

Robert Borden

The award ceremony for Vermont from the SCAN Foundation will be held here at the Sally Fox Conference Center on Thursday, September 21 beginning at 6:00. Robert will be speaking and representing the DAIL Advisory Board and sharing the board's function, how important it is and how respected the board is by DAIL. Robert asked if there is anything the board would like him to mention. Beth suggested that he look back at agendas and mention the variety of topics that are covered by the board. Ginny suggested that he talk about the aging demographics and the number of people living with disabilities and what they contribute to our communities. Christine would like Robert to mention the genuine compassion and passion that the people in this room bring to their work and this board. It has such a positive impact. There will be past Commissioners there and all is welcome. Please, come and help celebrate this honor and be Robert's posse!

Judy Peterson

Judy and Kim Fitzgerald just saw each other at the closing of the Respite House which was sold to Cathedral Square Corporation. Cathedral Square will soon be opening a residential memory care program in that space. It is considered a win-win to have another community service program taking over that space.

The VNA of Chittenden and Grand Isle County is in the middle of a due diligence process through the UVM Health Network. Judy has mentioned this to the board before but wanted to update. There will be an annual board meeting in September and they will decide if they want to affiliate.

State Long Term Care Ombudsman:

Sean Londergan – Ombudsman

State Statute requires that every year the Commissioner establish a committee to review conflict of interest in the State Long Term Care Ombudsman Program. The Ombudsman Program must then attach a certification regarding this review when the annual report of the program is submitted to the Legislature. The Commissioner has designated the DAIL Advisory Board to be the review committee; and following up on last year's review and recommendation from the Advisory Board, a subcommittee will need to be established to review conflict of interest in the Ombudsman Program in order to make sure that it is able to independently advocate for those receiving long term services and supports. Recently, the Federal Administration for Community Living implemented new regulations for State Ombudsman Programs. The Ombudsman Program and Angela Smith-Dieng of the Adult Services Division have been working together to make revisions in policies and procedures to come into compliance with the new regulations, including conflict of interest. Last year this was still in process and the subcommittee was made up of consumers of LTSS. They then reported back to the full Advisory Board about their review. One of the recommendations they made was that a subcommittee be established again this year now that the new policies are in place and adequately addressing conflict of interest. The group met once or twice by phone last year. So, Sean is looking for volunteers to serve on the subcommittee. Those who volunteered are: Jim Dean, Martha Richardson, Nancy Lang, Robert Borden. In addition, Diane Novak was nominated. Camille will

follow up with Diane to request her service on the subcommittee and Sean will coordinate with Liz Perreault to convene the subcommittee.

Act 186 Indicators for Outcomes 7 & 8 – Part 1:

Camille George, Deputy Commissioner and Bard Hill, Director of Policy, Planning and Analysis

Bard began by saying that there is an Act 186 that includes indicators. How do we measure the performance of the state in achievements, goals and aspirations for the state? The legislature has identified outcomes and they have changed one broad outcome to two separate outcomes that address older adults and those with disabilities. At one time, they had indicators included in statute, but now only the outcomes are included in statute.

Outcome number 7 is phrased as “Vermont’s elders live with dignity and in settings they prefer.” We brainstormed about what population indicators are available that address that outcome. In a Results Based Accountability (RBA) approach, it is the state population, not a program population that is used. Using population indicators is harder to find unlike our program indicators that we do track. Most of the indicators we found was through the Census, Department of Health and AARP.

As you look at the scorecard, our Division of Licensing and Protection did have the population indicators for the rate of confirmed reports of abuse, neglect and exploitation of vulnerable adults per 1,000 vulnerable adults. Most of the indicators information came from AARP and you can go to AARP site and for every one of their measures, they have a paragraph describing where they got their methodology. It is transparent if not tedious to find the information.

Many of these indicators are based on samples and have a significant margin of error on a state-wide level so you can’t even try to use them at a county or community level.

As you look at the outcome, which indicators do you think speak most directly to that outcome or which indicator has the best tracking that we can use moving forward.

The question of population measures is affected by systems which are driven by programs. Is this the sort of thing that will lead down the road to the outcomes in finding the best people at the program level that impacts the system that in turn drives the population level? It comes down to program performance which can influence the system but can’t control it. The goal is to find the indicators that can influence the outcomes without the expectation that they will control them.

After this discussion with the board, we’ll be sending our top recommendations back to the Government Accountability Committee for their approval.

