional disturbance and their families: A way to enrich family life. *Focal Point*, 15(2). 26-30.

Smith, V.K., Gifford, K., & Ellis, E. (2010). *Hoping for economic recovery, preparing for health reform: A look at Medicaid spending, coverage and policy trends. Results from a 50-state Medicaid budget survey for state fiscal Years 2010 and 2011*. Washington, DC: Kaiser Family Foundation. Retrieved July 2011 from <http://www.kff.org/medicaid/8105.cfm>

Stagman, S. & Cooper, J.L. (2010). *Children's mental health: What every policymaker should know*. NY: National Center for Children in Poverty. [http://nccp.org/publications/pub\\_929.html](http://nccp.org/publications/pub_929.html)

Stroul, B. (2002). *Issue Brief – System of care: A framework for system reform in children's mental health*. Washington, DC: Georgetown University Child Development Center, National Technical Assistance <http://gucchd.georgetown.edu/products/SOCIssueBrief.pdf>

Substance Abuse and Mental Health Services Administration (SAMHSA). (2011). *FY 2011 grant request for applications (RFA): Planning grants for expansion of the Comprehensive Community*

*Mental Health Services for Children and their Families*. [http://www.samhsa.gov/grants/2011/sm\\_11\\_008.aspx](http://www.samhsa.gov/grants/2011/sm_11_008.aspx)

Substance Abuse and Mental Health Services Administration (SAMHSA). (2010a). *Addressing the mental health needs of young children and their families*. <http://store.samhsa.gov/product/SMA10-4547>

Substance Abuse and Mental Health Services Administration (SAMHSA). (2010b). *Children and youth services: Child/youth and caregiver respite care*. [http://www.samhsa.gov/healthReform/docs/Children\\_Youth%20Services\\_Respite%20Services\\_Reformatted\\_v2\\_20101202.pdf](http://www.samhsa.gov/healthReform/docs/Children_Youth%20Services_Respite%20Services_Reformatted_v2_20101202.pdf)

Substance Abuse and Mental Health Services Administration (SAMHSA). (2007). *Definitions and terms relating to co-occurring disorders*. COCE Overview Paper 1. DHHS Publication No. (SMA) 07-4163. Rockville, MD: Author.

Wright, E.R., Anderson, J.A., Kelley, K., & Kooreman, H. (2007). *Longitudinal impact of family functioning on children served in systems of care*. A project funded by with a report submitted to ORC

Macro, Calverton, MD. [http://nd.edu/~kkelley/publications/miscellaneous/Wright\\_Anderson\\_Kelley\\_Kooreman\\_FamilyFunctioning\\_2007\\_Macro.pdf](http://nd.edu/~kkelley/publications/miscellaneous/Wright_Anderson_Kelley_Kooreman_FamilyFunctioning_2007_Macro.pdf)

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