

Respite Care: What Families Say

February 2013

Parent/Professional Advocacy
League

Massachusetts Department of
Mental Health



Parent/Professional Advocacy League (PPAL) is a statewide family organization dedicated to improving the mental health and well-being of children, youth and families through education, advocacy and partnership. PPAL is the leading public voice for families whose children have emotional, behavioral and mental health needs in Massachusetts.

The Department of Mental Health, as the State Mental Health Authority, assures and provides access to services and supports to meet the mental health needs of individuals of all ages, enabling them to live, work and participate in their communities. The Department establishes standards to ensure effective and culturally competent care to promote recovery. The Department sets policy, promotes self-determination, protects human rights and supports mental health training and research. This critical mission is accomplished by working in partnership with other state agencies, individuals, families, providers and communities.

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Respite Care: *What Families Say*

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Executive Summary

In 2012, the Massachusetts Department of Mental Health (DMH) and the Parent/Professional Advocacy League (PPAL) collaborated to conduct a survey of parents of children with mental health needs about respite services. The goal of the study was to inform public policy with a better understanding of the need for respite services among Massachusetts families caring for children with mental health needs, the value families place on these services, and the challenges they may face in accessing these services.

A 29-question survey was developed and both paper surveys and an online survey link were distributed through email, listserv postings and social media. 280 surveys were completed and returned and a post-survey focus group of four parents provided additional information. Nearly all respondents (96.8%) reported their child had special health care needs: 87.5% identified themselves as parents of children with mental health needs and 9.3% had other special health care needs. All the children were insured: 30.3% of parents reported that their child had private insurance, 44.2% Medicaid, and 25.5% a combination of both.

The findings of this survey indicate that the need for appropriate and affordable respite care is high, yet access is limited and current utilization among respondents is low.

Few families were currently accessing respite care

- only 17.6% were currently using respite care
- 44.6% reported they currently do not use respite but have used it in the past
- 37.8% said that they have never used respite services
- A number of parents said they were hearing about respite care for the first time when taking the survey.

Nearly all believed respite provides important benefits

- More than half (56.5%) stated that it reduces stress level of the parent
- 9.2% found respite care reduces the stress level of the child or youth
- 6.9% said it reduces the stress level of siblings
- Nearly one in five parents said that respite care reduces out of home placements.

Many parents face barriers to respite care

- 64.3% reported that they couldn't find anyone to provide respite care
- 51.9% said respite care was too expensive
- Almost one-quarter (23.7%) paid for it out of personal funds while 58.4% accessed state agency funds or used unpaid care (31.8%), usually through a relative or friend.

Most parents desired respite care twice a week or less

- 32.7% said that respite services one to two times per week was the right amount
- Another 30.0% said that one to two times per month was the right amount
- 10.6% said they desired respite care three to four times per week
- 26.7% said they preferred respite care to be used intermittently.

Parents varied in their choice of respite care provider

- 65.8% said that family members such as grandparents or aunts and uncles were their primary choice
- 63.2% said staff trained in behavioral management
- Nearly half (49.2%) said a program with multiple staff would be a good match for their child
- 44% chose close friends to provide care
- 27.1% said they preferred staff trained to administer medications.

The experience of parents participating in this survey suggests the following policy recommendations:

- Develop public policies that recognize the multiple benefits of respite services to families of youth with mental health conditions including short and long term positive effects on parent, child and siblings and the social costs of avoidable out-of-home placements.
- Fund a variety of respite care models, including informal respite arrangements, to best meet the needs of families of youth with a range of mental health needs.
- Ensure eligibility criteria recognize respite services as a prevention strategy for those youth with less severe mental health conditions.
- Disseminate information about respite care to families and caregivers of children at risk for or living with mental health needs, including what respite care is, how to access it, sources of funding, and how to develop informal sources of respite care.
- Develop policies that allow flexibility in choice of respite providers and promote the development and training of an accessible and skilled respite workforce.

Introduction

In Massachusetts and across the country, children with mental health needs now receive most of their care in their homes and communities. Much has been written about the value of this shift away from out-of-home care. Less attention has been given to how this shift has led to increased burdens on families. The caregiving demands on parents of children with mental health needs affect their employment and health, add to family stress, and can negatively impact child well-being (Rosenzweig, Brennan, Ogilvie, 2002; Rosenzweig, Brennan, 2008). A survey of caregivers of children, adults and the disabled conducted in 2000 by the National Family Caregivers Association, found that 70% of respondents reported finding an inner strength they didn't know they had. At the same time, 27% reported having more headaches, 24% reported stomach disorders, 41% more back pain, 51% more sleeplessness and 61% more depression -- all health concerns associated with stress.

All families experience stress due to financial pressures, balancing work and family, and other responsibilities, but parents whose children have mental health needs often report that their stress is particularly acute and intense. They become both caregivers, managing the fluctuating moods and behaviors of their children, and case managers, coordinating the services their children need. Mental illness in children affects more than just the children—it impacts the entire family. Parents of children with mental illness struggle to meet the needs of their child with mental health needs, other family members, and themselves. They may face challenges such as financial burden, sibling rivalry, stigma, self-doubt and blame, marital stress, and difficulty accessing services, in addition to dealing with the symptoms their child is experiencing (Delinger-Wray, Uhl, 1996).

