



Supporting Military Families Through
Research and Outreach

Respite Care for Families with Special Needs

September, 2014

Developed in collaboration with the Department of Defense's Office of Family Policy, the National Institute of Food and Agriculture, and the U.S. Department of Agriculture under The University of Minnesota Award No. 2013-48710-21515.

Submitted by:

The Military REACH Team
The Research and Outreach (REACH) Laboratory
The University of Minnesota

The University of Minnesota

Lynne M. Borden, PhD (PI)
Octavia Cheatom, BS
Kyle R. Hawkey, MEd
Michelle Wittcoff Kuhl, PhD
Michelle D. Sherman, PhD
Lara Westerhof, BS

For additional information, please contact:

Lynne M. Borden, PhD
Department of Family Social Science
The University of Minnesota
lborden@umn.edu
(612) 625-4227



Contents

Respite Care for Families with Special Needs 1

Definition and Purpose of Respite Care 1

Research Findings 2

Utilization of Respite Care 2

Rationale for and Benefits of Respite Care 3

 Caregiver 3

 Health and physical 3

 Financial 3

 Familial relationships 4

 Marital relationships 4

 Child 4

 Broader community 5

Amount of Respite Care Needed to Achieve Benefits 5

Need and Accessibility of Respite Care among Military Families 5

Availability and Accessibility of Civilian-Based Respite Care Services in States with a Significant Military Population 6

 General accessibility and potential barriers to use 6

 Survey: Accessibility of respite services by state 6

Future Directions for the Field 8

Summary 8

Additional Resources 9

References 10

Appendix A: Interview Phone Script 1

Appendix B: State Respite Care Data 1

Respite Care for Families with Special Needs

Approximately four million Americans have an intellectual disability, developmental disability, or chronic illness (U.S. Department of Health and Human Services' Administration for Community Living, n.d.). Among children ages 0-18 with intellectual disabilities, developmental disabilities, or chronic illnesses, 84% live with parents rather than in a facility or group home setting (NAC, National Alliance for Caregiving, and AARP, American Association for Retired Persons, 2009). Given that the primary caregivers are families, this often include parents, grandparents, or other family member caregivers. Despite familial connections, many caregivers become overwhelmed by the responsibilities of their demanding role, which can result in a reduction in the quality of care provided to their loved ones.

In 1986, Congress enacted legislation for states to provide temporary, non-medical child care (respite) services for families of children with disabling conditions or chronic illnesses (Shelton, 1987). Respite care, which is further defined in the following section, can provide temporary relief so that caregivers have time to perform everyday duties and tasks. These tasks may include chores, errands, self-care, and opportunities to socialize or work outside the home (Morris, 2012). Within the context of this brief the terms 'carer' or 'caregiver' are used synonymously to refer to anyone that may act as the guardian of a child or children with special needs.

To date, the Department of Defense's Office of Special Needs has not included respite care for military family members with special needs as a policy mandate. However, military families with special needs have cited respite care as one of the most important benefits of Exceptional Family Member Program (EFMP) enrollment (Benchmark Study, 2013; Military Family Needs Assessment, 2010). Thus, careful examination of the benefits of these services, as well as the availability and accessibility of respite care in the civilian sector in military-impacted communities, is important.

Definition and Purpose of Respite Care

Respite care is commonly defined as temporary relief care designed for families of children or adults with special needs (Department of Human Services, n.d.). Respite care services can range from a few hours of care provided on a one-time basis to overnight or even extended care sessions. Services can be utilized on a regular or irregular basis, and may be provided by family members, friends, skilled care providers, or professionals.

Generally, respite care includes three broad categories of services: (1) home-based respite care; (2) day-center based care; and (3) out-of-home respite care (Neufeld, Query, & Drummond, 2001). Each type of respite service (see Table 1) has unique advantages and disadvantages. The needs of the child, family, and caregiver must be considered when determining the type of care that will best suit the family. Level of need often changes over time, so families may use a range of respite care services depending on the situation and specific needs.

Respite care is commonly defined as temporary relief care designed for families of children or adults with special needs.

Table 1. Types of Respite Care

Type of Respite Care	Description of this Type of Care
Home-based respite care	Allows an alternate caregiver to provide respite services in the home.
Day-center based care	Provides respite care services outside of the home during the day, but the child returns home at night.
Out-of-home respite care	Utilizes host families, residential care homes, camps, hospitals, and long-term care institutions to provide respite services.

