

**Forces Additional Needs  
and Disability Forum**



**FANDF**

Giving a voice to Forces  
families with additional  
needs and disabilities

*30th Anniversary Report*

**“Families Fighting On...”**

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## EXECUTIVE SUMMARY

**The Forces Additional Needs and Disability Forum consists of serving Forces families who have a close loved one with an additional need or disability. Established in 1989, the FANDF have lived experience and knowledge of the challenges families face, helping to give a voice to Forces families with additional needs and disabilities.**

To mark the 30th anniversary of the creation of the forum, the FANDF committee conducted a survey of issues faced by serving Forces families with additional needs and disability. This is the largest known survey into MOD families with additional needs or disabilities in the UK Armed Forces. The resulting report, Families Fighting On, provides a platform for the families to explain in their own words their lived experiences and the issues they face on a daily basis.

### SURVEY GIVES A VOICE TO FORCES FAMILIES WITH ADDITIONAL NEEDS

255 families, who identify as having a member with additional needs or disability from across the tri-service Armed Forces, completed our survey. The survey's questions were formulated from consolidated key issues lists that drew on previous informal data activities, including the biennial FANDF conference and regional outreach activities. The survey responses formed the quantitative data base for this report. This has been supplemented by free text responses that have allowed respondents to explain more fully in their own words their lived experiences; formulating the base for the extensive qualitative research element of this report. The responses were reviewed, analysed and coded to identify the key trends.

The survey was extended to all families of the serving Armed Forces and was open access but was only to be completed by families who have a member with additional needs or disability. The respondents were not all FANDF families, and all responses received were included in the quantitative results, in order to avoid selection bias. The sample cohort also represented all three Forces and drew from across the ranks, no Force, job role or rank was excluded. Naturally, being a sample of military families with a loved one with additional needs or disability means that all respondents will have been impacted both by their military career and the needs of their family member. This inherent bias is unavoidable but understanding this impact, whether its negative or positive, and what could improve the situation for these families was the intention of the survey.

The author of this report, Michelle Claridge, is herself both a former Army Education Officer (with a special interest in additional learning needs), the spouse of a currently serving member of the Armed Forces and has a child with additional needs. Michelle has been a member of FANDF for eight years and a volunteer committee member for six, at the time of this report's creation she was serving as Vice-Chair on the committee and undertook this research work pro bono.

The scope of our survey was wide, exploring everything from accessing health care provisions and educational services to the impact on employment, civilian and military careers and the mental health of carers and the family.

### SEEKING TO UNDERSTAND

There has been significant improvements into the inclusive nature of the Armed Forces in recent years. 2018's announcement that all roles in the military were now open to women, including combat roles, marked a watershed moment in British military history. The Armed Forces have adapted to the changing face of its personnel: no longer are women who serve expected to give up their career if they start a family, whilst the number of serving personnel who are single parents, or a primary carer has also increased. The MOD's defence and inclusion (D&I) strategy, launched in 2015, indicated the commitment to creating a diverse and inclusive organisation. The strategy recognises there is still work to be done and states that 'The Whole Force' are expected to play their part in making a difference to the experience of everyone in Defence<sup>1</sup>.

Following 2018's biennial FANDF conference, the MOD requested that the FANDF committee conduct research into the lived experiences of its families, to enable better understanding of the challenges they faced. The resulting findings of the survey provide a rich evidence base for the MOD to draw on as they continue to fulfil their vision of Defence harnessing the power of difference to deliver the capability that safeguards our nation's security and stability.

<sup>1</sup>MOD A Force for Inclusion, Defence Diversity and Inclusion Strategy 2018-2030.

## KEY CONCERNS FOR SURVEYED FAMILIES

Our research reveals the additional strain that serving in the Armed Forces is placing on families who are already under great pressure caring for loved ones with disabilities and additional needs, complex medical needs, long-term and life-limiting illness. For some, the itinerant nature of Armed Forces life with the requirement to move with postings- often every two years- and the disruption this causes to education support, medical treatment, and services provisions are felt to have a detrimental impact. Our survey found that health provisions and education were the key concerns facing families with 41% and 38% of all respondents identifying these issues respectively.

Whilst 21% of families surveyed said that the impact of change was a key issue for them, the impact of change is at the root of many of the other negative aspects families face. Health provision, continuity of care, access to treatment and support, the acceptance of both medical and educational diagnosis from one health or education authority to another were all affected by change. The respondents talked of finding themselves returning to the bottom of waiting lists following a move, finding that under their new NHS Clinical Commissioning Group (or NHS Trust) treatment programmes - including those for cancer - were no longer available to them. They had to 'start from square one' following a move going back through the diagnosis process before being able to receive the treatment or support they had previously had access to. Such delays range from frustrating and stressful, to life impacting and threatening.

With 48% of respondents identifying Autism Spectrum Disorders (ASD) as the primary need affecting their families, the impact of a mobile life is a significant issue as a key difficulty for many of those who have ASD is dealing with change.

### WIDER IMPACT ON SOCIETY

The impact of the mobile life is not just on the family. In addition to the 48% of respondents who identified ASD as the primary need, a further 17% of survey population highlighted learning disabilities/difficulties. Combining this result means a significant 66% of military families with additional needs or disabilities having conditions. This is a significant number that directly impacts local education authorities. The geographical location of our survey responses indicate that there are hotspots for educational and health support needs, with the location of military bases meaning that serving families with additional needs and disabilities are likely to be located in particular geographical areas. Wiltshire, set to be the Army's training area in the UK, produced by far the highest level of responses (17%). Hampshire which includes the Army HQ in Andover and one of the Navy's three operational bases, HMNB Portsmouth drew the second highest level of responses (11.59%)<sup>2</sup>.

### A NEED TO BE SUPPORTED

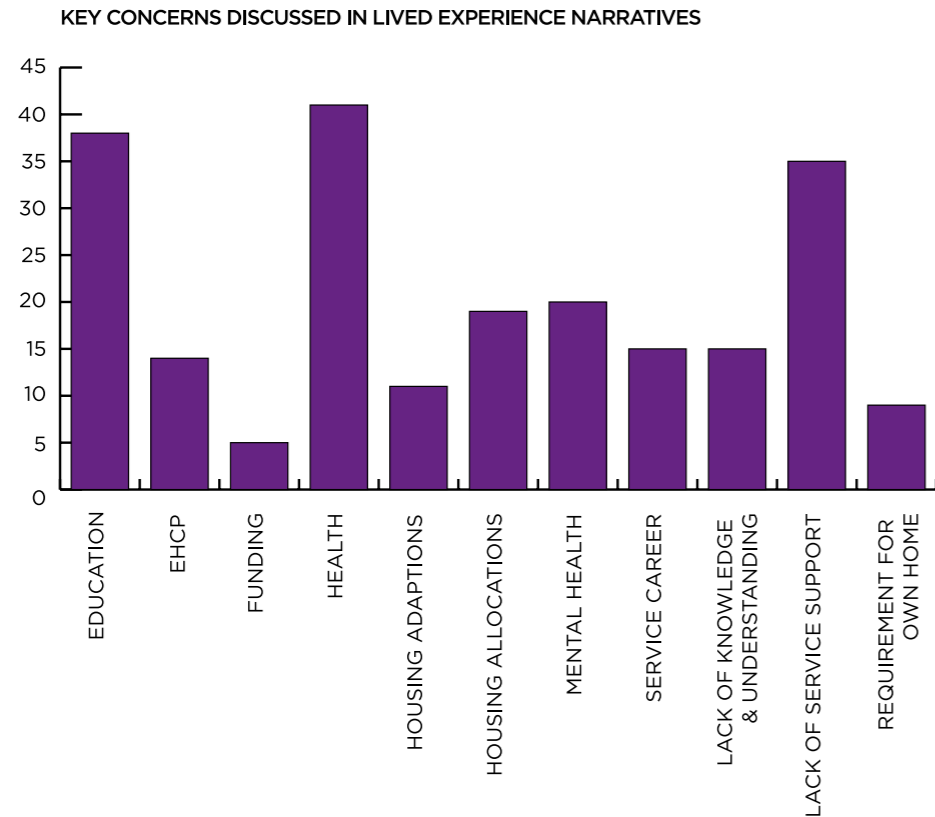
Whilst the majority of respondents felt supported by their employer, crediting their boss or Commanding Officers as being understanding of their family needs, some families surveyed did not feel that the MOD and the individual military services understand their particular needs. 35% of surveyed families said they felt a lack of support from the Service. Despite existing policies, there seems to be a lack of consistency across the Services, with the level of support often being determined by individuals in key positions within the unit and wider associated organisations.

Multiple respondents, (especially those of lower rank) while recognising that the Armed Forces have limited influence over external health and educational issues, did not feel that the MOD was doing all it could to influence issues such as housing and notice of assignments.

As a result of our findings, we have produced a list of recommendations that aim to address the issues which these families are currently facing. These recommendations require actions to be taken by the MOD, the Services, the FANDF and its committee with the aspiration that serving in the Armed Forces no longer negatively impacts on families with additional needs and disabilities.

<sup>2</sup>Appendix A, page 29 has the complete breakdown of responses based on geographical area and Service type.

## SUMMARY OF THE SURVEY'S KEY FINDINGS



- Lengthy waiting times for educational assessments and diagnosis which were not completed before posting.
- Educational diagnosis is not accepted between local education authorities resulting in children being subjected to multiple repeated assessments.
- Support requirements identified on educational assessment were not met within the classroom setting or were not retained on moving.
- There is a lack of pre-school and school age wrap around provision for children with additional needs.
- Educational Health and Care Plans (EHCP) are not being accepted between counties and devolved governments within the UK. A universally accepted document and personal data exchange process should be developed.
- There is a perception that, in some cases, Service children are not invested in as they will be moving on shortly.
- Medical diagnosis from one Clinical Commissioning Group (CCG) and NHS Trust are not being accepted by another CCG following military-service required relocation.
- Patients placed at bottom of waiting lists for diagnosis / treatment regardless of how long they had already been on a waiting list in their previous location.
- Access to treatments, medication and therapies is not consistent across all areas.
- Lack of consistency in consideration given to additional needs or disabilities during both the personnel assignment and housing allocation processes.
- There are issues with the procedures and time taken for housing adaptations.
- There is a perceived lack of support from the Services for those families with additional needs.
- Significant numbers of carers within the military community develop mental health issues.

