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Contact: Ann Kim [Gattine] 233-1838; Mario Moretto [Haskell] 460-4669

**Public speaks out against DHHS approach to assessing needs of
Mainers with disabilities**

Dramatic loss of support services threaten their ability to live in their communities

AUGUSTA – Dozens of Mainers on Monday spoke out against relying on a single high-stakes test to assess the needs of adults with intellectual disabilities, developmental disabilities and autism as the state Department of Health and Human Services had proposed.

The public hearing before the Health and Human Services Committee drew a crowd that filled the committee room and overflowed into two others. The hearing was originally scheduled to address DHHS’s “Supporting Individual Success” initiative, which attempted to replace the “person-centered planning process,” the current assessment by family and medical professionals codified in Maine statute, with the Supports Intensity Scale. SIS was designed to be a complementary tool, not the sole method of assessment.

The DHHS proposal – a change to the rules around support services through Medicaid – sparked an outcry among Mainers with disabilities, as well as their families, guardians and caregivers, because the resulting loss of critical support services would threaten their ability to live in their communities and potentially force their institutionalization.

“Mainers were loud and clear today. They spoke eloquently about how adults with disabilities have worked hard to remain independent and integrate into their communities. They told us the state must not misuse tools like SIS to pull critical services out from under them. They demanded that DHHS include them in decisions that can profoundly affect their lives and well-being,” said Rep. Drew Gattine, House chair of the committee.

While DHHS announced Friday that it was withdrawing its proposal, about 80 Mainers used the public hearing to voice their concerns about the lack of transparency from DHHS, the need for collaboration with stakeholders and why future proposals must avoid the approach of the original plan. DHHS said it would begin a new rulemaking process in the next several months.

The department originally categorized their proposal as a “routine technical” rule change, which did not require legislative review.

However, because of the harm they could suffer under the proposal, affected individuals and their families turned to a little-known petition procedure to request a formal review of the rule change by the Legislature. The petition had 268 signatories and another 1,308 signatures were

collected online. The Health and Human Services Committee decided in a bipartisan 9-4 vote to review the plan.

“We heard today that these Mainers and their families feel their voices were not being heard by the Department,” said Sen. Anne Haskell, D-Portland, the lead Senate Democrat on the committee. “Their input was requested, but ignored. They felt their intimate knowledge of their own needs, or the needs of their loved ones, was deemed non-credible. It’s no wonder they took the unprecedented step of petitioning the state to give them a fair hearing. Now they have been heard, and we in the Legislature are better off to have listened. We only hope the Department was listening too.”

The withdrawal of the DHHS proposal provides an opportunity to engage parent, guardians and others, testified Cullen Ryan, the father of a 19-year-old son with an intellectual/developmental disability and chair of the Maine Coalition for Housing and Quality Services.

“I am struck by how much I am hearing about parents who felt left out of the process. Instead of participating in design, we are invited in at the end and left to comment on things that look and feel like a done deal,” he testified. “This rule making process could have been better by being more open, interactive and proactive. The outcome at this point could have been better if it has included wider participation in the design stage.”

Deborah Dionne of Georgetown was among those who testified about how services help Mainers with disabilities live in their communities. She told the committee that after her daughter suffered severe brain damage from complications during her delivery, medical experts strongly advised that she be institutionalized, specifically at Pineland, the institution shut down in 1996 after it became notorious for the abuse and neglect that took place there.

“Thirty-six years later, Kate has surpassed what any expert predicted she would be able to do” such as bowling, volunteering at the library, holding a job and making dinner with her roommates and staff at her group home, Dionne said. “She is happy, integrated into her community and safe. What more could a parent want for her child?”

The hearing provides the HHS committee with information if it decides to craft a bill that addresses support services and related assessments.

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Ann Kim | Communications Director

Maine State House Majority Office

2 State House Station

Augusta, Maine 04333-0002

Phone: 207-287-1488 | Cell: 207-233-1838

Fax: 207-287-8338

www.housedemocrats.maine.gov