DD Act Regulations Hearing – 10/11/22
Notes taken by June
Participants – 3

- Elizabeth Barker – retired special ed director and a parent of an adult child – Section Eligibility for young child – condition about measurable delays – changed to adaptive self-help skills. Requested explanation as to why change was made.

- Delana Norton – DS Director – Changes to children's eligibility section – clearer than what was there before.

- E Barker – Change to IQ score is helpful.

DD Act Regulations Hearing – 10/19/22
Notes taken by June
Participants – 6

Darlene Jenson – parent of 29-year-old with CP
Shelby Canterbury – HC
Allie Fitzsimmons – HC
Chuck Medick – HC
Barb Prine – DLP
Ann Schumacher – HC

- Shocking not to see the programs listed in the regulations. Unsettling. This detail is what is of the most interest. Concern about ICF no longer an option but that's not for discussion regarding the regs.

- Thank you for supreme court decision regarding IQ.

- Grievance and Appeal – fair hearing section. Referring people to the regular Medicaid regs – which is an internal appeal. It's not clear where and when an internal appeal goes to the various entities. DDSD needs to tell a person which decisions go where (eligibility, equity, ability to self/family manage). Just to say it will be put into plain language, it's an impossible task if the state does say what is meant by internal appeals.

- As parent, I don't know what the appeal information means. It's confusing. Plain language is important. It needs more information as Barb pointed out. There's a lag in when information gets out to everyone. Even the agencies don't fully understand the rules.

- Clarity of eligibility is clear and helpful. In terms of IQ and supreme court decision, HC has had a number of applicants that now quality due to that change. So, the change mattered.

- Clearing up language and having things match is appreciated

- Increase of IQ standard and resource crunches is a concern.

DDSD Regulations Implementing the Developmental Disabilities Act of 1996

Public Comment/Public Input Session

Proposed Changes to the Regs

October 11, 2022

DDSD Attending: Jennifer, June, Hilary, Melanie, Clare, Judy

Attending:

Elizabeth Barker, retired SPED director and parent of adult child with DD

Jen Hayes,

Jessica Moore,

Jennifer McCabe,

Delaina Norton, Director Howard Center

1. Changes to eligibility requirements for young child--

   Elizabeth Barker—eligibility for young child says have to have various conditions. Changed to age 6. Preconditions changed from daily living skills to adaptive self-help skills, what is the reasoning for that?

   Clare--Essentially same types of functional error. Changed to be current with terms that are being used in early childhood ed and family services (?)

   Elizabeth—clarity is good

   Delaina—language is clearer than old regs

2. Change in IQ threshold

   Elizabeth—it's quite helpful because often we have kids who are fairly functional so allowing for raise in adaptive is helpful. My daughter skills can sometimes pop up above thresholds even though she is below 70.

3. Removing Service Descriptions and just having in SOCP

Clare—benefit from our perspective is that the SOCP is easier to update. Any changes to regs need more rigorous review than the SOCP. Allows us to make adjustments quicker than revising the regs.

No comments

4. Clarifying language around roles responsibilities for family management

No comment

5. Strengthening language around training for communication and SDM

No comment

General questions or input, comments.

No comments

Clare provided information for written comments -email and physical address.

Public Hearing re: Reg Implementing the DD Act

Darlene Jenson, Allie Fitzsimmons, Chuck Medick, Barb Prine, Shelby Canterbury, Ann Schumacher

Clare, June, Jennifer

Clare provided overview and major proposed changes to the Regulations

Barb Prine: It is really shocking to not see the programs described in the Regulations. Realize that it is what the law says. It is unsettling. Thanks for the work related to the eligibility. Concerns remain around grievance and appeals sections. Referring to regular Medicaid section doesn't tell people what to do. A plain language group won't tell people when it goes to DAIL, versus when it goes to the agency, versus a contractor.

Completely support crafting a plain language document, but the State hasn't provided a process and policy around where which kind of internal appeals should be targeted through the Regulations that a plain language document would provide assistance with.

Darlene Jensen: Thank you Barb. Realized as Clare was going through slides, didn't understand what everything meant. Really appreciated Barb pointing out that people need to know what tract an issue needs to follow. There is a lag in how information is disseminated to agencies (DAs and SSAs). Was on the committee for H. 720/housing options. Really appreciate that State is taking a closer look at things. Appreciate that there is a lot of hard work happening—really appreciate everything.

Barb: Think that part of the problem is that with the programs being out of the Regs, people are concerned with what the programs are and how they will work.

