

## **Maine Coalition for Housing and Quality Services**

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Re: Proposed Rules: MaineCare Benefits Manual, Chapter 21, Section III, Allowances for Home and Community Benefits for Members with Intellectual Disabilities or Autism Spectrum Disorder and Chapter 21, Section II, Home and Community Benefits for Members with Intellectual Disabilities.

January 12, 2015

My name is Cullen Ryan and I am submitting comments on behalf of the Maine Coalition for Housing and Quality Services (the Coalition), a coalition of some 4000 people, consisting primarily of parents, that focuses on housing and quality services for people with intellectual/developmental disabilities (ID/DD). Ultimately, the goal of the Coalition is to create a system of quality housing and personal supports that is person and family centered, with choice, dignity, and efficiency being at the forefront of efforts.

I write in part to thank DHHS for doing some listening to parents and other concerned individuals in the development of these proposed rules. It is apparent that some of the feedback provided thus far resulted in changes to what was proposed. Thank you for listening. It is always beneficial to have a productive dialogue between policy makers at DHHS and families affected by policies.

But we need much more listening to occur from DHHS. We are all on the same team. Yet we feel like we have recently been benched on the sidelines. We feel left out of the planning, and the thinking, about how plans would affect our loved ones. That is unfortunate, and I hope it will change.

We have growing concerns about lack of interactive, proactive dialogue between the department, and key players who stand ready to help with policy development. As a Coalition we stand ready, poised, and willing to provide interactive feedback with DHHS. However, many of our parents feel left out of the process. Instead of participating in design, we are instead invited in at the end, and left to comment on things that look like a done deal.

→So my initial (and perhaps most important) comment is that this rule making proposal process could have been much improved by being more open, interactive, and proactive. The outcome at this point could have been better if it had included wider participation in the design stage. Why doesn't DHHS prioritize actively seeking input during the design and implementation stages of a system of care from the established stakeholder groups? Why don't we work inclusively to create rules for a system of care for our loved ones?

The Maine Coalition for Housing and Quality Services (the Coalition) organized in May of 2006. In late 2009 and throughout 2010 the Coalition initiated a parent-led project to redesign, from the ground up, a system of care for persons with developmental or intellectual disabilities. This work culminated in a White Paper in September 2011. In 2012, the Maine Legislature created the LD 1816 Developmental Services Workgroup that was charged with studying ways to create a more efficient and effective service delivery system. This legislatively appointed workgroup soon decided that the Coalition's White Paper proposed a service delivery model that addressed nearly all of the concerns

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the Workgroup was tasked to solve. On February 1, 2013 the Developmental Services Workgroup adopted the interim report, the Developmental Service Lifelong Continuum of Care, to be sent to the Legislature through the DHHS Commissioner.

The Developmental Services Lifelong Continuum of Care model holds central the concept of “No one-size-fits-all”. It takes into account that formal support, such as that required for unique or complicated medical conditions, must be flexible and designed to meet the person where he or she is. And, support must ebb and flow over the lifespan as the individual’s needs change. Included within the model is quality flexible wraparound support, which means varying services as needed (from minimal to maximum) to promote personal development, safety, stability, and inclusion. At its heart, it is designed to provide an individual with the exact amount of support the person needs, no more and no less. Everyone, including leadership at DHHS, believed that this would be a superior model, one which would maximize efficiency of resources, and maximize the success of every individual as part of the community.

In the proposed rule, DHHS is implementing a resource allocation model for this waiver program. DHHS is proposing utilizing the Supports Intensity Scale (SIS), a standardized assessment process, as the primary assessment and resource allocation tool. Using the SIS has broad support from the Coalition and others. It is a good tool for assessing individual needs. However, it is only one tool in the toolbox. It was not designed as a resource allocation tool, and it should not be the primary tool used. It should be secondary to, and used in conjunction with, the person centered planning process. The person centered planning process should be the primary tool used for resource allocation.

→As such, my second comment is that the SIS is being weighted too heavily in the proposed rule; the SIS should be secondary to the person centered planning process, not the other way around. Why doesn’t DHHS rely first on the person planning process and use the SIS to inform and strengthen it?

Person centered planning is intended to give overall decision-making power to the individual and those with the most intimate, detailed, and specific knowledge of him or her. Using the SIS and setting pre-determined limits on the amounts and kinds of support the individual receives before the person centered plan is developed, undermines the person centered planning process. This potentially limits the person’s opportunities for growth and self-determination. A strength-based standardized individualized assessment, such as the SIS, that assesses an individual’s strengths and needs, would be beneficial when used to *inform* and *strengthen* the person centered plan, not supersede it.

The proposed rule changes would place heavy emphasis on one assessment (the SIS) versus a broader approach that takes into account the person as a whole. This would essentially create a several-sizes-fits-all model, creating a narrow pathway that leads to five human boxes and three funding boxes, into which people must fit. We have been working diligently to move away from a one-size-fits-all system and towards a system that meets each person where they are at, providing services appropriate for each person – no more, no less. Although this is a step in that direction, this represents an opportunity lost. The vast array of people with ID/DD fit no better into three or five boxes than the rest of the public. Let’s do this right and meet people’s need as individuals – this can and should be done.