Caring for a child with mental health needs requires particular knowledge of the child's mental health condition and how it affects his/her behavior and relationships, as well as specific skills to appropriately respond to those behaviors. Because their children can't be left with a sitter or participate in typical childhood activities, such as sleepovers, 'play dates', sports, and school events, parents often feel they are unable to get a break from caring for their child.

According to Access to Respite Care and Help (ARCH), a respite care assistance organization, respite care can be defined as "providing temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs." The MA Department of Mental Health's definition of respite is "brief or short-term care of a child or youth with SED that is provided by adults other than the birth parents, foster parents, adoptive parents or legal guardian with whom the child/youth normally resides. Respite is typically used to give the parents/LAR and child/youth time away from each other in order to decrease stress and support the family system.

Respite care may be provided in the home or in settings outside the home, including overnight respite facilities.”

In most communities, respite care is a patchwork of formal and informal arrangements. It can range from in-home care provided by a grandparent or out-of-home care by a trained service provider. It can be delivered on an as-needed basis or scheduled in advance. It can be available through an afterschool program, a camp or recreational program or from parents providing respite to one another. The quality and availability varies widely across the state in type, duration, cost and ability to access it. In many cases, the qualifying conditions or eligibility criteria for the service can create additional barriers. Respite care is frequently identified by parents whose children have mental health needs as one of the most needed yet least available services for families.

In 2012, the MA Department of Mental Health (DMH) collaborated with the Parent/Professional Advocacy League (PPAL) to conduct a survey of parents of children with mental health needs about respite services. The goal of the study was to inform public policy with a better understanding of the need for respite services among Massachusetts families caring for children with mental health needs, the value families place on these services, and the challenges they may face in accessing these services.

Methodology

In the spring of 2012, the Parent/Professional Advocacy League (PPAL) and Massachusetts Department of Mental Health (DMH) developed a survey about respite care for parents whose children have emotional, behavioral and mental health needs. The survey was designed to collect information about parents’ knowledge and use of respite care as well as the value they place on it. It was piloted with a group of parents in the Boston area, and their comments were integrated into the survey. The survey consisted of 29 questions: 28 structured questions and one open-ended question.

Between June and July 2012, PPAL distributed online and paper surveys through a variety of mechanisms. The online survey was distributed through social media, newsletters and postings on several parent listservs using an on-line survey tool, Survey Monkey. Members of PPAL statewide support groups were directly invited to participate in the survey, and could respond to the survey either on-line or on paper. The paper survey was also administered in face-to-face meetings with parents from Lynn, MA and Roxbury, MA in order to increase the racial and ethnic diversity amongst respondents. A link at the end of the online survey to a weekly gift card raffle was provided and a separate postcard to enter the raffle was available to parents filling out the paper survey.

A total of 280 surveys were completed and returned. Because the survey was only administered in English, the sample size was limited to those who spoke English. Although some families had more than one child with mental health needs or had more

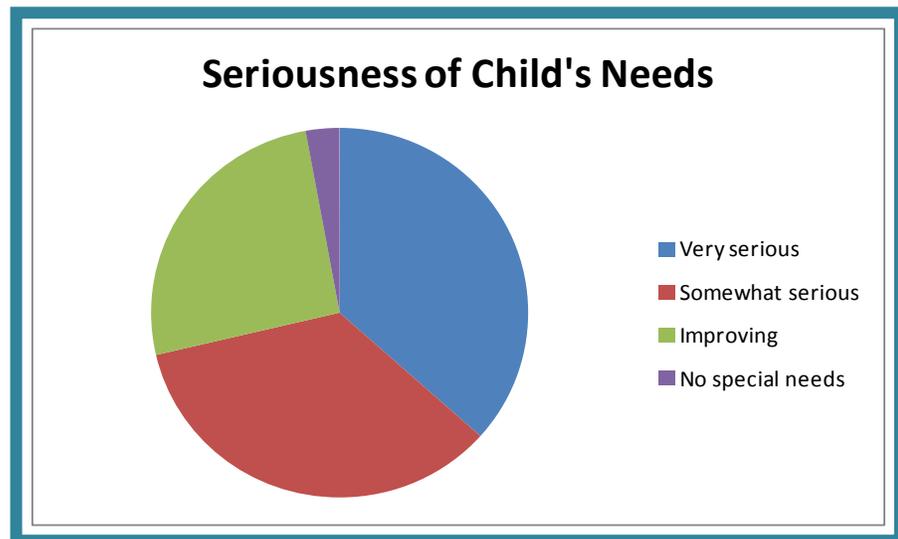
than one child receive respite care, only one survey was filled out per respondent. Nearly all (278) respondents resided in Massachusetts; one had just recently moved out of state and completed the survey based on her experience in Massachusetts. One parent living in New Hampshire had a child in a therapeutic residential school in MA. All 280 responses were used in the analysis.

A focus group with four parents was conducted after the close of the survey to gain a deeper contextual understanding of the findings. Their comments are included here.

