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FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON THE COVID-19 PANDEMIC RESPONSE

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Submission Cover Sheet

COVID-19 pandemic response

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Select Committee on the COVID-19 Pandemic Response
Legislative Assembly ACT
GPO Box 1020 Canberra ACT 2601

Submission to the Inquiry into COVID19 Pandemic Response

People with Disabilities ACT acknowledges the traditional owners of the land on which we work and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders past, present and emerging.

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About PWD ACT

People with Disabilities ACT Inc. (PWDACT Inc.) is a disabled peoples organisation (DPO) owned by people with disabilities. PWDACT works to promote the inclusion of people with disabilities in all aspects of community life, to remove barriers to our inclusion and to inform the community discussion of disability issues by bringing to bear in this discussion the daily lived experience of people with disabilities. PWD ACT advocates from a human rights perspective and acknowledges the *UN Convention on the Rights of Persons with Disabilities*.

The text of this Convention can be found at:

www.hreoc.gov.au/disability_rights/convention.htm

Article 11 of this Convention, “humanitarian emergencies”, Article 10 “Right to Life” and Article 25, “health”, which specifies that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, are especially relevant to this submission. Other Convention Articles are relevant to particular aspects of the Pandemic Response and these are referred to where they are relevant.

The ACT Government also needs to comply with the *ACT Human Rights Act 2004* in its responses to the Corona Virus Pandemic. COVID-19 has created a rapidly changing environment. In this situation, PWDACT may provide supplement submissions on new issues as they arise.

COVID Ethical concepts For Planning Framework Document

PWDACT provided the Canberra Health Services Clinical Ethic committee’s with comments on its proposed COVID-19 Ethical Concepts for Planning Framework Document. These comments are reiterated here.

PWDACT supports the basis of the draft framework as set out on page 10 of the Document. It is there stated that Canberra Health Services will adopt the Ethical Guidance for Crisis Standards of Care in Illinois. (“It is inappropriate and not permissible to ration based on: gender, race, ethnicity, citizenship, national origin, religious belief, sexual orientation, cisgender/transgender status, social value, pre-existing physical or mental disability unrelated to the medical diagnosis or need, or socioeconomic status including ability to pay, judgments that some people will have a greater quality of life than others, as determined by the values of the decision maker. These criteria are not taken into account when rationing care insofar as they generally have no impact on the ability of persons to benefit from care.”)

The document is mostly neutral in its dealing with disability. However, we note with concern the statement on page 9: “However, for the most part, eligibility for escalation of care will not be made in reference to particular individuals but via the setting of upper and lower thresholds regarding the patient’s potential to benefit from ICU care, keeping resources in mind. As demand increases, there will be a need to assign ICU beds and ventilation machines to those who are assessed as having a higher potential to survive than those who are less likely to do so.”

There is a substantial risk that this approach will discriminate against people with disabilities who already have pre-existing health conditions, or need more support in general for life. For example, a paraplegic who already requires assistance with breathing should not be assigned less assistance or treatment because they’re deemed as not having a “higher potential to survive.” The possibility that this statement will result in triage guidelines being applied in a manner detrimental to a person with disability is magnified when it is acknowledged that people with disabilities experience poorer health outcomes and have a higher likelihood to have chronic diseases and comorbidity conditions than the general population. This is clear from the reports of the Australian Institute of Health and Welfare over many recent years. PWDACT would assert that medical treatment should be provided on the basis that all people have the right to the highest standard of health, as per Article 25B of the UN Convention. In particular, States Parties shall: b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

Accordingly, PWDACT submits that Health Services Canberra needs to be mindful that all human life is sought to be saved as equal, and allocate health resources appropriately to provide equal health services, specifically, those provided in response to the COVID-19 Pandemic.

COVID-19 Human Rights and Ethical Decision Making

PWDACT shares the concerns expressed by National Disabled People Organisations and respected Australian disability advocates in the “Statement of Concern” issued on 15 April 2020.

PWDACT draws the Committee’s attention to the human rights principles for ethical decision-making proposed in this Statement:

Health care should not be denied or limited to people with disability on the basis of impairment.

People with disability should have access to health care, including emergency and critical health care, on the basis of equality with others and based on objective and non-discriminatory clinical criteria.

Health care should not be denied or limited because a person with disability requires reasonable accommodation or adjustment.

Health care should be provided on the basis of free and informed consent of the person with disability.

Health care should not be denied or limited based on quality of life judgements about the person with disability.

Ethical decision-making frameworks should be designed with close consultation and active involvement of people with disability and their representative organisations.

PWDACT's concerns

Concerns about the access of people with disabilities to health care in the current pandemic are well founded. People with disability are a high-risk group to COVID-19. They are at further risk from the pervasive devaluing of people with disabilities that leads to discrimination in access to life-saving health and medical services. Medical decision making during the pandemic must be based on critical care decisions based on the likelihood of recovery and not simply on an individual's characteristic, including disability.

Both the *Human Rights Act 2004* and the *Convention on the Rights of Persons with Disabilities* require that human rights prevail in situations like the COVID-19 pandemic.