Clare: Draft of the System of Care is out and posted on the Division's website

Shelby Canterbury: Clarity around age 6/young children. Its simple. Don't do a lot of that, but helpful for FFF. The increased clarity is always helpful. As for the IQ changes, have had a fair amount of increased applications that this impacts.

Ann Schumaker: Clearing up language is always appreciated. Concern—IQ expansion and the resource crunches is always a concern.

Everything else is clear and appreciate the time.

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October 26, 2022

Sent via email only to: Jennifer.Garabedian@vermont.gov

Jennifer Garabedian, Division Director
Developmental Disabilities Services
Department of Disabilities, Aging and Independent Living

Re: Comments on Proposed Changes to Developmental Disability Services Regulations

Dear Jennifer:

Thank you for the opportunity to provide comment on the proposed changes to the Developmental Disability Services Regulations in the Health Care Administrative Rules.

To begin, we are heartened with several of the changes. We appreciate the inclusion of the revised language clarifying the use of standards errors of measurement for determining eligibility.

We also appreciate the inclusion of language for in-service training in supporting communication and decision-making. HCAR 7.100.10€(1)(B). We were glad to see that certification quality standards include that individuals receiving services will "receive support in decision-making when needed". HCAR 7.100.11(e)(2).

That said, we have two ongoing areas of concern.

First, as raised at the hearing on these rule changes, it is startling to see the absence of descriptions of available Developmental Services programs. In our pre-comments, we asked that the ICF/DD not be stricken from the regulations, because it remains a State Plan services that some individuals want to choose, even if it is not currently available within the bounds of the state, and the regulations should remain consistent in explained the state plan and waiver-based programs accessible through DDSD.

Although Act 186 no longer requires the eligibility and access criteria to be established in rule, *nor does it prohibit* leaving this section in place as it is. Given that the System of Care Plan and these regulations operate in tandem, there is no burden to leaving them in place in the regulations and including them in the System of Care Plan. This improves access to understanding the available programs, to have them exist in both documents. Even beneficiaries and family members who are long-time users of the programs are often unaware of the System of Care Plan. Limiting their placement to only one of these two documents that govern these programs is, in our view, less transparent. The notice and comment process, and the oversight of LCAR regarding these criteria, is to the benefit of our system, and we request that the Department choose to leave Section 4.7 in place.

Second, we continue to have grave concerns about the failure to describe the process for Grievance, Internal Appeals and Fair Hearings. The current DD Regulations on Grievance, Internal Appeal and Fair Hearings, at Part 8, are extremely difficult to understand due to the multiple references to the "Managed Care Entity" and the alphabet soup of acronyms. We agree they need to be stricken from the rules.

However, the HCAR regulations at 8.100 have their own difficulties in not stating a clear path for DD applicants and recipients. The HCAR rule defines how to grieve and appeal from a decision of a "Medicaid Program." A "Medicaid Program" can be DVHA, DAIL, a Designated Agency, a Specialized Agency, or a subcontractor. HCAR 8.100.2(g).

The first level of appeal is the Internal Appeal. HCAR 8.100.4. In the DD context, an internal appeal may, depending on the circumstances, be an appeal to the Designated or Specialized Services Agency, to ARIS or Transitions II, or it may be a Commissioner's Review with the DAIL Commissioner or her designee. However, these terms are entirely absent from the HCAR rule, and it only refers to the Internal Appeal from the "Medicaid Program". As the HCAR rule is currently written, it is often unclear to whom, among these various entities, an internal appeal must be directed. It is also unclear who are the "parties" representing the adverse decision in the internal appeal and the Fair Hearing . HCAR 8.100.4(j); 8.100.5(i). Is DAIL or the Designated Agency the one representing the position to deny, reduce or terminate?

For families and individuals who self-, family- or shared-manage the appeals process becomes even cloudier.

We appreciate that the Division will develop a plain language guide to grievances, internal appeals, and fair hearings. However, a plain language document can only be written after the Division has identified the process through regulations. In multiple conversations with stakeholders, agencies, and division staff, stakeholders who use these processes do not agree on how and when each of the processes should work, and that is because DAIL has not spelled it out.
Thank you for your consideration.

Sincerely,

/s/ *Rachel Seelig*
Rachel Seelig
Director
Disability Law Project

/s/ Barbara Prine
Barb Prine
Staff Attorney
Disability Law Project

From: Jim Caffry
To: McFadden, Clare; Garabedian, Jennifer
Cc: "Elizabeth Campbell"; "Barbara Lee"; "Connie"
Subject: RE: DDSD Workplan for 2022 - 2025; DD Regs, SOCP & Housing
Date: Thursday, October 20, 2022 4:00:42 PM
Attachments: Att. 2-DAIL.Memo re SFM 24-Hr Home Supports.3-9-05.pdf

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Clare and Jennifer:

Howdy. I am following up on the DD Standing Committee meeting this morning regarding the draft System of Care Plan, that I just started looking at, having been away last week. I have a couple of quick questions.

