Commissioner Squirrel and Deputy Commissioner Fox,

As members of the Adult State Program Standing Committee, it is our role to advise the Department of Mental Health (DMH) on matters that impact the people that we represent--mental health service users, family members, and providers. This is a very difficult time and we appreciate that you are working hard to respond swiftly and appropriately to the COVID-19 pandemic. Thank you for your labor. There are many difficult decisions to make and while no solutions will be perfect, we want to share the solutions that we envision, based on our personal and professional experience within the mental health system.

An issue of grave concern is how to prevent the spread of the virus in congregate living situations, such as hospital units and residential programs operated by DMH-designated hospitals and DMH-designated community mental health agencies. It is our expectation that thorough efforts will be taken to prevent the spread of the virus in these facilities, and that patient rights will not be dismissed during this crisis. We want to emphasize that it is in no way acceptable for the following scenarios to take place:

- Patients being forced to remain in institutions, where disease could spread rapidly
- Patients being discharged to involuntary homelessness or unsuitable/unsafe living situations
- Discriminatory withholding of any healthcare based on disability status
- Hospitals failing to provide up-to-date information about news, patient rights, and outside resources
- Patients lacking alternative access to outside support, communication, and advocacy, as in-person visits are restricted
- Interventions or restrictions which weaken immune systems or increase exposure
- Patients being confined to their rooms

We fully assume that you share the goal of saving lives while upholding civil rights! In a spirit of support and collaboration, we would like to make the following suggestions:

1. Issue an immediate moratorium on involuntary admissions
2. Patients* who wish to leave the facility and have a place to go to should be immediately released. Prisons are releasing inmates over fears of the virus spreading in institutions, and psychiatric facilities need to follow suit.
3. Patients who wish to leave the facility and do not have a place to go to should be provided with a safe emergency living placement. This would include the following possibilities, depending on the individual needs and preferences:
    - Voucher for motel room or other emergency housing, with virtual support provided through hospital staff working from home, peer support workers of programs which are temporarily closed, and designated agencies
    - Shared Living Provider (SLP) placement with an individual or family with an extra bedroom, similar to the model used in Developmental Services (DS) in Vermont,

Windhorse Integrative Mental Health in Western Massachusetts, and the Family Care Foundation in Sweden. SLPs would be expected to provide food, shelter, internet, and emotional support for the person who is placed with them. Hospital staff working from home or DMH care managers could interview potential SLPs, get a video tour of their house to ensure that it is a suitable living environment. Protection and Advocacy would do regular check-ins with the person. Malaika Puffer, Peer Support Manager at HCRS and Home Care Provider with Families First, is able to provide free training to SLPs. Services could also be provided to the person using telemedicine. The SLP would be paid a stipend similar to the average amount that SLPs in DS get paid, plus room and board. The cost per day of this model versus the cost per day of keeping a person in the hospital is substantially less while the amount of support (minimum 1:1 ratio) is substantially higher. This also will help to provide opportunities for Vermonters who are now unemployed.

4. All patients who wish to remain in facilities should be able to do so, with patient numbers per facility/unit small enough to follow CDC recommendations on maximum numbers, including numbers of staff. Facilities/units that are most spacious should be prioritized for remaining open while facilities/units that would force people in close proximity should be closed first, if any. See recommendations below for facilities which remain open.
5. Work with the Vermont Department of Health to develop a plan for and give providers guidance on how to respond should an outbreak occur in a facility
6. Staff people who are at low risk of serious illness will provide coverage in the facilities, following proper precautions both at and outside of work, while more vulnerable staff are reassigned to working from home. Role for staff working from home could include:
    - Provide additional support virtually to patients who remain in facilities
    - Provide emotional and logistical problem solving support to people who return to living in the community, whether in a motel room, independent housing, family and friends, or shared living placements, as well as their families/support networks as appropriate
    - Coordinate shared living placements and offer support to shared living providers
    - Providing emotional support to essential workers in any industry in Vermont and their families

For the safety of patients who remain in congregate settings, please implement the following:

- Test all patients and staff for COVID-19 immediately and upon admission for new patients
- Monitor the availability of necessary personal protective equipment (PPE) and disinfecting supplies in order to provide systems-level support in ensuring adequate supply. Ensure staff receive instruction on how to use PPE's effectively to prevent the spread of disease. We are hearing accounts from staff in psychiatric facilities in Vermont that they don't have gloves and are running out of hand sanitizer and disinfectant wipes.
- Immediately stop the use of seclusion, restraints, and non-consensual medication. All of these measures are likely to increase physical and emotional stress, thereby weakening

the body's ability to resist disease and heal. Restraints used during a pandemic of respiratory distress could be lethal and atypical antipsychotics commonly used in involuntary treatment are known to suppress the immune system. Additionally, both interventions force close proximity between patients and staff.

