

DAIL Advisory Board Meeting Minutes

October 12, 2017

Sally Fox Conference Center, Waterbury

ATTENDEES:

Board Members: Robert Borden, Terry Collins, Kim Fitzgerald, Mary Fredette, Jeanne Hutchins, Nancy Lang, Laura MacDonald, Nancy Metz, Diane Novak, Martha Richardson, Christine Scott, Lorraine Wargo

Guests: Jill Olson, Janet Hunt, Toby Howe, Lynne Cleveland Vitzthum, Marie Zura

State Employees: Commissioner Hutt Hutt, Camille George, Liz Perreault, Angela Smith-Dieng, Bard Hill, Clare McFadden

Motion to Approve Minutes: September 14, 2017 minutes: Approved: Terry Collins
Seconded: Mary Fredette

Abstained: Nancy Metz, Kim Fitzgerald and Diane Novak

Minutes are approved.

John Pierce:

Camille George was informed by John Pierce that he is regrettably resigning from the board, effective immediately. Robert Borden wanted to take a moment to recognize John's contribution over these many years and for the minutes to reflect and acknowledge "his faithful attendance, his wisdom and his openness to hearing everyone's point of view."

Reframing Aging:

Angela Smith-Dieng, ASD Unit on Aging

Angela Smith-Dieng came to give an overview of the work DAIL is doing around reframing aging in Vermont. A year ago, the Tristate Learning Collaborative on Aging convened a summit in Concord, New Hampshire and had a presenter from the Frameworks Institute, a national non-profit advocacy organization that conducts communication research based in social cognitive science. They look at how we think and how we should communicate social issues to impact public discourse and eventually create policy change. Their presentation at the summit was so good, we asked them to come to Vermont and give a training to the Aging Network, in March. Since then, the conversations are continuing and the practice of reframing is evolving.

Frameworks conducts its research by collecting the information that is already out there in the media, doing on the street public interviews across the nation and setting up even more in-depth

interviews with people from all demographics to find out what the consistent perception of aging is. They then test market the language they create to see how people react. It is more about forming concepts than it is about language. One interesting finding is that people don't tend to respond to things on an empathetic level, most times that approach turns people away. Getting the public to see something as a collective problem that we are capable of solving is a more effective slant.

The goal is to address reframing, not only with the Aging Network, but for everyone from educators, policy makers, the media and the general public. If you are interested in the practice, go to the Frameworks website for information on the research that has been done. You will find the communication tools they have created to reframe aging that will help move the conversation forward.

Frameworks is also doing similar research and reframing for individuals with developmental disabilities. Commissioner Hutt will have Liz Perreault send out some of the preliminary work they have done around the concept of public perceptions so far. They don't yet have the tool kit developed, but are working toward that. The reframing is important in not only public perceptions but how policy makers perceive individuals with developmental disabilities. It helps us engage others and to articulate clearly when we ask for funding.

How hard is it to change the language? Does the change come from above and when considering funding do decision makers look for certain language in the funding requests? Or, does the change come from a grassroots level? DAAL is working on changing its language and that helps shape the larger world since we are the ones always talking about aging and developmental disabilities. Also, the Vermont legislature recently passed a bill focused on *Respectful Language* for disabilities. This bill called to strike certain language across all state statutes. You will still see it in places because it is difficult to change everything, but the effort was made and taken very seriously. This is a great opportunity to align the *Respectful Language* legislation with the Older Vermonters legislation.

Frameworks begins with cultural models. These models help us think fast and have been created within us through years of experience and expectation. They are mainly automatic assumptions. People rely on cultural models to interpret, organize and make meaning out of all sorts of stimuli, including experiences, feelings, thoughts and communication. There are productive and unproductive models and the trick is to trigger the productive models through the use of language.