## RECOMMENDATIONS

- **Freedom to Speak Up champion.** A single MOD funded "Freedom to Speak Up" champion at OF 5 level (Army Colonel, Navy Captain, RAF Group Captain) who carers can approach directly, without fear of blame or career impact, if they perceive that issues within MOD are impacting on health or wellbeing. This would primarily be a signposting Service but could also be at times an advocacy Service if required.
- **Promote official registration of needs.** FANDF to work with MOD to promote voluntary registration of additional needs or disabilities on Joint Personnel Administration (JPA). Improving the culture within the Services to ensure registration is not detrimental to career.
- **Adherence to Assignment Guidelines.** Consistent application of guidelines for welfare cases at single Service assignment boards for those with families with additional needs. Whilst recognising the needs of the Service have primacy, implementation of options such as a formal mechanism for Service personnel to accept a pause in their career pathway to meet needs of the family should be available.
- **Improving Support study.** Utilise existing MOD-funded welfare working group to conduct a study, working collaboratively with FANDF, into those areas that can be supported better by MOD, specifically (but not exclusively) surrounding this study's evidence-base relating to those on the autistic spectrum.
- **Identify landscape of need.** FANDF to work with Department of Children & Young People (DCYP) and Children's Education Advisory Service (CEAS) to identify families who have children with ASD, additional learning needs or who are in receipt of Special Educational Needs Educational Allowance (SENA), improving understanding of the Armed Forces additional needs and disabilities landscape.
- **Respite Provision.** FANDF work with SSAFA and Service Welfare agencies to investigate respite support for Service families with children who have additional needs or disabilities.
- **Mental Health Awareness engagement.** FANDF to work with mental health specialists to provide mental health awareness, training & education opportunities as part of their outreach activities.
- **Impact on Carers focussed study.** An in-depth investigation of the impact on carers within the military community.
- **Communicating Support campaign.** An ongoing MOD targeted and funded campaign to communicate, specifically to the carers of Service families with additional needs/disabilities, the current Service and charitable support that is available to them.
- **Recognising Carers Review.** MOD Review of the DMICP Register of Carers and campaign to promote registration. Additionally, FANDF to work with military welfare organisations in developing a campaign to raise awareness amongst both families and the Chain of Command of the Care Act 2014 and the legal rights of carers.
- **Adherence to Armed Forces Covenant.** Existing formal links within MOD partnership boards, including devolved administrations, should be exploited to address issues with healthcare and education and prevent Armed Forces families from being overtly disadvantaged.
- **Universally accepted EHCP and personal data transfer.** Either the existing EHCP system is made universally acceptable making it transferable from county to county, devolved authority to the next, or a new system be created that is adopted universally by all education authorities and private schools, to ensure personal data pertaining to educational needs, health etc. is transferred with the pupil.
- **Adherence to the Care Act 2014.** MOD to work with CCGs to ensure that, in line with the legal requirements of the Act, Service personnel and their families should receive continuity of care from day one of new posting.
- **Application of Additional Needs & Disabilities Criteria for housing.** Development of Additional Needs & Disabilities Criteria (to include those undergoing diagnosis) for allocation/retention of Service Family Accommodation (SFA) to support consistent application across.
- **Adapted SFA Database.** Improvement of the Defence Infrastructure Organisation (DIO) database of adapted SFA properties and implementation of a flag system for adapted SFA properties and those SFA properties housing families with additional needs or disabilities.
- **Support for Moving from SFA study.** A study should be commissioned to investigate methods to best support, financially and work wise, those who choose to buy their own home in order to ensure continuity of care for their family member(s) with additional needs or disabilities.

## INTRODUCTION

All Service personnel from across Her Majesty's Armed Forces who have a family member with an additional need or disability are eligible to be members of the Forces Additional Needs and Disability Forum (FANDF). The FANDF Committee is made up of FANDF members who are volunteers, either from Armed Forces personnel or dependants, who are selected to represent the views of the wider forum. FANDF is an MOD group facilitated by SSAFA, the Armed Forces Charity.

A reflection of the society they proudly serve, FANDF members experience many of the same issues as the general population, including having family members who have additional needs or disabilities.

Mobility is a key requirement of life in the Services. FANDF members accept this, as for many it is an attractive part of life in the Armed Forces. However, when additional needs or disabilities of family members are thrust upon them, it is dealing with the impact of change caused by that mobility which is their biggest challenge and concern.

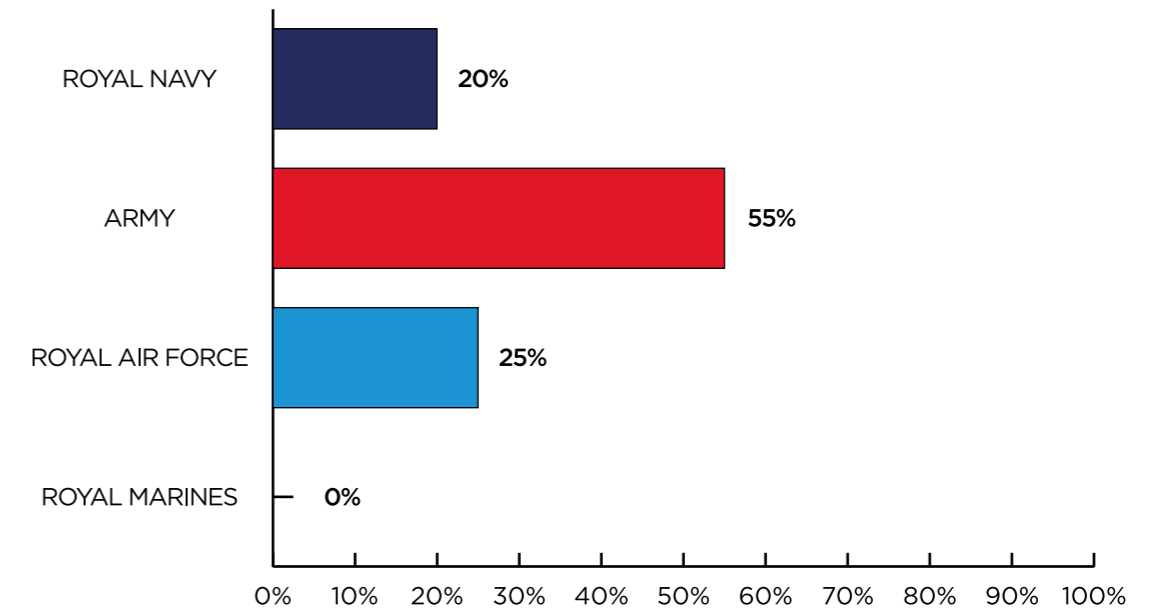
***“Mobility is part and parcel of military life, but my son has moved 11 schools in his short life. Not moving brings its challenges with regards to promotion...I think overall there needs to be a balance with family and Service, one which sadly there isn't at the moment.”***

2019 sees FANDF celebrate 30 years of Service to the Armed Forces community. In recognition of this, the Committee undertook the largest ever survey of members to ensure their activities continue to represent members needs and effectively communicate these needs directly to policy directorates within the MOD.

## OVERVIEW OF THE FAMILIES WITH ADDITIONAL NEEDS AND DISABILITIES IN THE ARMED FORCES

### SERVICE DISTRIBUTION

Responses indicate that the number of families dealing with additional needs and disabilities is in proportion to the size of each Service (i.e. Army is approximately twice the size of both the Royal Navy and Royal Air Force<sup>3</sup>).



Above: Graph indicates the distribution of the survey responses across the Armed Forces. There were a total of 255 responses.

The breakdown by Service of respondents confirms the percentage of families dealing with additional needs and disabilities in each Service is also similar:

Royal Navy = 0.16%

Army = 0.18%

RAF = 0.19%

Efforts were made to distribute the survey and make it accessible to all. Despite this we believe that a significant number of families are not represented in these figures, either because they were unaware of the survey or did not feel able to complete it.

<sup>3</sup>MOD UK Armed Forces Quarterly Service Personnel Statistics 1 July 2019 (Published 15 August 2019)



## IMPACT ON MILITARY CAREER

18% of families surveyed felt that having a family member with an additional need or disability had negatively impacted on the Service person and their career:

***“Serving person had promotion taken away due to child being on chemo.”***

***“This has affected my morale, my working day and my career, promotion and pension.”***

***“I can’t go away with the Service; I can’t get promoted and I struggle every day with the lack of policies for this within the Service.”***

### RECOMMENDATION - FREEDOM TO SPEAK UP CHAMPION:

A single MOD funded “Freedom to Speak Up” champion at OF 5 level (Army Colonel, Navy Captain, RAF Group Captain) who carers can approach directly without fear of blame, or impact on career, if they perceive that issues within MOD are impacting on health or wellbeing. This would primarily be a signposting Service but could also be at times an advocacy Service if required.

## LANDSCAPE OF NEED

The ‘formal notification’ of a family member with an additional need or disability is only a mandatory Service requirement for Army personnel<sup>4</sup>, primarily to ensure this is taken into consideration for allocation to assignments, particularly overseas. Personnel from the Royal Navy and the Royal Air Force can elect to inform the chain of command.

The true number of Service personnel who have families with additional needs or disabilities is therefore not known, and currently the MOD do not track this group as they do with other diversity or inclusivity groups such as BAME recruits or female Service personnel. Whilst all Service personnel who have a family member with additional needs or disabilities are eligible to become members of the FANDF, the forum’s own database of members is not believed to be true reflection of the number of families who would qualify. The FANDF committee recognise that there are many families out there who are unknown to them and who may not even be aware of the forum. The survey responses of 255 represents a wider pool than the forum’s membership was at the time of the study, and even the report’s sample size is believed to be smaller than the true population size of serving families with additional needs.

A concerted effort to improve the registration and tracking of this group is essential. Not only will it mean that those responsible for the welfare and professional requirements of Service personnel - i.e. CO’s - are aware of the family situations of their team. It will also ensure that policy directorates within the MOD will know the population figure of military personnel with families of additional needs and disabilities and be better placed to assess the level of need within the Armed Forces in order to develop appropriate policies, accordingly.

### RECOMMENDATION - PROMOTE OFFICIAL REGISTRATION OF NEEDS

FANDF to work with MOD to promote voluntary registration of additional needs or disabilities on Joint Personnel Administration (JPA). Improving the culture within the Services to ensure registration is not detrimental to career.