~Discussion of Act 186 to be continued later in the meeting

Health Disparities Among People with Disabilities and VDH Grant:

Kirsten Murphy, DD Council and Allie Perline, VDH

Allie Perline is out of the VDH Health Promotion Disease Prevention Unit and has been working there for the past several months. She came on to work with the money that the department got from the CDC for disability and health funding opportunity she was brought on to manage that money. Kristen is going to share some good information on health disparities among those with disabilities and Allie will add on at the end and tell us how this information is driving the work she is doing at VDH.

Kristen Murphy is from the Developmental Disabilities Council and has brought slides with information that the council has gathered over the last three years to show the health disparities among those with complex disabilities.

Kirsten Murphy:

Every state and territory has a DD Council and they are part of three different organizations that were put in place by Federal Statute. Congress understood that if foundational legislation were actually going to take effect at the state level there needed to be three organizations in every state to do the work. Nancy Frye represents the Protection and Advocacy arm and use the tools of the court. The Center for Disability and Community Inclusion at UVM that is your training and research arm and then there is the DD Council that works to include those with DD and their families, making them a part of helping form the policies that concern them. Kristen is technically a state employee but the board she reports to is 50% or more, made up of those who experience Developmental Disabilities and family members of those with that experience. The rest of the board is made up of those who work in departments of state government. They are also charged with doing a state-wide needs assessment of those with Developmental Disabilities, every five years. This study is looking at the health status of those with DD and what was found was very concerning and interesting national health data.

Special Olympics has become a premier public health organization by having the largest world-wide data base of the health status of those with intellectual and developmental disabilities. Vermont also has a data base with the healthy athlete program which does screening but for the DD Councils reporting purposes, the data base is too small and they use the national data base. When looking at the data there is much concern. The study identified three health behaviors that contribute to four chronic diseases that account for 50% of deaths. This is just a sample of the health concerns that the study exposed. The other thing to keep in mind is that these are athletes who are motivated and have the supports to participate in Special Olympics.

It was found that dental health for those in countries that provide universal health care is the same as those people in countries that don't. The question that raises is "why?" Adults with disabilities are also 4x more likely to report poor health.

This group of people are medically underserved because they don't have the same access to medical care which is the health disparity that they experience. There are many groups the federal government considers medically underserved that are identified by Health Resources and Services Agency (HRSA) and through this identification; these groups receive some resources in order to

offset the disparity. However, they don't include people with DD in the identification even though they meet the requirements of the formula they use. The reason they don't include those with DD is because they're in an internal conflict at Health and Human Services in Washington about whether it is just people with disabilities or developmental disabilities that are underserved. Then there is the expense of identifying such a large group to have to serve.

While working with the Green Mountain Health Advocates, the DD Council received a grant from the Health Innovation Project to convene a small group with three young women with experience with DD and three doctors a nurse and one person with a profound disability and spent 9 months talking to each other and stakeholders and government leaders and asked what works well, what doesn't work well. One thing that came to light was that doctors and providers do not receive any training, outside of pediatrics, that includes those with disabilities or developmental disabilities. The DD Council then got a second grant that allows training with peer coordinators that did not include anything clinical but things like communicating. How to communicate in a way that is respectful to help build a provider's confidence in working with those with DD.

With the life expectancy expanding long beyond what was once thought possible, there is a population of folks with DD growing older and needing medical supports that were never needed in the past. With this aging population, their caregivers (parents) are also aging and unable to provide the same supports they were once able to give. There aren't any real transitional services from pediatrics to adult care. Things that help plan the appointments and how to follow up. Also, the 15-minute doctors' visits are not long enough.

Access to basic tools at the doctors would not only benefit those with disabilities but those that are aging as well. There is a story about a young man named Patrick who is in a wheelchair and his mother said that since moving to Vermont, he has not been examined outside of his chair. The doctor's office does not have a table that lowers and raises and to be weighed, Patrick goes to the Vet to a large scale that sits on the floor that he can get his chair onto. If we addressed these barriers we would be aligned with US Access Board Standards per the Affordable Care Act and be compliant with the ADA.

If a person receives HCBS in Vermont they are required to have an annual primary care visit. However, if it is only a 15-minute visit, it probably won't be that thorough. The UK has a standard of a nurse coming to the home of the person with DD prior to an annual visit. There are usually 3-5 health issues that are identified and the information is given to the primary physician which leads to a much more thorough appointment. This has been piloted in San Diego and it has been successful. Here in a more rural area it might be harder although we do have a strong network of visiting nurses and that type of system could be used for this purpose.

Green Mountain Self Advocacy is a state-wide board that is comprised of people with DD and have about 600+ members and 23 chapters around the state.

