

# A letter for public review and sign-on

August 31, 2015

To: Maine DHHS, Office of Aging and Disability Services  
From: Concerned Citizens of Maine  
Re: Improving the HCBS proposal

We are aware that Department of Health Human Services (DHHS), Office of Aging and Disabilities Services (OADS) has been working hard to create a new Home and Community Based Service (HCBS) waiver proposal that supports individuals with Intellectual Disabilities and/or Autism. We agree with the intentions of DHHS to revise the current waiver in order to provide fairness, personal choice, community integration and independence for people receiving services. We write to you as a group of individuals, family members/guardians, providers, clinicians and community members invested in supporting the creation of an effective and efficient proposal.

We appreciate that some of our feedback has already been incorporated into the proposal prior to it being finalized such as an option for 2:1 staffing and no cap on Qualified Extra Support Staff (QESS) to support the most exceptional situations. We continue to want to work with the Department to assure that its efforts will be successful in supporting this population. As such, we believe that it is essential to address and rectify several problematic themes outlined below. We ask that these be changed prior to the announcement of the public hearing and comment period.

The Office of Aging and Disability Services renamed the Support Intensity Scale (SIS) initiative the Supporting Individual Success (SIS). We believe that it is essential to make the recommended changes that follow in order to truly support individual success and live up to its title.

## ***1) Support Individual Success by allowing individuals a fully meaningful Person Centered Plan. Individuals are more than just a SIS number.***

- The Person Centered Planning team should drive the process, rather than the SIS assessment results. At the Autism Society of America's (ASA) national conference in July, 2015, a draft of the SIS-A Autism Spectrum Disorder (ASD) Extension created by the American Association of Individuals with Intellectual and Developmental Disabilities (AAIDD) and ASA was reviewed. There was discussion and consensus among the audience and presenters that the SIS- A should *not* be the only tool utilized in resource allocation. This is what we want in Maine.
- The history of the individual is important and needs to be fully considered. The current three to six month look back is inadequate to generate supports that will help individuals succeed. Just as the medical profession uses a comprehensive history when making a diagnosis, it is appropriate for the state to use members' history to accurately assess support needs. As this is a unique population, it can take years to determine what works for a given individual. Using only a three to six month look-back to evaluate service needs may fail to recognize why supports in place are important. In some instances, SIS scores may go down due to the existence of appropriate supports, and individuals can appear over served. But this is a fragile population that can quickly regress without the right supports. Including a comprehensive historical perspective provides a safeguard for crisis prevention and optimizes opportunities for individual successes, promoting higher levels of functioning. A lack of historical perspective can lead to health and safety risks for a vulnerable population, and unintentionally create crisis situations with very real individual and system costs.

- The process for exceptional needs, QESS, should support individual needs rather than rely exclusively on cookie cutter credentialed Direct Support Professional (DSP) system that can include unnecessary and costly qualifications, resulting in limited choices for individuals and families. The Person Centered Planning process, with team members and clinicians who know the person best, should be able to determine the qualifications needed to support individual success.
- Healthcare (including dental) access and coordination is a chronic issue for this population that begs for improvement. It is ignored by the new HBCS waiver with its focus on support needs primarily generated through the SIS instrument. Changes within the skilled nursing proposal may be one avenue to address healthcare coordination, but some people who may need it might not qualify. Gaining stakeholder input on how to integrate healthcare coordination into the proposal would be an excellent approach to crafting the best solution. We urge DHHS to use the new proposal as an opportunity to improve quality healthcare, and likely reduce costs. It is critical that this part of a person's life be addressed within the Person Centered Plan as needed.
- Encourage team collaboration rather than relying exclusively on stakeholder input through silos to help find solutions to logistical and other issues that can create barriers to individual success.