<sup>4</sup>Army General Administrative Instructions (AGAI) 108.

## NEED FOR GREATER UNDERSTANDING

The qualitative data this report gathered via the free text survey responses revealed that there is not a uniform or consistent level of support or understanding within the Armed Forces when it comes to the impact of additional needs and disabilities. Some families with additional needs and disabilities have received support and understanding from the Chain of Command as their lived experience responses illustrate:

***“My son has Down Syndrome, so far we have had understanding employers who have been able to be flexible, but this could change.”***

***“My son has only been diagnosed within this assignment and luckily I got an extension to remain here which offers continuity of his support and education although I know not everyone has this luxury.”***

However, some respondents when invited to use the free text narrative option in the survey, indicated that they feel there could be greater understanding of the challenges that families with additional needs and disabilities face:

***“The main issue we find is the lack of knowledge, understanding and support from the Armed Forces.”***

***“Work colleagues and hierarchy don’t understand the reality that you live...this puts a strain on my marriage and personal life as a committed serviceman and husband.”***

***“I was told the (Service) comes before my family and that I needed to get my priorities right.”***

***“His end of year report questioned his commitment to the (Service) (after 26 years!) because he wanted to be at home when he got the chance, people just don’t understand.”***

The free text responses also showed there is a general belief that rank can influence the impact on the Service person’s career:

***“It’s cynical, but I feel I have more power now as an LE Major than I ever had as an INF Sgt/CSgt. Rank has brought greater control over my ability to assist my wife as carer.”***

There was also evidence that families from across the rank structure are affected:

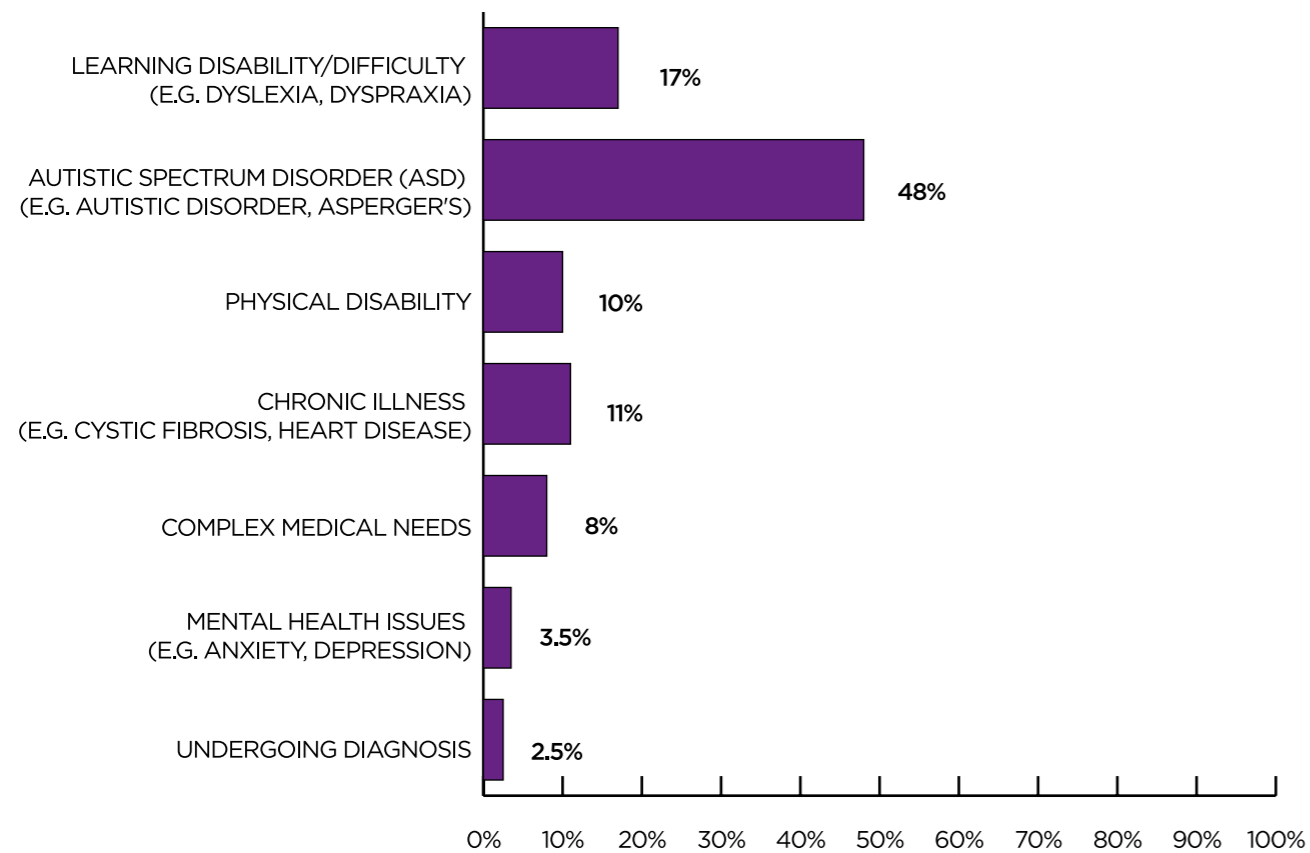
***“During time at staff college, I received no comment for my commitment to carry on with the course after taking only a day compassionate when child had emergency Neurosurgery, I was just told to catch up, no compassion.”***

The divergence in support across the Service is clear within the qualitative evidence drawn from our survey. Despite existing policies, there is a lack of consistency across the Services, with the level of support often being determined by individuals in key positions within the unit and wider associated organisations. Our research found the culture within units or wider associated organisations can significantly shape the experiences of families with additional needs and disabilities.

### RECOMMENDATION - ADHERENCE TO ASSIGNMENT GUIDELINES

Consistent application of guidelines for welfare cases at single Service assignment boards for those with families with additional needs. Whilst recognising the needs of the Service have primacy, implementation of options such as a formal mechanism for Service personnel to accept a pause in their career pathway in order to meet needs of the family should be available.

## TYPE OF NEEDS AND DISABILITY



Above: Graph shows the types of needs that were indicated by survey respondents, total responses 255.

## AUTISTIC SPECTRUM DISORDERS

Autistic Spectrum Disorders were identified by 48% of members as the primary additional need or disability affecting their family, approximately 0.9% of the Armed Forces population. This is in line with the number of individuals affected by autism in the UK population, approximately 1%<sup>5</sup>. Analysis of qualitative data confirmed that in many of these cases families were dealing with one or more autistic family members.

Autistic Spectrum Disorders (ASD) are a hidden disability and a key difficulty for many of those who have ASD is dealing with change:

***“The constant changing of plans affects my children badly, routine is key to helping them remain calm and ‘non-violent’. When plans change the night before there is not enough time to prepare them. My wife is then left with two very strong aggressive little boys who cannot understand nor cope with last minute changes constantly and nobody cares.”***

***“Life in general is more complicated. We need routine, no unexpected changes, schedules.”***

***“We have moved seven times and he is seven years old. Transition from school to school is horrendous, different counties need different paperwork, my son has had to go through numerous diagnosis to confirm he has ASD.”***

<sup>5</sup>The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care

In particular, moving to a new house can lead to significantly increased stress and anxiety due to the need for routine and familiarity<sup>6</sup>.

Families reported issues when assignment requires relocation. Some respondents expressed the feeling that there was a lack of understanding from the chain of command, housing and welfare staff on the impact that change can have on those with ASD:

***“Moving around with a child with additional learning disabilities is challenging, especially Autism. Children with Autism find it difficult to change, so moving affects them excessively.”***

Service personnel and their families accept being mobile is part of military life, in fact it is one of the attractions, and improved understanding of ASD and other family needs and the measures which can be implemented to help or support such individuals during move will allow families to embrace military life more sustainably.

### RECOMMENDATION - IMPROVING SUPPORT STUDY

Utilise existing MOD-funded welfare working group to conduct a study, working collaboratively with FANDF, into those areas that can be supported better by MOD, specifically (but not exclusively) surrounding this study’s evidence-base relating to those on the autistic spectrum.

## LEARNING DIFFICULTIES

Learning disabilities/difficulties were highlighted by 17% of the survey population, a key figure for education authorities in areas supporting large military populations. However, individuals with ASD also (generally) have issues related to education. When the two issues are combined it results in a significant 66% of military families with additional needs or disabilities which local education authorities will be responsible for supporting.

The geographical location of our survey responses indicate that there are hotspots for educational and health support needs, with the location of military bases meaning that serving families with additional needs and disabilities are likely to be located in particular geographical areas. Wiltshire, set to be the Army’s training area in the UK, produced the highest level of responses (17%). Hampshire which includes the Army HQ in Andover and one of the Navy’s three UK operational bases, HMNB Portsmouth, drew the second highest level of responses (11.59%). Please see Appendix A on page 29 for a full breakdown of the geographical location of responses.

Regrettably, the perception is that in some areas with high military populations, this educational support is not available:

***“(they) do not have suitable schools for ASD - they say they cater for it but in reality, the children are often left to sit in a corridor or at the back of the classroom.”***

***“Local authority aren’t great in supporting him and the school has little funds.”***

***“Lack of suitable school provision.”***

***“Trying to find childcare for children with additional needs is almost impossible, especially when it’s not a visual disability.”***

### RECOMMENDATION - IDENTIFY LANDSCAPE OF NEED

FANDF to work with Department of Children & Young People (DCYP) and Children’s Education Advisory Service (CEAS) to identify families who have ASD, additional learning needs or who are in receipt of Special Educational Needs Educational Allowance (SENA), improving official understanding of the additional needs and disabilities landscape within the Armed Forces community.

<sup>6</sup>National Autistic Society: <https://www.autism.org.uk/about/family-life/in-the-home/moving-house.aspx>

## COMPLEX AND MULTIPLE NEEDS

Families were invited to provide additional details if they were dealing with complex medical needs, or they had more than one family member with additional needs or disabilities. 54 families (21% of the survey population) provided additional data in response, confirming that many were dealing with the impact of significant additional needs or disabilities<sup>7</sup>.