Research Findings

Utilization of Respite Care

Research has identified numerous characteristics of both children and caregivers that relate to utilization of respite care services. Each family’s situation is unique and dynamic, but these findings reflect issues that appear to increase respite care utilization.

Regarding the child, factors associated with increased use of respite care include: severity of the child’s disability; level of care that the child requires; presence of challenging behaviors; age of the child (school age children are more likely to use respite care than other ages); and the child’s degree of communication impairment (Chadwick et al., 2002; Chan & Sigafos, 2000). Specific behaviors among youth with special needs that may make respite care services especially helpful include: displays of severe and/or frequent aggression; extreme tantrums; self-injury; property destruction; overactivity; and sleep disturbance (Chan & Sigafos, 2000). All of these behaviors can be taxing on caregivers and extended family, and may increase their need for additional external assistance.

The family/caregiver characteristics that influence the use of respite care are: level of family stress; accessibility of informal support networks; and the number of children (with disabilities or otherwise) under the guardianship of the caregiver (Chan & Sigafos, 2000). Overall, researchers have concluded that respite care use is indicative of psychological distress among carers (Hoare et al., 2002). One factor that was not found to be indicative of caregiver stress was socioeconomic status (Chadwick et al., 2002; Hoare et al., 2002). According to researchers, provision of respite services does not differ significantly across income levels (Wheery, Sherma, & Kelleher, 1995). However, a survey of 3,178 caregivers of children with special healthcare needs (CSHN) found that families whose respite services were covered through a private insurance agency were 50% less likely to report unmet respite care needs in comparison to caregivers using public insurance (Nageswaran, 2009).

The need for respite care is greater during certain times of the year; for example, respite care is elevated in the summer when public schools are closed (Abelson, 1999). During the summer months, caregivers may become more overwhelmed because they have to increase the amount of care that is provided. Overall, when determining the amount of respite care needed, the parent’s personal level of need as well as the child’s physical care needs should be considered (Herman & Marcenko, 1997).

Research has examined characteristics of carers who do not use respite services for their children; these caregivers tend to be more optimistic about their ability to cope with caregiving stresses (Hoare et al., 2002) and experience higher levels of social support (Factor, Perry & Freeman, 1990). It is possible that

caregivers with strong supportive relationships from family and friends receive sufficient relief from their duties, thereby obviating the need for formal respite services.

Rationale for and Benefits of Respite Care

Respite care is not a luxury (Abelson, 1999). Instead, respite care is a system that helps to improve the quality of life of the caregiver, improves the quality of care that the child receives, and positively impacts the broader community.

Caregiver. Caring for a child with special needs can be both difficult and time consuming. On average, caregivers of children with special needs spend 29.7 hours per week providing care, and one in four caregivers provide care for at least 41 hours a week (NAC and AARP, 2010). Dedicating this large amount of time to caregiving can take a toll on the caregiver, child, and broader family relationships. Use of respite care may help to minimize the likelihood of caregiver burnout, ensure that the child is getting the care that they need, afford the caregiver greater opportunities to sustain employment and other personal activities, and prevent the need for long-term institutional care (Cowen & Reed, 2002; Neufeld, Query, & Drummond, 2001).

Respite care is a system that helps to improve the quality of life of the caregiver, improves the quality of care that the child receives, and positively impacts the broader community.

Caregiving for a child with special needs can impact a caregivers' physical health, financial wellbeing, relationship with the child and other family relationships, and intimate relationships.

Health and physical. A study of caregivers of children with special needs found that 64% experienced physical strain. Only 40% of these caregivers considered their health to be excellent or very good, with over a quarter of the sample believing that their health was either poor or fair (NAC and AARP, 2009). In addition, caregivers of children with special healthcare needs have greater increases in depressive symptoms over time compared to parents of children without special healthcare needs (Smith & Grzywacz, 2014). These findings may suggest that caregivers may not be getting adequate time for self-care and attending to their own wellness. Respite services may allow the caregiver to engage in health-promoting activities on a regular basis, including keeping appointments with healthcare providers, engaging in physical exercise, and spending time with supportive people.