- Ensure patients have access to fresh air and sunshine
- Ensure that bathrooms are sanitized after each use but are not locked as this will inevitably result in unsanitary conditions and reduce access to hand-washing
- Ensure patients have the freedom to move about and socialize while also following social distancing protocols (leaving a minimum amount of space per CDC recommendations). For patients who wish to remain in their rooms, ensure alternative means of connection, socialization, and mutual support with other patients, such as through video conferencing are offered.
- Ensure that patients are provided with the means (personal devices such as smartphones, tablets, or computers and internet access) to communicate via phone, email, text, and video without limitations and without surveillance. Given the pandemic, shared access to one shared computer and one shared phone is inadequate and unsanitary.
- Ensure that patients have access to the latest information about COVID-19
- Ensure advocates (such as Protection and Advocacy, Adult Protective Services, or Vermont Psychiatric Survivors' Patient Representatives) have private video check-ins at a minimum of once a week with all people in hospitals, residential programs, and SLP placements to monitor for and respond to incidents of abuse, neglect, or exploitation. As a Committee, we suggest that DMH may want to encourage advocacy groups to cooperate as an emergency response coalition, so that issues can be centralized and work shared during this time. We would advise DMH to task such a coalition with the authority to ensure facilities are respecting patient rights by ensuring access and providing information.

Additionally, for the system of care in general, we ask that DMH:

- Encourage or require Designated Hospitals and Designated Agencies to provide Hazard Pay for all essential workers who are continuing to provide in-person services
- Ensure access to psychiatric drugs during the COVID-19 outbreak for those who want them. Consider utilizing the doctors who are normally used for second certifications to provide prescription coverage for people who may otherwise not have access to a prescriber. This is important because this is a particularly bad time to experience unwanted psychiatric drug withdrawal and because we imagine that access to prescribers may be more difficult.
- Consult with and actively involve people receiving services in Vermont's mental health system of care and the groups which represent them, including the State Program Standing Committees, Disability Rights, Vermont Center for Independent Living, NAMI VT and Vermont Psychiatric Survivors, in decision-making regarding DMH's response to the COVID-19 pandemic.

DMH has the critical responsibility of providing for the mental health needs of Vermonters during this unprecedented crisis. Given the state of emergency declared both by Vermont and the federal government, DMH must appeal to legislators for emergency funding, in order to adequately meet the needs outlined in this letter.

In our role as the community representatives to DMH, we will be sharing these ideas in public forums as encouragement for mental health service users, their family members, and providers to make their voices heard. Recognizing the gravity of present circumstances, we are including others who have a role to play in decision-making and reporting on the state's response to vulnerable Vermonters.

We ask that you provide creative, collaborative, and courageous leadership to ensure that the scared, brilliant, hilarious, wise, loved humans who rely on you are safe and respected.

Sincerely,

The Members of the Adult State Program Standing Committee:

Malaika Puffer
Vicki Warfield
Dan Towle
Brandi Parker
Robert Dyer
Marla Simpson
Thelma Stout

*We are using the term "patients" to refer to voluntary and involuntary patients in psychiatric hospitals as well as residents in residential programs.

The solutions outlined in this letter are in alignment with the joint statement "COVID-19 and Persons with Psychosocial Disabilities" by the Pan African Network of Persons with Psychosocial Disabilities, Redesfera Latinoamericana de la Diversidad Psicosocial, TCI Asia Pacific (Transforming communities for Inclusion of persons with psychosocial disabilities, Asia Pacific), European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP), Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP), and the World Network of Users and Survivors of Psychiatry (WNUSP), from http://www.chrusp.org/home/covid19.