Cultural models are often referred to as a swamp. There is muck and mire but also beautiful orchids in this swamp. In the swamp of aging we find people think, among other things, of deterioration, us vs them, the feeling that older people are where they are due to their own poor choices in the past. The solutions that are created when in the mire are things like the problem is a silver tsunami; not much can be done, financial interventions to help them plan for their older years or if we could just educate them we could avoid the challenges of aging. There is also the nostalgic idea that in the past things were better because families took care of each other, the economy is different now than it was years ago and Social Security is doomed.

The orchids in the swamp of aging are: older Vermonters are problem solvers, there is a collective responsibility and what is around us, shapes us. Using these American values to communicate with people is more effective.

Words change our thoughts and thoughts change our perception. An example of that is how the Governor speaks about older Vermonters. When he first began his Governorship, his focus was solely on rejuvenating the younger population and that the older population seemed a bit burdensome. Since then, he has heard us speak about the value of older Vermonters and Vermonters living with disabilities and how they should be considered a natural resource that can fill some of the workforce gap.

While trying to counter negative perceptions about aging three approaches tend to be used: more data, correct the public's perceptions mistakes and try to share individual stories. However, instead of moving the perception in the direction we want, more data tends to confuse people. Correcting people's perception with things like fact versus fiction, people tend to remember the fiction. When individual stories are told, people generally think that these stories are the exception and not the rule. Frameworks suggest that when you share stories, you share many stories, so people see the pattern.

When you reframe, you change perceptions. Some of the reframes are; building momentum, ingenuity and justice. Building momentum is about individuals gaining knowledge and wisdom, social, emotional and cognitive growth. Ingenuity is the ability to problem solve and the ability to replace outdated practices. Justice speaks to a society that treats all in the society as equals.

We all have the ability to shape the language that is used in the way we speak and write and how we respond to others when they use language we want to avoid. We are trying to move away from elder, senior, senior citizen and use instead; older Vermonter, older adult, older person when communicating with the broader world. When using the preferred language, it evokes a feeling of competency while still identifying the age range.

There isn't much terminology for identifying older people. It seems there is a lumping of people from age 60-100 together. DAIL tends to use "we" when talking about aging. How do "we" want to age and how do "we" want the world to look? DAIL tends to look at it as a spectrum and generally use the term older Vermonter.

DAIL supports looking at the community as a whole. The same sidewalks that work well for pushing a baby stroller are good for someone in a wheelchair or using a white cane. DAIL promotes using universal design in housing and communities to address all physical, emotional and social needs so it is inclusive to all. One potential danger in State Government is that we sometimes get stuck on focusing on one specific group when the real goal is inclusiveness. Another struggle is keeping the

vision beyond the tip of the triangle that we serve. This is why language and messaging are so important to keep the focus on the whole and not a small segment of the population.

One example of success in changing language and perception is that the Governor has said on two occasions that we need to encourage young families to Vermont and grow the economy and that as a state we do not ignore our natural resources and older Vermonters are a natural resource and are in our workforce.

Recently we were approached by two different VPR reporters wanting to do two different stories about the aging demographics in Vermont and how that will affect Vermont's economic future. They had started their research by speaking to the agency and asking the Medicaid budget and going down a rabbit hole of very narrow thinking. Commissioner Hutt reached out to them and said she would love to speak to them on this subject. For the first interview Bard Hill and the Commissioner spoke with Bob Kinzel and the second interview was with Howard Weiss-Tisman and the Commissioner. By the time the interviews were done they were very excited at the potential that this generation of people could bring to the table. Having had the conversation with Commissioner Hutt really changed the stories the reporters were going to write. They saw what could be gained with older Vermonters in the workforce.

Along with changing the messaging, there has to be inclusiveness. Older Vermonters need to be engaged and part of the conversation. The old messaging has been so successful that older people tend to believe it themselves. There are two groups that exist right now for older people to get involved with, AARP and COVE. These two groups can be very influential in changing legislation, the messaging to the general public and to older Vermonters themselves.

It is encouraging that younger people are working in the field of aging. It is important that they are asked the question of how do they want to age. What do they want their life to look like when they get older? They are rich in ideas on how to reframe.