Financial. Caring for children with disabilities can also impact caregivers financially. In comparison to typically developing children, children with disabilities have been found to be 3.5 times more likely to reside with caregivers with high levels of both financial and psychological stress (Goudie et al., 2014). One study found male caregivers to be more likely to have financial troubles than female caregivers (NAC and AARP, 2009). In addition, carers who provide care for disabled children are more likely to experience financial strain and to seek financial assistance than those caring for adults with special needs (NAC and AARP, 2009). One reason why caregivers of children with disabilities may be more likely to experience financial hardship is because they are more likely to refuse employment opportunities and miss pertinent work hours due to their responsibilities as a carer (Abelson, 1999). According to Morris (2012), caregiver mothers with young children reported that working outside of the home caused more stress than staying home with their child. These mothers reported that their increase in anxiety and depression was due to the fear of leaving their children in the care of others. However, the same study found that as children get older mothers find relief from caregiver duties by working outside of the home (Morris, 2012), ultimately increasing the need for respite services over time.

Familial relationships. In a survey of 173 caregivers caring for children under the age of 18, more than half (60%) reported that caregiving limits the amount of time they spend with family and friends (NAC and AARP, 2009). In many families, children with disabilities have siblings without disabilities. Due to the demands of providing care for the child with disabilities, parents often have little energy left for nondisabled siblings (Abelson, 1999). Fortunately, researchers have found that respite care utilization among caregivers is associated with reductions in stress and enhanced family coping (Abelson, 1999). Caregivers can devote the time, energy, and attention to both self-care and the other children while the child with the disability is using respite resources.

The relationship between the caregiver and child with a disability can also be challenging: managing sleep problems, disruptive/aggressive behavior, self-injury, and tantrums can place considerable strain on the relationship. Managing the child and maintaining a positive parent-child bond can be especially taxing when the caregiver is overwhelmed by stress. Research has identified caregiver life stress as a predictor of maltreatment and the development of dysfunctional parenting behaviors (Cowen & Reed, 2002). Early identification of parents who need or would benefit from respite care services may prevent the development of unhealthy parenting behaviors (Cowen & Reed, 2002), which may lead to abuse or neglect.

Marital relationships. Having a co-parent or partner in raising children with a disability can support the caregiver in several ways. Intimate partners can provide tremendous emotional, practical, and logistical help to the primary caregiver, decreasing the caregiver's stress and enhancing social support. The additional monetary income from the intimate partner can also buffer family stress and increase their ability to pay for expensive medical care (Herman & Marcenko, 1997).

However, along with the potential benefits that intimate partnerships can afford caregivers, coping with the significant stressors of caregiving can take a toll on close relationships. The caregiver often devotes tremendous time, resources, and emotional energy to the child, which can decrease their availability to their partners. Intimate partners can feel left out, neglected, and sometimes even resentful of the child with the disability. Frequency of marital conflicts may increase as the individual needs of intimate

Adding just one additional hour of respite care per week can improve marital quality and reduce feelings of marital distress among couples.

partners are neglected (Abelson, 1999). In addition, research has found that the responsibilities of caregiving have been associated with reductions in marital quality (Harper et al., 2013).

Fortunately, the relief offered by respite care can help. According to Harper et al. (2013), adding just one additional hour of respite care per week can improve marital quality and reduce feelings of marital distress among couples. The reduction in stress enables

parents to cope with caregiving stressors and leads to more adaptive family functioning.

In sum, although respite care is unique and benefits each caregiver in different ways (Strunk, 2010), research has found that respite care can positively influence caregiver role functioning (Cowen & Reed, 2002), physical health (NAC and AARP, 2000), finances (NAC and AARP, 2009; Abelson, 1999), familial relationships (Abelson, 1999), and marriages (Harper et al., 2013).

Child. Respite services offer several benefits to the health of children with special needs. Among a sample of 28,000 children and young adults (ages 5-21) with autism who were enrolled in Medicaid, every \$1,000 spent on respite services over the course of 60 days resulted in an 8% decline in the likelihood that the child or young adult was hospitalized for psychiatric issues (Mandell et al., 2012).

Another study found that children who were enrolled in a respite intervention program saw a 75% decrease in hospitalization, a 64% decrease in physician visits, and a 71% decrease in the use of antibiotics in comparison to the previous year (Mausner, 1995). It is likely that respite care affords caregivers time to engage in self-care and reduce personal stress levels, which can benefit both themselves and the care they provide to the child.

