



Special Needs Smart Book: Introduction

As parents-to-be dream about their future as a family, very few picture themselves raising a child with special needs. Even fewer parents can imagine the hurdles ahead when they first learn of their child's special needs, or that a family member of any age has become disabled. When the family is active duty military, they do know that an already demanding lifestyle is likely to become even more challenging.

To the extent that school-age children of military families mirror the same age group within the US population as a whole, approximately one out of every 17 will have a significant sensory, physical, mental, or self-care disability. This number is based on the Census 2000 Brief on Disability which indicates that 5.8% of the non-institutionalized population aged 5-15 was identified as disabled in the most recent census. The proportion of disabled Americans increases with age to 18.6% of the 16 to 64 age group and 41.9% of the population over age 65. Thus, it should come as no surprise that a significant number of US military personnel—75,000 or more—have disabled children or adult family members with special needs for therapeutic treatment, education, personal care, recreation, housing, or employment.

Military families with special needs members inevitably must weigh the benefits of comprehensive health care, support services, and membership within the larger military family against the hardships of frequent moves, family separations, and limitations on housing, education, and employment options. A large number of special needs families choose to make the military a career. The parents in these families tend to be among the most resourceful, resilient, and empowered military parents and are also among the most motivated and dedicated soldiers, sailors, airmen, and marines.

The Hodges of Fredericksburg, Virginia epitomize the career military family that is living through the hardships, uncertainties, and frustrations of raising a special needs child while serving their country. Yet, as they near 20 years together as a Marine Corps couple, Isabel and Chief Warrant Officer 4 Bruce Hodge find themselves stronger as parents and more capable of fighting for their children's needs than they might have been with a less demanding lifestyle. The Hodges' toughness and self assurance comes from the experience of traveling a long and sometimes lonely road distinguished by frequent obstacles, sharp curves, and the occasional wrong turn. But they will be the first to admit that without support along the way from parents, friends, medical and educational professionals, and the Marine Corps, they might not be where they are today.

Isabel and Bruce met at Parris Island, South Carolina and married in 1988, when they were both young enlisted Marines. Isabel stayed in the service until their first child, Kristen, was six months old. Allistair came along in 1991, and Andrew in 1995. Bruce, a telephone systems officer, has moved his family with him to assignments at Camp Butler, Okinawa; Camp Pendelton, CA; Camp Lejeune, NC; Parris Island, SC; Cherry Point, NC; and currently to Quantico, VA. The Hodges always lived in base housing prior to purchasing their first home in Virginia. Fredericksburg is within commuting distance to Quantico, and it is where they plan to retire and stay—at least until the kids finish high school.



CWO4 Bruce Hodge, Andrew, Kristen, Isabel & Allistair

Bruce and Isabel first noticed that Allistair was not developing the way children are supposed to when he was 18 months old. He didn't respond to people and seemed to prefer being alone. He could be fixated on wheels and other spinning things for hours at a time. Diagnosed with autism, Allistair did not speak until age four. By this point, he had also become a silent runner and could go tearing away from the house at any time night or day. He was extremely sensitive to stimulation from noise or touch and would go white and start shaking and screaming uncontrollably or bolt for the door at the slightest cue.

It took a long time for Allistair to respond to a simple yes or no from his parents. Very gradually, he learned to say what he wanted, often using dialog from movies. It was a huge step forward for the Hodges when Allistair was able to verbalize his feelings about being autistic. Today, Allistair still prefers to spend most of his time alone in his room. He doesn't make eye contact or engage in conversation with new people, and he can easily become the captive of obsessive behaviors such as picking paint chips off the wall. But thankfully for Isabel and Bruce, his behavior and tolerances have improved, and, in his own way, Allistair has been able to form friendships with a few other children.

As they look to the future, Isabel and Bruce are uncertain about what life will be like for Allistair. They worry that, on his own, he could easily be taken advantage of or make inappropriate decisions. They hope he will be able to turn one of his innate abilities, such as constructing elaborate structures out of K'NEX toys, into a vocation. The Hodges have



told Allistair that he will have a home with them for as long as he wants, but they recognize the need to plan for his future after they are no longer able to be there for him. Military families with special needs share many commonalities in the challenges they face. The Hodges' experiences described in the following paragraphs illustrate a few of these challenges and underscore the important role of military special needs programs in helping to empower families by offering meaningful information, advice, and support.

