



The Experience of Military Families with ASD Therapeutic Services



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Abstract

"It's challenging to be a subset of a subset." This poster presents the experiences of military families with children with autism spectrum disorders (ASD).

Background

Military families are an underrepresented group in the ASD literature, despite the number of military dependents with a diagnosis of ASD reaching approximately 23,500 (Tricare, 2011). Although there have been no peer-reviewed studies about military and ASD related topics to date, some reports and parent guidelines from the Department of Defense (DOD) have outlined some possible challenges military families with a child with ASD may experience (e.g., OAR, 2010; Andrews et al 2011; Beuttner et al., 2011; National Council on Disability, 2011). These documents indicated issues such as greater emotional reactions, reduced continuity of care, changes in service eligibility across state boundaries, and access to appropriate educational programming as potential effects for children with ASD and their families as a result of military separation and relocation (OAR, 2010; National Council on Disability, 2011). Given the unique challenges families encounter with having a child with ASD and the unique stressors for military families, military families who also have a child with ASD may have experiences that differ from either group. Professionals need to understand the bidirectional nature of family factors and children with ASD and how these influence intervention outcomes in order to provide the family-centered services that evidence-based practices recommends (National Research Council, 2001; Pediatrics, 2004).

Purpose

The purpose of this study was to describe the experiences of military families with a child with ASD regarding therapeutic services to determine areas of strength as well as areas of need. Understanding the experiences of military families with a child with ASD may help improve interactions and collaborations with professionals during clinical services. It may also impact laws and policies for access and/or funding for services required by these families. Specifically, this study answered the following research question: What is the therapeutic experience of military families with a child with ASD?

Methods

In order to understand and describe the experiences of military families with a child with ASD, a qualitative methodology was chosen. Participants were recruited via social media to participate in approximately one hour, semi-structured interviews about their experiences with obtaining and maintaining therapeutic interventions for their child with ASD. Fourteen participants were recruited for the study and their demographic information is displayed in the table below.

Age	Ethnicity	Racial Background	Location*	Branch of Service	Number of Relocations**	Number of Separations**
Average: 37yrs Range: 27-55yrs	Not Hispanic/Latino: 11 Hispanic/Latino: 2	White: 11 American Indian/Alaska Native: 2 African American: 1	Western: 5 Southerm: 6 Northeastern: 1 Overseas: 2	Army: 6 Navy: 3 Air Force: 3 Marine Corps: 1 Coast Guard: 1	Average: 4 Range: 2-12	Average: 3 Range: 2-7, "various"

*Based on US Census 2010 regions
**Number since the birth of the first child with ASD

Analysis

The interviews were analyzed using a six step process adapted from grounded theory (Charmaz, 2006; Charmaz & Henwood, 2008) and focus group analysis techniques (McNaughton, Light, & Groszyk, 2001; Vaughn et al., 1996).

- Interviews were divided into thought units
- Thought units were coded into broad themes
- Most frequent broad themes were operationally defined and used to code the whole data set
- A trained coder coded 22% of the data set. Point-by-point reliability was calculated to be 89%, Cohen's kappa was .86
- Each theme was analyzed for subthemes.
- Participants were sent a summary of the themes and subthemes.

Coding Scheme

Interviews were coded into four themes and five subthemes. Relocation and separation are discussed on this post. Only ideas and experiences that were discussed by more than 50% (i.e., 8/14) participants were included in the results.

Theme	Subtheme	Example of Subtheme	Number of Participants (% of sample)
Relocation	Barrier	Delayed service or service effectiveness	10 (71%)
		Limited providers or services	12 (86%)
		Lack of service continuity	10 (71%)
		Lack of service quality	10 (71%)
	Support	Service quality	10 (71%)
		Service maintenance	9 (64%)
Separation	Barrier	Child emotional or behavioral reactions	13 (93%)
		Family stress	8 (57%)
		Lack of control	8 (57%)
	Support	Lack of external support	8 (57%)
		Lack of internal support	11 (78%)
Negative Impact	External support	8 (57%)	
	Internal support	8 (57%)	
	Child emotional or behavioral reactions	14 (100%)	
	Family stress	11 (78%)	

Results: Relocation

Barriers: any comment about a person, organization, situation, or action that impeded the family's ability to participate in services

Delayed service or service effectiveness

"Whenever we move, we always go to the back of the line and that's frustrating because...you're getting ready to move and so you're probably not taking him as much or whatever because you're transitioning out, and then the time you're in transition, and then trying to get him enrolled in something. So yeah, that really affects things."