Socially, respite care can provide children opportunities to play and interact with their peers, ultimately increasing their social competence (Neufeld, Query, & Drummond, 2001). Children with disabilities often become lonely and socially isolated (Murphy & Carbone, 2008), so the opportunities to play with other children can be a tremendous benefit of respite care.

Broader community. Although respite care most directly influences the child and caregiver, there are also benefits of respite care for the broader community. Respite care can allow people with disabilities to receive additional education, to work, and to participate in recreational activities (Abelson, 1999), all of which enhances their integration with the community and further develops life skills.

Economically, services associated with supporting special needs youth living with their parents at home (including respite care) are less expensive than the costs of funding group homes and state hospitals, ultimately reducing the burden on taxpayers (Chadwick et al., 2002). Respite care services have been associated with decreasing the likelihood that children with disabilities become institutionalized (Neufeld, Query, & Drummond, 2001).

Amount of Respite Care Needed to Achieve Benefits

The currently existing research on respite care for young people and adults does not specifically address the requisite amount of services that will yield desired results for the family. The amount of respite care that is necessary to achieve desired outcomes depends on the unique situation of the family (including the severity of the child's disability, the needs of the caregiver, and the amount of caregiver stress), and changes over time.

Need and Accessibility of Respite Care among Military Families

Research focusing on military families has found that respite care would afford caregivers time for tasks such as attending medical and educational appointments (Benchmark Study, 2013) and free time with a spouse (Military Family Needs Assessment, 2010). In addition, primary caregivers expressed that respite services would provide additional support when a service member is deployed, help relieve stress, and provide opportunities for children to socialize and be included in the community (Benchmark Study, 2013).

Challenges associated with military-allocated respite services include: (1) non-equitable allocation of respite care; (2) lack of availability of adequately trained care providers; (3) waiting list constraints often associated with funding (Benchmark Study, 2013); and (4) cumbersome paperwork (Military Family Needs Assessment, 2010).

Availability and Accessibility of Civilian-Based Respite Care Services in States with a Significant Military Population

General accessibility and potential barriers to use. Although respite care can be extremely beneficial for caregivers of children with special needs, there are multiple barriers that limit the accessibility of these services for families. Barriers can relate to the individual program, inadequate publicity about services, and issues pertaining to the specific family.

At the programmatic level, barriers may include a lack of programs available within a close geographic proximity; cost; restrictive eligibility criteria; long waiting lists; poor accessibility (e.g., excessive application procedures); and a lack of available trained providers. When access to respite care is difficult or the interaction with staff is negative, use of respite care can actually increase caregiver stress (Herman & Marcenko, 1997).

Although respite care can be extremely beneficial for caregivers of children with special needs, there are multiple barriers that limit the accessibility of these services for families.

Although programs may exist in the family's region, poor publicity and outreach may prevent families from accessing much-needed services. Families may perceive respite services as crisis oriented, rather than planned and coordinated weekly services (Neufeld et al., 2001); families may not realize that they can utilize multiple types of services to suit their needs. Reaching out to families with a range of communication approaches is often necessary to inform them about the availability and potential usefulness of respite care. Communication directed to the service providers and community organizations is also important because they may be able to connect families with beneficial services.

Each family may have individual feelings and situations that deter them from seeking respite care services, including guilt/shame about feeling overwhelmed and asking for help, failure to self-identify themselves as a caregiver, and low trust in outside providers (National Respite Coalition (NCR), 2010). Many parents are apprehensive and need encouragement and validation to work on personal goals that have been set aside due to caregiving demands (Herman & Marcenko, 1997). Caregivers may be apprehensive about using respite services due to familial or cultural belief systems, guilt, loss of privacy, fear of separation, and concern about leaving the child with a stranger (Neufeld, Query, & Drummond, 2001). Thus, even if the services are available and families know about them, families may not utilize them due to internal barriers.

Survey: Accessibility of respite services by state. This request focused on examining availability and accessibility of respite care services in the civilian sector. Specific information about the following 11 heavily military-impacted states was requested: California, Colorado, Florida, Georgia, Kentucky, North Carolina, Oklahoma, South Carolina, Texas, Virginia, and Washington.

Based on consultation with national experts in disability research and with approval from the Office of Family Policy/Children and Youth/Special Needs, the Military REACH team contacted leaders in each state by telephone and/or email. At least four contacts were made with personnel from each state. Questions posed to the contacts can be found in Appendix A.

