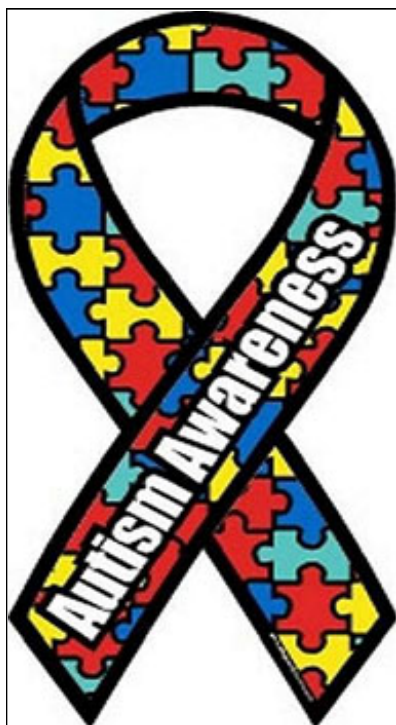


Exceptional Family Member Program: military families and autism

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Exceptional Family Member Program: Military families living with autism



“I would give anything to have my daughter talk to me, she can’t say I love you,” said Bernadette Jarosz. “It hurts. I will never see Gabby graduate from college, get married, or hold her children. I will never experience any of those milestones with her. Even though she is physically growing she will most likely remain perpetually one and a half years old.” Gabby is severally autistic.

Bernadette Jarosz and her husband, Marine Lt. Col. Jeffrey Jarosz, a student at the Army War College, have three children, all of them 10 years old. Bernadette first realized that something was wrong when the triplets were two.

“One in 88 military families has a child with autism,” said Anne Hurst, Carlisle Barracks Exceptional Family Member Program Manager. “This is far greater than the national average of one in 110. Every year we get more and more families with autistic children moving on post.”

The Carlisle Barracks EFMP program provides comprehensive support for military families by providing access to two major resources; Dunham Army Health Clinic for diagnosis and Army Community Service for other support.

Exceptional Family Member Program

While Hurst identifies autism as one of the fastest growing segments of the EFMP program, any spouse, child or dependent parents who require special medical or educational services for their physical, intellectual or emotional condition qualify for EFMP.

The U.S. Army Medical Department estimates that 16 percent of Army Families have members with special needs. Enrollment in EFMP is mandatory upon identification of a special need, so the military

can consider a family member's special needs when determining assignments for the military member. Special needs can include cancer, diabetes, asthma, Graves' disease, depression and learning disabilities like dyslexia or Attention Deficit/Hyperactivity Disorder.

The military's EFMP program supports families with special needs, and is designed to be a comprehensive, coordinated, multi-agency program that provides community support, housing, medical, educational, and personnel services to military families with an EFMP member.

How Carlisle Barracks is helping EFMP families

EFMP families relocating to Carlisle Barracks have a wide support system. The Carlisle Barracks EFMP program coordinates with Dunham Army Health Clinic for diagnosis and medical intervention, as well as ACS for referrals and outside support.

To help families with autistic children, and other special needs the Exceptional Family Member Program offers respite care.

"Respite care provides family members with a break," said Hurst. "We match caregivers with families, who can watch their special needs family member for a few hours, which allows the family members a chance to have time for themselves and recharge."

The EFMP manager serves as an advocate for families, both with on-post and off post organizations. Hurst has accompanied EFMP parents to school meetings and remembers being thanked by a spouse, whose husband was deployed, for being there for her and her family.

Hurst is currently working with EFMP families who will be PCSing here over the next few months and encouraging them to update and transfer their individual education plan before they arrive to make the transition easier.

"I usually start working with the EFMP office about six months before we relocate somewhere," said Jarosz. "This way I can make sure everything is in order for Gabby prior to arrival."

While support for Carlisle Barracks EFMP families primarily comes from Hurst, the clinic or ACS, it can also come from the community.

"The residents and employees at Carlisle Barracks have been great," said Jarosz. "When we arrived we needed a fence so Gabby could safely play in the back yard. At first a small fence was built but the area was too small and Gabby would move a chair over and climb the fence, we needed a bigger area for her," she said. "One day I found the garrison commander standing in my yard looking at my little fenced in area. He said it was completely unacceptable and we got a better fence."

Diagnosing autism

“As a Mom you know when something is wrong with your child,” said Jarosz. “I noticed that she was different from her brother Jackson and sister Sophia. She would fixate on things, avoid eye contact, and she was losing her words.”

After realizing something was wrong, Jarosz called their family doctor who did a hearing test on Gabriella. Her hearing was fine. “I was describing her symptoms to my friend, who told me to get her tested for autism,” said Jarosz. Gabriella was tested and it came back positive.