Whilst in some cases, this may be several family members diagnosed with ASD:

***“Both my sons are autistic. My eldest low functioning, non-verbal with severe mental impairment. My youngest is high functioning, currently being assessed for ADHD. My daughter will be getting assessed soon.”***

A number of families were dealing with several members suffering from a wide range of additional needs or disabilities:

***“We have 2 disabled children, one with heart disease, sensory processing disorder and is in a wheelchair... other one has c-acc (part of his brain missing) genetic disorder, deaf, cleft palate, leg braces, standing frame, and a bent spine and is also peg fed.”***

Within the general population the prevalence of disability rises with age. Around 6% of children have a limiting long term illness, impairment or are disabled, compared to 16% of working age adults and 45% of adults over State Pension age<sup>8</sup>.

Due to there being no official database of military families with additional needs or disabilities (see page 10 for more), this report is reliant on the survey responses to ascertain a sense of the distribution of disability in Service families population.

The survey’s finding indicate that contrary to the general population trend, Service families are dealing with a higher levels of physical disability and chronic illness in children than in adults (Table, right).

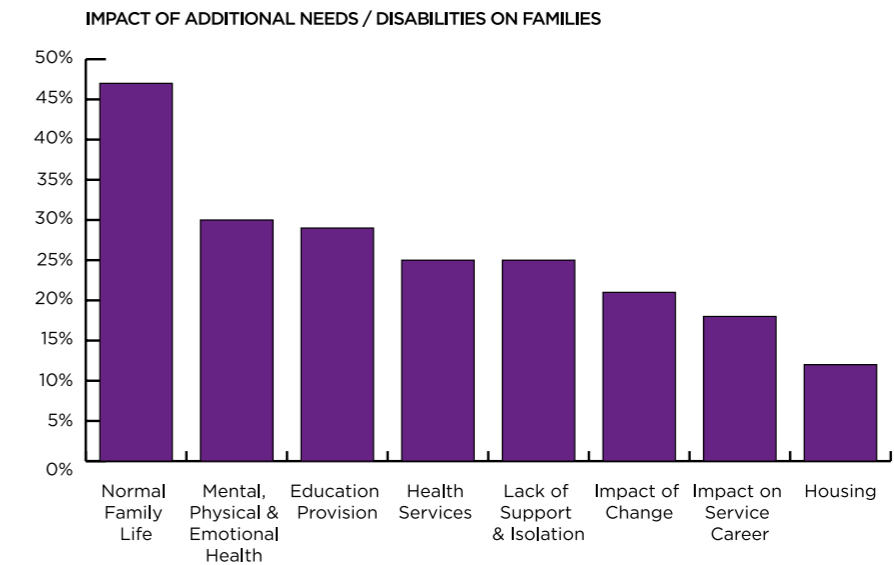
The demographics of the Armed Forces community with adults generally younger and fitter, is likely to be one of the factors affecting this finding.

Further research is required into why the percentage of children with physical disability and illness appears so high.

Family Member(s) Affected by Additional Needs or Disabilities	Number of Responses
Child with complex medical needs	20
Adult with complex medical needs	4
Child and adult	9
Two children	13
Three children	4
Two children and one adult	3
Three children and one adult	1
<b>Total</b>	<b>54</b>

Above: Table shows the number of surveyed families who indicated they were dealing with complex medical needs or with more than one family member with additional needs or disabilities

## THE IMPACT OF ADDITIONAL NEEDS AND DISABILITIES ON FAMILIES



## DISRUPTION OF NORMAL FAMILY LIFE

The disruption or prevention of a ‘normal’ family life was highlighted as a primary impact by 48% of families surveyed.

The quantitative data from our survey showed the types of disruption families faced:

- Behaviour of a family member prevented the family from participating in activities or had significant impact on sleeping patterns/arrangements. (9%)
- There was a requirement for 24/7 care or constant supervision. (12%)
- Siblings were acting as carers or suffered as a result of care or supervision commitments of parents. (12%)
- Service spouse was the primary carer and as such was prevented from working due to care requirements, lack of support or no special needs childcare. (5%)
- There was a financial impact on the family as a result of funding specialist medical or education equipment, medication, food and specialist support. (11%)

The following free text responses from the survey show the reality of life for these families:

***“Some days we remain housebound, including his two younger siblings, as he is emotionally overwhelmed or it’s too noisy and bright outside.”***

***“Completely different lifestyle to what other families could go out and enjoy. Sensory overload causes my two sons to have ‘melt downs’. As my eldest (11) is incontinent we can’t go to theme parks etc...as there’s no changing facilities for him.”***

***“My son does not sleep well, he is on medication which only allows him to calm before bed and he is disruptive in the night, which wakes my other children...he becomes physically violent to both me and his siblings which scares them.”***

***“No childminders will take him due to being aggressive and non-verbal.”***

## RECOMMENDATION- RESPITE PROVISION

FANDF to work with SSAFA and Service welfare agencies to investigate respite for Service families with children who have additional needs or disabilities.

<sup>7</sup>Anonymised qualitative data for this question can be found at Appendix B.

<sup>8</sup>Department for Work & Pensions, Office for Disability Issues, Official Statistics Disability Facts and Figures Published 16 January 2014.



## STRAIN ON WELLBEING OF FAMILIES

Whilst only 3.5% of families surveyed indicated mental health as their primary additional need or disability issue, a significant number of qualitative responses confirmed that family members who are carers are themselves suffering from mental health issues, as a result of dealing with the primary additional needs or disability within their family.

In their own words respondents told us of the stress and strain that having a dependant with an additional need or disability had on the family. One respondent listed the impacts as:

***“Worry, stress, continuous appointments. Financial strain, anxiety, sleepless nights. Emotionally and physically drained.”***

Their words were echoed by other respondents who said that the possibility of deployment or work-induced absence added to the stress of having a child with health needs.

***“Extra stress on the family, extra financial worry...constant worry that the Service person will be away when the child is hospitalised.”***

***“At times of low mood, it makes it very difficult for myself and my wife to function normally.”***

30% of respondents identified that dealing with the family member(s) additional need or disability directly impacted on their mental, physical and emotional health and wellbeing.

***“Depression and anxiety, loneliness and family break down.”***

***“My wife really struggled with her mental health at this stage as we both felt he was being failed and we were not listened to.”***

***“As a result of our (child) being born deaf/blind, both parents find it hard to cope and suffer from depression.”***

***“Living with a young person on the spectrum is hard for the rest of the family and my own physical and mental health has been suffering.”***

***“The drop in services brought about a major dip in my partners mental health which resulted in a failed suicide attempt. One of four in total.”***

### RECOMMENDATION - MENTAL HEALTH AWARENESS ENGAGEMENT

FANDF to work with mental health specialists to provide mental health awareness, training & education opportunities as part of their outreach activities to military families.

## LACK OF SUPPORT AND FEELINGS OF ISOLATION

In many cases families felt the impact on mental, physical and emotional health and wellbeing was exacerbated by a lack of support and isolation (25%).

Examples of lack of support included:

- No family support due to mobile nature of Service life.
- Isolated location of military bases.
- Families living in their own home (married unaccompanied) had no contact with the Service person's unit or welfare organisations.
- Lack of support, knowledge or understanding from chain of command for the Service person.
- Spouse feeling isolated due to a lack of knowledge and understanding from other Service families.
- Lack of any support to gain respite care.

Illustrative comments from lived experience data include:

***“Physically and mentally daily life is very stressful, and it is easy to become run down, the added isolation and unpredictability of my husband's job makes arranging any type of support very difficult.”***

***“Simple moral support or respite for us is unavailable due to family living so far away.”***

***“I find being a military wife with a disabled child very lonely and I can't talk to anyone as they just don't get it or understand.”***

### RECOMMENDATION - IMPACT ON CARERS FOCUSED STUDY

An in-depth investigation of the impact on carers within the military community.

Whilst some families felt they had received support from the Services and their colleagues:

***“As a single parent this took its toll on my mental health and I am thankful that I have such understanding colleagues who helped support me.”***

***“The Service generally has helped, but at higher levels of policy there is nothing in place.”***

A number of families reported feeling let down by the lack of Service support:

***“The (Service) has not been helpful when requesting welfare aid.”***

***“Being in the (Service) makes life harder as there is no help or support coming from them.”***

***“My husband being told to ‘consider his position, if his wife cannot cope with the rigours of military life’ when asking not to be deployed due to our child's additional needs”***

### RECOMMENDATION - COMMUNICATING SUPPORT CAMPAIGN

An ongoing MOD targeted and funded campaign to communicate, specifically to the carers of Service families with additional needs/disabilities, the current Service and charitable support that is available to them.

Whilst there is existing policy<sup>9</sup> requiring Service personnel - who are carers - to be registered on Defence Medical Information Capability Programme (DMICP), it is unclear how widely this has been implemented across the Armed Forces.

The policy clearly states the value of registration: “identification and awareness of carer status by relevant DPHC staff, including locums, therefore allows additional services and support to be offered appropriately”.

### RECOMMENDATION - RECOGNISING CARERS REVIEW

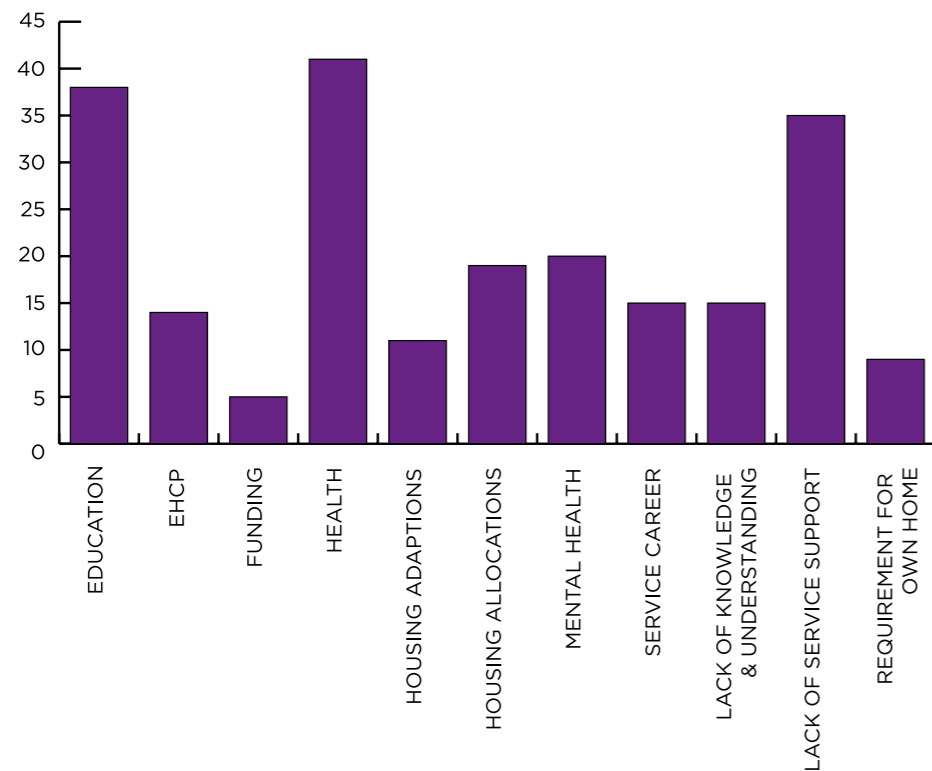
MOD Review of the DMICP Register of Carers and campaign to promote registration. Additionally, FANDF to work with military welfare organisations in developing a campaign to raise awareness amongst both families and the Chain of Command of the Care Act 2014 and the legal rights of carers.

