

# **Report 2020**

Defence Special Needs Support Group Inc

# Report

#### Introduction

The Defence Special Needs Support Group Inc (DSNSG) is a not-for-profit benevolent volunteer organisation established to assist Navy, Army and Air Force families with a family member with Special Needs. The Group provides support, information, assistance, advocacy, and programs for all ADF families current and ex-serving who have a dependent child, spouse or other dependent with Special Needs.

DSNSG is a well-respected National Organisation with approximately 1200 serving members, combined with 3460 dependents, these dependents include spouses, Special Needs children, dependents 18 plus, and dependents without Special Needs.

DSNSG has two National Co-Patrons, the Minister for Veterans' and Defence Personnel, Hon Darren Chester, MP and the Chief of the Defence Force, General Angus Campbell, AC, DSC. DSNSG also has our Ambassador, Air Commodore Henrik Ehlers, AM.

DSNSG has supporting partners that support our programs and other services. Our supporting partners are: Defence Health, APS Benefits, Australian Military Bank, Navy Health, Defence Housing Australia, Toll Transitions and Defence Community Organisation. We are deeply grateful for their partnership and very practical assistance. Our strong business relationship has resulted in numerous successful projects which has brought more benefits to our Defence families. Partnerships of this kind are hard to find in the business world, where competition is always fierce for the sort of valuable philanthropic support we receive. DSNSG is fortunate to have such amazing supporting partners that provide professional, effective, and true support.

DSNSG particularly thanks DGDCO, Mr Paul Way, DCO National Helpline and Dependents with Special Needs (DWSN), along with the regional DCO Offices in helping us to increase the understanding of Special Needs Families and working closely with DSNSG and our members. Over the years DSNSG has built a wonderful and committed relationship with HQDCO. We receive reasonable funding assistance from DCO to help with the operational costs of DSNSG and our programs.

DSNSG is very much about building, supporting, and advocating for Defence Special Needs Families. DSNSG has built solid relationships over the years with organisations in a variety of sectors Australia wide. This has been possible because of our relentless commitment to work closely in understanding the needs of our Defence Special Needs Families.

This report summarises the feedback from our members received by Kim Collins, General Manager, and inputs from our dedicated National Executive Committee (NEC), General Manager, National Ambassador. It is important to note the feedback reflects the experiences and perceptions of members and our General Manager and has not been edited.

This report suggests some possible solutions to problems DSNSG members, and their families continue to face and hopefully, sets a good starting and continuation points for our ongoing work with Defence and other stakeholders in the forthcoming year.

The lives of service families can be quite different from those in the civilian world. We move more frequently and often have less control over our destiny. Whilst these experiences can enrich our lives, the upheaval of postings, deployments, field exercises, uncertainty about the future, lack of choice, as well as the isolation of being far from friends and family can make life much more difficult.

The challenges of military life are greater when you or a member of your family has a disability or an additional need. There are many questions to consider: When will we move? Will the housing be suitable? Will the local school be able to offer adequate support? How far are the local hospitals? What is the transport like? Will the same treatment, medications or services be available? Moreover, the challenges our members and families face have been exacerbated and brought into sharp focus as Australia and the world navigates the Covid-19 pandemic.

There is a responsibility on both the serving personnel and the partners/spouses to ensure that the family member's needs, including medical, educational and welfare requirements, are assessed properly before posting or overseas deployment. It is important to inform the chain of command of any additional needs and ensure that families are recognised as dependent with Special Needs. Often families are not aware of the process that they should follow or what information is available. A key DSNSG role is to support members in understanding the relevant processes and partner strongly with DCO in enabling the relevant support from Defence.

Before outlining the feedback received over the past year, it is important to note that some issues will always be issues that cannot necessarily be solved – they are outlined here as a reminder of the constant pressures on DSNSG families and the importance of decision-makers taking into account family circumstances in making decisions on support for families. We also recognise there are examples of excellent support to our members and, human nature being what it is, this feedback is generally directed at the local level and not shared widely. We nonetheless reflect here our appreciation for those that are supporting DSNSG members and families.