Demographics

Of the 280 respondents, 43.9% parents had children between the ages of 13 and 19 while 35.1% of respondents had children ages 7 to 12, 14.8% reported that their children were age 19 or older, and 6.3% had children age 6 or younger.

Unsurprisingly, as the survey was offered only in English, 98.2% of the respondents reported English as the primary language spoken at home; 1.8% spoke Spanish at home and 1.8% spoke another language (identified as



Portuguese, Vietnamese and American Sign Language); some respondents reported more than one primary language spoken in the home. The respondents were allowed to indicate more than one race/ethnic category. The overwhelming majority was Caucasian (82.8%); other respondents identified themselves as African American (10.5%), Hispanic/Latino (7.1%), and Asian (2.6%). An additional 3.7% of the respondents described themselves as “mixed” or that their child was a different ethnicity.

Nearly all respondents (96.8%) reported their child had special health care needs: 87.5% identified themselves as parents of children with mental health needs and 9.3% reported that their children had other special health care needs. An additional 3.2% stated that their child had no special needs.

When asked to describe the seriousness of their child’s mental health needs, 36.6% reported it was very serious and 34.8% reported it as somewhat serious. An additional

25.8% reported that their child was improving or that their child had no special needs (2.9%).

"It's so important to have this care for families so parents can have less stress, get things done for the family, spend time with the other kids and go on family outings with all."

Among the families who reported that their child had special health care needs, 73% reported that their child had received mental health services in the past 12 months. Of the 3.2% who reported their child had no special needs, 78% reported that their children had received therapy in the prior 12 months. In the post-survey focus group, parents were asked why respondents would report their children had no special needs but had received therapy. Participants suggested that parents who described their child as having no special needs but still receiving therapy may have done so because the child had not received a formal diagnosis but was receiving preventative or family therapy.

Respondents were also asked for the type of insurance that covered their child's health care. For some families whose children have significant mental health challenges, this can differ from the parent's insurance coverage. 30.3% of parents reported that their child had private insurance, 44.2% Medicaid, and 25.5% a combination of both. Further analysis shows that parents who reported that their child's mental health or special health care needs were very serious were most likely to report that their child's insurance coverage was a combination of private insurance and Medicaid.

Services and seriousness of condition

Parents were asked to indicate if their child had received any mental health services in the last year, and if so, what kind. Respondents could indicate more than one type of service. The majority of parents (82.8%) reported that their child had received mental health services in the past 12 months. Responses indicate a wide variation in the types of clinical services that children and families received. The largest number (81.0%) reported that their child had received outpatient therapy, followed by medication management (58.1%), family therapy (31.2%), group therapy (28.1%), in-home therapy (26.9%) and in-home behavioral therapy (17.4%). Nearly one in four parents reported that their child had had a psychiatric hospitalization (24.1%) and 1 in 5 (19.1%) had used mobile crisis services. Parents who described their child's mental health condition as "very serious" reported higher utilization of psychotropic

"I would like to have training provided for respite care providers, supervision, and accountability for services rendered so my child is safe without worry. It is difficult to accept random respite and relax. I need to trust the place and providers."

medications (65.3%), inpatient care (44.2%) and mobile crisis services (33.7%) than those who described their child’s mental condition as less than “very serious.”

Less than 20% of families received some type of assistance with care coordination

“Parents need to know there is somewhere to turn when things are too difficult.”

within the last year: 18.2% had received MassHealth Intensive Care Coordination, a service that facilitates care planning and coordination services for MassHealth (Medicaid) youth with serious emotional disturbance under the age of 21 and enrolled in MassHealth Standard or CommonHealth; and, 17.4% received MA DMH Case Management.

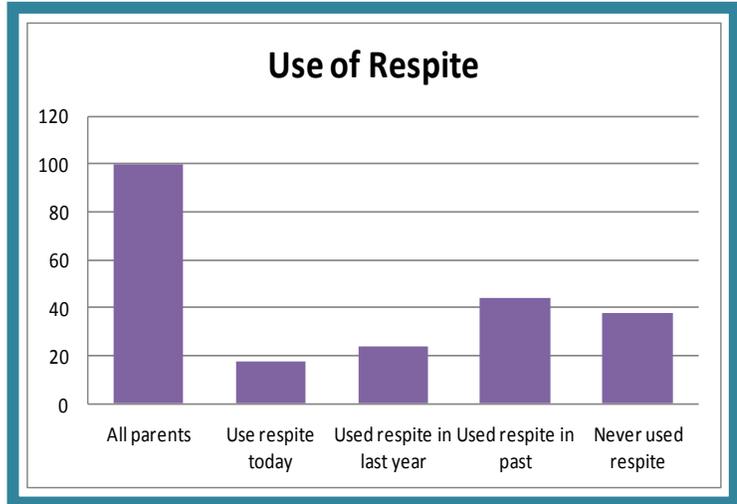
Regarding non-clinical services, 26.1% said they attended a parent support group, 24.9% reported that their child had a therapeutic mentor, and 20.9% worked with a parent support provider (e.g., family partner or family support specialist). The percentage of parents who reported accessing these non-clinical services varied little among parents who reported that their child’s needs were very serious, somewhat serious or improving. Only parents whose children had no special needs reported that they were unlikely to access any of these services. Parents of children who reported the use of private insurance only (30.3%) are unable to access Therapeutic Mentoring and Family Support and Training (Family Partner), the non-clinical services offered through MassHealth.