In each state, information was gathered from both the Department of Human Services (DHS) and the state chapter of the ARC Program (the largest national community-based organization serving people with intellectual and developmental disabilities and their families). Findings from this survey are summarized in Appendix B.

The response rate to this survey was 82% (9/11 states). Despite four separate contacts via phone and email, researchers did not receive data from Washington and Virginia.

Of the nine responses gathered, 100% reported that respite care is offered to military families. Regarding eligibility for respite services, 22% (2/9) of states surveyed reported that their state did not have a comprehensive respite application process due to a lack of availability of respite services and/or due to the underdevelopment of systematic processes. Almost all states expressed that there was some type of application process to determine respite eligibility. In addition, three states (33%) stated that families must become eligible through verification of disability status, Medicaid, or Supplemental Security Income (SSI), which would qualify them to be preapproved for respite services. If the family is looking to receive respite care and does not qualify for Medicaid or other services, then they are required adhere to the eligibility standards of individual programs and complete that program's application process.

The cost of respite services varies by state. Five of the nine states (56%) reported that the cost of respite services varies by income; among these five states, two states report that the family must not earn a certain percentage above the poverty line in order to qualify for respite services. In addition, four of the nine states (44%) said that eligible clients could receive respite services free through Medicaid, Oklahoma reported that respite services were free if the child received SSI, and South Carolina reported that respite services were free and completely funded through waivers, state funded dollars, or a grants. If the family is not receiving funding from SSI, Medicaid, or receiving a waiver/voucher, the cost of respite services varies based on the individual program or care provider.

Three of the nine (33%) states surveyed reported that there is no waiting list to receive respite services. On the other hand, two different respondents reported that clients could potentially be waitlisted up to ten years. The remaining four states (44%) reported that time on the waiting list varies based on the availability of respite services, availability of care providers, and/or the specific program. Over half (66% or 6/9) of states reported that their state suffers a deficit of care providers. Among these states, none of the respondents reported that the deficit of care providers was specifically in the geographic areas with large populations of military service members; rather, the deficit exists across the entire state. Three of the nine (33%) states (California, Oklahoma, and Texas) reported that their state has enough respite care providers to meet client needs.

All of the states surveyed reported that they offer care to military families.

In summary, all of the states surveyed reported that they offer respite service to military families. Most states offer programs that reduce or eliminate the costs of respite services for eligible families. However, considerable variability exists across states in regard to the availability of care providers, the costs of care, and the application process. Despite the differences across states, over half of states report that there are not enough care providers. Lack of care providers can be very problematic, especially if eligible families have to wait up to a decade to receive much needed services.

Future Directions for the Field

Based on the current state of respite care literature, and the survey results explained herein, several policy and programmatic recommendations are made.

1. Policies are needed that address securing quality respite care and improving accessibility to such services regardless of specific diagnosis, age, or geographic location.
2. On a programmatic level, respite care providers and funding agencies may want to increase their outreach to families with children with disabilities to help increase parental/career awareness of respite services.
3. Caregivers may be more likely to be reassured that their child is being cared for by a quality provider if family members and friends were trained and funded to be respite providers (Neufeld, Query, & Drummond, 2001). It may be beneficial if programs were created to train caregivers' family members and friends to provide respite care.

Summary

Respite care is not a luxury; instead, it is a service that facilitates the goal of incorporating those with disabilities in our communities to be educated, to work, and to recreate (Abelson, 1999). Research shows several benefits to receiving respite care for caregivers, the care recipient, and the broader community. With the help of respite services, caregivers see improvements in their health, finances, familial relationships, and marital relationships. In addition, respite programs also benefit the child by minimizing their hospital visits, improving the child's quality of the care, and improving their social lives. Overall, respite services benefit the broader community by minimizing the number of children that are institutionalized and allowing care recipients to become contributing members of society.

Despite the benefits of respite care, there are barriers that limit the accessibility of respite services, and some of these barriers appear to exist in states serving a large military population. According to our survey, a majority (56%) of respondents reported that their state suffered a deficit in respite care providers. This finding is problematic for caregivers in need of relief from day-to-day tasks or for those who need a care provider in order to work and sustain their family. Although the limited availability of respite care providers hinders families from obtaining services, all of the states surveyed reported that they offer care to military families; most have programs that help to reduce or even eliminate the cost of respite services for eligible families.