1. The version of the proposed 2022 DD Regulations that I found on the DDSD website look like they were made public last spring, prior to the passage of Act 186. Can one of you please send me a link to the current, proposed changes to the DD Regulations if there were any changes made to the proposed Regs following the Legislature's passage of Act 186?

2. Clare, you said today that, 24 hour Home Supports cannot qualify for the FICA tax exemption under IRC 131 (https://www.law.cornell.edu/uscode/text/26/131) if done under the Self & Family Management program. What legal authority are you relying on for that opinion?

Since any adult foster care provider (Shared Living Provider) must go through all of the same review and training processes, regardless of whether that foster care provider was chosen by a family under the SFM program or chosen by a DA/SSA, an argument could certainly be made that any SLP chosen by a family, that is vetted by Transition II, then that SLP was "place by" a "qualified foster care placement agency" under IRC 131. Presumably, every DA and SSA is covered by that, so why wouldn't Transition II? Do you have some definitive legal opinion from the Internal Revenue Service, or anyone for that matter, that a Shared Living Provider, hired by a Family Manager, under the oversight of Transition II for the SFM program, is not eligible for the income-tax free payment?

To my knowledge, when families were managing 24 hours from 1996 – 2005, those payments were income tax free just like any other SLP payment for any home provider found through a DA/SSA. Again, what is the legal authority that prohibits an SLP chosen by the family, and vetted through Transition II, from being paid tax-free under IRC 131.

I am pretty sure that if the DDSD wanted this to work for a tax-free stipend under IRC 131 for Family Management of 214 hour supports, the DDSD could make that work.

One of the main points of Act 186 was to encourage flexibility and creativity for living arrangements. If families are given the opportunity for that full engagement, then creative, sustainable, housing opportunities will more readily flow from there.

As Clare knows and she summarized today during the meeting, apparently, some things went awry before 2005 with 24-hour home support management being managed by families, so the moratorium was imposed by administrative fiat in 2005 (see attached). Then that 24-hour prohibition was adopted in the 2011 version of the DD Regulations. That rule change was made over the unanimous objections of every single rule commenter. I know that there was unanimous objection to the 24-hour prohibition because I filed a Freedom of Information Act request in the fall of 2010 when the DD Regulation changes were proposed, and I read every one of those public comments filed.

Without question, bad things can happen, particularly when there is a lack of governmental oversight.

Obviously, we all know that there have been "problematic" Shared Living Providers that were approved for 24-hour Shared Living by a DA or an SSA: https://vtdigger.org/2022/09/13/4-caregivers-for-vulnerable-adults-charged-with-abuse-and-neglect/. I would assume that the recent arrests of the these "problematic" Shared Living Providers in Milton and Swanton are not going to lead the DDSD to put a moratorium on the SLP program.

I do not have the figures in front of me, but my recollection is that there were about a dozen DDSD Quality Management Reviewers in the early 2000s when I first started paying attention to this. The most recent org chart I found for the VT DDSD is from 2017, and there are only 3 Quality Reviewers, 5 if you include the Team Leader and the Nurse Surveyor (https://ddsd.vermont.gov/sites/ddsd/files/documents/DDSD_OrgChart.pdf).

My last thought for the day, with all of the enthusiasm amongst parents for positive progress going forward following the passage of Act 186, it was rather deflating to see the draft 2023-2025 SOCP change in pretty insignificant ways. The barriers to housing alternatives, primarily in the laundry list of 20 "Limitations on Funding" in Section Five, Subsection IV.D from the prior SOCP remains unchanged, in particular, Subsections IV.D.13, 14 and 15. Additionally, there are minimal references to Act 186, and no substantive discussion of the current barriers to providing meaningful housing alternatives, many of which I spelled out in my email to the two of you in May (and included below).

I look forward to continuing the conversation.

Jim

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From: Jim Caffry <jim@caffrylaw.com>
Sent: Wednesday, May 4, 2022 12:54 PM
To: Clare.McFadden@vermont.gov; Jennifer.Garabedian@vermont.gov
Cc: 'Elizabeth Campbell' <eliz888@comcast.net>
Subject: DDSD Workplan for 2022 - 2025; DD Regs, SOCP & Housing

Clare and Jennifer:

Howdy. I must admit that I am relieved that Clare is not very good at being retired, as there is a whole lot on the plate of the DDSD right now. I am guessing that Jennifer is also glad that Clare is not very good at being retired.