Nearly half (47.2%) of the parents who used respite services in the last year reported that their child had “very serious” mental health needs. Another 33.3% said their child’s needs were somewhat serious and 19.4% of the parents accessing respite care said their child’s needs were improving. No parents who described their child with no special needs had accessed respite care.

Information, access and using respite care

Few families reported currently accessing respite care -- only 17.6%. Another 44.6% reported they currently do not use respite but have used it in the past; and the remaining 37.8% said that they have never used respite services. When asked if they had accessed respite care in the last year, 23.6% reported that they had. Families most often learn about respite care services through word of mouth from other parents (32.0%) and the MA Department of Mental Health (22.5%). Only 6.3% of parents reported that their child’s doctor or therapist had provided the information, and 5% found information by searching the internet. A number of parents said they were hearing about respite care for the first time when taking the survey. Some remarked, “I didn’t know there was any” or “I didn’t know it existed.” Among families who received case management services from DMH, an agency that provides respite care services to DMH-enrolled youth, 51.4% learned about respite care through that agency while 29.7% got information from other parents.

When asked where they found the most useful information about respite care, 29.8% of parents again said it was through other parents and in comments many mentioned their local PPAL family support connection. Some said that state agencies provided the connection (18.8% identified DMH, 13.3% other state agencies). Only 5.5% reported that their child’s doctor or therapist had been helpful.



Almost one-quarter were unsure if they’d ever gotten helpful information about respite. “I never got any useful respite care information,” one parent stated. This is consistent with the PPAL 2010 study (“Overcoming Barriers in Our Community: How Are We Doing?”), which found 19% of parents and guardians reported having no knowledge of respite.

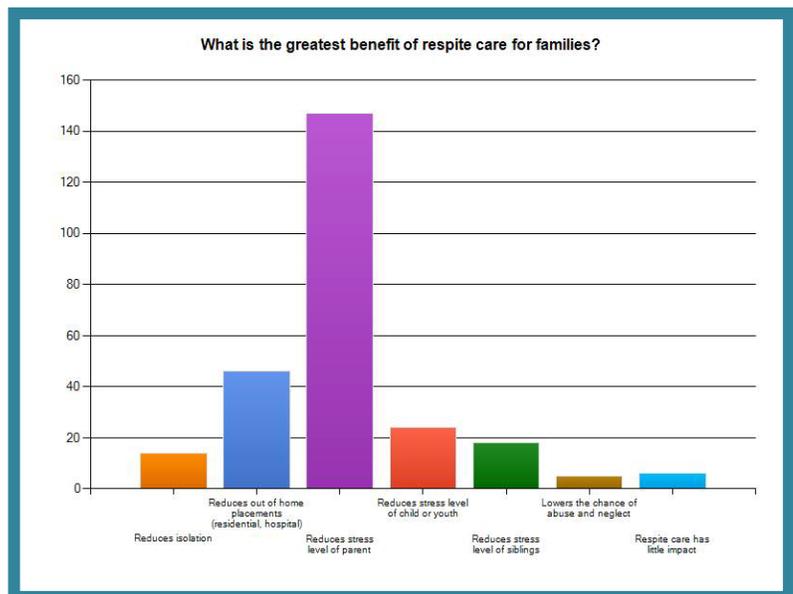
Benefits and barriers

These parents’ comments illustrate the extent to which the caregiving needs of children with mental illness impact family life:

“We live on pins and needles and stress is so high all the time.”

“We need help to save my marriage.”

While only one in five parents surveyed currently receives respite care, almost all believed it provides important benefits. The majority of parents saw a direct impact on stress. More than half (56.5%) stated that it reduces stress level of the parent, 9.2% found respite care reduces the stress level of the child or youth and 6.9% said it reduces the stress level of siblings. Additionally, 5.4% identified multiple benefits to respite. One parent



commented: “I personally bless our respite provider. She takes our child when she is stressing and causing major disruptions in our family. The stress level is greatly reduced in our family and we can function like a normal family without treading on glass.” Another simply stated, “It’s a godsend.”

“If my child and my family had more help in our home my daughter wouldn’t have to be at a residential school over an hour away.”