When we look at DAIL across populations, there is so much work the disability community did from both a language and planning perspective. The mantra of "nothing about us without us" should be the same strategy we use with aging.

Processing and Follow-Up from Previous Meetings

Camille George, Deputy Commissioner and Bard Hill Director of PPAU

Having gone over so much information the past few months, we wanted to give an opportunity for the board to reflect and ask any questions about the conversation we had regarding health disparities among people with disabilities, senior health rankings, LTSS scorecards, demographic and utilization projections, and the input that the advisory board provided on the two Act 186 outcomes that was brought back to the Government Accountability council.

Government Accountability Committee -

The Government Accountability Committee's job is to link funding to outcomes to all programs across state government. The Government Accountability Committee was looking for a couple of indicators for the two outcomes for people with disabilities and older people. Not only is this exercise important for accountability for the broader government, but we as a department can use this information to help guide us. If we can identify programs that don't work to achieve these ends, then we can eliminate the program and optimize the programs that lead to the desired outcomes.

Act 186 includes many outcomes: Vermont has a prosperous economy, Vermonters are healthy, Vermont's environment is clean and sustainable, Vermont's communities are safe and supportive, Vermont's families are safe, nurturing, stable and supported, Vermont's children and young people achieve their potential, Vermont's elders live with dignity and in the setting they prefer, Vermonters with disabilities live with dignity and in setting they prefer, Vermont has an open, effective and inclusive government; and, Vermont's state infrastructure meets the needs of Vermonters, economy and environment.

Keeping an eye on the outcomes forces us to look beyond the programs and people we directly serve because it is important to be aware of the population of the state and not just the small tip of the triangle of the population that we serve. Any advice you have as to how we can use the indicators will help us inform our mission and our moving forward to providing services.

UMass -

The UMass slides could be easily misconstrued. In the area of the older age group the utilization of services is projected to be flat, however, in the age group of ages 18 – 64, utilization of services went up. The need for workforce is still growing, but it will be needed for a different age group than we would have anticipated considering the aging population of Vermont.

The challenge is finding population data that we can use going forward. We can use Medicare and Medicaid claims as resources and that does give us a little broader view of the population than just our program data. Finding data on people with disabilities is even harder to do. One place for finding information is the American Community Survey that is done by the Census Bureau, the Department of Health does a Health Risk Survey and a Youth Risk Survey. These provide some snap shots at data we look for.

Falls -

Falls are the leading cause of death and visits to the ER for older Americans. The Falls Free Vermont website is a wonderful resource and has information available about how to talk to your physician about falls, how to prevent falls and even information about local activities available in your area. Liz will send the board a link to the website, so you can visit and see what it has available.

Developmental Disabilities Services Division- Meet Clare McFadden, Director

Clare McFadden, DDS Director

Clare has been to the board on several occasions reporting on DDS developments, but we wanted you to have opportunity to meet Clare now that she has stepped into the Director role of DDS.

Clare has a Master's Degree in Special Education although never worked in a school. She has worked at Washington County Mental Health at the beginning of her career and has worked in the field of Developmental Disabilities Services all of her career. In 1990, she came to the state to work for DDS and in the last 27 years, she has worked in various roles except guardianship.

Two recent accomplishments in DDS are the development of the new *DS System of Care Plan* and promulgating major revisions to *Regulations Implementing the DD Act of 1996*. These updated documents have just been implemented on October 1. It took about a year and a half to complete the revisions of these documents. There will be training in the next month or so with the provider network, so everyone understands the new procedures and regulations we will be working under.

Some of the priorities that have been identified in the *DS System of Care Plan* include a project of collaboration between a variety of stakeholders on a community of practice in cultural and linguistic competence. This is a 5-year implementation plan. Another project is collaborating on a grant with the Health Department on Chronic Disease. There will be outreach to improve mobility, access and inclusiveness. It is the same grant we heard about in our last meeting and DDS is part of that process with working with the Health Department. This is also a five-year project and it is in its first year.

In addition, there will be enhanced training for the DS provider network, including training on person-centered services and emotional regulation for people who have psychiatric and challenging behaviors and developing a better training for service coordinators working in the field.