Respite care has the potential to positively impact the lives of caregivers and care recipients. Unfortunately, limited access to care providers may force carers to go without the help that they truly need, which could be detrimental to the quality of life for the child, caregiver, and broader family.

Additional Resources

Organization	Website
Child Welfare Information Gateway: Respite Care Services	https://www.childwelfare.gov/systemwide/service_array/respite/
ARCH National Respite Network & Resource Center	http://archrespite.org/
Children’s Respite Care Center	http://crccomaha.org/
Respite Child Care	http://respitechildcare.com/
Autism Speaks: Respite Care and Autism	http://www.autismspeaks.org/family-services/community-connections/respite-care-and-autism
ChildCare Aware of America: Exceptional Family Member Program (EMFP) Respite Care	http://www.naccrra.org/navy/exceptional-family-member-program-efmp-respite-care

References

- Abelson, A. G. (1999). Respite care needs of parents of children with developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 14(2), 96-100. DOI: 10.1177/108835769901400204
- Administration and Community Living. (2014). Data and Evaluations. United States Department of Health and Human Services. Retrieved August 19, 2014, from http://www.acl.gov/Data_Outcomes/Index.aspx#Data_and_Statistics
- Bronfenbrenner Center for Translational Research, Cornell University, Beach Center on Disability, & The University of Kansas. (2013). Department of Defense Exceptional Family Member Program Benchmark Study. http://www.militaryonesource.mil/12038/MOS/ResourceGuides/EFMP_Benchmark.pdf
- Chadwick, O., Beecham, J., Piroth, N., Benard, S., Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? *Child and Adolescent Mental Health*, 7(2), 66-72. DOI: 10.1111/1475-3588.00013
- Chan, J. B., & Sigafos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child and Youth Care Forum*, 29, 27-37. DOI: 10.1023/A:1009420206722
- Chan, J.B., & Sigafos, J. (2001) Does respite care reduce parental stress in families with developmentally delayed children? *Child and Youth Care Forum*, 30(5), 253-263.
- Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing*, 19(4), 272-283. DOI: 10.1046/j.1525-1446.2002.19407.x
- Department of Human Services. What is Respite Care? Retrieved August 19, 2014, from <https://dhs.sd.gov/dd/resp/whatis.aspx>
- Factor, D. C., Perry, A., & Freeman, N. (1990). Brief report: Stress, social support, and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders*, 20(1), 139-146. DOI: 10.1007/BF02206863
- Goudie, A., Narcisse, M. R., Hall, D. E., & Kuo, D. Z. (2014). Financial and psychological stressors associated with caring for children with disability. *Families, Systems, & Health*, 32(3), 280-290. DOI: [10.1037/fsh0000027](https://doi.org/10.1037/fsh0000027)
- Harper, A., Dyches, T. T., Harper, J., Roper, S. O., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(11), 2604-2616. DOI: 10.1007/s10803-013-1812-0
- Herman, S. E., & Marcenko, M. O. (1997). Perceptions of services and resources as mediators of depression among parents of children with developmental disabilities. *Mental Retardation*, 35(6), 458-467. DOI: [http://dx.doi.org/10.1352/0047-6765\(1997\)035<0458:POSARA>2.0.CO;2](http://dx.doi.org/10.1352/0047-6765(1997)035<0458:POSARA>2.0.CO;2)
- Hoare, P., Harris, M., Jackson, P., & Kerley, S. (2002) A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. *Journal of Intellectual Disability Research*, 42(3). DOI: 10.1046/j.1365-2788.1998.00134.x
- Huebner, A., Alidoosti, B., & Wade, K. (2010) Summary of Findings: Military Family Needs Assessment. 1-53. http://militaryfamilies.extension.org/wp-content/uploads/2011/04/MFNA_2010_Report.pdf
- Mandell, D. S., Xie, M., Morales, K. H., Lawer, L., McCarthy, M., & Marcus, S. C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Archives of Pediatrics & Adolescent Medicine*, 166(1), 68-73. DOI:10.1001/archpediatrics.2011.714.