Allie Perline:

Liz should scan and send out to everyone – see link

<http://www.healthvermont.gov/health-statistics-vital-records/population-health-surveys-data/brfss>

Social determinates of health are really impacting the overall health and wellness of all Vermonters with disabilities. Factors like transportation, education, employability and income add to the disparities to health for Vermonters with disabilities compared to Vermonters without disabilities. This is deep rooted problem that hasn't really been looked at especially in the public health realm. Currently, this issue is starting to be addressed.

The 3, 4, 50 Campaign is a great overview of the health behaviors that are resulting in 50% of deaths. The opportunity to access the funding from the CDC is a perfect fit for addressing these issues. The funding is on a five-year cycle and began last summer and we began by collecting data. While looking at the data we are able to identify where to build the outreach program.

It is a state-wide partnership to figure out how to improve the resources to address the health of this population. By including the partners who work and provide programs it makes things more accessible to people with disabilities. Between the Advisory Board, partners and Chronic Disease Unit (CDU), we have a unique opportunity to have significant outreach and impact in disease prevention and education to improve the health of people who have disabilities. This funding is now building a capacity within the Department of Health and educating the department of this significant need that has been identified and in many ways, begin to be addressed. Having the resources and expertise of the advisory group and organizations that already have the connections to the communities, resources and skills that can be embedded into the work of the CDU. Things the CDU are looking at specifically are mammography screening and oral health which have huge disparities when compared to Vermonters without disabilities. Our oral health program has piloted a public health service/training program in several senior housing sights and think it would be a great way to also reach those with disabilities.

We are starting year two and the first year was focused on collecting data and working closely with the advisory group and CDU staff to look at the statistics to see which areas are primed for some good work. Working to bring attention to this population and the health disparities.

In the next couple of months, they will be making the decisions on the areas they can start to dig into, and identify the areas that will be looked at further down the road. This is a great opportunity to bring the health of Vermonters with disabilities into the forefront within the Department of Health.

Why does this matter to DAIL? The statistics show that people with disabilities is 20 years shorter and people with autism has a 15-year shorter life expectancy. When you consider DAIL's mission of making Vermont the best place to grow old in and have disabilities in, you have to consider this disparity.

Once we move into this next stage, conversations will happen more frequently with organizations like the ACOs and OneCare discussing the preventative measures and accessibility that can happen.

Medicaid is a huge payer for this population and implementing these preventative measures and creating access will not only improve the quality of life for the individual but will also save a significant amount of Medicaid money.

Roy Gerstenberger, DDS Director, is encouraged at the partnership with the designated agencies. The DAs would like to be involved sooner than later to help because it is thought they don't have enough of a presence in these types of conversations. The advisory meetings happen every month and everyone who would like to join is welcome to contribute to the conversation. Nancy Metz has been appointed to the ACO Advisory Board.

Population Projections and Utilization Projections for LTSS:

Bard Hill, DAIL PPAU Director, Marybeth McCaffrey and Michael Grenier, University of Mass. Medical School – Center for Health Law and Economics

DAIL contracted with UMass Medical School in 2014 to produce a report of profiles of current and projected demographics and profiles of current and projected service utilization in order to provide data for planning future Long-Term Services and Supports (LTSS).

The following is taken from the UMass material presented at the meeting.

Some of the key findings:

- About 11% of the Vermont population currently has a cognitive disability, functional disability, or both
- Projections vary depending on the assumptions used for overall population growth, but the numbers of people with disability may decrease slightly by 2030

Overall, the Vermont population under age 65 is projected to decline, while the population aged 65+ is growing. However, if current service use trends continue, we project:

- Choices for Care participants
 - aged 18-64 will increase
 - aged 65-84 will remain about the same
 - aged 85+ will remain the same or decrease slightly
- Developmental Disabilities Service participants
 - aged 18-64 will increase considerably
 - aged 65-84 will increase considerably

Most of the data was gathered from the American Community Survey, US Census Bureau and Medicaid claims data. UMass customized the definition of disability to generate results more targeted to DAIL's program and planning needs. To approximate the population needing LTSS, UMass used categories with individuals who need functional assistance with mobility, self-care or

independent living. The service trend numbers are from the actual number of people receiving choices for care and their claims, not who applied.