Finally, I would like to reflect on the value of reports such as this and engagement with policymakers in Defence. The 2019 report addressed the need for flexibility in a range of policies and practices in Defence. We were incredibly pleased with how well the report was received and actions taken in response. DSNSG was delighted to receive a letter with feedback from the Head of People Capability, Major General Natasha Fox, AM, CSC, which is attached at Appendix A to this report. Key points from her letter that are very pleasing to DSNSG are:

- Consistent feedback from our membership indicated the Defence approval forms and processes
  were complex and at times difficult for families. DCO took this feedback on board and has reduced
  the number of forms, updated them into smart form format, and aims to create one smart form
  which will allow the member to apply for multiple assistance measures at one time without
  duplication.
- The expiration of the recognition period was another area of concern DSNSG raised, and over the
  past six months, changes have been implemented that allow applications for recognition to take
  into consideration age of medical evidence and the condition being diagnosed. This will enable the
  Delegate to grant recognition with medical evidence for disabilities and medical conditions which
  are lifelong.

- A key success of the past year has also been Defence's work with the NDIA to create an option to set alert in the NDIA participant record that will record they are ADF members. With this alert, when an ADF member receives a posting order they may contact an NDIA representative to trigger a review of their plan in preparation for the move. This will escalate the plan review noting the change of circumstances to a new posting location.
- In the recent Federal budget, the Government announced an initiative started by Defence Health five years ago after consultation we had with the DSNSG. From 1 April next year, dependents with a disability will be able to stay on their parent's health insurance policy regardless of their age. This is a major win. Insurers do not have to offer this, but at Defence Health they will. Defence Health will continue to stay close to the department of Health while it develops the policy and will provide you information on what we intend to do from 1 April next year.

Prepared by:

Kim Collins General Manager Defence Special Needs Support Group Inc.

November 2020

Authorised by:

Claire Macfarlane-Rowles
National Coordinator
on behalf of the National Executive Committee
Defence Special Needs Support Group Inc.

November 2020

#### 2020 Member and Families Feedback

# Postings:

Posting in the ADF is always a source of stress for families. We have had consistent feedback relating to:

- The lack of adequate notice (i.e. less than 6 months) and out of cycle (i.e. Unexpected) postings are
  preventing some families from accessing funding for those children who qualify for assistance with
  schooling. We know that simply enrolling a child in a school or accessing support through the school
  network can be a problem.
- Even with help from Defence School Mentor (DSM), and the Education Liaison Officer (EDLO), children are still not coping with the changes of schooling and missing friends. Because of this, behavioural issues increase at school and at home.
- The ADF member's temporary accommodation on posting has been booked through Toll without any regard to the physical restrictions of Special Needs dependants which were stated in their accommodation requirements. Members have had to source alternative accommodation at their own expense.

#### Financial:

Loss of income to the household makes it increasingly hard to afford the required specialist appointments for the family. In some location's spouses are at a disadvantage due to potential employers asking if they are Defence; with the implied concern of short-term employment and preference for 'local' hires only. In many cases some spouses are unable to work in their desired profession. Further:

- Families with small home businesses are not well supported. One of the reasons spouses have home businesses is to help support the family, to put food on the table, and pay for Special Needs bills. Defence currently does not move home based business equipment. Families are at a loss with funds trying to organise the removal of the home-based business items. A huge financial loss is then placed on the family having to transfer across the nation for their work.
- Waiting lists for a new specialist to get new or updated diagnoses when moving from state to state can also be an unexpected financial cost. The cost of a diagnosis is rising. Families are struggling to get into specialists and often require going onto long waiting lists. In most cases families can be on a public waiting list for 6 months to 3 years. There are substantial differences in cost between public health and private sector specialists. Families are unable to afford \$1000's differences in fees. e.g. Ophthalmologist after posting into their new location.
- Families have been out of pocket about \$10,000 over a 3-year posting. The high volume of paperwork required to try and recuperate the costs through DCO is highly underestimated, especially if needing to put in paperwork for each child. Families have been put off applying for assistance because of the difficulty with completing the forms. Families must pay for the specialists up front and then seek reimbursement, while not an issue for some families, single income and the more junior ADF families may not be able to afford to pay for these services. Families need to

see the specialists to get the paperwork required to fill in the AD835. In most areas families cannot get the social worker at DCO to help with completing the form due to DCO resourcing constraints.

## **Family Support:**

Being new to a community, the ADF member and family may not be aware of all the support services available for a family with Special Needs.