A number of the families who identified the impact of change (21%) as a primary consideration were families who had family members with ASD. This was also a major concern for families dealing with all forms of additional needs and disabilities primarily due to the knock-on effects on education, healthcare and housing as fully revealed in the examples of lived experience provided.

<sup>9</sup>DPHC HQ 01/256 dated 7 Feb 18 - Carers Register: Identification and Support for Carers within Defence Primary Healthcare (DPHC).

## CONSTANT FIGHT FOR SERVICES

KEY CONCERNS DISCUSSED IN LIVED EXPERIENCE NARRATIVES



Respondents identified education (38%), health provision (41%) and a lack of Service support (35%) as the main concerns and challenges for military families dealing with additional needs and disabilities.

In their own words families told us that given the itinerant nature of Armed Forces life - moving locations, authorities, schools and health trusts every two years- caused significant difficulties. One respondent said:

***“Transfer and continuation of care when moving around is a nightmare.”***

Whilst others commented:

***“Constant worry about changes in health & education provision from one location to another.”***

***“Impact on professional services and having to be referred and stay on waiting lists.”***

### RECOMMENDATION - ADHERENCE TO THE ARMED FORCES COVENANT

Existing formal links with the MOD partnership boards, including devolved administrations, should be exploited to address issues with healthcare and education and prevent Armed Forces families from being overtly disadvantaged.

### THE BATTLE FOR EDUCATION

Service parents of children with an additional need or disabilities reported ongoing issues with obtaining an educational diagnosis and support for their children (29%):

***“We have been rejected for an EHCP once already as ‘we’re moving and an EHCP will need to come out of another budget, not the local budget here’.”***

***“Key issue is obtaining accurate diagnosis and appropriate support within the school setting.”***

***“He took 4 years to get an EHCP and started school full time 2 years later than his peers.”***

***“It took us 6 years to have both our children diagnosed due to constant change and postings, when we moved, we had to start from the bottom of the pile and, were not able to get our children the correct support and help.”***

Indeed, one parent expressed the sad view - supported by many responses - that their child was:

***“Just not worth investing in because they know they are a Service child and will move on and it would be a waste of resources.”***

As well as families experiencing difficulties obtaining a diagnosis, they also feel their children with additional needs or disabilities suffered when the family moved on assignment because Local Education Authorities (LEAs) would not accept the EHCP or diagnosis prepared by the previous LEA:

***“The needs set out in an EHCP don’t have to be met by the next place of posting, so all the support you have been fighting for goes and you have to battle again. It’s hard for the child and makes you low and depressed about constantly having to fight.”***

***“Moving is stressful enough. More needs to be done to help the transition be easier when it comes to moving a child with a disability ...there should be one document that every county accepts instead of starting the process again every time we move.”***

Access to specialist school places has also been a significant issue:

***“We tried to move and so we could live together at this posting, but the transfer of his needs, despite provision, for education were too difficult. A typically developing child can be allocated a place in a school before they arrive, for a special school we would not even be looked at until 6 weeks after arriving in the area and then could not guarantee his needs would be meet.”***

***“I had to home school my son when we are initially posted here as there were no places. I do not have the qualifications to do this and give my son the help he needs and deserves.”***

### RECOMMENDATION - UNIVERSALLY ACCEPTED EHCP AND PERSONAL DATA TRANSFER

Either the existing EHCP system is made universally acceptable making it transferable from county to county, devolved authority to the next or a new system be created that is adopted universally by all education authorities, and organisations including private schools, to ensure personal data pertaining to educational needs, health etc. is transferred with the pupil.

A summary of key education issues reported comprises:

- Lengthy times for educational diagnosis which were not completed before posting.
- Diagnosis not accepted between education authorities resulting in children being subjected to multiple repeated assessments.
- Support requirements identified on assessment were not met within the classroom setting or were not retained on moving.
- Lack of pre-school and school age wrap around provision for children with additional needs.
- EHCP not being accepted between counties and devolved governments within the UK.
- Obtaining special school places.

## FIGHTING FOR HEALTHCARE

Healthcare services generated a similar level of concern (25%) in our survey's respondents, with access to continuity of care being the major challenge.

The Care Act 2014 states that: 'Continuity' means making sure that, when an adult<sup>10</sup> who is receiving care and support in one area of England moves home, they will continue to receive care on the day of their arrival in the new area. This means that there should be no gap in care and support when people choose to move<sup>11</sup>.

Our research indicates that many military families with additional needs or disabilities are not able to access continuity of care on assignment to a new location. Indeed, many families talked of "The constant fight for services".

### Delay in accessing medical services following new posting

Respondents highlighted that the current policies and practices of the NHS are significantly detrimental to people required to move location for work regularly, like Armed Forces families, especially when you or a loved one have a health condition. The reality of this impact was explained by a respondent:

***"It takes a year to transfer from one health authority to another and by the time this happens you are posted again."***

Another respondent, who is an Armed Forces spouse and living with a life-impacting medical condition, said that:

***"My biggest issue is getting consistent support from health services every time we move. I have to explain my conditions, medications and treatment plan...then go to the back of the waiting list queue."***

### Starting from square one

Not only did our research highlight continuity of care and swift access to health care as a problem, respondents also told us that their new Clinical Commissioning Group (regional NHS bodies) would not accept diagnosis provided by former CCG. This effectively means that for families they are starting from square one every time they move, as one respondent explains:

***"We pleaded with NHS ( ) to accept the diagnosis we had from NHS ( ), but they did not want to accept their findings...we were delayed 18 months before our son was re-diagnosed and able to access services."***

***"Our child is in the care of CAMHS and for us to move would mean beginning the care process again which could take months."***

### Bottom of the waiting list

Survey respondents reported that following relocation due to the demands of Service they or their loved one found themselves placed at bottom of NHS waiting lists for diagnosis/treatment regardless of how long they had already been on a waiting list in their previous location.

***"I was made to wait 9 months for an initial consultation...after being in active treatment in the county we were posted from."***

***"It's hard when we move to have to start all over again with new paediatricians."***

***"Lost my place on waiting list for spinal surgery, having already waited a year and now been put to the end of it again."***

<sup>10</sup>This includes adults who are carers of children as well as adults receiving care. Care Act 2014 Part 1 Factsheet 8 - The Law for Carers: Para f

<sup>11</sup>The Care Act 2014 - Fact Sheet 9 - Continuity of care when Moving Between Areas.

## Access to treatments, medication, equipment and therapies not consistent across all areas.

The qualitative responses from our research also found that there was a lack of continuity in treatments, medication and access to previously received therapies, following relocation due to the Service personnel's re-assignment. Respondents reported:

***"Treatment only available in England, not the remainder of the UK."***

***"Moving after first stage of treatment (cancer) to find that on-going treatment is unavailable in the new location."***

***"Moving to the new NHS trust has shown a vast difference between the care received and the involvement of services."***

***"Having to give vital equipment back and then wait to receive the same equipment is frustrating."***

### No proof of address caused difficulties registering with doctor's surgery.

Whilst Service families who do not have pressing medical concerns are often able to wait out the delays that occur as part of relocation - such as having no proof of address- for families with additional needs and disabilities, the need for a proof of address was a pressing concern as they often need immediate access to local medical services. Respondents said:

***"Trying to register at a doctor's is a nightmare as we don't have proof of address, no tenancy agreement, council tax or utilities bills in my name."***

