

January 14, 2021

Chairwoman Carney, Chairman Harnett, Distinguished Members of the Joint Standing Committee on Judiciary:

My name is Alan Cobo-Lewis. I live in Orono. I am director of the Center for Community Inclusion and Disability Studies at the University of Maine (CCIDS).

CCIDS is Maine's federally funded University Center for Excellence in Developmental Disabilities (UCEDD, pronounced "YOU-said", authorized by the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 ("DD Act"). The purpose of the national network of UCEDDs is to provide leadership in, advise federal state and community policy leaders about, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life. Part of the federal mandate of CCIDS is to educate and advise policymakers, including members of the state legislature. Consistent with CCIDS responsibilities under the DD Act and consistent with University of Maine Board of Trustees policies [212](#) and [214](#), I am testifying on the bill for myself and for CCIDS, not for the University of Maine or the University of Maine System as a whole.

In updating probate code in the 128th Legislature, this Committee adopted supported decision making into statute and put requirements in place to minimize the use of highly restrictive court actions such as plenary guardianship.

Although supported decision making is an area of ongoing research¹, it is well established that people with significant disabilities are able to make choices². It is also well established that people with significant disabilities are at heightened risk for abuse—definitely when living in institutional settings, but also sometimes when and when living in a community setting such as with family³.

¹ Shogren, K. A., Wehmeyer, M. L., Lassmann, H., & Forber-Pratt, A. J. (2017). Supported decision making: A synthesis of the literature across intellectual disability, mental health, and aging. *Education and Training in Autism and Developmental Disabilities*, 52(2), 144-157. Khemka, I., & Hickson (Eds.), *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*. Cham, Switzerland: Springer.

<https://doi.org/10.1007/978-3-030-74675-9>

² Lancioni, G. E., O'Reilly, M. F., & Emerson, E. (1996). A review of choice research with people with severe and profound developmental disabilities. *Research in Developmental Disabilities*, 17, 391-411

[https://doi.org/10.1016/0891-4222\(96\)00025-x](https://doi.org/10.1016/0891-4222(96)00025-x); Canella, H. I., O'Reilly, M. F., & Lancioni, G. E. (2005). Choice and preference assessment research with people with severe to profound developmental disabilities: A review of the literature. *Research in Developmental Disabilities*, 26, 1-15 <https://doi.org/10.1016/j.ridd.2004.01.006>; Tullis, C. A., Cannella-Malone, H. I., Basbigill, A. R., Yeager, A., Fleming, C. V., Payne, D., & Wu, P.-F. (2011). Review of the choice and preference assessment literature for individuals with severe to profound disabilities. *Education and Training in Autism and Developmental Disabilities*, 46(4), 576-595.

³ Thornberry, C., & Olson, K. (2005). The abuse of individuals with developmental disabilities. *Developmental Disabilities Bulletin*, 33(1-2), 1-19. <https://files.eric.ed.gov/fulltext/EJ844468.pdf>

The goal of supported decision making is to ensure that people with intellectual disability have the **freedom** and tools they need to participate as equal citizens and be free to direct their own life. On the other hand, the goal of guardianship orders is to achieve **protection**. While these goals are sometimes perceived to be in conflict, LD 1774 would actually promote both goals.

Supported decision making is something that we *all* use. This very Committee is supported by nonpartisan legislative staff even as the Committee makes its own decisions. I am supported by financial advisors before making retirement account elections. I am supported by real estate brokers before buying or selling a house. I have hired attorneys and non-attorney advocates to resolve disputes about the education of my child who has a disability and about his disability support services.

I have the right to choose my attorney. I also have the right to choose other supporters and non-attorney advocates and to communicate with them. That is the essence of proposed 18-C MRSA §5-310(2)(C) (lines 12-17 of the bill): that, even with a guardianship order, an adult subject to guardianship may retain an attorney for any reason (not just pertaining to the guardianship proceeding) and to communicate freely with ombudsman, advocate, court, etc.

This promotes the rights of a person subject to guardianship to make **choices** while also **protecting** them from potential abuse or coercion.

Respectfully

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