**Parent Meeting with DHHS Office for Aging and Disability Services (OADS) Minutes**

**June 18, 2015**

**Brunswick, Maine**

1. Introductions by parent, David Cowing to include: Karen Mason, Gary Wolcott and Jen Fales.
2. Purpose of the meeting was reviewed—to continue dialogue with the Department about the pending system’s change with the implementation of the SIS. The Parent Group expressed gratitude and appreciation for tonight’s meeting and the willingness of the leadership at OADS to come together to hear concerns and answer questions.
3. A small representative group of parents from the Maine Coalition for Housing and Quality Service [www.maineparentcoalition.org](http://www.maineparentcoalition.org) met in advance to identify a few concerns and recommendations to share with the larger parent group and OADS tonight. The group shared the following:

* Laurie Raymond (parent of adult child) shared: At the recent Maine Coalition for Housing and Quality Services meeting, you shared that 85% of the current packages match the service packages that would be provided under the Support Intensity Scale when it is implemented.  As a parent, my greatest concern, like many other parents, is that our sons or daughters will not be adequately supported.  I recently received a letter from my son's case management agency outlining his current level of funding for home supports and the funding under the SIS as a Level 2, his designation.  It was helpful for me to see in black and white this apple to apple comparison.  ***It is my strong recommendation that you provide this information to every family--- with proposed rates and SIS designation so that people have a chance to evaluate it. Will this be a part of the process?***
* Karen, Gary and Jen all indicated that this is the type of information that they would like for families to get and would continue to be something they support for all case management agencies.
* David Cowing (parent of adult child) shared: It seems important for case managers to be fully up to speed and knowledgeable about all these system changes. From talking to several parents, there seems to be evidence that case managers aren’t getting fully trained in a system in transition that has a lot of complexity. ***How will parents get the help THEY need, in order to help their sons and daughters transition from the current system to the new one?***
* DHHS reported that training will continue for case managers, acknowledging that this is a significant change that will require ongoing support to those in the case management role. The question was posed about parents attending the case management training. Karen indicated that training will be offered for the different groups that need it. David highlighted how helpful it would be for parents to attend the case management training to learn the details of the service packages and related information.
* Debbie Dionne shared: I am the mother and guardian of a 35-year-old young woman who has been receiving section 21 Waiver services for the past 13 years. It is my belief that the SIS assessment is a high stakes test that does not allow flexibility for those who do not fit neatly into a single category, and should be part of the assessment, but not the only measure. In addition to my daughter’s diagnosis of an Intellectual Disability and Cerebral Palsy, Kate is also non-verbal. She uses limited language, sign or gestural language and most recently an iPad to communicate. When my daughter went through the SIS interview process 2 years ago, I did not feel that this important communication piece was factored into the scoring of the questions, as she could not answer completely and by herself; it felt as though we were coached through the process. As a result, I believe her final score and tier level of funding does not match what her actual service needs are, in order for Kate to be physically and emotionally safe, healthy, and integrated and involved within her community. If the PCP process was a part of this assessment piece, I believe that the assigned score and level of funding would be more accurate, and truly exemplify the Supporting Individual Success initiative you are striving to achieve. ***I urge you to build more flexibility into the system and allow input and data from the most important PCP process, as well as to have personal outreach to the families about the SIS scores and services.***

I have spoken with Jenn Fales about my own concerns and she has been responsive and helpful. This should happen for all the 200 families who are worried and are overwhelmed about their loved one’s SIS scores and proposed level of funding. Families are an important part of the process to make the system better. ***Will you allow for more flexibility in this most crucial assessment process and reach out to these 200 concerned families?***

I know in the guide for case managers on the OADS website, the SIS is referred to as a conversation starter. As a parent, it feels like much more than that. Having a single score on one instrument dictate what is available for services also seems too simplistic and goes against best practice. ***I’d like to know more about how an individual’s Supports Intensity Scale score should be factored into the PCP process.***

There are many logistical issues, concern that too much is being done at once, that the system is too complicated. We know that over 200 people feel their SIS level and associated packages do not fit the need that there are over 100 complex cases that do not fit the proposed system. ***I urge that the timeline of implementation must be delayed until these problems are resolved***.

