2019 National Lifespan Respite Conference

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

Bonnie Storm, Senior Director
Exceptional Family Member Program (EFMP) Respite Care
The Navy and Air Force recognize that their families who have children with special needs often need respite care.

Respite care is needed outside of traditional operating hours of a child care center.

There are instances when group care is not the appropriate environment due to the child’s specific needs.
Exceptional Family Member (EFM) Respite Care Eligibility

• EFM Respite Care is designed for Air Force and Navy families who have children identified as exceptional family members (EFMs) and who are stationed throughout the United States.

• Overseas respite care is available at certain installations run by each Service.

• 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 families by providing respite care so parents can leave the house, go to an appointment, or just rest, while knowing their child is well cared for.
- Respite care gives families a break and allows them to do things that are necessary, relaxing 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 well-trained and screened provider interacts with their children.
Exceptional Family Member (EFM) Respite Care Overview

Child Care Aware® of America has been providing respite care for Military families for 10 years.

Air Force and Navy Respite Care are available throughout the United States for eligible families who have children with special needs.

Air Force and Navy Respite Care are available 24/7, arranged at times convenient to the family.

Children with special needs are eligible until they turn 19 years old.
Exceptional Family Member (EFM) Respite Care Overview

• Currently more than 2,500 Air Force and Navy families with almost 6,000 children are receiving respite care throughout the United States

• The most common enrolled child’s diagnosis is Autism Spectrum Disorder

• 70% of EFM children receiving care are boys
Exceptional Family Member (EFM) Respite Care Overview

- Respite care is provided by trained & screened providers
- Providers have various levels of education and experience
- All providers complete specialized training on the care of the children with special needs
- In-service training continues as long as a provider works with children and families
Exceptional Family Member (EFM) Respite Care Overview

• Respite care is provided at no cost to the family
  ▪ Families do not pay the provider up front and wait for reimbursement
  ▪ Families do not have monetary considerations when picking a provider

• Payments are made directly to the provider
Exceptional Family Member (EFM) Respite Care Overview

• 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
  ▪ Parent do not have to worry about risk factors e.g., severe food allergies, low immune systems
  ▪ Parents can remain in the home during respite care until they are comfortable with the provider
  ▪ Providers can help children with their daily routines, and chores
Why is a Trained, Screened Provider Essential?

Pre-Service Criteria

- 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.
What is the Value of Taking Additional Time to Ensure a Good Match?

• A good initial potential match is vital if respite care is going to be successful & it saves parents’ time

• 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
How Do We Assess Candidates for a Good Match?

WE:

- Ask what the family is looking for in a provider before we refer a provider for an interview
- Ensure the potential provider is available when the family needs it
- Facilitate providers’ interviews with a family
- Ensure parents request additional providers if the initial family-provider connection isn’t right

Copyright Child Care Aware® of America.
How Do We Validate a Good Match?

WE:

- Monitor the care regularly
- Follow-up with the family after their initial respite care session to evaluate the match
- Survey families and providers annually
- Train and screen family’s preferred friend, neighbor or relative to ensure the family’s comfort
- Provide multiple providers so that there is maximum availability
- Provide technical assistance and additional resources to families and providers
According to CCAoA Annual Navy Parent Assessment, Respite Care:

- Strengthens marriages
- Reduces suicidal ideation
- Improves children’s development
- Reduces absenteeism
- Increases productivity & longevity
- Allows 1:1 time with siblings
- Reduces family stress
- Strengthens marriages

Copyright Child Care Aware® of America.
According to CCAoA Annual Parent Assessment, 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 investment

Is the MOST important benefit for some families
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
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 survival 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...”
Summary

- 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
Provider – agency and family – MOA 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
What are 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 Lessons Learned?

• The number one reason providers say they opt to provide respite care is their desire to provide a service to a Military family

• A well-matched provider often becomes 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!”