

Respite and Children's Behavioral Health: Families' Needs and Policy Considerations

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Introductions - Who We Are

- Parent/Professional Advocacy League (PPAL) is a statewide family organization that serves as the leading public voice in Massachusetts for families whose children have emotional, behavioral and mental health needs.
- MA Department of Mental Health (MA-DMH), 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.

Outline of Presentation

- PPAL-DMH Respite survey
- Policy recommendations
- Opportunities for interagency collaboration
- Discussion

Definition of Respite

(MA Department of Mental Health Child/Adolescent Services)

Respite is brief or short-term care of a child or youth with Serious Emotional Disturbance (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.

Why Focus on Respite?

- Respite is one of most frequently requested services by parents/caregivers of youth with behavioral health needs, yet presents unique policy challenges
 - Establishing eligibility criteria: who gets it/who doesn't, how long to fund it, when is it 'enough'

Common misperception:
"Why should we pay for respite - isn't it just babysitting?"

Why is Respite Important?

- All families experience stress from financial pressures, balancing work and family, and other responsibilities
- Parents of children with mental health needs have exceptional caregiving demands and often report that their stress is particularly acute and intense



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

Why is Respite Important?

- Parents of children/youth with mental health needs :
 - Are both caregivers and case managers
 - Often struggle to meet the needs of their child, other family members, and themselves
- Other challenges: stigma, self-doubt and blame, financial burden, sibling rivalry, marital stress, and difficulty accessing services (Commonwealth Institute, 1999)

Our Goals

1. Understand families' needs and how families can benefit from respite services
2. Identify key policy considerations to improve access to and availability of respite services
3. Identify opportunities for interagency collaboration to improve access to and availability of respite services

Goal 1: Understanding Families' Respite Needs

- Who uses respite services
- What kind of respite services are used
- Where and when are respite services needed
- How much respite do families need
- How are respite services funded
- How does respite help families
- What are the barriers/challenges to getting respite services

PPAL/DMH Respite Study

- Summer 2012: Electronic (Survey Monkey) and paper survey distributed through PPAL family network: social media, support groups, targeted focus groups
- Respondents: 280 parents of youth with behavioral/mental health needs in MA
- “Respite Care: What Families Say”; Fauntleroy, Fluet, Lambert; 2012. Available at www.ppal.net

Who Responded?

- Age of Child: 89% between 7 and 19
- Language at Home: English 98.2%
- Special Needs of Child: 87.5% with mental health needs
- Seriousness of Child's Needs: 71.4% very serious or somewhat serious
- Received mental health services: 73%
- Insurance: 30.3% private; 44.2% Medicaid, 25.5% combination

Finding: High need, low utilization

Few families were currently accessing respite care:

- 17.6% currently using respite services
- 44.6% currently not using but have used it in the past
- 37.8% have never used respite services

Finding: Respite provides important benefits

Parents who had received respite care reported that it:

- relieved family stress - 41%
- relieved personal stress - 40.1%
- helped them care for their own health and go to other appointments. - 31.1%
- helped free up time to give to their other children - 22.6%
- helped keep their child at home - 22.6%
- prevented out of home placement - 14.6%
- helped keep their child in the same school placement – 6.6%

"It's a godsend ..."

Finding: A little respite goes a long way

Most parents desired respite care twice a week or less

- 30.0% said that one to two times per month was the right amount
- 32.7% said that respite services one to two times per week 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

Finding: A variety of options are needed

Parent preferences for respite providers:

- family members, e.g., grandparents, aunts, uncles - 65.8%
- staff trained in behavioral management - 63.2%
- program with multiple staff - 49.2%
- close friends - 44%
- staff trained to administer medications - 27.1%
- Parents who identified their child as very serious reported that they prefer a program with multiple staff (67.7%) or staff trained in behavioral management (63.5%)

"It is difficult to accept random respite and relax. I need to trust the place and the providers."

"Because our son requires a highly structured environment, it is not possible to just ask a friend to help."

