

From: Vermont State Program Standing Committee for Developmental Disabilities Services
To: Developmental Disabilities Services Division, DAIL, State of Vermont
Sent: March 21, 2019
Subject: Support for Facilitated Communication

We, the undersigned, are members of the Vermont State Program Standing Committee for Developmental Disabilities Services, appointed to this body by the Governor of Vermont to advise the Developmental Disabilities Services Division and the State service provider network. We are self-advocates (some of whom use supported typing as their primary means of communication), clinicians, academics, agency administrators, attorneys, family members, direct support personnel, advocates and interested citizens, who over a number of years have experienced and/or witnessed the efficacy and positive impact of facilitated communication on the lives of those who use it.

In the early 1990's, several Vermont professionals working with people with developmental disabilities, as well as a few parents, traveled to Syracuse University to meet with Dr. Douglas Biklen to learn about a support technique called facilitated communication. This technique involves providing physical support, encouragement, and education to individuals experiencing significant challenges expressing their thoughts through typical communication means. We came away from this visit with a questioning enthusiasm, determined to see if this approach could assist any of the people we knew in Vermont to communicate more effectively than had been possible through other means that had been tried. To say that we were stunned by some of the early results of this effort would be an understatement. Not everyone we worked with was successful, and in fact many were not. Those who were, however, have benefitted immeasurably from this technique, also known as supported typing. Some of these individuals have moved on to near independence in their communication skill using this method. Slowly but surely, the number of people who have achieved greater independence in their lives continues to grow in Vermont.

Those of us privileged to witness supported typing in action have learned to presume the competence of people who do not speak, or who speak with great difficulty, because not doing so would likely sentence them to a severely restricted life. They have proved again and again that this is the correct presumption. In addition, we have learned that the phenomenon of movement disturbance (difficulty in starting, stopping, executing, continuing, combining, and switching of activities) can impede the performance of many people with developmental disabilities, especially those who do not speak. We have come to understand that access to facilitated communication can, for some individuals, both ameliorate some of the movement difficulties involved in communication and demonstrate the ability to think and feel deeply. For these reasons and more, we have worked to ensure that supported typing is an option in Vermont.

Vermonters have been aware of the controversy that has surrounded the use of this technique across the country. Partly in response to the controversy, the State has put in place a set of guidelines (updated in 2018) to provide something of a blueprint for individuals who choose to try supported typing. This technique is being practiced within a consistent structure and approach that recognizes the fundamental right of communication in the lives of all people. The guidelines emphasize the importance of training and the goal of assisting people who choose this option to move to increasing levels of independence over time. The guidelines also recognize the importance of validating authorship. This validation can take many forms, including but not limited to reducing the amount of support over time; having more than a single typing assistant; and observing consistency in language and responses across settings and assistants. Currently there are a number of talented and bright Vermonters who are using supported typing in their personal and professional lives. Some of these individuals are well known across the State and nationally, as they have become effective trainers, advocates and contributors to the betterment of the lives of people with and without disabilities.

The use of facilitated communication needs to be protected as a right and as a choice. As with all approaches, standards of practice for this type of support are essential. Vermont has adopted facilitated communication in a cautious and responsible manner. While not all individuals are good candidates for this technique, those who are must have their right to communicate protected.

The following comments were written by three Vermonters: Tracy Thresher, a well-known disability rights advocate and co-star of the film “Wretches and Jabberers”; Mark Utter, well-known blogger and star of the film “I am in Here”; and Andreas Yuan, a fairly new user of supported typing.

Mark Utter: *I am Mark Utter and instead of talking with my mouth I type to communicate. I have been doing this since the 1990s. It was the writing of my personal experience with having communication obstacles that gave me an opportunity to truly engage with the world. I am wanting you to know that turning the story into a movie and raising money and getting the whole thing finished was all done using FC. I had been the man behind the facade and awful term of “nonverbal” and now people were engaging with me. I welcome people to watch my movie and join the 100s of people who read my blog. www.utterenergy.org*

Andreas Yuan: *I would like to talk about using typing to talk to you. Initially, you don't know timid thoughts but they have to be typed to be understood. I think people don't know what I think. I think I should type every day. Have to use my ipad to type and do work every day. Think time to type thoughts is not enough. Know that it is easy in the morning.*

Tracy Thresher: *I am Tracy Thresher and I want to share my thoughts on using Facilitated Communication (FC) and having a voice. I have been using FC since 1990 and was one of the first people in Vermont to be introduced to it.*

Not being able to express myself was like being in a world of silence. I couldn't tell people what I liked and didn't like. People thought I was retarded, that I didn't understand what was being said to me. It was frustrating and made me angry and I withdrew. The experience of the world looks different from my experience. Most people take their ability to talk for granted and I take my inability to talk quite seriously. I live with it every-day – it is always there each time someone wants to read my thoughts.

The impact of learning to speak up and have a voice has been quite meaningful for me. I have typed life goals and dreams that have actually come true. One dream of mine was to go to church and be baptized. I told my mother this and it happened. I have been able to meet with my pastor and discuss God and the Bible because religion is very important to me. I am learning to do the things I want to... teaching others about Autism and FC and movement differences. These are things I've wanted to do and now it's happening! I have spoken about these things I wanted for my life and some have come true. This would never have happened without a way to express myself.

We acknowledge and affirm the Developmental Disabilities Services Division's continued support of facilitated communication as a viable method of communication available to individuals in Vermont.

Sincerely,

Members of the Vermont State Program Standing Committee for Developmental Disabilities Services:

David Ballou, Co-Chair

Max Barrows, Co-Chair

William Ashe, Ed.D.

Anne Bakeman

Rachel Colby

Bethany Drum

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Susan Yuan, Ph.D. Psychology, Emerita, College of Education and Social Service,
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A Brief List of References

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