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May 12, 2021

Monica White, Interim Commissioner Selina Hickman, Director, Developmental Services Department of Disabilities, Aging and Independent Living 103 South Main Street Waterbury, VT 05671

Dear Commissioner White and Director Hickman,

As you know, the House Committee on Human Services has recently taken testimony on H.243, a bill designed to establish a working group to assess and plan for services for adults with Autism Spectrum Disorders. We very much appreciate the Department's input and testimony on this important topic.

Ms. Hickman testified that the Department will soon be undertaking the statewide process to determine the new three-year System of Care Plan for Developmental Services. We understand that the process has been delayed due to the pandemic. We are also aware that the Department has limited staff resources and has been putting forth extraordinary efforts, working with community partners, to help keep older Vermonters and those with disabilities as safe and healthy as possible during the pandemic. Those efforts are very much recognized and appreciated.

Still, it has been a very stressful time for individuals with disabilities and their families. A time that has seen reduced services and staffing availability to provide supports – yet people's needs have not been reduced, and have, in reality, increased. As we have seen in other areas like housing and health care, this pandemic has shone a light on the areas of our developmental services system that need critical review and improvement.

One of those areas is related to supports and services for adults with Autism Spectrum Disorders. While our Committee may continue work on H.243, it is clear that at this late stage of the legislative session that there is insufficient time to move this bill through all stages of passage in the House and Senate. However, we feel the issues brought to our Committee are important enough that they cannot wait another full year or more before being acted upon. We also recognize that while what we are asking is for a particular focus on adults with ASD, we know that all individuals with intellectual or developmental disabilities can benefit from what is learned.

We are requesting that DAIL convene a working group that includes relevant stakeholders including, but not limited to: adults with ASD; parents and other family members of adults with ASD; Green Mountain Self- Advocates; designated/specialized services agencies; DD Council; UVM Center on

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Disability and Community Inclusion; Disability Law Project of Vermont Legal Aid; a clinician with experience in ASD; interested legislators; other relevant AHS and Department staff. It may also be beneficial to hold one or more focus groups specifically for adults with ASD and a separate one for family members of adults with ASD.

It is extremely important that the following areas are considered by the above group(s):

- 1. Analysis of the gaps in existing services, including methods and avenues for providing families with advice and support in navigating decisions about services
- 2. Review of approaches in other states that might be consistent with Vermont values and the DD Act [e.g., Maine (family payments) and Massachusetts (housing models)]
- 3. Recommendations for appropriate education, training and expertise for staff/contractors who serve individuals with ASD, including DAIL staff
- 4. Review of any potential modifications to existing supported employment and post-secondary education programs to better serve the needs of adults with ASD, particularly around career development
- 5. Consideration of expanding different housing and residential support options for adults with ASD, including options for more supported/independent housing as well as options for individuals who may require 24 hour support
- 6. Consideration of what limited specific circumstances might warrant parental financial support for families needing to care for their adult child with ASD at home
- 7. Identification of staffing needs at DAIL to support work for adults with ASD statewide, including technical assistance as well as quality oversight

Again, we recognize that all of the above items are applicable to other individuals with intellectual or developmental disabilities and urge the group(s) to keep that in mind. We are also keenly aware of the staffing resources necessary to undertake the System of Care Planning process, and it is our hope that what is learned from the above, will also serve to inform the next three year plan.

We remain poised to both participate in the process and to learn the results. To that end, we hope that while what is outlined above is intensive that it also be time-limited, concluding with a written report to our Committee by December 1, 2021 outlining your findings and any recommendations for legislative action.

We would like to express our gratitude for your willingness to undertake this process.

Sincerely,

Ann Pugh, Chair House Human Services Committee