

***NOTE: Further issues and suggestions have been added subsequent to the Stage 4 and State of Disaster directives – see below for AUGUST UPDATE***

The health emergency that unfolded in Australia from March 2020 has highlighted the very significant difficulties that exist for many people with disabilities (including autism) and their families. Many families and their family member(s) have suffered challenges and hardships that should have been anticipated and better tackled by government and disability service agencies in the context of the pandemic.

AFSA wants to highlight some of these issues and suggest steps that should be taken to support families when such health emergencies occur.

Most families with a person with a disability are so busy looking after their loved ones that they have limited time and energy for advocacy. Sector wide leadership needs to occur to allow the voice of those with disabilities (and their families) to be better heard and responded to by governments and their agencies. AFSA stands ready to provide representatives to key bodies and agencies to bring the lived experience of caring for those with complex needs into the support and decision making processes.

AFSA would like to see the following approaches and policies adopted during the continuing health and economic emergency caused by COVID. AFSA would also like to see better preparation and planning for any future emergencies. Strategies and responses should be developed to provide the right care and support.

1. Specific financial and other support for people with disabilities and their families to recognise the extra burdens on caregivers and increased costs. This could best be done via adjustments to the Disability Support Pension, Carer Payment and Carer Allowance to recognise additional and ongoing costs. The two payments of \$750 were welcome but totally insufficient. Parents and family members were effectively being used as unpaid support workers.
2. Day Centres, accommodation and in home support services for adults with disabilities should be deemed essential services and resourced accordingly. Unlike the Aged Care sector, there was no common direction to ensure ongoing services. Some service providers successfully adapted their programs of support, others used isolation and closure of community activities as a 'reason' for abandoning all supports. There was poor communication between providers who may be supporting the same individual and their family.
3. The Education Department needs clear policies and approaches around "stay at home" and on-line learning for students with disabilities as well as clarification of any actual or presumed crossover between NDIS and DEET PSDI funding. The challenges of on-line learning for students with complex needs were not initially recognised and catered for. Families were left without necessary resources, especially personnel support. Access to NDIS and PSDI funding which would normally be assigned to schools could be used to provide additional supports to families to assist with remote learning.
4. The NDIA must provide better and targeted policies, approaches and communication to participants and their families. Clear and simple points of contact and consistent information must be provided. LAC's and Support Coordinators are the obvious contact points.

5. The NDIA and State Governments must hold providers to account for continued and safe delivery of services in all disability accommodation settings.
6. The NDIS needs to provide a clear and consistent approach to the funding of all NDIA Plans and any adjustments made in response to health emergencies. There has been much confusion about the 10% COVID loading for providers and how this impacts on a participant's funds.
7. The disability workforce needs support and development – short and long term – to ensure that the often casual (mainly female) disability support workforce is provided with better economic security and conditions, including improved training, to enable them to provide continued support to those with disabilities during times of crisis.
8. Dedicated expertise in the health and hospital sectors must be provided to support people with disabilities with existing health conditions, as well as COVID. Even minor medical procedures and care can be difficult at the best of times for many people with disabilities and complex needs.
9. The NDIA and State Government should establish and fund “flying squads” of multi-functional teams with a range of skills including allied health, disability support and social work who can step in and support families when illness or other challenges occur within the family unit.
10. The NDIS Quality and Safeguards Commission must be given real “teeth” and resources to enforce proper standards of care and hold providers to account.
11. The State Government should establish a “help line” so that those families who are isolated and/or essentially housebound and need help with day to day essentials such as medications and other necessities can obtain assistance.

## **AUGUST UPDATE**

Since the production of AFSA's “Statement Re COVID-19 and related health emergencies”, which was prepared in July 2020, Stage 4 Lockdown requirements (State of Disaster) have been implemented in Victoria.

AFSA has identified some further issues that also need appropriate strategies and responses.

### Personal Protective Equipment (PPE) supply and training

PPE must be supplied and training delivered for all disability workers. PPE must be readily available at all times for workers supporting clients who are at risk. Fact Sheets are not enough and providers, NDIA and DHHS must ensure PPE of the right quality is available and being used correctly.

### Contingency Plans for Families impacted by a positive COVID diagnosis

NDIA Plans must contain a COVID or health emergency contingency plan. This is to ensure that support arrangements can be quickly and effectively put in place when family members, carers or people with a disability test for COVID and are required to isolate. The contingency plan must include effective liaison between state and federal agencies.

### Exemptions under Stay At Home Rules must be widely publicised

Exemptions for care or compassionate reasons are provided under Stay At Home Directions for people with disabilities and their carers. The exemptions in Part 2 – reasons to leave premises and Part 4 – support workers attending to provide care - must be widely publicised.

## Templates For Permit Letters

Templates that contain approved wording for care or compassionate exemptions should be developed and widely distributed for use by carers and families. A range of exemptions may be required depending on individual circumstances and challenges specific to a person with autism. Such documents will need to clearly state what exemptions are being allowed so that they can be readily accepted by any Authorities who may challenge families or carers who utilise certain exemptions. Some examples could be with respect to mask wearing, number of workers/carers accompanying a person with a disability, curfew times, social distancing and the 5km travel distance.

### **For a single parent of a child with complex behaviours and medical conditions, COVID-19 meant:**

- Trained support workers were withdrawn so no in home support or provision of support to enable attendance at a specialist program deemed essential → 3 hour drive each day → deteriorating carer health
- Family members contracted colds → COVID testing → quarantine, no respite or in home support → isolation from extended family and friends
- COVID testing for an ASD challenged child means queues, waiting time, invasive nature of the test, need to socially distance → major behaviour meltdowns → carer stress and anxiety
- Elective medical appointments placed on hold → compromised functioning and general well being
- Procuring and delivery of the right supplies challenging in a family where routines, products and food types have to be very specific to avoid meltdowns
- On-line learning provided by the school was too generalist, not tailored to the individual needs of the student with ASD and required intensive 1:1 supervision → abandoning other family members and increased carer stress and anxiety

[www.afsaconnect.org.au](http://www.afsaconnect.org.au)