"It's a gap of four to six months each time you move... it's not really firing on all cylinders for another six or eight weeks, so the benefit is not immediately there and immediately apparent."

Limited providers or services

"The challenge that I faced was just we only had three options (for ABA providers). So that was not a lot considering [the city] has like 12 million people, but having only three that serviced our area. I was told that actually one of those three only serviced our area. I kind of felt like, 'I hope this works because if it doesn't, we have no other options.'"

"There's only one speech therapy practice and really only one OT...and the developmental pediatrician retired...so there's no one else here."

"So it's (services) very limited. And this was the best place on the Air Force side that we could go to."

Lack of service continuity

"Next year, we'll probably be moving again. To where, I have no idea...You can't really keep any continuity with your therapist, which is an issue because you kind of want that. It would be ideal. Like with nonmilitary families with kids with autism, they can have the same provider, get the rapport going, and make great strides."

"It (consistency of services) just doesn't exist because we are like the cattle call going through."

Lack of service quality

"[The public school] was a very bad situation because with the temporariness of us being there, there was no way to enact change in our situation legally."

"If we were going to be here longer...then people might take it a little more seriously. I kind of feel like sometimes [my son] gets pushed to the wayside because we're going to be gone in a short time."

Difficulty of starting over

"It is confusing, especially if you don't know about insurance, you're new to the area, you don't know what providers are taking."

"It's a little depressing because...you know, 'okay, we're moving, so I'm going to have to do this all over again."

Lack of external support

"[My son] had friends on the block and he could go outside. Now he doesn't have anyone...he's definitely regressed."

"They (the community) just doesn't embrace autism."

Support: any comment about a person, organization, situation, or action that facilitated the family's participation in services

Service quality

"When I lived in [Eastern state] and...[Southern state], people would say 'no' to me all the time. And then we moved here, people were like, 'Let's try it.' I think it has been a positive impact on our family unity and on my son and his skills and levels."

"This has been the best move. The services here for the boys are really, really good. The reason [my husband] asked to go somewhere to get deployed is because we didn't want to move the boys again in case he had to retire."

Service maintenance

"When we stay put, then it was relatively easy to get new prescriptions for each of the types of therapies."

"Once [services] are rollin', they're rollin.' I mean, we're doing pretty good with keeping them going until we get orders to move again."

Negative Impact: any comment about a negative experience that was perceived to have resulted from relocation

Child emotional or behavioral reactions

"[My son's] biggest area is in problems with transitioning and changes in the normal routine, so it (moving) always causes problems."

"It (moving) puts a toll on him more than anyone else. Financially on us, but more mentally for him and emotionally...He gets anxiety because he doesn't know what school and there's new friends and new people and new teachers."

Family stress

"The whole move...was the most stressful thing I've ever done in my life with two autistic children. If I have the option to relocate again, I would not do it."

"When you are PCS-ing (permanent change of station), the stress level goes way up."

Lack of control

"We have no control really over where we move. You do a dream sheet, but really, the needs of the Air Force come before your family needs. So I'm concerned about the schools as my son gets older...a lot of schools don't always work well with children with autism."

"I never know where I'm going to be in the following year. I don't know if we're moving next year. I don't know if we're moving the year after or three years from now."

Results: Separation

Barriers: any comment about a person, organization, situation, or action that impeded the family's ability to participate in services

Lack of external support

"When they send your family your spouse away for long periods of time, some spouses move back with family to kind of get support. My husband he's deployed right now, I have [my son] who's six...and [my son] who's three months old. It would've been ideal if I could've went back home. But then the problem is, I would've had to go through all of the rigmarole of finding new speech therapist, new OT, new ABA providers and it's only for like six months. So then I would've had to uproot him for six months and then try...and then when I come back, I would've had to try to get back on the waiting list again when I came back here. So you know whenever they send your spouse away for long periods of time it's hard to..you kind of stay out of wanting to try to keep continuity of care for your child. And then you go crazy in the process because you don't have support to help you get through it all. But those are the big things that I see in challenges to continuity."

