Kate and Renae Hilton enjoying their 2008 Kindergarten Christmas party at Canterbury Woods Elementary in Fairfax County, Virginia.

The Military Child and Special Education

By Jeremy Hilton

Since aging out of early childhood intervention and starting preschool at age 3, our daughter, Kate (now 6), has been in four different elementary schools (in Texas, Alabama, and Virginia). That's four different IEP teams, with different teachers and administrators, with different laws, regulations, and methods of implementing a special education program. We aren't nomads, but functionally might as well have been. What we are is a military family who has had to endure deployments and changing assignments based on the needs of the service. It is a part of life all military families come to understand. For "typically developing" military children, the mish mash of different state laws and regulations is hard enough. For military families whose children have disabilities and have to deal with the special education system, the adjustments are significantly more daunting. A critical problem we face is that because of our frequent moves, the vast majority of military families have little to no chance of effectively holding school districts accountable via the normal procedural safeguards established by the Individuals with Disabilities Education Act (IDEA). Military families whose children have Individualized Education Plans (IEPs) need to understand the tools available to give their children the best chance at receiving a free and appropriate public education (FAPE).

In the summer of 2006, after being deployed for close to six months, my wife Renae returned early from Afghanistan because our daughter needed major brain surgery (decompression of her Chiari malformation). Thanks to my wife's command and the Red Cross, we were able to have her home for the surgery. After recovery, we packed all our household belongings and made a permanent change of station ("moved" in civilian lingo) from Texas to Alabama. We were to be stationed in Alabama for ten months as my wife had a professional school she needed to attend. Arriving in Alabama, we were shocked when we found ourselves battering against the brick wall known as Alabama special education services. The list of procedural and substantive violations of the Individuals with Disabilities Education Act (IDEA) was seemingly endless.

Reviewing our procedural safeguards allowed by IDEA, we first asked for Prior Written Notice (PWN) regarding our concerns. Prior Written Notice was provided but it was not in compliance with IDEA. The school district's version of PWN consisted of saying that they were right…well…because they were right. At mediation, it became obvious that the school system had absolutely no intention of trying to work through the issues, compromise, or even to simply follow the law. We filed a state special education complaint, in which our concerns were dismissed without considering any evidence other than the school administrator's point of view. We contacted the two special education lawyers actively practicing in the state of Alabama who told us they didn't think our case was worth pursuing because we were at our duty station for such a short period of time. Even if we were there longer, we couldn't have afforded the legal and expert witness fees required to take a case to due process. We contacted the state's Protection and Advocacy division and explained our situation. They simply didn't have the resources available to help. We were later told through the parental grapevine that the county school superintendent would not bend in working with parents until the parents indicated the ability and willingness to file against the school system for due process. Essentially, what we found out in Alabama is that the procedural safeguards put in place for our children's protection are essentially useless. In fact, what we learned is that when a school district wants to, they can effectively limit procedural safeguards to those that can afford it. Without changes in IDEA or other laws, this isn't expected to change. However, out of this experience, we came away with a number of important lessons and options that exist to lessen this difficulty.

The most important lesson learned from our experience is that consistency is critical. If a military family with special needs finds the supports and services they need in one particular location, it is of paramount importance that they work within their chain of command to stay in that location. While it's not always the best solution, sending a service person to another duty station while the family remains in its current location should be considered. If the services aren't currently available at a duty station, the family should work to find out what services are available at other bases or posts where the service member might be able to find a position. For many families with a new diagnosis, it will be essential to fully inform the chain of command so that proper medical and educational interventions can be considered as soon as possible, to include a humanitarian reassignment to another location. The service's Exceptional Family Member Programs are supposed to be the conduit for helping families through these processes but the amount of help you get will depend significantly on which branch of the service you belong. In the end, a family may have to weigh the benefits to the service member's career against the stability of their family.

Another important lesson learned is that networking within the military special needs community is paramount. There are a number of different chat groups (or listservs) related to military

What is Chiari Malformation?

Chiari malformations (CMs) are structural defects in the cerebellum, the part of the brain that controls balance. When the indented bony space at the lower rear of the skull is smaller than normal, the cerebellum and brainstem can be pushed downward. The resulting pressure on the cerebellum can block the flow of cerebrospinal fluid (the liquid that surrounds and protects the brain and spinal cord) and can cause a range of symptoms including dizziness, muscle weakness, numbness, vision problems, headache, and problems with balance and coordination. There are three primary types of CM. The most common is Type I, which may not cause symptoms and is often found by accident during an examination for another condition. Type II (also called Arnold-Chiari malformation) is usually accompanied by a myelomeningocele-a form of spina bifida that occurs when the spinal canal and backbone do not close before birth, causing the spinal cord to protrude through an opening in the back. This can cause partial or complete paralysis below the spinal opening. Type III is the most serious form of CM, and causes severe neurological defects. Other conditions sometimes associated with CM include hydrocephalus, syringomyelia, and spinal curvature.

