

Richard Estabrook
Brunswick
LD 659

I want to join others to emphasize that this bill should be written so that regulations promulgated are major substantive. Why? First of all, any regulation would be major substantive-- they would entail revamping of the whole waiver system for persons with intellectual disabilities or autism. Hundreds of thousands of dollars are at stake. Second, the SIS ("Supports Intensity Scale") will be part of the Lifespan Waiver. You may recall that in 2017/2018 when DHHS tried to implement the SIS, an application for review had to be filed by the requisite number of registered voters pursuant to section 1112 of the Administrative Procedures Act to request a hearing before the HHS committee. That request for hearing was granted. This was because the SIS had been abused in its implementation. If these rules are allowed by statute to be "routine, technical" then it is certain that another such 1112 petition will be filed requesting a hearing. Let's not force 100 voters and the Legislative Council to go through that process again. There is too much of a danger that the SIS will be used as a resource allocation tool by DHHS, cutting services to Maine's citizens with intellectual disabilities or autism. I know that the DHHS avers that is not its intent this time, but in practice there will be great temptation for the functionaries who will be administering the SIS to apply it arbitrarily. The SIS was never intended by its developers to be a resource allocation tool. It was used that way before in Maine and it has been used/abused in other states the same way. When the SIS is used as a resource allocation tool, it undercuts Maine's personal planning system that is in place that is designed to identify each person's services, and the unmet needs that the person has. Last time DHHS' use of the SIS put too many vulnerable people at risk of harm. The result was a highly emotional hearing before HHS as guardian after guardian stood up and descried the cuts in services that their loved one would have to endure. It was heartrending; so much so that people in charge of DHHS at the time shelved the SIS.

As Cullen Ryan stated in his testimony, the Lifespan waiver is a good idea in general but the devil will be in details. The regulation promulgated under this law is certain to come before the HHS committee again, one way or another. That is assured. Let us enable that oversight in a way that honors the meaning of the words "major" and "substantive". The more legislative oversight that is built into the process at the beginning, the more likely it is that the result will be fair to everyone at the end. Do not allow this bill, assuming that it is enacted into law, to go into effect foreordaining regulations that are "routine technical". Make the rules major substantive at the outset. There is precedent for this. See, for instance, 34-B MRS Section 5206(8), requiring rules promulgated under the crisis services statute to be major substantive. As important as crisis services are, the importance of crisis services is utterly dwarfed by the Lifespan waiver law and regulation, in its impact upon the system of care as whole. If crisis services regulations are required to be major substantive, then the Lifespan waiver regulations should be too.