Alberta, Canada followed an almost identical path as the proposed rule changes would lead Maine. The SIS was adopted in Alberta, Canada for their 10,000+ individuals receiving services at substantial cost and with very poor results. It took protests to bring attention to its flaws. While

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those in charge did not get rid of it, the government is not using it in decision-making as they intended. This is Maine's opportunity to do right by the people being served and avoid a costly battle down the road.

→ My third comment is that the potential negative affect of the SIS assessment on services, which appears to be the case more often than not, has not been effectively communicated to consumers, their families, providers, case managers, or stakeholders. The SIS appears to be a gatekeeper designed to limit the amount of support provided. The Department has presented the SIS as the way to "ensure that people with intellectual disabilities and autism get the services and supports they need -- to reach their goals just as others do in their community." How can this be the case if a large number of people receiving services are looking at substantial cuts?

→ Please explain in detail how cuts to services for waiver recipients as well as administrative cuts to agencies:

1. Allow people to be truly included as part of their communities;
2. Improve staff training;
3. Increase agency capacity to adequately serve their clients; and
4. Improve staff retention rates.

The SIS proposal claims to help people access their communities. However, community access means a lot more than physically being in a community. It means a person is gainfully employed, can use public transportation, and can participate in activities and events of their own choosing. It means a person has relationships with neighbors and storeowners and other members of their community. This type of community inclusion cannot be fostered without support from trained staff. The proposed changes will lead to a reduction in staff and/or lower staff to client ratios. This change will affect opportunities for choice that a person is allowed. Relatedly, the reduction in services presents very real concerns regarding safety, both in the community and in the home, particularly for people with the most significant needs. Also, as there is no recognition of ancillary medical support services needed within the SIS, such as dietary or biomedical interventions; it appears to overlook the safety and well-being of individuals in this regard as well.

→ My fourth comment is that the Department has built in and is relying heavily on additional services such as the Qualified Extra Support Service (QESS) to provide support above and beyond the assigned SIS levels. There appear to be large flaws in the way the rules are written pertaining to this service. The qualifications needed by the direct support professionals (DSPs) providing this service are very extensive, and likely very difficult to attain. DSPs must have a minimum of three (3) years' experience working as a DSP in either Home, Community, or Work Supports, on top of an enormous list of other qualifications. There is a lot of turnover, especially among DSPs, at agencies; providers have reported that it is increasingly difficult to retain staff. The QESS process is flawed, as provider turnover happens faster than the three (3) year minimum requirement for providing the service. Has the Department considered this? Additionally, advocates believe there is a huge problem with how the process for attaining those services is defined. According to the proposed rule changes, "the service will be available to a member upon completion of a review process and an approval by the Extraordinary Review Committee (ERC). The ERC will review the necessity for additional hours of qualified staffing to meet a documented extraordinary support need." The way it is written, there is no standard for how a person qualifies for QESS. Without transparent written standards, contesting the Department's determination, as is a consumer's right according to the Department's appeals process, is considerably more difficult.

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→In contrast to the proposed rule, the Coalition's proposed Continuum of Care service delivery model would establish a broad menu option model designed to match the amount and kind of paid support services needed by each individual. The service system would provide choices that accommodate everyone. These choices would address the need for a variety of models and ongoing adaptability to life changes or greater independence. This is the opposite of a one-size-fits-all approach.

With the Coalition's Continuum of Care model, formal services would be based on individual and realistic needs, not on formulaic policies. Services would be flexible with only the necessary amount of paid support services. There would be no "one-size-fits-all" approach. The formal delivery system would become nimble and flexible to allow for changes in a person's functioning and support needs, minimizing obstacles to flexible adaptation. This would eliminate the need for people to fit into "categories" so they can receive services/housing. Each person would receive what he or she needs at a level appropriate to them at any point in time, whether those needs (identified via Person Centered Planning) increased or decreased.

This service delivery model has been endorsed by the LD1816 Developmental Services Workgroup and the Maine Coalition for Housing and Quality Services, which includes parents, families, caregivers, leadership from DHHS OFCS and OADS, Special Education, transition specialists, service providers, MACSP, Advocates, SUFU, and DOL. All involved agreed that this model is the most effective and efficient use of resources. Most importantly, it will ensure that each person served within Maine's Continuum of Care will transition successfully from childhood to adulthood and become an involved member of his or her community, where natural community supports will be available along with the formal support necessary to achieve autonomy and community inclusion.

→In closing, I urge the Department to revise the proposed rule changes and incorporate a person centered planning approach as primary, and have that process be informed secondarily by the SIS. Allocation of resources should come last, *after* a thorough and comprehensive plan has been developed to meet each individual's needs. It would be a mistake to replace the group planning process with a single high stakes test. Instead, I urge you to revisit and implement the Developmental Services Lifelong Continuum of Care, which has broad stakeholder buy-in across Maine. I further urge DHHS to actively tap into the many groups standing at the ready to participate and help in the implementation design and rule making process. The outcome will be far better for being truly inclusive.

Please, let's revise the proposed rule and use a revised inclusive rulemaking process as an opportunity to more carefully design these crucial services, and get this right.

Thank you for the opportunity to comment.

Cullen Ryan  
Chair