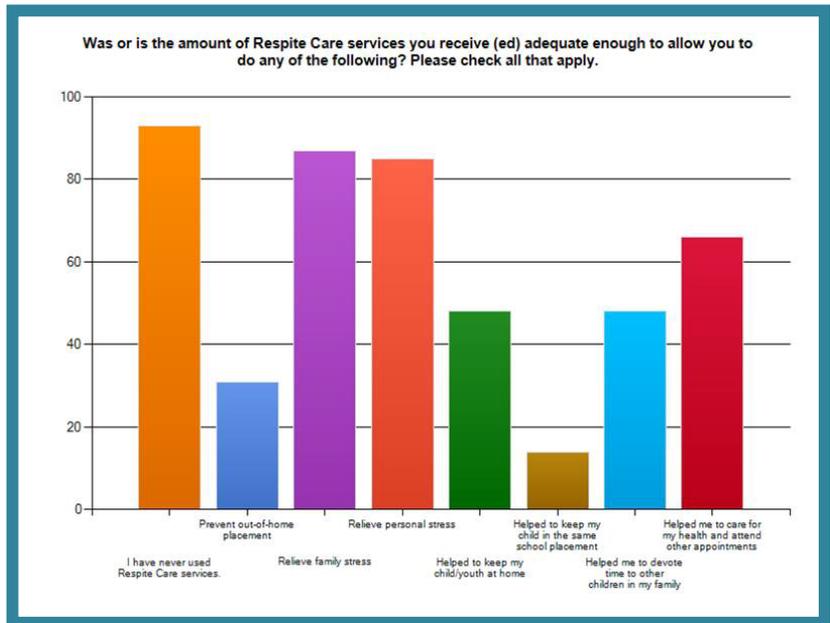
Nearly one in five parents said that respite care reduces out of home placements and 22.4% of parents who identified their children as the most serious reported that respite reduced out of home placements. One mother said, “If my child and my family had more help in our home, my daughter wouldn’t have to be at a residential school over an

hour away.” Parents who said their child was very serious were also more likely to say respite care reduced the stress level of the siblings. One said, “I have the ability to manage my son, but it is at the expense of my other two children.” Additionally, 5.2% said it reduced their isolation.

Parents who had received respite care reported multiple benefits: relieved family stress (41%); relieved personal stress (40.1%); helped them care for their health and go to other appointments (31%); and helped parents free up time to give to their other children (22.6%). Parents also said that it had helped keep their child at home (22.6%), prevented out of home placement (14.6%), and 6.6% said it had helped keep their child in the same school placement. One mother wrote, “I use it to ensure we can all deal effectively with each other to manage everyone's needs and keep all of the children in the home.”

Although parents greatly value respite care, they often face barriers in accessing these services, such as lack of knowledge, lack of providers, costs that are too high, finding someone with adequate skills and finding care nearby. When asked to identify the greatest barriers, the largest group (64.3%) reported that they couldn’t find anyone to provide respite care. One parent reported, “Because our son requires a highly structured

environment, it is not possible to just ask a friend to help.” Another 26.6% said that the respite provider they found did not have adequate skills.



More than half (51.9%) said respite care was too expensive. “For children with serious issues who are not involved with a state agency, respite care is affordable only to the very rich or the very poor. Sadly, families with mental health issues are already under tremendous financial pressure,” one parent wrote. Another pointed out, “Good quality respite care is difficult to find and fund. Most of us can’t access it and everyone pays in the long run with more hospitalizations.”

Almost one out of five parents (17.5%) said the location of the care was too far from their home. One said, “They should not put more burdens on the family to get the child there and back during commuting hours miles away.” Another said, “We were offered respite care, but often during the week in a city 40 minutes away from home. This was very impractical and would have caused more stress.”

Family members, agency staff and choosing locations

Parents’ preference for who provides respite indicates a variety of options are needed to meet the needs of the child and the family. The largest group (65.8%) said that family members such as grandparents or aunts and uncles were their primary choice. This was closely followed (63.2%) by the selection of staff trained in behavioral management. Nearly half (49.2%) said a program with multiple staff would be a good match for their child, while 44% chose close friends and 27.1% said they preferred staff trained to administer medications. One parent said, “Respite should look different for each kid. Right now, I want to get my kid out of institutional care and in the care of loved ones.” When parents identified their child as very serious, they were more likely to choose a program with multiple staff (67.7%) or staff trained in behavioral management (63.5%) while families whose children were identified as somewhat serious or improving were more evenly split. In the post-survey focus group, the majority of parents reported the desire to have respite care provided by an individual rather than an offsite institution. However, they stressed the importance of planning for the individual rather than the “one size fits all” approach.

While some parents stated that “the only people I would ever use for respite care are family,” others noted the benefits their child had received by receiving respite in a setting with other children or teens. One said, “Respite allowed my children access to other children and socialize on weekends with peers when they are not in school.” Another pointed out, “It was invaluable in helping my son develop much needed relationships especially with male role models.” Some also spoke of how family and friends tire and also need a respite from having to help.

“Timing is important. We were offered respite care, but often during the week in a city 40 minutes away from home. This was impractical and would have just caused more stress for a working family.”