“Jeff was deployed, I was freaking out,” said Jarosz. “I was told that Gabby needed 30 to 40 hours a week of Applied Behavior Analysis (ABA) therapy to help her, but TRICARE didn’t cover the therapy because autism was classified as a special education need not a neurobiological brain disorder. We were able to come up with some of the money for care by mortgaging our house but there are a lot of military families who don’t have that luxury. Treatment is a lifetime expense.”

Children with autism usually show signs of delayed development as babies. Some, according to the Mayo Clinic, show signs of having lower than normal intelligence, while others have a high I.Q. Autistic children have difficulty communicating and adjusting in social situations.

According to the Mayo Clinic, children with autism generally have problems in three crucial areas of development; social interaction, language and behavior.

The Mayo Clinic recommends having your child tested for autism if the child doesn’t --

- Babble or coo by 12 months
- Gesture, point or wave by 12 months
- Say a single word by 16 months
- Say two-word phrases by 24 months
- Loses previously acquired language or social skills at any age

“Early diagnosis of autism is important to start intervention and treatment,” said Dr. Linda Clark, Dunham Clinic pediatrician. “Pediatrician’s may test for autism if they notice a child under their care is either not reaching developmental milestones, or has lost previously attained milestones such as speech,”

Since there is no biological test for autism, the diagnosis will often include a complete physical and neurological examination. The child may also undergo genetic testing to look for chromosome abnormalities. The health care provider may also use a specific screening tool such as the *Diagnostic*

and Statistical Manual IV to diagnose autism.

If you suspect that your child may be autistic, call 245-3400 to make an appointment with Dr. Linda Clark.

Treating autism

Intensive, early treatment can make a big difference in the lives of many children with the disorder.

“A few years ago children were diagnosed around three years old,” said Jarosz. “Now the medical community is able to diagnose the disorder in children younger than two years old.”

According to the website autism.com, autism is a complex brain disorder. While there is no cure, there are treatments proven to be effective in helping children with autism lead full, active and independent lives. However successful treatment depends on quick intervention and intensity of service hours.

Most treatment programs build on the individual interests of the child and are most successful when geared towards the child’s particular needs. The therapies can include:

- Applied behavior analysis (ABA)
- Medications
- Occupational therapy
- Physical therapy
- Speech-language therapy

“While there are multiple treatments available to treat children with autism, the most proven one has been ABA therapy,” said Clark.

“ABA therapy is an autistic child’s version of what Annie Sullivan was to Helen Keller,” said Jarosz. “It gives them away to communicate by improving language and communication skills, social interactions as well as daily living skills.”

ABA techniques for autistic children combine comprehensive, individualized intensive programs that address communication, social, self-care, play motor and pre-academic skills in young children. This allows autistic children to have the same experiences their peers would have.

This type of intense therapy has shown to enhance some autistic children’s skills where they were able to participate in regular classrooms with minimal to no help.

Military families and autism

The transient lives of many military families complicate efforts to create and maintain extensive comprehensive care.

“The level of care available varies from location to location,” said Hurst. “So many military families -- when they find care -- try to stay at that location for as long as they can.”

“TRICARE classifies autism as a special education benefit instead of a neurobiological brain disorder,” said Jarosz. “Since autism is not classified by TRICARE as a brain disorder, treatment is not covered under TRICARE Prime, which is the healthcare service most military family’s use.

“Treatment is available through TRICARE Enhanced Care Health Option but the financial limit of \$2,500 a month for treatment does not cover the therapy recommended for severely autistic children,” said Jarosz. “We would not set monetary limits for cancer treatments or treatments of Soldiers wounded in battle. We shouldn’t let money dictate the level of treatment we provide to our military families. It is not right.”

Hurst advises all military families with autistic children, regardless of rank, to contact the Pennsylvania Department of Public Welfare/Medical Assistance program for assistance.

“Enrolling in this program provides a lot of free services,” said Hurst.

Jarosz urges wider health benefits for autism

Frustration at the limitations of care within TRICARE led to Bernadette Jarosz to work with lawmakers to include full autism treatment under all TRICARE programs.

“Currently 29 states have laws that make it mandatory for insurance companies to cover ABA therapy but since we are a military family, even if we live in one of those states, TRICARE is a federal program so it trumps state law,” said Jarosz.

“It was devastating for my family when Gabby was diagnosed with autism,” said Jarosz. “I can’t imagine what it would be like for a 19 year old lance corporal to be told his child was autistic and he couldn’t get the care needed. It would probably destroy the family.”

Jarosz noted that legislation has been proposed in the House of Representatives to get ABA therapy covered under TRICARE basic.

“I don’t care if passing this legislation ever helps Gabby,” said Jarosz. “I just want to see it done because it is hard enough being a parent with an autistic child, you shouldn’t have to worry about how you are going to pay for treatment.”

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