Our team of DSNSG Coordinators across the country are there to help families link into service providers in their location but need some help in making connections with members and families. Another solution to assist our families and Coordinators could be to have a website that lists disability services in States, regions, or towns.

Acknowledging the different requirements needed for recognition of conditions is important, but the requirements (once established) should not change from state to state. A recognition of Special Needs in one state should be enough to carry over into the next location. A National Recognition would relieve a lot of the financial burdens the ADF families are experiencing. This past year has seen a significant increase in an already disturbing trend of families becoming a Member with Dependants Unaccompanied (MWDU) as they feel they have no choice. This is not an ideal situation for the families and must also be impacting the morale and effectiveness of the ADF members who do not have their families accompanying them.

We have numerous occasions where we have received phone calls from families who have been informed to call DSNSG as we provide free programs and grants. This situation gives the families false hope, as when they call our helpline and discuss their options, they are informed that the information they have received is unfortunately incorrect. All DSNSG financial assistance to members is based on 'mutual commitment' and a financial contribution from families. Sadly, families become quite upset and angry, as they had their hopes up. We bring them back down and talk about the programs and explain what they need to do. Sometimes families are happy with the correct information and thank me for taking the time to explain it, but then we also have families believe that all DSNSG programs should be free for ADF members as "we don't earn a lot of money".

An option worth considering to help improve ADF member understanding of DSNSG programs is to work with DCO Social Workers, FLOs and EDLOs to run periodic information sessions via Google Meets/Zoom to do a Q & A with the DSNSG General Manager and the National Coordinator.

Families are facing an ongoing issue with having to supply letters to DHA and Toll when requesting help on posting. Where families are unable to get a letter of support from a specialist for DCO, DHA and/or Toll to show their diagnoses are the same due to a waiting list, or unable to provide the funds for appointment, another means of validating the member's request should be put in place. If they are still receiving the same services/therapies and treatment plan is same, it should be possible for DSNSG (General Manager or National Coordinator) to provide a letter on behalf of the family that is acceptable 'evidence' to DCO, DHA and/or Toll.

### Family Challenges:

Families face a lot of challenges even without having Special Needs within the family, but the struggles our families face are:

- Learning about the disability, having others in the workforce also understand what their Special Needs are, where to go to for help once you are diagnosed.
- Researching, locating, and accessing effective treatments and resources.
- Coping with emotional and physical demands of caring for an individual with a disability, in some cases there are multiples in one family with Special Needs.
- Getting to the innumerable appointments with medical providers, therapists, advocates, and school personnel, which in return impacts spouse having the ability to return to work, but yet still not available for carers support through Centrelink due income tested.
- Advocating for appropriate school intervention, accommodations, placements, for teenagers ready
  for independent living. Most families are not able to seek assistance through NDIA for teenagers
  due to the low diagnoses and the guidelines for this type of assistance. Families also report having
  issues with DHA with children living at home after a certain age.
- Paying for the many treatments and interventions not covered by the school system, NDIA,
   Centrelink will not or cannot assist towards.
- Further investigation into Talented and Gifted, at this present time, PACMAN only covers for academically Talented and Gifted. There are a lot of children that also fit the Talented and Gifted in other areas such as Music, Dance, Sports etc. These children and their families face challenges in being proximate to academies/programs along with the accrue extra fees, which can be a financial strain.

#### Housing:

Housing support is critical to most of our serving members and their families. The issues that have been raised with us are listed below (including some suggestions to address the issues).

- Special Needs Families feel like they are being poorly judged for requesting housing modifications.
- Having DHA staff trained so that they understand the requirements for the modifications would
  give them the ability to communicate with the families in a more effective manner. Perhaps a
  serving member (SERCAT 7 or SERCAT 3/5) with Special Needs experience could be attached to
  DHA in peak posting periods to assist the staff with assessments of the requests. This would make
  the families feel more at ease and, potentially, ease the workload on DHA.
- Removal companies rush to complete the pickup or delivery, pushing for signatures when members
  have not had enough time to count boxes and check for damages. Some removalists refuse to plug
  in the electrical goods to ensure they are working, whilst others refuse to conduct the valet unpack
  even when it is requested and approved.