What we know:

- State has shrinking population; fewer younger, working age people for the caregiving Workforce and more, older people
- People with disabilities are more likely to have lower incomes
- Service utilization patterns vary widely between CFC (more people, shorter time enrolled) and DDS (fewer people, longer time enrolled)

What we don't know:

- Whether rates of disability will increase or decrease
- Whether financial or functional eligibility requirements will change
- Whether poverty rates will change
- Whether new interventions (e.g. dementia treatment) or new service options (e.g. assistive technology) will impact future demand
- Whether future funding from federal/state government will be available
- Whether people age 65+ may become a greater part of the caregiving workforce

Legislators are interested in the aging of Vermont and this gives us an idea of what is to come. This study is a useful tool to show that even though Vermont's population is aging, it appears that there isn't going to be the "silver tsunami" that some may think. At the very least, it is much more complex than that, with many older people remaining active and healthy for longer than their predecessors. As a group, older people today appear to be generally healthier and with higher income than previous generations of older people, but some people are not. Some of the surprises in the data is the aged 65-84 population trend is going up, but the CFC service trend has been decreasing. As the population age 65+ represents a larger percentage of the population, we might consider ways in which healthy and able older Vermonters can be recruited and supported to serve as paid caregivers for other people. Some of the people who are served across the range of DLTSS in Vermont do not have physically demanding support needs.

Some of the shortcomings of this report is the narrow look at only Medicaid programs (e.g. CFC) and not considering other frail elders who may need services. The way this report will be presented to the legislature will be to give caveat/guidance. We will have it available on our website for viewing. The concern is that the legislature will see the service trend going down and believe that there isn't an increasing problem across all services. This is a projection based on the described method, not a prediction. This can also help the legislature realize the need for more money for other services e.g. accessibility in transportation, doctors' offices with beds that move up and down, and help with equipment for people's homes.

Statewide Needs Assessment of Older Vermonters:

Angela Smith-Dieng, ASD

There is a statewide needs assessment of older Vermonters being conducted to understand what people want and need as they age. It is also in anticipation of developing the next State Guide on Aging which is a four-year guiding document for our work at DAIL.

There is a survey for stakeholders and providers and a survey for older Vermonters for any one over the age of 60. It is online or you can fill out a paper copy. It is due October 1 and the report will ready in November.

“If you live in Vermont and are age 60 or older, you are invited to please take a few minutes to complete the survey. It can be found online at: <https://www.surveymonkey.com/r/AgingWellVT>. If you would prefer a hard copy of the survey, please contact Dr. Kelly Melekis at (802) 448-0928 or kellymelekisphd@gmail.com and a survey can be mailed to you at the address you provide. The deadline to complete the survey is October 1, 2017.”

Act 186 Indicators for Outcomes 7 & 8 – Part 2:

Camille George, Deputy Commissioner and Bard Hill, Director of Policy, Planning and Analysis

Outcome 7: Vermont’s Elders live with dignity in settings they prefer

The Clear Impact ‘scorecard’ is a web-based application with different types of ‘objects’, including population indicators, within it. The indicators are associated with a relevant outcome. Which indicators do you think are relevant and available that DAIL should present to the Government Accountability Committee for reporting under Act 186? The legislature is already considering the indicator, “percentage of Vermonters aged 65 and older who are participating in the labor force”. We have been asked to propose 2-3 indicators for each of the outcomes (7 and 8). When choosing the indicators, the focus should to be on the measures you think are relevant and important, and also have a valid and reliable a data source that we can access. The hierarchy to remember is: outcomes, indicators, programs, program performance measures. We avoid using program performance measures as ‘population indicators’, since program data rarely represents the entire population.

The Boards consensus is the one indicator that is least relevant is, “Percentage of Vermonters age 65 and older participating in the labor force”.

Outcome 8: Vermonters with disabilities live with dignity and in settings they prefer

The American Community Survey gathered the data for, “estimated employment rate of Vermonters aged 21-64” and it includes all disabilities. Most times statistics about employment for those with disabilities includes people who may be working few hours, e.g. working no more than 2 hours per week. Maybe look at the annual income trend instead, as an indicator, in the future.

The indicators that seem to be most relevant are: poverty indicator, rate of confirmed reports of abuse, neglect and exploitation.

It is important to remember that we can look at these indicators as community agencies, communities, or a department - and work to improve our programs so we influence the indicators and achieve the desired outcomes.

The takeaway – Program is not the same as population.

It would be helpful to have someone from Scan Foundation and/or AARP explain how they came up with the data. Bard had sent a link to the methodology for both United Health Foundations and AARP that describes the method and data sources in detail. We did extend an invitation to AARP for the July meeting. We will look into inviting them to a future meeting.

If you have any additional comments or suggestions about indicators, please contact Bard or Camille. Note that indicators that are not required under Act 186 could be presented in scorecards.

The Agency of Human Services is piloting community profiles. These would be measures by county and town level. This would give a better indication of local Vermont populations.

Meeting was adjourned at 2:15