<p align="center">**Vermont Developmental Disabilities Council**</p>

Notes for Team #3, Meeting 1 - December 21, 2020

<p align="center">**via Zoom**</p>

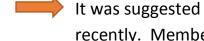**Present:** Anastasia, Ed, Courtney, Terry, Dion

Guest: Greg

Staff: Kirsten, Chelsea

Welcome

Greg began the meeting at 12 noon. He suggested that members mute themselves and raise their hand (or use Zoom's "raise hand" feature) if they want to speak.

Members to Team #3 went over the "Group Agreements." There were twelve (12) bullet points total. Members were asked if there was anything they'd like to add or change to the group agreements. They broke into small groups to brainstorm and returned after a few minutes.

It was suggested that members check in with those who have not spoken recently. Members also said that they like working in small groups because it makes it easier for everyone to participate.

Understanding our Goal Area and what is systems change?

Kirsten reviewed the 3 goal areas. They are the same as the goals in the current Five-Year Plan:

1) Identify and fix gaps in service, including one gap that exists because a group has traditionally been underserved.
2) Empowering self-advocates and families.
3) Policy change at the Statehouse or in agencies.

This team will work on goal area #3. The group discussed the meaning of the term "systems change."

A "service system" – sometimes called a "system of care" – is a set of policies and practices that result in the delivery of supports to a group of people. These policies or rules are applied to everyone in the group. Examples of systems:

- The prison system
- Public transportation
- Medical care

The policies and practices that make us a system are based on specific values, beliefs, and attitudes. For example, the Medicaid system – which pays for medical care and home and community-based care – requires people to be poor if they are going to enroll in the program. This is because our society believes that if you have money, you should not be getting government help.

You can see the policies & practices, but the values, beliefs, and attitudes may be hidden.

To change a system, you must change the policies and/or the practices, but this is often not enough, Kirsten said. You must also work to change the values, beliefs and attitudes that shape the system you want to change.

The results that a system produces are not an accident. Healthcare reformers have famously said, "Every system is perfectly designed to get the results it gets."

Summary: Goal area #3 includes these activities.

1. Legislative advocacy to change policies and practices that are in law.
2. Other government advocacy to change policies and practices that are in rules and guidelines.
3. Public awareness campaigns that seek to change the values, beliefs and attitudes that have led to the systems we have in place.

Understanding what the DD Act says and what we must do for the 5-Year State Plan.

Kirsten briefly reviewed what the DD Act requires in a Five-Year State Plan. She stressed that goals and objectives must be based on data. For Team #3 this means that for whatever system we want to change, the Council must be able to:

1. Use date to describe the results that the system is getting now.
2. Have research that suggests changes to that system will improve those results.

Kirsten also reminded the group that the Plan should identify partner organizations that will help us achieve each objective.

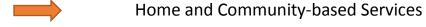## When you think about disability services in Vermont…

Using a Google Jamboard, everyone's hopes (blue) and fears (red) were collected with digital sticky notes. (See attached).

The group talked about similarities in these hopes and fears. Common themes were:

1. People with I/DD will have voice and choice.
2. Services must be representative of what people need to accomplish their goals. We need a strength-based, not "weakness-based," approach.

Request for information at meeting #2 in 3-4 Focus Areas.

Greg shared a list of "focus areas" and asked members to pick which topics they wanted to learn more about at the next meeting. The group picked:

Home and Community-based Services   Education

Housing, possibly a sub-set of HCBS

A drop-box will be made available to everyone so that they can review notes on all the focus areas.

Understanding what we learned from Focus Groups with self-advocates and families.

Family Focus Groups: There were 6 family focus groups and a total of 23 participants. Half the participants were from Chittenden County and the other half were evenly spread between the other counties. Four of the Chittenden County participants were New Americans.

Parents said there seem to be plenty of mental health therapists in Vermont, but there are few who are trained to work with children, youth or adults with developmental disabilities. They were also worried about staff shortages, limited housing, and whether flexibilities like paying parent caregivers could continue after the COVID-19 Emergency. The Council's Executive Committee has requested a seventh focus group for parents who support adults that are non-verbal and/or medically or behaviorally complex.

Self-Advocate Groups: To date there have been 2 focus groups with self-advocates. Participants in these groups have focused on wanting more control over what happens in their life. Their concerns ranged from restrictions on who they can spend time with to issues about working, living with a home provider, and guardianship. They also talked about loneliness, especially during the current pandemic.   Technology is not a substitute for fact-to-face contact, participants said.

Adjourn

The meeting adjourned at 2:00 pm.

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