

Lessons Learned in the Delivery of Respite Care for Military Families with Children Having Special Needs



CHILD CARE AWARE® OF AMERICA

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- The Military Services recognize that Military families who have children with special needs often need respite care
- Respite care is often needed or desired outside of the traditional operating hours of a CDC or Family Child Care Home
- Additionally, there are instances where group care is not the appropriate environment due to the child's specific needs

Exceptional Family Member (EFM) Respite Care Definition



- EFM Respite Care is designed for Military families who have children identified as exceptional family members (EFMs) and who are stationed throughout the United States
- This includes EFM children whose medical condition requires major medical facilities or whose needs are complex and specialized, requiring continuity of care

Exceptional Family Member (EFM) Respite Care Definition, continued



- EFM Respite Care helps eligible families by providing respite care so parents can leave the house, go for an appointment, or just rest, while knowing their child is well cared for
- Respite care is designed to give families a break and allows them to do things that are necessary, entertaining or restful. Parents can take a walk, have a nap, have a date night together, or go to the grocery store without children, while a welltrained and screened provider interacts with the children

Child Care Aware® of America has been providing respite care for Military families for 9 years

Military Respite Care is available throughout the United States for eligible families who have children with special needs

Military Respite Care is available 24/7 arranged at times convenient to the family

Children with special needs are eligible until they turn 19 years old



- Currently 2,000 Military families with more than 4,400 children are receiving respite care throughout the United States
- The most common children's diagnosis of those receiving respite care is Autism Spectrum Disorder
- 70% of EFM children receiving care are boys



- Respite care is provided by trained & screened providers
- Respite care providers have various levels of education and experience, to include RNs, LPNs, Spec. Ed. Teachers, ABA Therapists, etc.
- All respite care providers complete specialized training regarding the care of the children with special needs



- Respite care is provided at no cost to the family
 - Families don't have to pay the provider up front and be reimbursed
 - Families don't have to deal with monetary considerations when picking a provider



- The care is primarily provided in the child's own home
- Why in home care?
 - The home is a familiar environment where children are comfortable
 - Parents can remain in the home during respite care until they get comfortable with the provider
 - Providers can help children with their daily routines, and chores

Why is a Trained, Screened Provider Essential?

Provider interview and reference checks assist with determining candidate eligibility

Training ensures a basic level of skill

Screening ensures a background free from a history of family violence, child abuse, drug and alcohol abuse etc.



- A good initial potential match is important if the respite care is going to be successful
- The parent/provider interview is essential for a family to select a provider who best meets their needs
- When the provider-family match is a good one, respite care is a benefit to both the family and the children receiving it



- How do we ensure a good match? WE:
 - Ask what the family is looking for in a provider before we consider who to send for an interview
 - Ensure the potential provider has the availability the family is looking for
 - Facilitate providers' interview with a family
 - Ensure parents can request additional providers if the initial family-provider connection isn't right



- How do we ensure a good match? WE:
 - Monitor the care regularly
 - Follow-up with each family after their initial respite care session to evaluate the match
 - Survey families and providers
 - Train and screen family's preferred friend, neighbor or relative to ensure the family's comfort
 - Provide up to 3 providers so that there is maximum availability
 - Provide a nurse if the disability warrants

According to CCAoA annual surveys:

Respite Care:



Reduces family stress

Strengthens marriages

Reduces suicidal ideation Allows 1:1 with siblings

Improves children's development

Increases productivity & longevity

Reduces absenteeism

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Parents say:

"One of the MAIN reasons I stayed 30+ years was the Special Needs capability (of the Service) and other related programs like respite care for my daughter (now 17)."

"This (program) is an outstanding benefit to our family and an absolute factor to consider when the time comes to make the decision whether to transition into a civilian life."



Parents say:

"This program has had an incredibly positive impact on mine and my family members' lives. Without the respite care, I am not sure we would have made it through the challenges we faced this year because of the special needs of our family."

"The program is crucial to our family's <u>survival</u> and has adapted it's guidelines to meet our very unique needs for our critically ill child and ill primary caregiver who needed 2 surgeries."

"It {respite care} has literally saved my life. The stress with taking care of a special needs child is sometimes unbearable! It's wonderful to know I can go away to take a breath..."



How does respite care improve children's development?

New adults bring new verbal and physical interactions



Providers bring new activities experiences to children

Providers bring new strategies for effective discipline

According to CCAoA annual surveys,

Respite Care:



Factors in Service Members' decisions to remain on active duty

Frees Service Members from worry about the family during deployments

Provides the Services a return on their investment

Is the **MOST** important benefit for some families

Careful matching of parents with providers matters and saves time

Providing quality respite care makes a difference to parents and children

Continuous training and technical assistance helps providers and families

What are the (Hard) Lessons Learned?



- Comprehensive background checks matter: how do we know?
 - The fact of requiring background checks makes some providers opt out
 - We see "rap sheets" with prior abuse, felony drug charges, family violence, lewd & lascivious behavior, etc.

What are the (Hard) Lessons Learned?

Provider – agency and family – agency agreements are crucial to spell out expectations

Consistent communication between the family and provider is essential

Establishing boundary issues is crucial; spelling out comfort strategies saves later problems



- The number one reason caregivers say they opt to provide respite care is their desire to provide a service to a Military family and children who need them
- A well-matched provider tends to become like extended family and heightens the experience for families

Parents say:

"This program has saved marriages and statistics show that families with children with disabilities have higher divorce rates. This program is worth every penny..."

"This is an amazing program! It not only saved my marriage but

is helping to keep my family together. Our providers are

amazing!"