Work will continue on compliance with the CMS Home and Community Based Services (HCBS) Rules and updating the grievance and appeals procedures. The first step is to use the broad grievance and appeals procedures the Vermont Department of Vermont Health Access comes up with and tweak it to fit our needs.

There has been one change to the CMS HCBS Rules in that the dates for compliance for some components of the rules have been pushed out to 2023. The key CMS HCBS Rules focus on ensuring people are included in their community, that people have real choice, the settings people are living in are conducive to access to community and life like everybody else; and, ensuring privacy and access to food and visitors when you want.

DDS has had the providers complete a self-assessment survey. They sent the information back to the state and we are currently assessing that information making sure they are meeting the rules put forth by CMS. The quality assurance teams will be going out to see firsthand that providers are

following the rules. There aren't many providers with congregate settings that would lend itself to breaking the rules. However, there are some and we will be looking into these settings. Many of our agencies are well in compliance, but we do need to look carefully at the new rules and make sure the rules are being met.

There was some question to how accountable we need to be to the CMS HCBS rules with our Global Commitment agreement, but instead of wasting energy on debating that, we decided to go ahead and adopt the regulations since it was in line with our mission and approach anyway.

Board Member Perspective

Nancy Lang

Nancy found this presentation a great exercise to ask herself, "Who am I?"

Nancy is the oldest of 4 siblings. Her mother was Canadian, and an only child and her father was Costa Rican and was one of 10 children. Her parents, having come from such different backgrounds, made their marriage work by understanding that because they were so different, they had to work together. One thing Nancy learned from growing up in a diverse home was that there are a lot of things we don't know about people and to be careful about making assumptions.

Growing up, the family moved around. They lived in the Jersey suburbs, a small town in Indiana and Puerto Rico. Her Dad had a PHD and was a microbiologist and he led a research group. While living in Indiana, people were very discriminatory towards her father. They believed that because he was Hispanic, he should more appropriately be a janitor, not a prominent scientist that had many professional people working for him. This discrimination followed Nancy while in Indiana. Her friends started to call her out on her differences from the size of their family, her supposedly "darker" skin that "wouldn't burn", and they didn't attend the Catholic church. When Nancy's family moved to New Jersey, she went to the beach and got a bad sunburn by relying on what she had been told. She realized then that she had bought into the things her young childhood friends had been saying about her and her family. It was also enlightening to Nancy that while living in New Jersey, her dad was treated with complete respect for his work and education.

Nancy realized her identity was very wrapped up in her dad's side of the family and the fact that her mom was English didn't even factor in for her. She had her dad's last name. When she married, she took her husband's last name, Lang, and soon realized that people no longer knew automatically of her Hispanic heritage.

Life Lessons:

One life lesson that Nancy's dad taught her was while driving down the street in San Juan, Nancy saw a prostitute and Nancy laughed at her. Her father stopped the car little way down the road and turned to her and said, "Don't you ever laugh at another human being. You never know why people are where they are in life. You have no right to laugh at another human being." Her father never spoke to her like that and so when he did, that lesson really stayed with her through her life.

Her mother taught her sharing and forgiveness. By being one of four children, they would have each other and wouldn't be alone.

While Nancy lived in Puerto Rico with her family she was asked to teach swimming lessons to the women of the town they lived in. Many of the women were afraid of the water but through encouragement and some coaxing, they swam. The lesson that was learned was you can't force people to do things but when they want to, you can't stop them.

Once Nancy was grown, she taught high school and learned so much from her students. After college and before teaching, she worked for Harper Row Publishers in New York and actually met Robert Kennedy in the elevator. While in New York City, she took a volunteer teaching job in Hell's Kitchen and would have to take the subway into the neighborhood. Her students would walk her to back to the subway in the evening to make sure she got there safely.