1. PWDACT looks to the ACT Government to ensure that people with disabilities are not discriminated against or disadvantaged, including during the current pandemic. PWDACT welcomes the assurance by Minister Rachel Stephen-Smith that the treatment of people with disabilities in the ACT Health's operational planning will be grounded in equity and human rights.
2. PWDACT also welcomes Minister Suzanne Orr's announcement that there will be a specific COVID-19 operational plan for people with disabilities in the ACT.

Commonwealth Management and Operational Plan for People with Disabilities

PWDACT was asked by the Office for Disability to give its priorities for the ACT from the issues raised by this document. PWDACT suggest the priorities for the ACT are:

1. To ensure that people with disabilities and persons assisting them have access to support workers and that support workers have access to personal protective equipment and necessary information so that both people with disabilities and support workers can interact with each other with the ease and confidence necessary for people with disabilities to receive the services they need.
2. That specific ACT Government initiatives such as the Canberra Relief Network are provided in a way which is inclusive of people with disabilities. For example, that the content of hampers provided by the Network can be altered to meet specific needs eg plastic instead of glass containers for safety or foods to cater for specific dietary needs.

This is an area in which a one size fits all approach will not suffice. Delivery arrangements also need to be appropriate eg it may not be enough to leave a hamper at a door. It may be necessary to tell the person that the hamper has been delivered.

PWDACT also commented previously that it is important that information on specific ACT Government initiatives and measures reach people with disabilities.

PWDACT also proposed sixteen amendments to the wording of the document.

Personal Protective Equipment (PPE)

PWDACT supports concerns expressed by ACTCOSS to the Committee that people with disabilities are being prevented from receiving the services they need to sustain themselves in their homes and their daily life because personal protective equipment is not being made available to them and to the people providing the services for them. People with disabilities have had to refuse people providing services access to their homes because these service providers do not have with them appropriate protective personal equipment especially gloves and sanitiser. It appears that the roll out of personal protective equipment to people with disabilities and organisers providing services for them has been slower and less effective than it has been for older people and people providing services for older people. This is a matter requiring the urgent attention of the ACT Government.

An ACT COVID-19 Disability Hotline

PWDACT notes that at the National level a COVID-19 hotline has been established for older people. At the National level, there is, we believe, no specific hotline for people with disabilities. However, we note that both the National Disability Insurance Agency and the Royal Commission into Abuse and Neglect of People with Disabilities are fielding a high volume of calls from people with disabilities with their concerns. Without duplicating this effort, the Office for disability could add a third option to the menu on its central number (6207 1086) for callers to raise their COVID-19 issues with a staff member and if possible, have them resolved. This would give the Office a ground level insight into the practical impact of COVID-19 and Commonwealth and ACT Government response measures on people with disabilities.

We direct the Committee's attention to media reports, based on calls to the Royal Commission, of people with disabilities experiencing psychological stress and disorientation arising from disruptions to their normal routines of services and activities, for example, the mental anguish experienced because familiar support people can no longer visit them or they have lost the social activities you look forward to. (See the report by Nas Campanella on ABC Am on Wednesday 29 April.) The royal commission has released a Discussion Paper on COVID-19 and is seeking public comment.

The extent to which people with disabilities in Canberra are experiencing this kind of social and psychological stress, and the need for remedial services, should be recognised and addressed.

Education

The education of students with disabilities is a key area of responsibility of the ACT Government. Article 24 of the *UN Convention on the Rights of People with Disabilities* deals with the rights of people with disabilities to equal access to education.

The outcome of COVID-19 restrictions is that much education has moved online. The educational disadvantage experienced by people with disabilities is well documented in education literature. In the context of COVID-19 measures, a report by leading Australian scientists and educators was released on 3 May 2020 which recommended a return to face to face education to avoid extreme educational detriment to students, especially those who are already educationally disadvantaged. This included students with disabilities. Personal interaction of teacher and student is important to educational success. It is arguable that this is even more so for people with disabilities, in particular for people with sensory and intellectual disabilities and people with autism. The Committee should inquire of Education ACT as to the measures it is taking to address educational disadvantage experienced by people with disabilities arising from online education. The Committee should also seek evidence from students with disabilities and their families. Education ACT should also prioritise students with disabilities for the return to face to face teaching immediately this can be done having regard to the advice of the ACT Chief Medical Officer.

Social Separation and Isolation

People with disabilities experience exclusion and social isolation in ways which are more disadvantageous than social isolation experienced by other segments of the community. There is a real and substantial risk that the current stress on social isolation and locking down will be applied to people with disabilities in ways which exacerbate this exclusion and isolation. People with disabilities may find themselves confined inside the home by friends and family who consider that they either cannot understand or cannot implement strategies such as social distancing. COVID-19 containment requires social separation not isolation and lock down. People with disabilities, families, carers and support workers need to be resourced with information so that people with disabilities can participate in society in accordance with social separation rules. Isolating, shutting in and locking down should not be the first and standard responses for people with disabilities in the current COVID-19 environment.

Conclusion

There is evidence in the community of significant levels of concern and social and economic disadvantage being experienced by people with disabilities as a result of the COVID-19 Pandemic and Government measures to reduce the spread of the virus and support the economy. The Royal Commission into Abuse and Neglect of People with Disabilities is considering holding a special hearing on the impact of COVID-19 for people with disabilities. PWDACT recommends that the ACT Assembly Committee also devote specific hearings days to COVID-19 and people with disabilities.