



Air Force Exceptional Families – Parent Perspective

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Overview

- **Background**
- **Needs during PCS**
- **Needs day to day**
 - **Families**
 - **Community (feedback and affect change)**
- **Needs during deployment**
- **Serving EFM Parents – considerations**
- **Desired Knowledge, Skills and Abilities**
- **Summary**



- **Exceptional Family Members**
 - Includes spouses, children, or dependent parents who require special medical or educational services
 - Have a diagnosed physical, intellectual or emotional condition
- **Approximately 15,000 Exceptional Family Member dependent children in AF; numbers suspected to be low**
- **AF currently manages EFM through Special Needs Identification and Assignment Coordination (SNIAC)**
- **AF is only service without Headquarters and/or installation EFM Program Family Support manager**
- **EFM families have needs during PCS, day to day, and during deployment**



Needs during PCS

- **Accurate, up to date information regarding services available at all locations (specific to disability and severity)**
 - **Clear, simple, transparent policy on assignment procedures (with compliance)**
 - **Effective identification and communication of needs through an objective third party***
 - **Objective comparison of needs vs. services and replicable decision making process on assignment***
- * Most effectively accomplished by someone who knows and understands disability, individual child, and family**



Needs Day to Day - Families

- **Assistance with identifying and accessing child care and respite services (remove barriers)**
- **Assistance with enrolling and accessing military (ECHO) and local (Medicaid Waiver) special needs programs**
- **Assistance with identifying and accessing specialty care providers (dental, speech, behavioral, neurology)**
- **Assistance with identifying and accessing appropriate special education programs specific to disability**
- **Crisis support as needed for surgery, major in-patient procedures, emotional breakdowns, severe behavioral episodes**



Needs Day to Day - Families

- **Ongoing assessment of member/family, check of needs and adequacy of services (quarterly, annually?)**
- **Assistance with establishing and maintaining records**
- **Assistance with financial planning and special needs trusts/long term care**
- **Advocacy across all areas**
- **Advice, lessons learned, and strategizing specific to local community and conditions**



Needs Day to Day - Community

- **Establish partnerships with local community providers of child care and respite for special needs children**
- **Ensure current issues regarding accessibility and utility of ECHO and Medicaid programs are communicated on behalf of military members**
- **Ensure issues regarding access to specialty care are communicated back thru chain of command**
- **Ensure issues regarding adequacy of special education services are communicated back to local communities**
- **Facilitate participation in local community support groups, organize/establish military support groups, establish e-mail groups and list serves**



Needs During Deployment

- **Respite care, respite care, respite care**
- **Proactive assistance in evaluating and establishing/ increasing services as needed (counseling, behavioral therapy and supports in the home, see Dr. Cozza, USPHS)**
- **Touch points pre, during, and post deployment to assess needs and access to services**
- **Typical family needs (communication, resiliency training, mission awareness)**
- **Frequent contact and checks on needs and supports in coordination with unit**



Serving Exceptional Families

- **Families affected by special needs are unique and different from other customers**
- **Societal norms still tend to indirectly place “blame” on parents for child’s disability, especially behavioral**
- **1 in 6 children in U.S. diagnosed with a behavioral disorder (Centers for Disease Control, 2007)**
- **1 in 91 children diagnosed with autism (CDC, 2009)**
- **Personnel providing Systems Navigation, resource support need to be aware, not perpetuate myths**
- **Cause of disability should not be factor of consideration or influence (recent examples)**



Points to remember...

- **Most parents of special needs children...**
 - **Are sleep deprived**
 - **Don't have much of a social life**
 - **Don't have their own hobbies or interests (their child's disability is their "hobby")**
 - **Don't get support from their family, civilian community, or schools**
 - **Place an extraordinary value on time (they don't have seconds, let alone minutes or hours to waste)**





Points to remember . . .

- **Most parents of special needs children...**
 - **Have difficulty scheduling and completing simple daily living tasks (grocery shopping, doctors appointments, dental appointments, post office)**
 - **Experience financial difficulties (one parent unable to work, costs of care and medical expenses often out of pocket)**
 - **Are constantly worrying about today, tomorrow, and the future for their family and their child**
 - **Are used to and expect adversarial encounters with service professionals (doctors, teachers, therapists)**





Desired Knowledge, Skills, and Abilities

- **Empathy (understanding, being able to walk in parent's shoes, truly understand perspective)**
- **Knowledge of special education and disability law**
- **Knowledge of respective state Medicaid waiver programs, health and human services, and social security administration**
- **Knowledge of TriCare and military benefits, to include active duty, reserve, guard, and retiree (and differences between)**
- **Knowledge of current, research based treatments for a broad range of disabilities and disorders**



Desired Knowledge, Skills, and Abilities

- **Ability to advocate and negotiate**
- **Persistence and patience in dealing with clients and social/medical service systems**
- **Organization and efficiency (every minute is precious)**
- **Proactive, self starting (no current models within AF to follow, Marine Corps and Army are benchmarks)**
- **Thick skinned, ability to not take issues or reactions personally**
- **Combination of Mother Theresa, Sara Connor, Gandhi and Jackie Chan**



Summary

- **Effective systems navigation for special needs families will support and enhance mission readiness**
- **Airmen and families are our greatest resource**
- **Any services provided initially will be greatly appreciated by families**
- **We should fulfill core value of “Excellence in all we do” to make AF program model in DoD**
- **Requires resources (manpower and funding) supported at the highest levels**



The Hilton Family



**Year of the Air Force
Family**





The Vitaliano Family



**Year of the Air Force
Family**





The Tarwater Family



**Year of the Air Force
Family**





The Vance Family



**Year of the Air Force
Family**





The Linn Family



**Year of the Air Force
Family**