In a 2010 study of respite provided by a weekend camp, parents noted several benefits associated with using a specialized respite environment, such as a camp. First, they knew best how to care for and manage their children. Thus, it was important that parents could feel that their child would be safe while at camp and in an environment that was better suited to the campers than what they might receive from basic neighborhood babysitting. Because the camp was adapted to meet the disabilities of the children, had trained counselors, and employed good supervisory staff, parents felt that they could relax and recharge while their child was at camp. (Shelton, Duerden and Witt, 2010)

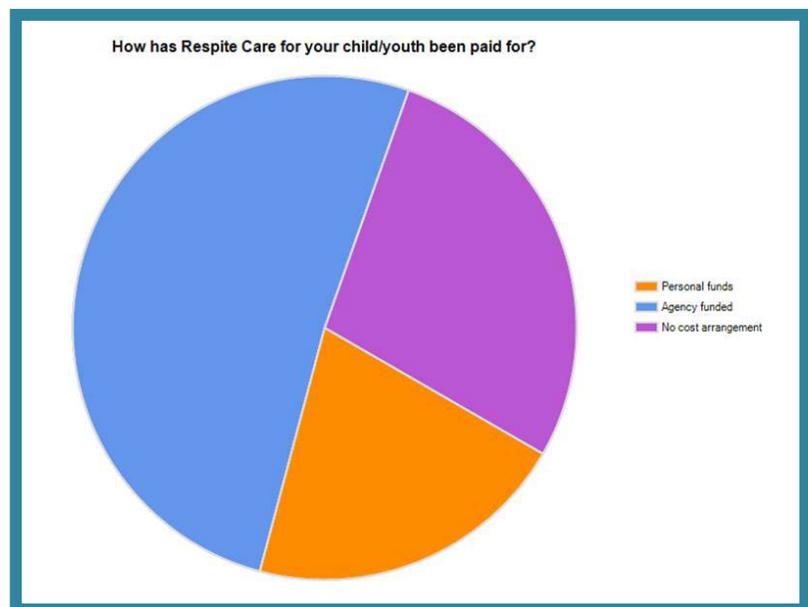
Other families may reject respite services when they don't trust the agencies and/or providers, or because of their own feelings of guilt or worry. One said that it was important to have the choice to use providers they already knew and had worked with. Another wanted the respite provided in her home as her son "has extreme difficulty being away from the house." One parent thought that there should be "training provided for respite care providers, supervision, and accountability for services rendered so I know my child is safe without worry. It is difficult to accept random respite and relax. I need to trust the place and the providers."

Funding and family financial burden

Parents financed respite in multiple ways including a mix of no cost arrangements, personal funds or agency funding. Almost one-quarter (23.7%) paid for it out of personal funds, 58.4% used state agency funds, and 31.8% used unpaid care, usually through a relative or friend. While respite care costs less than many other services that can be provided to a child with mental health needs, its cost still impacts the family finances. In paying for it, families are attesting to its value. Respite care is seen as providing benefits to all members of the family including parents, siblings and the child with mental health needs.

A 2009 study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on those caring for family members. The study found that six in ten caregivers are workers and during this economic

downturn 50% of them are less comfortable with taking time off from work to care for a



family member or friend. Respite care is seen as vital to managing stress and maintaining caregiver employment. As one parent reported, “I have had to quit my job because using regular babysitters has led to inadequate supervision and dangerous situations.”

How much is enough?

Parents reported that the amount of respite care they needed ranged from three to four times a week to once a month. One-third (32.7%) said that respite services one to two times per week was the right amount of care. Another 30.0% said that receiving respite care one to two times per month was the right amount, 10.6% said they desired respite care three to four times per week, and 26.7% said they preferred respite care to be used intermittently. Interestingly, 40.9% of the parents of children identified as very serious said that 1 – 2 times per week was the right amount of care.

When asked how often they had actually received respite care, the majority (39.2%) reported that it had been delivered intermittently, 30% reported that they had received it once or twice a month, 27.5% had received it one to two times per week and 3.4% had received it three or four times a week.

When asked when they would prefer to access respite care (multiple responses possible), 57.7% said when needed, 51.5% said on the weekends, 21.8% said overnight, and 20.5% said during the week.

One family's story

Jaylee is a 10 year old girl who first presented for MA-DMH services while she was in a CBAT (Community-Based Acute Treatment) placement. She had several prior inpatient hospitalizations. Jaylee's mother, Denise, was dealing with serious health issues and there were marital challenges at the time DMH opened Jaylee's case. Consequently, Denise was mostly on her own, parenting Jaylee and her three other siblings, trying to keep up with her job responsibilities and attending to her own health issues. Jaylee had significant separation anxiety, mood disorder and would tantrum for hours at home, often requiring crisis intervention. She targeted both her mom and younger sibling during these outbursts.

Denise had medical appointments and was also interested in seeing her own therapist. While she had some family who could assist, she was concerned about the drain this was on them as they had their own families and jobs. Jaylee's siblings began acting out and resented all the attention she was getting. All of the children struggled with their feelings related to their mom's diagnosis and surgery. It was an extremely stressful time, and Denise was finding it difficult to manage all of the challenges, despite support from her extended family.

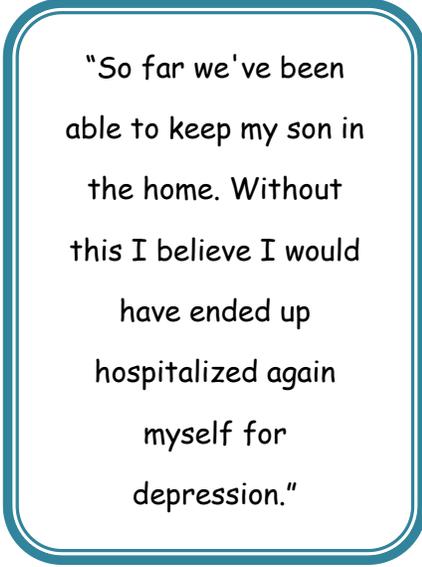
Several providers and relatives of Denise recommended short term residential services for Jaylee as her behaviors were too much to handle at home, with all of the other family challenges. But Denise did not want her daughter placed and was looking for help to maintain Jaylee at home and ease the stress on her other children and herself.