### Access to military bases for NHS staff.

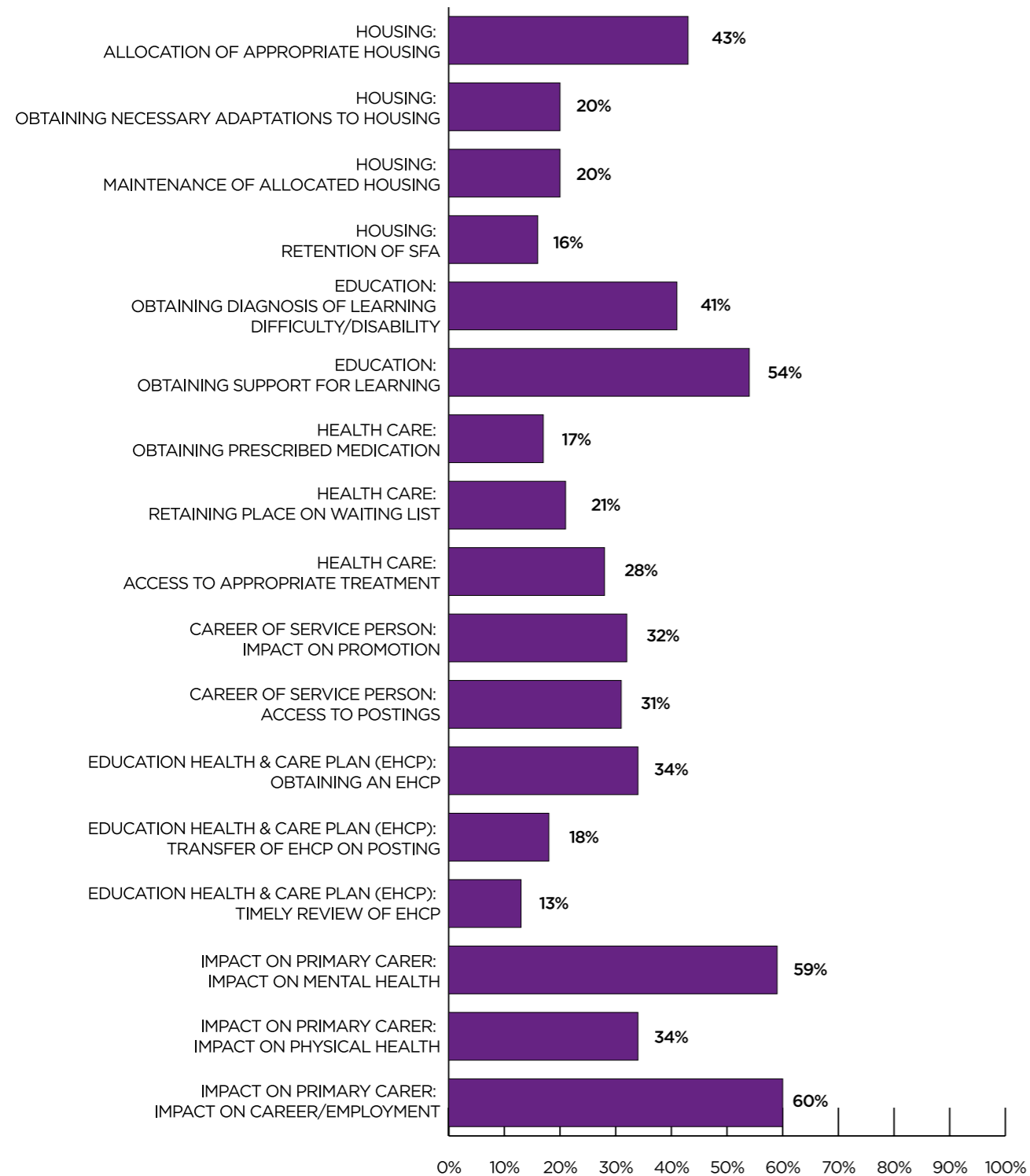
Respondents also highlighted the difficulties - due to security procedures- of civilian medical staff being able to provide treatment on military sites:

***"Eldest child has a central line, colostomy bag & catheter, my wife had to be trained up to deal with his central line as the district nurses had difficulty coming onto camp."***

## RECOMMENDATION - ADHERENCE TO THE CARE ACT 2014

MOD to work with CCGs to ensure that, in line with the legal requirements of the Act, Service personnel and their families should receive continuity of care from day one of new posting.

## KEY ISSUES FACED BY SURVEYED FAMILIES DUE TO SERVICE



## EMPLOYMENT

Our research found that there are significant impacts on the primary carer, both in terms of mental health (previously discussed) and also on their ability to gain employment or pursue a career. 60% of families surveyed identified the impact on the professional life of the primary carer as a key issue.

The lack of appropriate local childcare, regularity of hospital appointments, the dependency of children on the primary carer were all said to be barriers to gainful employment, as the following responses show:

***“I am unable to work as local childcare is not suited to our son’s needs and we have no family locally to support us.”***

***“Sadly, I am unable to work in a permanent position due to my son’s care needs as I often need to go into school.”***

***“I am unable to work due to my son, he needs lots of time off for hospital appointments.”***

***“Mum cannot work as she is a full time carer to an autistic son.”***

This situation is exacerbated when the serving person is *serving married unaccompanied*, meaning that their spouse and their disabled or additional needs dependants are living elsewhere, with the serving personnel commuting long distances or only at home on weekends. Similarly, for Service personnel in highly demanding roles their ability to provide support or care duties to the primary carer in the household is greatly diminished.

***“My wife has to deal with my autistic son and new-born daughter on her own due to a lack of support network and me working away in the week.”***

***“My husband finds it extremely difficult to get a good balance with work and home-life.”***

***“The stress of overwork for my serving husband reflects on our family.”***

The inability of serving personnel to support their spouse with the care means the bulk of the duties and strain of caring falls on their spouse, making employment or a professional life far more difficult. For many families there is a significant financial impact, initially due to the primary carer being unable to work and then aggravated by any additional financial burden of needs:

***“These therapies cost our life savings.”***

***“Requires aids that cost a fortune.”***

***“The additional needs do incur time and cost penalties.”***

***“Impact was that Mum could not work around child, so on a lower income however much bigger the outgoings.”***

In the majority of cases where both parents are/were serving, families felt that, largely due to a lack of childcare, that one of the family should forfeit their military career and become the Primary carer:

***“Both serving parents...I have now NTT’d<sup>12</sup> and in my final year. I’m now asking to do compressed hours so I can collect children after school as trying to find childcare for children with additional needs is almost impossible.”***

***“My husband and I are both serving...we have discussed me taking a career break ...it’ll be the only logical way we would be able to manage. I am also trying to get a final tour of duty at my current unit to prevent any disturbance or disruption as I do not want to start this (assessment) process again.”***

There were also a number of cases where, due to family breakup, there was a single parent who was serving:

***“Lots of hospital appointments, extra time to support him with his educational needs, childcare, transport to and from school”***

***“Incredibly difficult as a solo parent meeting learning needs at home.”***

<sup>12</sup> Notice to Terminate

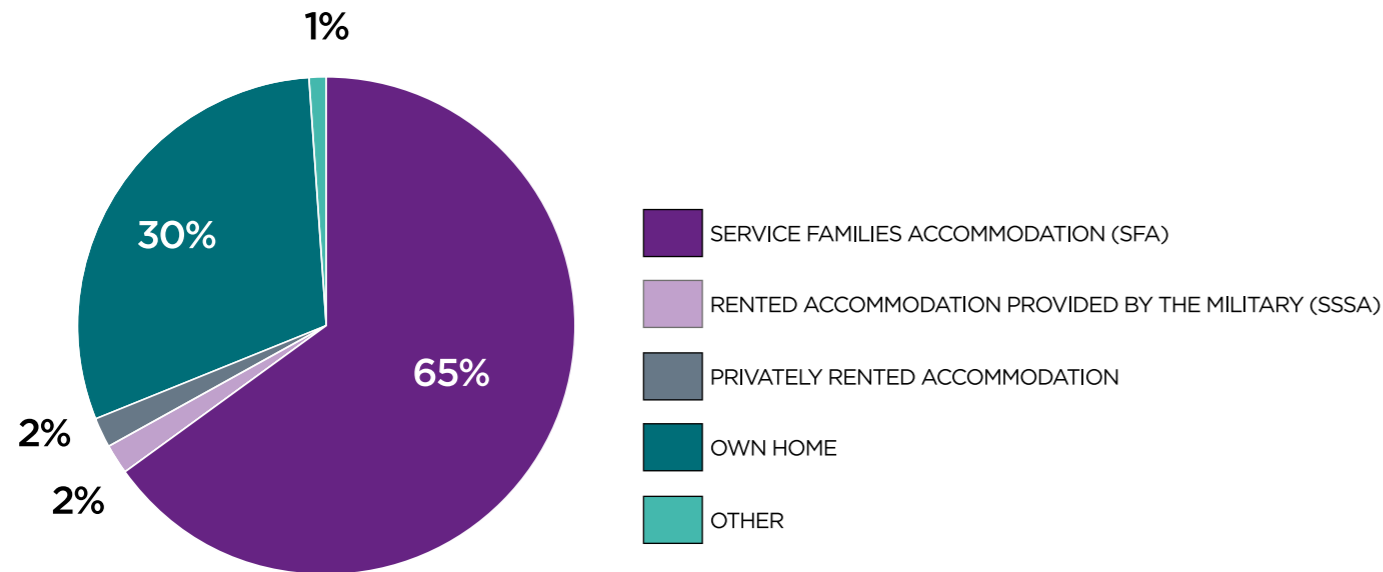


## HOUSING

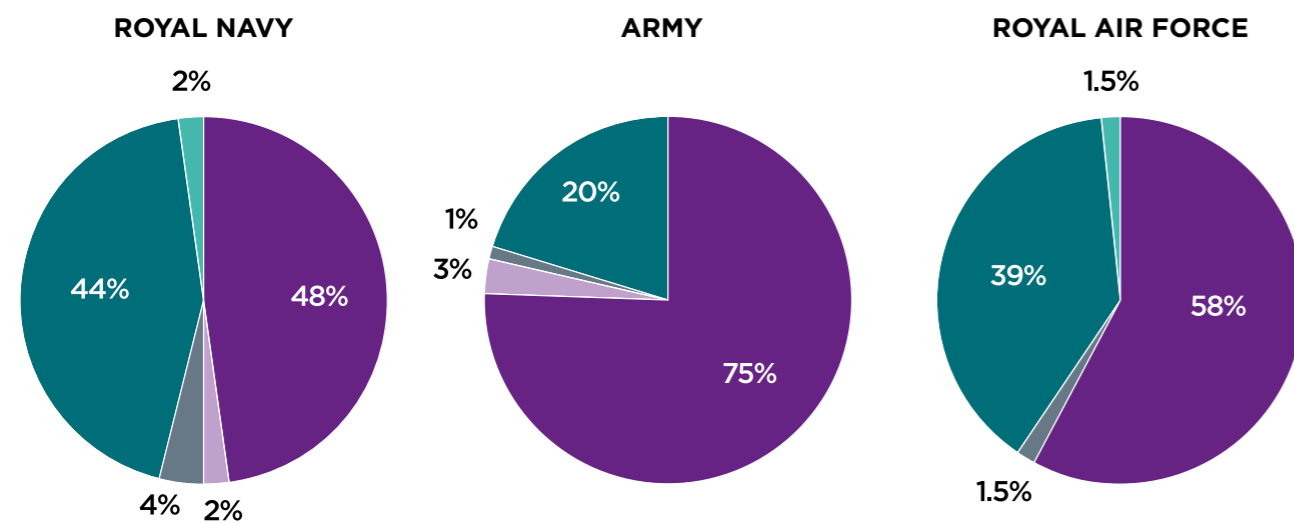
The majority of responses indicate that this military population group live in Service Families Accommodation (SFA), with the bulk of the remainder living in their own home. A review of data relating to how often this military population group had been required to move house can be found at Annex C.