She took a respite from volunteering in the community when she and her husband lived in San Francisco. Once they moved back to the New York City area and lived in a suburb, Nancy taught reading as a volunteer in the South Bronx where she was working with a young boy. When they were looking at pictures of things and reading the names of the item, they came to a picture of a vacuum cleaner. The boy had never seen one and didn't know what it was. Nancy saw this as another example of the importance of not making assumptions about people.

While volunteering in a "home" for young boys who had been removed by a state agency from their homes, she was helping a boy read. When he was reading well, he was so excited, he tried to give her a big loving kiss. Nancy realized that the boy had been abused and was confused about how to show his gratitude.

Nancy and her husband then moved to Vermont to try to simplify their life. They both ended up working in the same community where they lived, her husband, an attorney, and Nancy, a teacher. They enjoyed Burlington and soon adopted their two children.

Nancy has had a very active volunteer role as part of the community. After her career as a Burlington High School English teacher, she served on the Burlington school board. While on the school board, she served with a former student and parents she had known during her teaching days. It was a great combination of perspectives.

Once Nancy retired from the school board, she volunteered with AARP in Vermont. She served on the volunteer Executive Board and as volunteer State President. She later became Regional Volunteer Director of eight northeastern states and Puerto Rico. There were many similarities in state issues such as: transportation, health, livability, and how older people were perceived.

Some issues that were highlighted in her volunteer work with AARP also include senior employment, labeling, and universal design. Nancy asks that DAILEY pay special attention to communication with

people about disabilities, aging, and what we need to all live together. Another issue of concern is loneliness, a sense of community is important and needs to be accessible. Nancy has been on this board for a while and it has been important to her.

Conversation with the Commissioner

Commissioner Hutt

We have a wonderful balance of people on this board that take it so seriously, make it important and add value in such a profound way and it is so appreciated. It makes such a difference to the effectiveness of this board. When Robert spoke at the Pacesetter Awards he spoke to what brings everyone together and what drives the board and how wonderful the board is.

SFY 18 Current Budget-

Bill Kelly, Financial Director, will join us at a future meeting to look more closely at the budget. Right now, it looks okay and stable. We had started the DS budget in a hole because there was a rescission last year and the caseload was much heavier than we expected. When we look at caseloads, it isn't just new people to the system, but it is also changing needs of people already receiving services. The load is pretty evenly split. Bill advocates for this department and was able to fill the hole for this year that we will have to address next year, but for now we are more balanced. It is a one-time fix, but will be addressed again next year. TBI is seeing some unexpected pressure this year. Because it is a small program any changes in need are really felt. This is a rehabilitative program and people do move beyond it. Voc. Rehab runs on a federal fiscal year. We took a big hit last year with the loss of about \$5 million in federal re-allotment funds. This year, we hoped we would get at least the same as we did last year, but took another big hit and are getting approximately \$800,000.00 less. Part of that may be due to the hurricanes. States that have a larger need get the bigger allotments. The Federal Fiscal Year begins in October, so we are looking at mitigating the deficit in this year's budget.

We have been meeting monthly to keep an eye on the budget so shifts and changes don't catch us off guard.

SFY 19 Budget Development-

Budget development is happening now. We started meeting with AHS Secretary this week and we will be meeting with the administration November 3. The instructions are to level fund. There are caseload pressures in CFC, DDS and TBI. We are presenting our pressures and we are very clear about the implications of a level fund budget.

Currently there is a Mental Health crisis and that does affect our programs. We are fully engaged in talking about this issue since it involves the population we work with. The two pieces that we keep bringing to the table are our developmental disabilities services are linked to the community mental health services since all but one of our designated agencies are both DD and MH. What happens in one area affects the other. The DAs and SSAs did receive some additional funding to increase wages for certain workers, but it took all summer and public testimony for the legislature to recognize that

the agencies needed to shift the dollars as appropriated to where the actual need was. This is done through the budget adjustment process.

The other piece we keep bringing up is the “geri-psych” term that is over-used and doesn’t hold a specific description. When someone uses the term, we ask questions as to what exactly do they mean. Are they talking about people who need nursing home level of care? Are they talking about older people that need psychiatric care? Regardless of the answer, the age of the person is irrelevant. If a person needs a high level of care from a nursing home that is one conversation. If the person needs psychiatric care that is another and they should be able to receive care in the community, at a facility or at the psychiatric hospital.