In addition to providing Jaylee with behavioral health interventions such as the Therapeutic After School Program and Youth Mentoring, DMH utilized 1:1 in-home respite one afternoon a week to allow Denise to attend her medical appointments. A second respite worker engaged with the siblings by working on art projects and taking turns spending 1:1 time with each sibling. These respite services allowed Denise to have the time she needed to go to her own appointments and devote uninterrupted time with each of her children. The siblings also benefited from their own one-on-one time with the respite worker, They looked forward to a fun activity that allowed them to feel special, increasing their self-worth and having a good time as a family in their home. Without this service, Jaylee could have been placed in a residential program to avoid repeated crisis interventions and inpatient stays. Providing this family with some concrete relief in the form of ‘respite’ was a key intervention in the successful package of resources provided to support Jaylee and her family.

Discussion

Parents of children with mental health needs experience greater and more varied types of stress associated with their parenting responsibilities as compared to other parents. Yet, it can be difficult for these parents to get a break from their caregiving responsibilities. Their children need trusted caregivers who have particular sensitivity to and knowledge of the child’s mental health condition and its effect on his/her behavior and relationships. Caregivers also need specific skills to appropriately respond to these behaviors, which may include knowing how to safely administer medications. Hiring sitters and relying on family members as other families do is often not an option for parents of children with mental health needs.

The findings of this survey indicate that the need for appropriate and affordable respite care is high, yet access is limited and current utilization among respondents is low. Many parents reported that they did not know that respite was a service available to them or how to access it. Although parents overwhelmingly reported the value of respite care in relieving family stress and reducing the need for out-of-home placements for their child, they reported a number of factors that contribute to limiting access to these much needed services. Multiple types of respite care are needed in a community to meet the



"So far we've been able to keep my son in the home. Without this I believe I would have ended up hospitalized again myself for depression."

range of needs identified by families, yet the respite services available in the community may not match their needs. The setting, the experience of the respite provider and frequency of service must match the age and seriousness of the child's needs. The location of the services is also important. As one mother wrote, "It was too far away and not at all a restful experience." Nearly two-thirds of parents preferred using family members, such as grandparents, aunts, and uncles to care for their child. Ultimately, the parent must feel that the respite provider understands their child and that they can trust the provider to keep their child safe.

The degree to which families need respite care varies from three to four times a week to once a month. However, the majority of parents reported needing respite from between one to two times per week to one to two times per month. Not surprisingly, parents of children with more serious mental health needs more frequently reported needing respite one to two times per week.

Funding for respite services is often out of reach for many families, particularly for those whose children have moderate mental health needs or do not receive other types of public services. To best meet the needs of families, policies that support payment for

"It's the single most important service that we receive."

respite care from both informal (e.g., family members) and formal providers (trained agency staff) are needed. The Oklahoma Lifespan Respite Program provides one model for achieving this. All family caregivers are provided with vouchers every three months to pay for respite. The parent negotiates the rates (often lower than the state agency pays) and selects the provider who can be known to them or selected from a directory. They are allowed to hire someone they trust and control the amount the provider is paid. Nearly 100% of the parents/caregivers are very satisfied, partly because they are recognized as the expert and person who knows what is best for their loved one (Cernoch, 2004).

Nearly one in five respondents to this survey felt that respite services reduce out-of-home placement of the child. This finding is consistent with a study of Vermont's respite care program for families with children and youth with serious emotional disturbance which found that participating families experience fewer out-of-home placements than nonusers and were more optimistic about their future capabilities to take care of their children. (Bruns, Eric, November 15, 1999).

The potential for cost savings associated with providing respite is high, particularly for those youth with serious mental health needs. A comparison of the cost of respite and out-of-home residential services in Massachusetts suggests that providing respite services to caregivers of children with significant mental health needs may produce significant cost savings as compared to an out-of-home placement:

Respite Service: \$3,000/3 months

(\$25/hour*, 10 hrs/week**)

Out-Of-Home: \$29,000/3 months***

(Group home residential service)

- * The hourly rate is a 2013 estimated average cost of trained agency staff providing in-home respite to a DMH consumer; actual hourly rates vary, depending on the level of supervision and training provided, and degree to which the respite service is part of a coordinated continuum of services.
- ** 10 hours per week is a reasonable benchmark, given that nearly 41% of parents of children with very serious mental health needs indicated the 1 – 2 times per week was the right amount of respite care; and more than half (51.7%) prefer week-end respite.
- ***Based on 2013 per diem rate for DMH residential group home services with intensive clinical supports.