***2) Support Individual Success by creating a proposal that has fully developed quality and success measures developed.***

- We believe it is important to define quality and success and to implement methods for measuring these outcomes. Please include all stakeholders in determining what is important for individual success. There is much variability in this population. Providers, individuals, families/guardians, government, DSPs, case managers, and clinicians all share different but important perspectives. Including all of these perspectives in creating quality measures is critical. Stakeholders need to work together to describe objective indicators and reach agreement on how improvement outcomes are measured. We are eager to work with DHHS on this issue because we think it is important that it is able to define what constitutes individual success, as well as success for the program as a whole, prior to implementation.

***3) Support Individual Success by pretesting the program first and delay the program until the issues have been worked out.***

- While the goal of the new SIS level caps and staff ratios is to provide the right amount of service supports for most members, without pretesting these changes, there is no assurance that the program as a whole will work for most people.
- Logistical issues, unanswered questions, and complexities of the proposal will likely create glitches that will deprive individuals of a full opportunity to be successful.
- Multiple changes are occurring at once within DHHS including a new payment system and transition plan. At the same time, DHHS is also short staffed. The state is making significant efforts to reduce the waiting list. The availability of crisis beds is at full capacity. There is evidence that providers are hesitant to take on new clients, not knowing if they can sustain their organizations. These systemic capacity issues inevitably lead to access issues for clients. This can be seen by the low acceptance rate of individuals currently offered spots from the waiting list. Full-scale implementation of the new proposal, while there are so many other changes occurring simultaneously, makes it difficult to envision a successful execution of the new proposal. Delaying these changes until they are pretested just makes sense.
- In the new proposal there appears to have been little or no consideration given to the numerous programs and resource supports that aren't directly tied to individuals, but that agencies offer. Yet these resources have provided the opportunity for many individuals to have choice in their activities and to experience success. Individuals who depend on these services may regress without

them. Again, pretesting implementation protects resources from being lost that turn out to be necessary for supporting individual success.

- Health Service Research Institute (HSRI) helped Maine pilot the SIS assessment with 500 individuals. It is just as important to initially pretest a small number of members across agencies in the implementation process as outlined by DHHS at this link: <http://www.maine.gov/dhhs/oads/disability/ds/sis/documents/ProcessMappingYear1SISImplementation2ndversion.pdf>. Delaying implementation pending a smaller-scale pilot launch would increase the likelihood of success and ensure glitches are fixed early in the process, saving time and money.
- Having a contingency plan established prior to implementation is critical. If the proposal does not live up to its envisioned success, or falls far from the mark, then having a contingency plan developed will protect all involved from unfortunate consequences. Delaying implementation until backup measures are established is recommended.

**4) Support Individual Success by outlining an inclusive, effective process regarding resource allocation to those currently served as well as for individuals who qualify for services in the future.**

- Make sure that the HCBS waiver supports individual success as well as providing access to those currently on the waiting list, at every priority level. Design a mechanism that is transparent and effective to assure that individuals at all levels receive the timely supports they need in order to live a quality life. We share the goal of eliminating the waiting list, and we think it's vitally important that this happens. However, we are concerned that lack of funding for housing within the current proposal may mean that, for some families and/or agencies, it is difficult or impossible to provide the necessary supports for people. We hope you will systematically pursue and secure the funding necessary to achieve desired outcomes and truly support individual successes.

We are all working toward the same goal: ***to ensure that individuals with intellectual disabilities or autism are appropriately supported and able to show their workplaces, neighbors and the public their remarkable qualities, leading to stronger and more inclusive communities in Maine.*** In order to achieve these goals, we believe that the above recommendations are necessary. We urge you to make these changes and would like to see them added to the written rule.

Best Regards,

Kim F. Humphrey, family member, Auburn  
Debbie Riordan Dionne, family member, Georgetown  
Diane D. Boas, family member, Cape Elizabeth  
Thyle Shartar, family member, Wiscasset  
Anna McDougal, individual, Wiscasset  
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Laurie Raymond, family member, Portland

Go to this link to sign-on your support of our suggestions: <https://www.surveymonkey.com/r/633XKXY>

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