

Vermont Developmental Disabilities Council

Notes for Team #3, Meeting 2 – January 25, 2021

via Zoom

Present: Anastasia, Terry, Courtney, Dion

Absent: Ed, Hannah

Guest: Greg

Staff: Kirsten, Chelsea

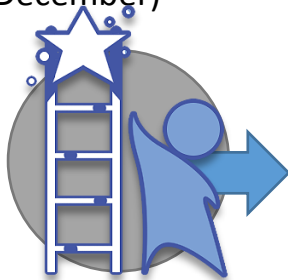
Welcome

Members briefly checked in with one another while they waited for everyone to sign in. The meeting began at 12:11 pm.

Where are we in the planning process?

Greg did a quick re-cap of Meeting 1 to remind team members what they talked about. He reminded everyone to “mute” themselves if it was not their turn to speak, then talked about the agenda and what people could expect.

Meeting #1
(December)



We're setting ourselves up for success.

Meeting #2, Part 1
(January)



Let's dig into the issues.

Meeting #2, Part 2
(Feb./March)



More digging, plus We'll make decisions about our priorities.

Meeting #3
(May /June)



We're almost there!

Kirsten explained that the information staff would share today is a small part of all the information that they have collected for the Needs Assessment, which is a report that must accompany the State Plan. They have pulled out a few very important facts (also called “findings”) and created a short list of “things happening right.” Some of these changes and trends are positive and/or create opportunities for the DD Council to help. Others are not as positive and may become barriers to improving the lives of people with disabilities.

This team will focus on two strategies to build on the opportunities and address the challenges in Vermont: (1) policy advocacy at the legislature or at government agencies like the Division for Developmental Disability Services; and (2) campaigns that change attitudes about people with I/DD.

Kirsten encouraged the group to ask questions and said that if there are areas where you would like more information, she will get that for the group.

Focus Area #1 (Education)

Sue gave a presentation about two issues in Education -- Special Education for student with disabilities and school discipline, which is often directed toward students with disabilities and students from other marginalized groups.

Special Education

Sue said that federal law requires every state to provide special education services. States must follow many federal rules, and they are monitored closely by the federal Department of Education. Vermont’s rating by the federal government recently dropped from “needs assistance” to “needs intervention.” Weak points included helping transition-aged students, taking too long to resolve family complaints, and poor scores on national assessments of academic performance.

Positive things happening in Vermont / Strengths:

- Allies share the same goals.
- Improved Special Education Advisory Panel
- Children have universal appeal (they are easy to advocate for)
- Data exists for some issues.

- System of Accountability exist for some issues.
- The Council has good relationships with key legislators.
- Education system is going through major change – Act 173.
- Poor federal rating may generate momentum to improve.
- Processes exist to advocate for a better system.
- Act 173 provides a way to improve outcomes for struggling learners.

Not-so-positive things happening in Vermont / Weaknesses:

- Education and special education issues do not have universal appeal.
- Education/Special Education costs money.
- Tax/spend issues alienate people.
- Act 173 is very complicated.
- Agency of Education is not motivated/organized to change.
- Lack of political will to implement new programs that cost money.
- Covid-19 makes it hard to implement Act 173.
- Covid-19 fiscal impact unknown in general – specifically unknown for school budgets and special education.
- Bias of low expectations.

School Discipline

Susan talked about a report titled “Kicked Out,” which showed that students with disabilities and students of color were 3x more likely to be disciplined in school or kicked out. Sue made several suggestions for “actionable items” in Vermont.

Terry wondered how it’s possible to excited people without disabilities about doing more with people with disabilities. She suggested hosting town halls. Courtney wondered if an art show would an opportunity to raise awareness – it’s a story, it’s auditory, it’s visual, etc.

Courtney wonders if it possible to have a network or organization dedicated to helping families advocate in the special education. She noted that on “diversity day” at school, there is an amazing display for New American kids, for LGBTQ kids, students of color, but nothing about children with disabilities. We need a week/day and a venue to educate about disabilities, she said.

Courtney said that Vermont needs more advocates in special education with advanced training.

Other ideas included updating the *Kicked Out* Report and having GMSA set-up a mentorship for transitioning students.

Focus Area #2 (Home and Community-based Services)

Vermont has about 5,050 people with developmental services who receive Home and Community-based Services (HCBS).

- 3,125 people get Developmental Services
- 1,225 are kids (Vermont decided that schools take care of kids. There are no other opportunities for HCBS).
- 700 people get Choices for Care.

It is not true that Vermont has no one in an institutional setting, since some people in choices for care are in nursing homes.

Where do people live? Most people live at home with their families or with a family *who is paid* to house them. People also live in a group/staffed home or live independently.

- 41% of adults work.
- 74% receive community support by a paid worker.
- 39% go to a self-advocacy group or event.
- 39% people volunteer.
- 33% go to an adult day program.
- 61% of people said they went on a vacation.