• Families often require an Occupational Therapist (OT) to do an assessment to provide a report of what modifications are needing be put in place, i.e. handrails, ramps, wider doors. There are significant delays in obtaining OT assessments in gaining localities, which impact families being able to fully occupy and utilise residences. It seems logical that, if a family had an OT assessment in the losing locality, the modification needs (not specific designs) should carry over into the gaining location. We suggest that OT assessments be retained on housing files and be utilised in making decisions on the need for modifications in gaining localities. Such flexibility would have a number of advantages for families and Defence in reducing costs, streamlining approval processes and, most of all, allow families to be settled and effective in their new homes much faster.

## Consideration for Defence Force Additional Needs and Disability Forum:

Such forums could be held in the relevant ADF base locations to provide a chance for service members and their families to get information from and connect with local Additional and Disability need support groups. This will allow the families to share their issues, raise concerns and ask questions about issues that are affecting them. Representation could come from DCO (who do the processing), DVA, Open Arms, DSNSG, Autism groups, Respite agencies etc. Acknowledging that Covid-19 restrictions may well remain in place for some time, forums could be conducted over the internet (Google Meet, Zoom, etc).

#### Conclusion:

Military lifestyle brings a range of opportunities and experiences, but it can also create specific issues for families when they are experiencing continual mobility, separation due to deployments and training, and isolations can have a much greater impact. Special Needs Families live a unique transit lifestyle. The stresses placed on Special Needs families when being posted are undeniably underestimated. DSNSG will continue to strive for our members and their families; we can only continue to grow and improve through effective engagement and collaboration with Defence and Supporting Partners.

# Opportunities for Collaboration in 2021

The feedback reported above has not been filtered and, in some instances, may not reflect extant policies or the experiences of all – it is, nonetheless, how our members and families feel.

DSNSG would like to work with Defence and supporting agencies to discuss opportunities to collaborate and act on the feedback we have received. Building on the successful engagements to date, we are hopeful that there can be a continued dialogue, opportunities to refine policies, improve communications and harness Defence and our supporting partners contacts across government and industry to move forward.

#### Kim Collins

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# Feedback on the 2019 DSNSG Defence Report from the Head of People Capability Major General Natasha Fox, AM, CSC



EC20-003846

Claire Macfarlane-Rowles National Coordinator Defence Special Needs Support group

#### Dear Claire

On behalf of Defence, I acknowledge that the Defence Special Needs Support Group (DSNSG) has had another successful year working with Defence. In particular, DSNSG has assisted to highlight opportunities to improve the supports that can be provided to ADF members and families with dependants who have special needs. DSNSG has continued to work closely with People Capability Division, and Defence Community Organisation (DCO), particularly the Community Support Team and the Defence Family Helpline, to provide advice and assistance. As a result of your effective stakeholder engagement, open communication and informed advocacy, there has been a significant positive impact on the support these families receive.

You raised the issue of approval forms and feedback from your membership that indicated the process was complex and at times difficult for families. DCO took this feedback on board and has reduced the number of forms, updated them into smart form format, and aims to create one smart form which will allow the member to apply for multiple assistance measures at one time without the need for duplication of effort.

The expiration of recognition period was another area of concern you raised, and over the past six months changes have been implemented that allow applications for recognition to take into consideration age of medical evidence and the condition being diagnosed. This will enable the Delegate to grant recognition with medical evidence for disabilities and medical conditions which are lifelong.

A key success of the past year has also been Defence's work with the National Disability Insurance Agency (NDIA) to create an option to set an alert in the National Disability Insurance Scheme (NDIS) participant record that will record they are an ADF member. With this alert set, when an ADF member receives a posting order they may contact an NDIA representative to trigger a review of their plan in preparation for their move. This will escalate the plan review noting the change of circumstances to a new posting location. This will allow connections with a local area coordinator or support coordinator to be made prior to arrival at the new location, and reduces issues in accessing reasonable and necessary supports required to meet the immediate needs of the NDIS participant once they arrive in their new location. This relationship between Defence and the NDIA was instigated by DSNSG advocating on behalf ADF families.

DSNSG should be proud of your success as an organisation and I encourage you to continue your focus to influence policy change and raise awareness of and advocating for ADF special needs families. These efforts make a great contribution to maintaining ADF capability by allowing these ADF members to have an active career whilst they and their families continue to manage the challenges unique to the military lifestyle such as absence from home and mobility.

Yours sincerely

Natasha Fox AM, CSC Major General Head People Capability

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