The SIS was pre-tested on 500 people. The people whose lives will be affected by the new proposal deserve as much care as testing of the SIS. ***I urge you to roll-out the program across agencies on a small # of individuals to pre-test this proposal before it is fully implemented.***

* Jen Fales advised that they are paying attention to the way the SIS is being done. There are ways to increase supports through the QESS and Skilled RN services for individuals who require more support than DSP. She acknowledges that mistakes have been made which the Department is working to address.
* Gary shared that the PCP is still central and core. The SIS is standardized tool that allows teams to get a general overview. From the beginning, HSRI and the whole team have been clear that we cannot devise a system that fits everyone. Through the PCP process, we have ways to fill in if extra services are needed. Gary encouraged families to be involved in the PCP process so this informs the process as much as possible.
* **Question from the audience:** I would like a list of states and contact people for places that have implemented the SIS.
* Gary agreed that DHHS OADS will get that together but highlighted that every state Medicaid program is unique.
* Kim Humphrey (parent of adult child) shared: To reinforce with numbers, the previous points, with the support of others, this spring I sent around a survey to learn what people know about the changes. 239 people responded. There was a good distribution of individual/families, providers, case managers and DSPs. We asked the questions to help us learn if individuals or their representatives have received the information they need to understand the impact the new system will have on their care.

***Individuals and families****:* Of the 79 individuals and guardians for someone receiving waiver services that responded, 36% knew the SIS level and only 25% felt all of their questions were answered. This means a range of 63% to 75% of families do not have enough information to understand the impact of the proposal.

***Case manager perspective:***  Here is a representative comment about SIS: “Too confusing to most; not enough information out there explaining what to expect and where to feel the crunch the most. Most Case Managers could still not tell you about the changes, so don't feel like there has been enough time for everyone to weigh in. Needs to be more meetings and town halls about the scores, their meanings, and how it will directly impact each individual's schedule/routine/services, etc. Too soon to implement.”

This program is called Supporting Individual Success. We agree with the concepts of the outlined in the program about the need to support independence, choice and individual success. ***I urge you to define, measure and monitor success and the other characteristics the program is intended to achieve. Do this for the individual and for the program as a whole. Include stakeholders in development of these. Include quality measures to assure that the program truly does support individual success. I urge you to delay the timeline so problems in the SIS implementation can be resolved. I also suggest you pre-test this with a small group.***