Every provider system is challenged when someone presents with multiple issues that are complex and span across the whole spectrum of need. There is not a single place that has the capacity to handle the multitude of potential issues. DAIL is currently working with a nursing facility that is willing to create a wing that is specifically for those with complex needs whether it is behavioral or other things. The people that go there will have a safe place to be assessed and the long-term plan can be developed. It will be a good transitional place for people coming out of a psychiatric hospital or level 1 bed.

In terms of the budget, this whole Mental Health conversation is a part of the overall budget development. It is still too early to give any more information. The AHS Secretary does have a big picture strategy and looks at the Agency to see where the balance can be achieved.

Home Health is looking at a 1 billion-dollar Medicare cut nationally as of January 2019. It is unclear what that means for Vermont. CMS has created a fact sheet with some information about this and Jill Olson will share with Commissioner Hutt.

Sterilization-

Through an e-mail from a legislator, Commissioner Hutt was asked if she was aware of a Vermont statute that allows for involuntary sterilization of adults with intellectual disabilities and the legislature has been talking about it. What is your take on having the statute stricken?

The statute is Title 18: Health, Chapter 204: Sterilization (Cite as: 18 V.S.A. 8705) and reads:

“§ 8705. Sterilization; policy

(a) It is the policy of the State of Vermont to allow voluntary and involuntary sterilizations of adults with an intellectual disability under circumstances which will ensure that the best interests and rights of such persons are fully protected. In accordance with this policy, a person with an intellectual disability, as defined by subdivision 7101(12) of this title, may not be sterilized without his or her consent unless there is a prior hearing in the Superior Court as provided in this chapter. A person with an intellectual disability under the age of 18 may not be sterilized.

(b) Sterilization is defined to mean a surgical procedure, the purpose of which is to render an individual incapable of procreating. (Added 1981, No. 142 (Adj. Sess.), § 1; amended 2013, No. 96 (Adj. Sess.), § 111.)”

Commissioner Hutt’s initial reaction was to say that this statute does not align with DAIL’s mission and as a department we couldn’t support it. However, the last time the state tackled this issue there was a large contingency of people who thought this statute was an important protection for their child. This is an old law that was revised in 1981 to require a court decision before the sterilization could happen in order to help protect the person with an intellectual disability.

An advisory board member shared her experience of having a partially verbal daughter and talked about the fear of abuse and potential of pregnancy. Fortunately, there is birth control but that can’t always protect the person from the trauma of a pregnancy coupled with the abuse. This is a tough conversation and it is such a personal decision. There are many reasons why families would want to have this option. It is important to know too that our public guardians do not have that authority to give consent.

When trying to answer the question about whether to support the statute being stricken, it was advised that DAIL consult with Green Mountain Self Advocates, the Vermont Family Network and the DS State Program Standing Committee to get their input.

It is not uncommon for a Commissioner to weigh in on these types of discussions and to speak on behalf of the department and to voice the department’s current policies and positions. DAIL’s General Counsel will also look at the statute. We also are interested to know how many times this choice has been exercised and we can get that information from the court records. It is also important to understand what is considered “voluntary.”

Does the board have any recommendations? It would be important for someone, like Kristen Murphy from the DD Council, to attend the legislative council meeting. There could be an opportunity to educate about what we consider individual choices and independence for people with intellectual disabilities.

Board Updates

Robert Borden – Robert announced that he thought it time to pass the chair position on if someone was interested in taking on that role. He has been the board chair for a couple of years and thought he should initiate the conversation since there isn’t a time limit. However, if no one is interested, he is happy to continue as chair.

Kim Fitzgerald – The memory care facility is a go and should open by the end of the year. Also, One Care has approved the funding of a mental health clinician for the SASH panel for mental health issues.

Meeting was adjourned 2:00