An adult day program is similar to a day program at a Senior Center where there are scheduled activities and people are with others who are served by the sponsoring agency. These programs are set-up by designated and specialized services agencies. They differ from programming create by private entities like Zack's Place (Woodstock), the Inclusion Center (Brattleboro), and Special Needs Support Center which services Upper Valley Vermont towns.

There are some strong transition programs for youth, but unfortunately they do not support adults who want to improve their job skills later in life – for example, someone in their mid-30's whose situation has changed making him or her interested in having a paid job.

Vermont reports to the federal government that it has “no waiting list.” This is not true. In 2019 there were 219 people on a waiting list -- not because there is no funding for them -- but because they did not meet a “funding priority” in the system of care plan. They are on a waiting list because they are not one of the crisis situations described by the priorities – for example, “at risk of homelessness.”

System-wide challenges:

In 2014, the State Auditor directed DS Agencies to change how they account for the money they receive. This is one of the reasons for “payment reform” in Developmental Services.

The State has been out of compliance with Case Management Service requirements since 2014. The system has many conflicts of interest.

Payment reform has revealed a split between families who have been served by the system for a long time and families that are new to the system.

Positive things happening in Vermont / Strengths:

- Developmental Services is guided by strong values and a focus on individual needs.
- Despite a growing caseload, the DS system has not reduced the average amount it spends per person, even when adjusted for inflation.

Not-so-positive things happening in Vermont / Weaknesses:

- The DS System sticks to models it has learned to do well (for example, supported living). There has not been funding and interest in experimenting with alternatives.
- The direct care workforce is unstable, underpaid, and – especially in the case of ARIS workers who are 56% of the workforces -- not well trained.

- To remain fiscally sound, the system has narrowed eligibility, as well as the types of things it will pay for.
- The system does not have what it needs to care for people with very high support needs including access to clinical expertise.

Courtney said that the workforce is always changing. It's heart-breaking for folks with disabilities who build these connections and relationships, only to see their staff leave them again and again. It creates trust issues. Courtney asked if it possible to have staff sign a contract that promises they'll stick around for a set length of time. Kirsten noted that ARIS workers are unionized, so a provision like this might be subject to the bargaining agreement with the union.

Team members wondered if there was a way to raise the starting wage for direct support workers, or the minimum wage in general.

One of the biggest problem's is that people "just ghost," said Terry. "My son doesn't have any expectations." She suggested that there be a Bill of Rights that spells out what an individual and family should expect from a provider relationship.

Adjourn

The meeting adjourned at

These notes were provided by Chelsea Hayward and reviewed by Kirsten Murphy.

Att. Lists of brainstorm ideas

Potential Council Projects

Education

- ▶ Message contributor vs. consumers. Customized employment, volunteerism, ...Anti-bias campaigns. Take story building and try to move the needle on what adult children can do. What are the ways DD kids can participate in communities? Messaging/public relations campaign to change minds. Town halls?
- ▶ Target a campaign to reach outside of the DD community. Linking stories to art so that the kids are connected to the stories. Target parents and kids in VT schools maybe?
- ▶ Diversity week/day as a venue to help educate about disabilities. Partner with Green Mt. Advocates.
- ▶ Need more advocates in special education. Advocates who are paid by school have a conflict of interest. Education to teach folks to advocate well. There are not a lot of agencies that can really go to bat for kids. A partner network that can actually advocate.
- ▶ Make the system more person-centered.
- ▶ Support new Senate bill (S. 16)
- ▶ Get data from public and private schools
- ▶ Update *Kicked Out* report
- ▶ Get monetary tie in to PBIS (or similar programs. Require schools to participate in this. Currently PBIS is predominately implemented in Chittenden, but less so in the central and south.
- ▶ GMSA doing a mentorship (to help with transition periods)

Potential Council Projects

Home and Community Based Services

- ▶ **System of Care:** Change the structure, especially the funding priorities. Add language to make it less restrictive so people who need them can get services they need. Also make it needs more pro-employment.
- ▶ **Direct Support Staff:** Turnover rate of staff is a huge issue.
 - Incentivize training/education for workforce. They are not trained in the basics – for example, how to initiate a day, how to end a day, how to not discuss people in front of them.
 - Look at the wages of workers and raise the wages.
 - Share real life stories of how turnover impacts people they serve. (School contact is the most stable workforce, but even that is not very stable)
- ▶ **Bill of Rights:** This would define expectations and boundaries for those being served.
- ▶ **Reduce stigma:** Direct support needs to be a respected field. Redefine what personal support is. Let's hear the stories of how the lives of the workforce have changes.
- ▶ **Families and Direct Support Providers:** How do we support those providing support services - families and direct support caregivers?
 - Money - raise minimum wage

- Training
- More Respite Care for Families
- ▶ **Building natural supports:** Ensure that transition-age youth have community experiences including self-advocacy and information about community opportunities.