* Gary shared that two months ago, Maine submitted their application to CMS for the Comprehensive Waiver (for Section 21). This is the renewal which is required every 5 years for the Federal Government. Their approval is important since they fund $2/to Maine’s $1. We submitted the proposed design to them and they have asked many questions for us. Maine has received the Federal Government’s questions and will need to get back to them in the next couple of weeks. The clock will stop until Maine gets them the answers to questions. Gary stressed that DHHS is still listening and still want our comments/feedback. The second process of this will be the Maine process after the Federal process is completed. We will still need rules and DHHS hopes by the end of next week, they will start rule making. Proposed rules will be posted and feedback requested. There will also be a public hearing, a 30 day period to accept written comments/emails/hearing papers. There is an opportunity for further input. The goal and design has been to get the best program possible. We will likely not see the SIS implemented until next April, 2016. Once program is official, Jen and her team can look at requests for readjustments or scores.
* **Cathy (parent) from the audience** shared that she has a 31 year old daughter who would be eligible for much more $ of support living in a group home than living on her own. The concern is the higher percentage of monies going to the group home worries her that this will push people toward that level of care. She highlighted that we want people to be as independent as they can be, to live full rich lives and that the community can be accepting. She does not want the system at play now to deprive them of that.
* Gary responded by highlighting that they took an in depth look at individual rates and relied on leading experts in building the rates. They pulled our data on utilization of services. We do not want to build a system that would deprive anyone of anything. In cases where someone needs more, the PCP builds this individualized program. They want to incentivize community based settings and not large congregate settings. Community Support and Work Support rates have increased. The goal is not to dis-incentivize community living. DHHS wanted a transparent rate model so nothing is hidden. Administrative overhead at 10%, all the assumptions the rates were built on –benefits, pay, etc…are spelled out in this model. The other purpose in having a transparent model was so the Department could sit with legislators and explain the process. They are hoping to have a much clearer dialogue with legislators. This is a $300 million dollar program so it is important to be able to speak about the rates.
* Gary shared that 2 consulting firms were hired to evaluate and design the system. They included HSRI and Burns and Associates. They both have worked in many other states.
* Gary shared that DHHS has a commitment to parent advocacy even though in their roles there are some limitations in these efforts by them directly. They fund SUFU, DRC, OAB, Maine Developmental Disability Council. They also support the work of the Maine Coalition for Housing and Quality Services. Through these organizations, people are brought together so the self-advocate and parent/family voice is heard. Karen Mason agrees to make sure that their intake department has all of this information so people are informed of where to reach advocacy supports.
* DHHS shared that over the past 4 years, they have been concerned about issues of transition. They have developed District teams and identified all children around aged 16 who may need adult services. There are efforts to do a SIS before adult eligibility, around aged 17 years, so formal eligibility determination can be made. This will result in those youth who may need services getting on a list. As of today, there is no waiting list for Section 29 support waiver. There are still 1100 people on the Section 21 waiting list, but none are priority 1. There is some money in this new budget to assist with the waiting list.
* **From the audience, a parent** shared that their adult child is on the Section 21 waiting list as a priority 2. In the meantime, this child has incredible support needs. Although he has Section 29, six or seven day habilitation programs have declined him because of his behaviors. He graduates Monday. What can I do? Are there steps I can be taking? The members of the panel advised that Karen Mason would get talk with the family to see how the Department may be able to help.

Gary shared that for 18-21 year olds there is additional confusion. The Department would like to create a seamless system so the hand off is automatic from Children’s Service to Adult Services. Karen shared that OCFS and OADS completed training 300 Children’s Case Managers in EIS system (states electronic record system). The second phase of this training will be Targeted Case Management training on reportable events, waiver applications and other related topics.

* **Parent from the audience** shared that his son with severe Autism and Developmental Disabilities had 5:1 staffing as a child. Now, he is managing in his own apartment with 24/7 staffing and a second staff person for community activities. Although he is a level 5, 1:1 is covered in budget, but the additional staff support is not. His question was related to the formula and if they can meet now, before the SIS process is all settled, which is what his provider suggested. Karen advised that it sounded like he was not getting the information he needed and they agreed to touch base to problem solve.
* DHHS outlined that the process is for the team to get together for the Person Centered Planning meeting. If that determines that the budget does not meet the individual needs, the team should specify what is needed and make an application for the additional process (for more hours/resources). This process will be standardized in the SIS. In a year, DHHS will be able to see where we are. This will be a huge advantage in legislative efforts of anticipated funding needs. Gary shared that the PCP team says the number of additional supports needed. These will be reviewed by a committee and authorized based on individual need.
* **Question from the audience:** In this family’s experience, the SIS was done without any input from the family. They were told about it but not at the SIS assessment interview. Gary advised that this was an error on their part so they should speak with Jen Fales and get added to the reassessment list.
* **Question from the audience**: When the SIS is up and running, will there be an evaluation of Reportable Events, ER visits and related? Gary shared that the USM Muskie School looked at costs of Medicaid/medicare for those on Section 21 compared to those on Section 29. What they found was that the Section 21 individuals had ½ the costs for medical in terms of hospitalizations/acute care. This study is available for interested parties.
* **Question from the audience:** APS Healthcare denied case management services while they are faced with guardianship, Medicaid application etc….The family has filed an appeal and grievance. DHHS shared that there are differences between the children and adult systems of care relative to case management services. Regarding APS Healthcare, they will be phased out with the SIS. The OADS website has information on guardianship and transition.
* **Question from the audience**: Son is a level 3 which allows for 125 hours per week. There are 168 hours in a week. He may need to be placed because the family needs to work and cannot provide back-up care. Gary shared that the system has three types of support: Home, Community and Employment. DHHS cannot pay a provider for more home supports, but can offer community support to people and they will pay for that. DHHS has tried to build into the system incentives to get individuals out into the community. The system will have increased flexibility and possibilities.
* **Question from the audience**: 18 year old brother for whom she is co-guardian is two years out of high school. He is still receiving Section 28 Services, getting 27 hours per week and school. He is on the list for Section 21 and gets 19 hours of support a week through Section 29. What will happen since mother needs to work full time and he will only have 19 hours of home support? The mother is very small in stature and the brother is tall, heavyset, and volatile, and inadequate support may lead to a life threatening situation for the mother. Gary agreed that the waiting list is unacceptable. He encouraged families to create a vision of what the ideal is and to consider making the transition to adult case management. Contact information from the panel was shared with family members.
* **Question from the audience**: The group home sent them a letter about the SIS asking the family for more information about their child’s level 4 and whether she would remain at the group home through J. F. Murphy Homes. Karen suggested the case manager may need to get more involved. They will follow up on this situation.
* **Question from the audience**: Where is the SIS coming from and why is it being done? Who is AAIDD? Were there any parents involved in it? Where is the money coming from to pay the consultants? The base budget living home vs. living group home is different—why is that?