Is there any treatment?

Medications may ease certain symptoms, such as pain. Surgery is the only treatment available to correct functional disturbances or halt the progression of damage to the central nervous system. More than one surgery may be needed to treat the condition.

What is the prognosis?

Many people with Type I CM are asymptomatic and do not know they have the condition. Many patients with the more severe types of CM and have surgery see a reduction in their symptoms and/or prolonged periods of relative stability, although paralysis is generally permanent.

What research is being done?

The NINDS supports research on disorders of the brain and nervous system such as Chiari malformations. The goals of this research are to increase scientific understanding of these disorders and to find ways to prevent, treat, and, ultimately, cure them.

For more information, please visit: www.ninds.nih.gov/disorders/chiari/chiari.htm families with special needs. Most notably at the national level is STOMP (Specialized Training of Military Parents, www.stompproject.org), the only national Parent Training and Information (PTI) resource for military families. Two other great resources include Military Homefront (www.militaryhomefront.dod.mil), which has a special needs area, and the Wrightslaw website (www.wrightslaw.com/info/dod.index.htm), which addresses military special education issues. Many bases also have local support groups available to help determine appropriate resources. In the Marine Corp and Army, each base has significant resources available to help families with their unique special educational and medical needs (the Air Force and Navy are considering funding for these resources but do not currently have them in place). It is important to get a ground level view of what resources are truly available to families versus what the school or medical system will officially tell you. For example, there may be a feeding clinic at Minot AFB. What's not researched effectively is that there is a year long waiting list for that clinic. Only the people actually there and actively involved in the process can tell you that type of information.

Another avenue many times overlooked is the chain of command. It is the responsibility of the chain of command to understand the issues affecting its people, particularly when it can impact the military mission. If a Soldier, Sailor, Airman, or Marine is worried that his child's education is being negatively impacted, it can be hard to focus on the mission at hand (particularly in a deployed environment). Too many commanders simply refer a military member to the chaplain or family services. Particularly with systemic issues, it most likely isn't just one military family who is being affected by a school district's malfeasance. Advocacy at the military's senior levels of leadership could be very effective. When a school superintendent understands that the post or base commander is actively involved with these issues, it will make them think twice about denying military children their rights to an appropriate education.

By understanding state and federal special education law, understanding the power of negotiating effectively, and realizing that you are the only ones that are going to effectively advocate for your child, your child stands a significantly improved chance at an appropriate education.

Finally, the last lesson learned is the importance of understanding the psychology of negotiating for your child's education. The sad truth of the matter is that funding plays a large role in decisions that are made in special education. There is only so much money to go around and those that advocate effectively stand a much better chance of receiving appropriate goals, placement, and services for their child. As parents, we must understand that there doesn't have to be a tradeoff between collaboration and advocacy. We must be willing to work within the team but at the same time strongly advocate for our children. Though parents may like to think of teachers and administrators as our friends or peers, for purposes of special education, they simply are not. Finally, whatever the relationship, a military family's official position with the school district should be that they intend to stay at that current duty location as long as possible. Letting the school district know how long you will be there or when you expect to move can be a recipe for disaster.

To this end, it is so important that a family understand the best manner to put your family in the strongest negotiating position possible. A great way to start is by purchasing a well reviewed negotiations book (*Getting to Yes* by Bruce Patton is one of my favorite) and read it a couple of times. Reading these books and putting their suggestions into practice in your everyday life will make your analysis and advocacy at IEP meetings and with school personnel that much more effective. The next step is by reviewing and understanding both the state and federal special education regulations. Since the state regulations are based on the federal regulations, one would think there wouldn't be that much of a difference. However, there are significant nuances in the way in which different states put the federal regulations into practice. It is well worth your time to review these state regulations before your first dealings with school personnel in a new state. By understanding state and federal special education law, understanding the power of negotiating effectively, and realizing that you are the only ones that are going to effectively advocate for your child, your child stands a significantly improved chance at an appropriate education.

In the end, we'd like to encourage everyone that there is a light at the end of the tunnel. We moved from Alabama to Northern Virginia where we've been consistently impressed with the quality of personnel and education. Did we make an impact on Alabama special education? Maybe. But at the very least, maybe we made it easier for those that came after us. So, wherever you go, try to make a positive impact. By trying to make an impact for our military kids, hopefully we'll help others as well. •

Jeremy Hilton, a 1995 graduate of the US Air Force Academy, cross commissioned into the Navy and served as a submariner until 2003. Since then, Jeremy had been advocating for his daughter's medical and educational needs as well as the needs of other families whose children have disabilities. Jeremy is a 2009 graduate of the Virginia Partners in Policymaking course and a board member for Parents of Exceptional Children (www.poec.org), a Northern Virginia parents group. Jeremy resides with his wife, Renae, and his daughter, Kate, in Annandale, Virginia, just outside the nation's capital.