- Mausner, S. (1995). Families helping families: An innovative approach to the provision of respite care for families of children with complex medical needs. *Social Work in Health Care*, 21(1), 95-106. DOI: 10.1300/J010v21n01_08
- Morris, L. A. (2012). Testing respite effect of work on stress among mothers of children with special needs. *Journal of Family and Economic Issues*, 33(1), 24-40. DOI: 10.1007/s10834-011-9267-y
- Murphy, N. A., & Carbone, P. S. (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*, 121(5), 1057-1061. DOI: 10.1542/peds.2008-0566
- Nageswaran, S. (2009). Respite care for children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*, 163(1), 49-54. DOI: 10.1001/archpediatrics.2008.504.
- National Alliance for Caregiving and AARP. (2009). Caregivers of children: A focused look at those caring for a child with special needs under the age of 18. http://www.caregiving.org/pdf/research/Report_Caregivers_of_Children_11-12-09.pdf
- National Respite Coalition (NRC) (2010). Public Witness Testimony of Jill Kagan Chair, National Respite Coalition. http://archrespite.org/docs/NRC_FY11_House_Testimony_Lifespan_Respite.pdf
- Neufeld, S. M., Query, B., & Drummond, J. E. (2001). Respite care users who have children with chronic conditions: are they getting a break? *Journal of Pediatric Nursing*, 16(4), 234-244. DOI: 10.1053/jpdn.2001.24183
- Robinson, C., & Stalker, K. (1993). Patterns of provision in respite care and the Children Act. *British Journal of Social Work*, 23(1), 45-63.
- Shelton, T. L. (1987). Family-centered care for children with special health care needs. Washington, DC. Association for the Care of Children's Health.
- Smith, A. M., & Grzywacz, J. G. (2014). Health and well-being in midlife parents of children with special health needs. *Families, Systems, & Health*, 32(3), 303-312. DOI: [10.1037/fsh0000049](https://doi.org/10.1037/fsh0000049)
- Strunk, J. A. (2010). Respite care for families of special needs children: A systematic review. *Journal of Developmental and Physical Disabilities*, 22(6), 615-630. DOI: 10.1007/s10882-010-9190-4
- Substance Abuse and Mental Health Services Administration (SAMHSA) & US Department of Health and Human Services. (2011). FY 2011 grant request for applications (RFA): Planning grants for expansion of the Comprehensive Community Mental Health Services for Children and their Families. Retrieved June, 2011 from http://www.samhsa.gov/grants/2011/sm_11_008.aspx
- Wherry, J. N., Shema, S. J., Baltz, T., & Kelleher, K. (1995). Factors associated with respite care use by families with a child with disabilities. *Journal of Child and Family Studies*, 4(4), 419-428. DOI: 10.1007/BF02237272

Appendix A: Interview Phone Script

Phone Script for Interviews of Department of Human Services and ARC personnel

Our focus today is respite care for families in which a member has moderate to severe special needs.

1. Do active duty military families have access to respite care services in your state?
Yes No

If NO, could you please describe the eligibility requirements (e.g., why military families are not eligible?)

If YES, are such services different depending on if the family lives on or off base? If so, how?

2. What is the application & approval process?

3. What are the costs for participating?

4. Is there typically a waiting list? Yes No

If YES, what is the average wait time?

5. For this final question, would you please think about the parts of your state where most military families live. I know that in [STATE] you have military installations in (CITIES). Could you please describe the availability of respite care services in those cities/areas? We want to understand if there are enough skilled respite care workers to meet the need?

6. We know from the literature that some parents of children with disabilities are more comfortable with trusted friends or family members providing the respite care services. Does your state offer training to friends and family members to be respite care providers?
Yes No

Appendix B: State Respite Care Data

State Surveyed	Organization	Eligibility Requirements	Application Process	Costs	Waiting List	Availability of Respite Care Services in Military Areas
California	The Arc of California	To be eligible, applicants must have a developmental disability as defined in Section 4512 of the Welfare and Institutions Code; show proof that onset was before the age of 18, and the disability is expected to continue indefinitely.	Regional centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services and supports that are needed. There is no charge for the diagnosis and eligibility assessment.	If income is 400% over the poverty level, there is an annual fee of \$150.00.	No.	Unsure about specific cities, but overall there is good availability of services and there are plenty of service providers in those areas.
Colorado	The Arc of Colorado	Colorado does not yet have a comprehensive, systemic process. The state is in the process of adding legislation for respite care for families.	No response.	There are no costs.	Yes. 6 months to 10 years.	Across the state there is a deficit of respite care providers. Unaware of any difference between military-impacted areas and other areas.
Florida	Ounce of Prevention Fund of Florida	Eligibility requirements vary by program. Programs may be operated and funded by state agencies, not-for-profit organizations, or other organizations. There is no comprehensive, state-run respite service program; and there is no comprehensive directory of programs.	The application process varies by program.	Costs vary by program.	The waiting list varies by program.	This state has a deficit in respite care providers.