Finding: Many parents face barriers to accessing respite care

- can't find appropriate provider – 64.3%
- respite provider did not have adequate staff – 66.6%

66.6%

expensive – 51.9%

location of the care was too far from their home – 17.5%

17.5%

"I think there should be training provided for respite care providers, supervision, and accountability for services rendered so I know my child is safe without worry."

"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."

Finding: Benefits aren't just to families

Comparison of costs of respite and out-of-home residential services in MA suggests that providing respite services to caregivers of children with significant mental health needs can result in substantial cost savings:

- \$3,000 for 3 months respite care
- \$29,000 for 3 months out of home placement

"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."

One Mother's Story

Lisa M: “Life was tough - my sister died suddenly 4 weeks after childbirth so her husband, their older child and newborn moved in with us; I was working 3 nights a week at a job with no benefits; it was getting harder and harder for my husband to handle my daughter’s behaviors; and my mother told me she couldn’t babysit anymore because she couldn’t handle my daughter’s aggressive behaviors either. Then I was diagnosed with breast cancer.....”





“When things started to fall apart, the hospital and other service providers suggested that my daughter go to a residential program. But I wanted her at home with us....”

“Ourspite was provided ser
by two lovely young mal’ life, b
college students for 3
received she’s come so far,
hours on Tuesday
happy life .
afternoons. It got so that I
couldn’t wait for Tuesdays
because I knew that I
would get a break and my
children would have fun at
least once a week I
could go to my medical
appointments, and
sometimes I would just sit
in my car with a cup of
coffee and think.”



Goal 2: Policy Considerations

- Identify key policy considerations to improve access to and availability of respite:
 - service design
 - funding
 - workforce development
 - training

Policy Recommendations

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

Policy Recommendations

- Develop policies that recognize that a variety of respite care models (planned and unplanned/crisis; formal/informal; in-home/facility-based) are needed to best meet the needs of families of youth with a range of mental health needs
 - ‘One size fits all’ approach is insufficient
 - Establish funding mechanisms that support a variety of respite care models
 - Allow flexibility in choice of respite providers, both formal and informal

Policy Recommendations

- Consider eligibility criteria that recognize respite services as a prevention strategy for those youth with less severe mental health conditions
- Promote the development and training of a skilled and accessible respite workforce

Policy Recommendations

- Develop and disseminate information about respite services to families and caregivers of children at risk for or living with mental health needs, including:
 - what respite services are
 - how to access them
 - sources of funding
 - how to develop informal sources of respite

Policy Recommendations

- Encourage community-based providers to work with families to identify how informal respite services can be provided through natural supports
- Encourage primary care providers and pediatricians to discuss respite needs with parents and caregivers and provide information about local respite resources

Goal 3: Opportunities for interagency collaboration

- Opportunities relate to:
 - Funding
 - Training
 - Workforce development
 - Education/awareness
- DMH-PPAL/MA Lifespan Respite Coalition collaboration

For Discussion

1. What criteria are used to determine eligibility for respite services?
 - Preventive respite, e.g., preventing need for more intensive services, such as for youth with less intensive behavioral health needs
 - Maintenance respite, e.g., youth stable in home with respite but without would require out-of-home placement
 - Acute need respite, e.g., crisis situation; family emergency; transition from residential to home
2. Workforce development:
 - Can respite providers be trained to serve individuals with a variety of needs (e.g., children with behavioral health needs, individuals with complex medical needs, elders, etc.)?
 - Recruiting: what are effective models (e.g., Central MA Respite Project)?

For Discussion

3. Training:

- For informal and formal providers
- Mandatory or voluntary
- List of expectations/accountability: safety, payment, CORI, medication certification, knowledge of behavior management techniques, etc

4. Is it feasible to develop and maintain a directory of qualified respite providers? If so,

- What information is important to include
- Who would do this (state, provider agency, 211)

For Discussion

5. Interagency collaboration:

- How can we work together to support caregivers of youth with behavioral health needs (e.g., DMH, DCF, DDS, DYS)?
- How can we work together to support caregivers across the lifespan?
- How can we leverage dollars across public agencies to support these efforts (e.g., DMH, DCF, DDS)?

THANK YOU!