Gary explained that AAIDD is an international organization of professionals and advocates who came together to create levels of care that can be used for planning. It is a non-profit organization. They commissioned a scientific team to accurately assess individual support needs over a 5 year well documented study. It involved parents, individuals served, providers and extensive interviews. The Consultant did the rate study. In Maine, 60% of people with DD/ID live in group homes. This system will be based on choice and the system we already have is too. This new system is built to care for everybody where they are today—rather than requiring them to move. Resources were shared as well.

* **Question from the audience:** With budget cuts, how do you expect the quality of the pay to trend for direct care workers? Gary stated that there are no budget cuts here. They will be spending the same amount of money. When you level the playing field, some people will get more and some less. More organizations come out the same. He highlighted that agencies can look at new opportunities in the system.
* **Question from the audience:** Concern was raised about turnover among direct care staff in the group home and the confusion it causes clients. Gary agrees that one of their major concerns is that problem. He believes that some providers like turnover because it keeps down the direct care wage. Staff consistency was a problem and usually it takes a year to work well with a client. They tried to keep them 3-4 years and it is part of the formula.
* **Question from the audience:** The rights of the individual sometimes means we cannot say no to them and staff cannot make a decision for them. Gary explained that the laws exist to protect the individual from abuse, neglect and exploitation. We have learned with in this system. We are as good as anyone else out there in other states. We stabilize behaviors in Maine and address issues through the Crisis Worker system. It is a matter of getting management and staff in using these techniques. Ensuring there is no exploitation/neglect/abuse is a number 1 priority to the Department for all---aging, physical disabilities, developmental/intellectual disabilities and TBI---across the board this is an issue to continue to work on and work toward.
* **Question from the audience:** Family member cares for a 52 year old niece. The big concern is about aging. What is going to happen to our people when we are no longer here? Gary stated that supporting people is their priority. We are a leading state in the country and history is the best predictor of behavior. They have a wonderful team of dedicated people. Our Governor and Commissioner Mayhew respect and advocate for supporting our most vulnerable Mainers. We need to work on the hand off to the next generation. They are committed to doing this.

**Wrap Up:** DHHS OADS shared contact information, call in number for SIS, website and information on the Maine Coalition for Housing and Quality Services. Continued questions and answers will follow for individual situation. Special thanks to the Department staff---Gary Wolcott, Karen Mason and Jen Fales for taking the time to meet and their openness to a continued dialogue through this period of change.