While a comparison of the costs of respite and out-of-home services indicate that substantial savings are possible when providing respite to families of youth with the most serious mental health conditions who may be at risk of out-of-home placement, access to respite services for families of youth with moderate and mild mental health needs also lead to improved child and family outcomes across multiple life domains.

As one parent said, “Good quality respite care is too difficult to find and fund. Thus most of us can’t access it and everyone pays in the long run with more hospitalizations and exacerbations of stress and problems with siblings.”

Recommendations

The findings of this survey indicate that respite care is an important element in the array of services and supports utilized by Massachusetts youth with mental health needs and their families. The experience of parents participating in this survey suggests the following policy recommendations:

- Develop public policies that recognize the multiple benefits of respite services to families of youth with mental health conditions. These include both short and long-term positive impacts on parent, child, and sibling physical and mental health, the social costs of avoidable out-of-home placements, and improved quality of life for families.

- Equally important are policies that recognize that a ‘one size fits all’ approach to providing respite to meet the needs of families and children is insufficient. Funding of respite care that supports a variety of respite care models, including informal respite arrangements, is needed to best meet the needs of families of youth with a range of mental health needs.
- Policies often limit or prioritize access to respite care services to families of youth with the most serious mental health needs. However, respite services can prevent the escalation of a youth’s mental health needs and the need for more intensive services, including both out-of-home and intensive community-based services. It is recommended that eligibility criteria recognize respite services as a prevention strategy for those youth with less severe mental health conditions.
- Disseminate information about respite care to families and caregivers of children at risk for or living with mental health needs, including what respite care is, how to access it, sources of funding, and how to develop informal sources of respite care. Community-based providers are encouraged to work with families to identify how informal respite care can be provided through natural supports. Primary care providers are also encouraged to address respite needs with parents and caregivers.
- Develop policies that allow flexibility in choice of respite providers, both formal and informal, and promote the development and training of an accessible and skilled respite workforce.

Bibliography

ARCH National Resource Center for Respite and Crisis Care Services. (1996) Bringing Respite to Your Community: A start-up manual. Chapel Hill, NC: Chapel Hill Training-Outreach Project.

Brennan E. M., Poertner J. Balancing the Responsibilities of Work and Family Life: Results of the Family Caregiver Survey. Journal of Emotional and Behavioral Disorders Winter 1997 vol. 5 no. 4 239-249

CAHMI. 2005/2006 National Survey of Children with Special Health Care Needs; Children and Adolescent Health Care Measurement Institute; 2007

Cernoch, J. M. (1994). Respite for Children with Disabilities and Chronic or Terminal Illnesses: (ARCH Factsheet Number 2) [Electronic Version]. Chapel Hill, NC: ARCH National Resource Center for Respite and Crisis Care Services, Chapel Hill Training-Outreach Project.

Delinger-Wray M. & Uhl M.(1996). A practical guide to respite for your family. Richmond, VA: The Respite Resource Project, Virginia Institute for Developmental Disabilities, Virginia Commonwealth University.

"Disability Rights Section" updated August 12, 2004. U.S. Department of Justice, Civil Rights Division: <http://www.usdoj.gov/crt/drs/drshome.htm>

"Emergency Information Form for Children With Special Health Care Needs" The American College of Emergency Physicians and the American Academy of Pediatrics (Policy #400267, Approved October 2002)

The State of the States in Family Caregiver Support: 50-State Study; Family Caregiver Institute; 2004.

Kniest, B.A. & Garland, C.W. (1991). PARTNERS: A manual for family centered Respite care. Lightfoot, VA: Child Development Resources.

McKune, SL. Caregiving: A National Profile and Assessment of Caregiver Services and Needs; 2007.

Miller, Scott (1992). Respite Care for Children with Developmental and/or Physical Disabilities: A Parents Perspective (ARCH Factsheet Number 4) [Electronic Version].Chapel Hill, NC:ARCH

National Resource Center for Respite and Crisis Care Services, Chapel Hill Training-Outreach Project. National Family Caregivers Association, <http://nfacacares.org/survey.html>, April 30, 2000.

National Information Center for Children and Youth with Disabilities. (1996). NICHCY briefing paper: Respite care. Washington, DC; www.destinyresidential.com

Parent/Professional Advocacy League. (2010) Overcoming Barriers in our Community: How are we doing? [http:// www.ppal.net](http://www.ppal.net)

Percival, Oklahoma Respite Resource Network, 2005.

Rosenzweig, J. M., Brennan, E. M., & Ogilvie, A. M. (2002). Work-family fit: Voices of parents of children with emotional and behavioral disorders. *Social Work, 47*(4), 415-424. doi:10.1093/sw/47.4.415

Rosenzweig, J. M., & Brennan, E. M. (2008). Work, life, and the mental health system of care: A guide for professionals supporting families of children with emotional or behavioral disorders. Baltimore: Paul H. Brookes.

Shelton, K., Duerden, M. D., & Witt, P., Therapeutic Camps as Respite Care Providers: benefits for Families of Children with Disabilities, American Camp Association, October 22, 2010

Wade, C., Kirk, R., Edgar, M., & Baker, L. (2003). Outcome Evaluation: Phase II Results. Chapel Hill, NC: ARCH National Resource Center for Respite and Crisis Care