Systems Naiveté

When Allistair was first diagnosed, Isabel and Bruce were completely unaware of how to find and negotiate services for disabled children. Even in locations with good programs and support in the military and civilian communities, young parents will feel confused and overwhelmed as they try to understand the services their child needs, their eligibility for different programs, as well as their legal rights. Just as they begin to master systems in one location, they move to another location with different systems and different rules. Isabel feels they were lucky to get Allistair into the civilian early intervention services while they were at Camp Lejeune. But they didn't know about Supplemental Security Income (SSI) until long after Allistair was diagnosed, only to lose those benefits when Bruce made Warrant Officer. Their early experiences taught the Hodges that there is no simple roadmap, and parents of special needs children must take the initiative to educate themselves and advocate for their children, even in the most supportive communities. Isabel and Bruce are good examples of just how proactive military parents can become. Isabel has worked tirelessly on behalf of other military parents with special needs children as Exceptional Family Member Program (EFMP) coordinator at Marine Corps Air Station Beaufort, SC, EFMP support coordinator at USMC Headquarters, and family member special needs consultant to the Department of Defense Office on Military Community and Family Policy. Bruce takes an active role in his children's school systems and he served on the School Board at Laurel Bay DoD Elementary and Secondary Schools (DDESS) in Beaufort, SC. Additionally, Bruce and Isabel both established and ran a support group for military and civilian parents with special needs children for five years with the support of MCAS Beaufort and the Special Education Director at Laurel Bay DDESS.

Isolation

Military families are particularly vulnerable to the isolation commonly experienced by families with a special needs child. As Isabel and Bruce explain, families do not go out in public together when one of the children is likely to create an embarrassing scene or go running off. Throughout their marriage, the Hodges have mostly spent their time together at home. It was difficult asking other people to take care of Allistair, and even his visiting grandparents were uncomfortable taking responsibility for him. Without deep roots in their communities and networks of extended family and friends nearby, it becomes very easy for military parents to become isolated and then suffer depression and stress within the marital relationship. That is why Isabel is a strong advocate for respite care being easily available to special needs families within the military community. The Hodges were only able to access respite care while Allistair was receiving services from the North Carolina State Early Intervention Program, which ended when Allistair turned 3 years old; however, it gave them the occasional opportunity to relax together and focus on their relationship with each other. Today, the Hodges' daughter Kristen (15), who is a Red Cross certified babysitter, helps out by watching her brother while her parents take a break and go out to dinner or see a movie together. For the last 10 years the Hodges' have not received any respite care services.

Difficult Transitions

The latest military-family research is confirming what many parents have always known—that moving children frequently from one school to another over the course of a military career presents significant challenges to their social, emotional, and educational development. Non-disabled youth growing up in military families universally experience the pain of leaving a beloved school and friends behind to face the uncertainty of finding their place within a new school and peer group. For many disabled youth, starting over can be just as devastating emotionally, but the developmental setbacks can be much more far reaching than having to take additional courses to graduate or missing key curricular or extracurricular events. Months of needed services can be lost while the new school system develops its own individualized education plan (IEP) for a child. Frequently, the services provided will not be the same as what the child had been receiving. Each time the Hodges moved some service Allistair had been getting was interrupted. Most recently, it was occupational therapy that the new school could not provide because of a shortage of occupational therapists. Isabel worries that some schools take advantage of military special needs children by stalling on expensive equipment or services that they are legally entitled to knowing that it will only be a matter of time until the family moves again. She believes that every military family should go to the first IEP meeting at a new school prepared for a struggle and with a special education advocate, if possible.

Discrimination

Legislation, such as the Americans with Disabilities Act (ADA), protects disabled persons from the overt or institutional discrimination that they routinely experienced not so long ago. But subtle forms of discrimination continue to be a fact of life for the disabled. While certainly not a characteristic of the military lifestyle, discrimination can be an issue for military families, especially when it is experienced by members least able to initiate the recourse that laws provide. As Allistair becomes more capable of verbalizing his feelings, Isabel and Bruce are challenged to help him deal with the mistreatment that he sometimes experiences. Like many families with a special needs child, siblings also know the sting of discrimination. Kristen Hodge is very aware for her fifteen years, having many times defended her brother from the cruelty of other children. In one example, she went on her new school's closed circuit TV to explain autism after she was teased for holding hands with Allistair in the hallway. Isabel and Bruce are as proud of Kristen's courage and loyalty as they are of Allistair's accomplishments in dealing with his disability. And Isabel is quick to urge parents and special needs professionals not to lose sight of the non-disabled children while they focus on meeting the needs of the exceptional child.

Extended Deployments

In recent years, long and stressful deployments to combat zones have become a new challenge for military special needs families. When choosing to make the military a career, most special needs families did not anticipate the long-term separation that many have come to know. For the most part, these families accept their duty without expecting any particular considerations for their special needs status. In fact, many of the stay-behind parents of special needs children use the advocacy skills they have learned to take leadership roles within their units' family support groups. Nevertheless, these anxiety-ridden separations can take a toll on parents accustomed to working together as a team to care for a disabled family member.

This document is intended as a resource for all professionals serving the military special needs communities. Whether involved with the screening and assignment processes, special education and early intervention, medical and financial benefits for disabled family members, or support services, helping individuals will be better equipped to support special needs families if they have good information about a wide range of issues and can provide it with sensitivity and understanding of their special challenges.