### HOUSING PROFILE OF SURVEY RESPONDENTS

#### MILITARY POPULATION



Further analysis of the data by Service revealed significant differences between the Royal Navy, Army and Royal Air Force:



Responses from Army families confirmed that 75% of families live in SFA and only 20% own their own homes. This may have significant implications for both SFA allocations and housing adaptations, particularly during this current period of Army re-basing.

## ALLOCATION AND RETENTION OF APPROPRIATE HOUSING

Many of the issues that identified housing (12%) as a primary impact upon families with additional needs or disabilities related to the allocation of appropriate housing. This could be a requirement for additional space for specialist equipment, respite carers or the need for a child to have their own room for medical reasons such as infection control.

*"Housing allocations are difficult; you never deal with the same person twice."*

*"It took a long time to get allocated a house...school allocations had to wait and then rush to transfer EHCP."*

*"Postings are very stressful with the lack of support and information on housing."*

*"There is a lack of understanding about special needs requirements."*

*"I was made to feel unworthy, that I was not considered and judged by strangers who had never met me, my family or even seen our home."*

Associated with this was the retention of allocated accommodation, when a Service person has been reassigned to enable the family to retain educational or medical services, whilst the Service person commutes to their new place of work.

*"The process for retention of SFA is stressful. Careful and continued engagement with Career Managers is essential to sustain case for retention."*

*"Stress around retaining SFA in middle of diagnosis."*

### RECOMMENDATION - APPLICATION OF ADDITIONAL NEEDS AND DISABILITIES CRITERIA FOR HOUSING

Development of Additional Needs & Disabilities Criteria (to include those undergoing diagnosis) for allocation/retention of SFA to support consistent application throughout the MOD

## ADAPTATIONS AND SAFE SPACES

In addition to comments relating to requirement for Occupational Therapy reports in order to gain authorisation for adaptations, issues were also raised relating to the process of obtaining adaptations to SFA, or for a requirement for safe/secure outside space.

*"The two young ones don't feel pain. He burnt himself on a cooker, we asked for a gas cooker or protective top and housing said I should stay with the cooker till it cooled!" (Mum of 3 children all with additional needs/disabilities.)*

*"Adaptations were completed a year after we moved in."*

*"We had real difficulty getting our SFA adapted in a timely manner to suit the medical needs of our eldest child (life threatening condition)...the distinct lack of understanding shown by anyone involved in this case was absolutely appalling."*

*"Adaptations to the property still to happen. Daughter is wheelchair bound and completely dependent on us for all her needs."*

*"We are unable to have adaptations done to the MQ we are in as it is surplus and non-entitled accommodation, due to Service person being assigned elsewhere."*

*"Our fixed hoist broke whilst my husband was deployed but (they) argued that we didn't have one in the property. It took 2 months to be resolved."*

### RECOMMENDATION - ADAPTED SFA DATABASE

Improvement of the Defence Infrastructure Organisation (DIO) database of adapted SFA properties and implementation of a flag system to make best use of existing adapted SFA properties



## FAMILIES FORCED TO 'DISPERSE' TO LESSEN IMPACT

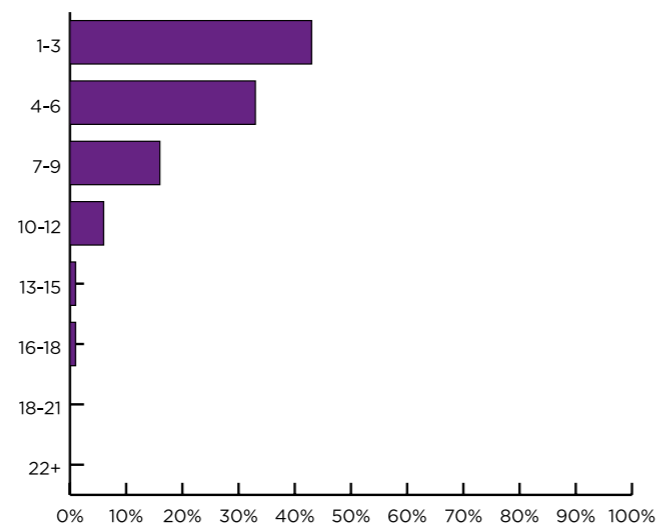
Whilst appreciating that there is a limit to the amount of housing stock and the types of houses available across the Defence estate, many families felt that more could be done to ease the process:

***"I understand the (Service) have very little control over education and health care, however housing could be one less stress removed if they would look at previous reports and allocate housing and adaptations required."***

Families were asked how many times they had moved house as a result of their Service. Analysis of the responses by Service reveals that, perhaps as expected, Army families are required to move more frequently than the other Services (see appendix c for break down by Armed Force)

The graph to the right shows the quantitative results of their answers. With 43% of survey respondents having moved between 1-3 times, staggeringly 2% had moved more 13 times or more.

The data does not take into account the length of Service which may affect the number of times a family is required to move.



Above: graph shows the number of times survey respondents have moved.

Sadly, despite following the 2011 Armed Forces Act with the introduction of the Armed Forces Covenant and the Care Act in 2014, many families felt that the only way to ensure access to consistent healthcare services and education provision was to purchase their own home and live as a 'distributed' family. The Service person remaining loyal to their Service but having to be separated from their family.

***"We had to buy our own home to maintain health support."***

***"We had to give up moving with the Army to make a secure home for our disabled children."***

***"We had to buy our own house to maintain health support. Because of this we have had to commute or live apart as a family."***

***"We are currently buying our own home whilst still unsure where the serving person will be stationed. Our child didn't just fall through a crack in the system, they fell into an abyss with no concern or empathy shown by my manual records or top brass in units."***

As well as the emotional effect this can have on family life, it also brings additional physical and mental challenges for the single carer left at home as they are further isolated from existing military welfare and support agencies:

***"As a dispersed family we are simply forgotten."***

## RECOMMENDATION - SUPPORT FOR MOVING SFA STUDY

A study should be commissioned to investigate methods to best support, financially and work wise, those who chose to buy their own home in order to ensure continuity of care for their family member(s) with additional needs or disabilities.

## CONCLUSION

### FINAL RECOMMENDATION - REPEAT AND EXPAND THIS STUDY

Defence statistics, or another recognised external organisation, repeat this study in 24 months to monitor progress and ensure the needs of those military families with additional needs or disabilities are being met and the legal rights of carers are being observed.

It would also be advisable to include additional questions relating to length of service, rank and trade on leaving, to see if having a family with additional needs and disabilities is currently impacting on retention. This follow-on study could potentially be conducted via the inclusion of SEND questions on The Families Continuous Attitude Survey (FAMCAS)<sup>13</sup>.

Wishing to better understand the lived experiences of this population group, the MOD requested the FANDF committee conduct research on their behalf into the issues experienced by Service families with additional needs and disabilities. The subsequent research and recommendations detailed within this report provide a rich source of evidence for the MOD to draw on as they refine the existing, or develop new, policies to better support these Service families.

It is clear from the data received that a significant number of the key issues impacting on Service families with additional needs and disabilities are associated with the mobility of Service life. Many of these issues, such as education and healthcare provision, are further exacerbated by the lack of consistent provision between counties and devolved administrations within the UK.

We recognise that, in this time of significant budgetary constraints, there will be no 'quick fix' for these issues but feel that greater awareness and adherence to both the Armed Forces Covenant and the Care Act would better support military families who have additional needs and disabilities.

One area that was beyond the scope of this report was whether having a family member with additional needs or disabilities was impacting on retention. Informal evidence gathered at the biennial FANDF conference, regional outreach and anecdotal comments as well comments made by survey respondents for this report indicate some personnel are considering leaving the Armed Forces or have left due to finding Service life incompatible with their family's needs. Further research needs to be done into this area, investigating Service length, rank and trade at time of transition, as well as reason for leaving, to see if there is correlation between support for families with additional needs and retention. This would enable identification of what is needed to reduce the loss of experienced, and highly-trained professionals from the Armed Forces; ensuring they do not have to choose between family and country.

## ACKNOWLEDGEMENTS

The Forces Additional Needs and Disability Forum (FANDF) would like to thank the MOD for the ongoing support of this MOD forum and funding of the Additional Needs and Disability Advisor (ANDA) role. SSAFA's commitment to funding and facilitating the FANDF Committee and the Forum is greatly appreciated.

Specific thanks must go to the military families who completed this survey and provided the rich source of data for this report. Their honesty and sharing of lived experience not only highlights the many issues that military families with additional needs and disabilities face, it also emphasizes the enduring commitment of these families to the Armed Forces.

On a personal note, the author would like to thank her family for surrendering their 'family time' so that this important piece of work could be completed.

### Michelle Claridge

Michelle Claridge MAEd CMgr MCMI  
Specialist Trainer & Consultant  
Bespoke Education & Training

m: 07790 578275 e: michelle@bespokeeducation&training.com

<sup>13</sup>Families Continuous Attitude Survey (FAMCAS): Annual Tri-Service Families Continuous Attitude Survey

## METHODOLOGY

### CONSTRUCTION

The survey that formed the evidence base for this report was designed by Michelle Claridge, Vice Chair of the FANDF Committee and constructed utilizing Survey Monkey, before being endorsed for distribution by the FANDF committee. The construction and question format were reviewed by an external specialist before the survey was piloted with a group of military families who had family members with additional needs or disabilities.

The survey's questions were formulated from consolidated key issues lists that drew from previous informal data activities, including the biennial FANDF conference and regional outreach activities. Families were given the opportunity to provide free text responses that allowed respondents to explain their lived experiences more fully in their own words, formulating the base for the extensive qualitative research element of this report. The responses were reviewed, analysed and coded to identify the key trends.

Subsequent to the free text responses, survey families were then given a list of previously identified consolidated issues from which they could select any which had caused issue for their family. These answers formed the evidence-base for the quantitative data that informed this report. It is interesting to note that all of the issues highlighted by families in their free text responses align with key issues identified through the previous informal data gathering, therefore enhancing the reliability of data.

### DISTRIBUTION

The voluntary survey was distributed electronically via weblinks and Facebook through the following:

- FANDF
- SSAFA, the Armed Forces charity
- Single Service welfare agencies
- Service Families Federations
- Service community pages
- Field Army and Home Command Intranet

### ENGAGEMENT

The survey was completed by 255 Armed Forces families who have a family member(s) with additional needs or disabilities.