Lack of internal support

"My kids like consistency of schedules. Those are what harm me because if I'm out of commission, if I can't do everything, then everything falls apart. [My daughter] was saying, 'If Mom's okay, I'm okay.' Well what if Mom is not okay?"

"When you're a single parent, it is impossible to do everything you need to do and be on your game 24-7 and smile and have people in your house...Some days, you just want to be like, 'We're shutting done. Nobody's coming in my house. We're keeping our pajamas on all day. We're going to eat in bed, but you can't do that."

Support: any comment about a person, organization, situation, or action that facilitated the family's participation in services

External support

"Respite is so important, especially when your husband is gone for so long. It's so important, just a few hours a week to decompress."

Internal support

"It's easier to get things done with the military side of the house around."

"We've been lucky that he's been at stations where it's only been like a week or two deployments."

Negative Impact: any comment about a negative experience that was perceived to have resulted from relocation

Child emotional or behavioral reactions

"Children may not know how to address their emotions anyway, but for someone who really has a hard time grasping onto normal emotions of everyday life, having to deal with it (deployments) was just very, very difficult."

"He flaps more, he gets more irritated, he's more distracted, cries more, whines, more. Everything. It's multiplied times 10."

Family Stress

"Then we have mid-tour break where my husband comes home and things are okay. And then you start over. We have two months where things are okay and then [my son] severely regresses. And then things slowly start to get better and then my husband comes home and you do the process again."

Discussion

Overall, results indicate that military families with a child with ASD experience challenges associated with both the military lifestyle (e.g., Andrews et al., 2011, Burrell et al., 2006) and having a child with special needs (e.g., Little, 2003; Mackintosh, Goin-Kochel & Meyers, 2012). Due to their membership in two groups prone to support limitations and service accessibility issues, military families with a child with ASD may be at additional risk for high levels of stress and difficulty with ASD related services.

Implications for Practice

Medical and educational providers need to be aware of how membership in the military may impact service provision and family functioning (e.g., relocations and separations may produce increased levels of stress, anxiety, and challenging behaviors in the child with ASD). Assessments administered during military related lifestyle changes may be inaccurate and should not be used for eligibility determination. Academic/therapeutic performance may stall/slide during major life transitions. Providers should note possible explanations for the changes, but not hold these performances against the child. Relocations and separations may also produce increased levels of stress and anxiety in the parent(s) at home. During these times, it may be important for providers to intervene at the family level. Providers should also help the spouse at home to locate additional services, such as respite, if needed.

Implications for Policy

The federal special education laws (e.g., IDEA, 2004) uphold the rights of parents to seek mediation or due process when they believe the school is not abiding by those special education laws. However, military families may only be in one location for a relatively short amount of time (e.g., 2-3 years) and may not have time to complete these processes and obtain appropriate education and therapeutic services for their child with ASD before receiving orders to the next location. Policy makers should consider adding provisions to the law that enable military families with a child with special needs to have access to the same rights as nonmilitary families in a timely manner. Additionally, states can adapt and enforce the Interstate Compact on Educational Opportunity for Military Children Act (2011) to help reduce barriers to continuity of education for children of military families, including those with special needs.

Conclusion

This qualitative investigation contributes significantly to the field as it is currently the only empirical study to examine the "secret little world" of military families with a child with ASD. Previously, the only information available for clinical decision making and policy determination were technical reports from the Department of Defense (e.g., Andrews et al., 2011); surveys from military organizations (e.g., Blue Star Families, 2013); and newspaper, magazine, and social media reports from families (e.g., Doyle, 2008). Without empirical data from rigorous, methodologically sound research investigations, there is no literature upon which to determine evidence-based practices for this population. Lack of evidence-based practices may result in ineffective, inappropriate, or insufficient services provided by poorly equipped professionals that do not address challenges specific to military families with a child with ASD. In order for military families with a child with ASD to receive services that meet their needs and for professionals to be knowledgeable in delivery of those services, additional research must be conducted.

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