State Surveyed	Organization	Eligibility Requirements	Application Process	Costs	Waiting List	Availability of Respite Care Services in Military Areas
Georgia	Department of Human Services – Division of Family and Children Services	Everyone who is eligible for respite care can utilize services, regardless of military status.	The application process depends on the individual respite provider or specialized camp.	Each care provider determines the cost of services. The provider may accept Medicaid or insurance to cover costs.	Each provider may or may not have a waiting list.	There are not enough respite care providers across the state.
Kentucky	Office of the Kentucky Health Benefit Exchange - Division of Behavioral Health - Developmental Delays	Medically eligible if care recipient is an individual with intellectual disability or a developmental disability and meets requirements for nursing facility level care.	Families must complete an application packet and an interview.	For Medicaid there is a waiver that could cover the cost of respite services. Otherwise, the cost of services is determined by income.	Time on the waiting list may vary due to the availability of services.	Unsure of availability of respite care services in parts of state with military installations.
North Carolina	The Arc	Medicaid members receive a waiver for things that are medically necessary but not normally provided, such as respite care. Some services may be available but they may be limited based on the type of insurance that they have; if they have grant funding then it is not based on insurance.	If the family receives funding through Medicaid, they are approved for respite care services.	If the family has funding through Medicaid, then they are pre-approved. If they do not receive Medicaid, then cost may vary based on income.	If the client is waiting for a waiver through Medicaid, they could be waiting between 5-10 years. If the client is not using Medicaid, then it will depend on the program that is providing care.	There are not enough skilled respite workers across the state, especially if an individual has complex medical needs.

State Surveyed	Organization	Eligibility Requirements	Application Process	Costs	Waiting List	Availability of Respite Care Services in Military Areas
Oklahoma	Department of Human Services	The child must be receiving SSI.	Medically eligible if care recipient is an individual with mental retardation or a developmental disability and meets requirements for nursing facility level care.	There is no cost but the child must be receiving SSI. In addition, programs provide a voucher up to \$400 to find their own provider (as long as the provider is not a family member).	No.	There are enough providers to meet the need.
Texas	Health and Human Services Commission of Texas	Lifespan Respite Care (LRC) Project: Caregivers who care for people of any age with a chronic health condition or disability who are not eligible for services through other programs.	Clients must compete a long term care application. After completing the application a case manager will complete a needs assessment to determine the number of hours of care that the family will receive and determines the type of services that the family qualifies for.	Free through Medicaid. Respite services are only available to low income individuals; income cannot exceed 220% above the federal poverty line.	Respite care does not have a waiting list.	There are no geographic restrictions as long as there are enough providers in the area. There is a large turnover of care providers, but the state appears to have enough care providers.

State Surveyed	Organization	Eligibility Requirements	Application Process	Costs	Waiting List	Availability of Respite Care Services in Military Areas
South Carolina	The Arc of South Carolina	<p>State Funded Respite: The applicant has to have an active case manager within the SC Department of Disabilities and Special Needs and NOT be receiving a waiver service.</p> <p>Waiver Funded Respite: The applicant has to have been awarded a waiver slot (we have an extensive waiting list - several years).</p> <p>Center Based Respite: This is typically emergency based respite. i.e. Parent is hospitalized, etc.</p> <p>SC Respite Coalition: There are mini grants that the family can access through their case manager.</p>	<p>State Funded Respite: The Case Manager completes application stating why respite is needed - it typically takes a week or two to get the approval. Case Managers contact the families to ask questions pertaining to the respite assessment.</p> <p>Waiver Funded Respite: Case Managers authorize this as a service in the budget of the waiver.</p> <p>Center Based Respite: Case Managers request emergency placement (takes one hour to one day).</p> <p>SC Respite Coalition: Case Manager sends family the application, the family fills it out and returns it. The Case Manager approves contents and submits to the SC Respite Coalition. This can take several weeks to get approved.</p>	There is no cost associated as these services as they are approved either through a waiver, state funded dollars, or a grant.	1 Week - 1 Month - Dependent on finding a respite care provider.	There is deficit in care providers in South Carolina.