Survey responses did not discriminate between children, adult dependants or Service personnel in the first instance and did not include adults of state pension age. Responses were received from all three of the services- Army, Royal Navy and Royal Air Force - currently serving in the UK. No responses were received from the Royal Marines or families currently deployed overseas. Whilst the survey was available to these groups, and Service welfare agencies are aware of families with additional needs or disabilities currently serving abroad, no responses were received.

Analysis of qualitative data responses to other questions within the survey indicated that, whilst some families had been posted overseas and had later returned to UK, a number of families had been prevented from undertaking overseas postings because of the additional need or disability of their family member and a number of those families felt that this had negatively impacted on the career of the Service person.

The respondents were not all FANDF families, and all responses received were included in the quantitative results, in order to avoid selection bias. Naturally, being a sample of military families with a loved one with additional needs or disability means that all respondents will have been impacted both by their military career and the needs of their family member this inherent bias is unavoidable.

## APPENDICES

### APPENDIX A- RESPONSE SOURCES GEOGRAPHICALLY

For ease of reference, only counties identified as a home location by respondents have been included in the table. Counties which have >5% response rate coincide with those which also host major ports, garrisons or flying stations.

COUNTY	% OF TOTAL	NUMBER	RN ONLY	ARMY ONLY	RAF ONLY
Bedfordshire	1.59	4	0	2	2
Berkshire	2.38	6	0	6	0
Buckinghamshire	1.59	4	0	0	4
Cambridgeshire	2.38	6	0	1	5
Cheshire	0.79	2	1	1	0
Cornwall	2.78	7	5	0	2
Devon	2.78	7	7	0	0
Dorset	3.17	8	1	7	0
Durham	0.79	2	0	1	1
Essex	1.59	4	0	4	0
Gloucestershire	1.98	5	0	3	2
Hampshire	11.59	29	15	8	6
Hereford & Worcester	1.19	3	0	3	0
Hertfordshire	1.19	3	3	0	0
Leicestershire	0.79	2	0	2	0
Lincolnshire	3.17	8	0	1	7
London	0.40	1	0	1	0
Merseyside	0.40	1	0	1	0
Middlesex	0.40	1	0	0	1
Norfolk	1.19	3	2	0	1
North Yorkshire	5.16	13	0	10	3
Northumberland	0.79	2	0	1	1
Nottinghamshire	1.19	3	0	3	0
Oxfordshire	5.56	14	0	6	8
Rutland	2.38	6	0	3	3
Shropshire	1.98	5	0	4	1
Somerset	1.19	3	2	1	0
South Yorkshire	0.40	1	1	0	0
Staffordshire	1.98	5	0	5	0
Suffolk	1.59	4	1	0	3
Surrey	2.38	6	0	6	0
West Midlands	1.59	4	3	1	0
Wiltshire	17.06	43	0	39	4
County Antrim	2.78	7	0	6	1
County Down	1.19	3	0	3	0
Argyll & Bute	3.17	8	8	0	0
Dumfries & Galloway	0.40	1	1		
Dunbartonshire	0.79	2	1	1	0
Edinburgh	0.40	1	0	1	0
Fife	0.79	2	1	0	1
Moray	2.78	7	0	3	4
Cardiff	0.40	1	0	1	0
Glamorgan	0.79	2	1	0	1
Monmouthshire	0.40	1	0	1	0
Skipped Answer		3	0	3	2
<b>TOTAL RESPONSES</b>		<b>255</b>	<b>52</b>	<b>137</b>	<b>61</b>

## APPENDIX B- COMPLEX AND MULTI NEEDS

Responses to the question: What is the primary nature of your family members additional need and/or disability?

### CHILD 37%

1. Diagnosed post-natal with Down's Syndrome
2. In process of diagnosis
3. Diagnosed with hypersensitivity personality
4. Down syndrome
5. Deaf, blind, autistic
6. Rare genetic condition called Williams Syndrome
7. Severe learning disability and autism
8. Epilepsy, global development delay, chromosome deletion
9. 22q11 deletion syndrome
10. ADHD, learning disability, multiple function disorder
11. Micro chromosome deletion 16p11.2 Severe communication difficulty. Global development delay
12. Chronic illness with physical disability
13. Possible ASD / ADD - awaiting diagnosis
14. ASD and hypermobility
15. Dyslexia, suspected ASD, auditory & Visual Processing disorder
16. Bowel disease, kidney disease and is in remission from neuroblastoma
17. Drug resistant epilepsy, profound learning disability, sensory processing disorder, challenging behaviour & autism.
18. Non-verbal Autistic
19. Genetic syndrome that results in speech and language difficulties, learning issues and global developmental delay
20. Undergoing diagnosis for dyspraxia

### ADULT 7%

1. Spinal cord injury, causing pain and mobility problems
2. Anxiety & Depression
3. Mental health issues and seizures
4. Physical disability, plus heart disease and arthritis

### 1 CHILD & 1 ADULT 17%

1. Child with learning difficulties. Adult with PTSD
2. Autistic child. Adult with C.H.D and Myocardiopathy
3. Child with Aspergers. Adult with pulmonary hypertension
4. Autistic child with sensory processing disorder, 1q44 deletion, microcephaly and hyper mobility. Adult registered disabled with Psoriatic arthritis, anxiety, depression, fatigue syndrome and sciatica
5. Child (age 2) tube fed due to severe hypoglycaemia due to unknown rare metabolic cause. Adult non epileptic attack disorder and many other unrelated symptoms caused by viral encephalitis
6. Child with ASD and behavioural issues. Adult with Complex Mental Health Issues
7. Child with ASD. Adult suffers from acute mental health issues, namely BPD (Borderline Personality Disorder).
8. Child born deaf and blind and has autism with global development delay. Adult has depression and anxiety
9. Child has dyslexia and egg allergy. Adult has physical disability.

### 2 CHILDREN 24%

1. One child with Aspergers, ADHD, complex special needs. Second child under investigation for Dyspraxia, Auditory Processing Disorder, learning difficulties
2. Two children with ASD
3. One child is Autistic. Second child is dyslexic
4. 2 children with ASD / ADHD
5. One child with Dyspraxia, hypermobility and autist traits. Second child undergoing diagnosis for Tourette's syndrome
6. 2 disabled children one with heart disease, spd, and is in a wheelchair... other one has c-acc (part of his brain missing) genetic disorder, deaf, cleft palate, leg braces, standing frame, and a bent spine and also peg fed
7. Two children with dyslexia
8. 2 children with ASD / ADHD
9. One child with ASD and second child with ADHD/ASD
10. 2 Children with Epilepsy, ADHD, Dyspraxia
11. Two children with ASD, dyslexia and Dyspraxia
12. Two children with ASD
13. 1 child dx ADHD, 1 child under assessment for ASD

### 3 CHILDREN 7%

1. Two children diagnosed with ASD (ongoing assessment for ADHD) and one child being assessed for ASD
2. One child genetic epilepsy condition caused by deletion of CHD2 gene. Second child had high functioning Asperger Syndrome. Third child had additional support needs as a result of anxiety
3. Cerebral palsy x 1 ASD x 1 ADHD and development delay x 1
4. Three children, two diagnosed with autism, one with various other diagnoses. Ongoing assessment for ADHD.

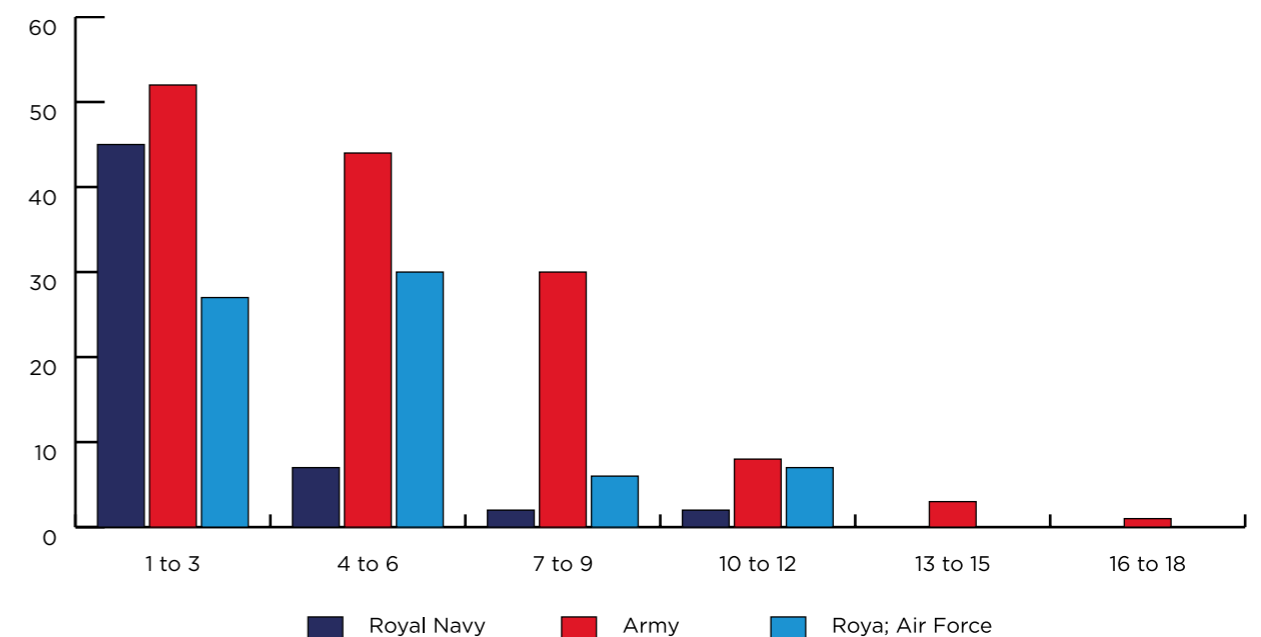
### 2 CHILDREN & 1 ADULT 6%

1. One child ASD, second child with ADHD, depression & anxiety. Adult has a brain injury
2. Two children with Chronic Fatigue Syndrome (one also undergoing diagnosis for ASD. Adult with PTSD
3. Two children and one adult all with ASD

### 3 CHILDREN & 1 ADULT 2%

1. Three children with ASD, one of whom has ADHD and one has PDAS. Adult with PTSD

## APPENDIX C- HOUSE MOVES FOR RESPONDENTS COMPARED BY SERVICE





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