I have quickly looked at the recent information put out by the DDSD about the various initiatives: https://ddsd.vermont.gov/programs/projects-initiatives/2022-update-regulations-and-system-care-plan/proposed-changes-vt-socp-dds.

I decided that I should send the two of you a few thoughts about some of these things while I am thinking of them, and before the various initiatives get too far down the tracks.

As you probably know, I have been part of the Developmental Disabilities Housing Initiative ("DDHI") efforts led by Elizabeth Campbell and others, so I have copied Elizabeth on this email. As you also know, in addition to my personal interest in these matters as a parent, I have worked with the only two existing residential models (to my knowledge) in Vermont that provide an alternative to the Shared Living Provider model (a/k/a adult foster care under Section 131 of the Internal Revenue Code).

I have publicly commented many times before that Shared Living is really the only option for adults who are eligible for 24/7 home supports, and that the statistic of 76% is misleading. It is my understanding that individuals only end up in the Staffed Living or Group Living (those "statewide resource" group homes that are owned and operated by Designated Agencies) if those individuals have previously tried, and failed, in multiple Shared Living homes – either due to high behavioral or medical needs. See: https://ddsd.vermont.gov/sites/ddsd/files/documents/Summary_of_Housing_Options_Issue.pdf. The 270 individuals that have Supervised Living Supports have the requisite skills and independence that they do not require 24/7 oversight and support.

The reality is that for individuals requiring 24/7 supports, that do not have high behavioral or medical needs that lands them in Staffed Living or Group Living, then Shared Living is the only choice for 100% of people receiving Home Supports without increased those high behavioral or medical challenges (excepting the small number of people living at Heartbeet or Yellow House).

The often-stated fact that Group Living and Staffed Living are more expensive ignores the fact that they are more expensive because the people served in those models have the highest needs. They are also more expensive because both of those models operate entirely on shift-staff.

Having gone through most of the materials on the DDSD website now, there are a few things that I think DDSD needs to be kept in mind as the Division moves forward in 2022:

1. **<u>Shared Living can look different than it does now in Vermont under the federal IRC Section 131</u>.**
    - Section 131 of the Internal Revenue Code allows for the income tax exemption for up to five adults under one roof.
    - While there is some sound reasoning behind the "not more than two" policy position, there are also sound public policy reasons to allow more than two. I recall finding out several years ago that Oregon and Minnesota allow adult foster homes for up to five developmentally disabled adults. I have not conducted an exhaustive search of what other states allow, and I recall that Oregon and Minnesota had more robust training and licensing requirements than Vermont for its Shared Living Providers.
    - As noted in some of the DDSD materials, under the current Shared Living operations, there are a few instances where a Home Provider moves into a home that is owned by an individual, or a family (or a Special Needs Trust). Therefore, when a Home Provider changes, the individual with ID/DD does not have to move out to some other home which could be anywhere within the DAs service territory.
    - If the payment model of Shared Living could be incorporated into a residential model where 3, or 4, or even 5, individuals with ID/DD live in the same house, ***that is their house***, then modifying the current Vermont Shared Living program could be a means to achieving "consistency of place" in a cost-efficient manner.
    - Perhaps one, or two, live-in support persons could be compensated as Shared Living Providers under IRC 131, and then there could be additional supports from shift-staff workers. This could result in some cost savings, in addition to addressing two of the DDHI's biggest concerns: (A) our adult children would not have to move every time a Shared Living Provider changes, and (B) the opportunity to live with some peers – for years on end.

2. **<u>33 V.S.A. § 502(1) Needs to be Revisited</u>.**
    - There is more statutory consideration that must happen outside of anything in the DD Act of 1996 (18 V.S.A., Chapter 204A).
    - Act 37 of 2007, introduced to the Legislature in February 2007, was the first time that Vermont put into statute the limitation on adult foster care payments to 2 people, codified at 33 V.S.A. § 502(1). It appears that the primary purpose of Act 37 was repeal the $6,500 cap on the exclusion of adult foster care payments for property tax calculation purposes that had previously be in 33 V.S.A. § 6061(5)(c). For a general discussion of the Shared Living Provider model and context on Act 37, please refer to the attached Report on Adult Disability Care Payments in Household Income (DAIL Commissioner Flood, Jan. 2007).
    - Prior to 2007, it had always been a policy-based decision to limit Shared

Living to 2 people, even though federal law allowed up to 5. That non-binding policy decision then became Vermont law with little fanfare or public debate because the focus was on the property tax exemption.

3. **Consider IRC Section 119.**
   - The other provision of the Internal Revenue Code that should be considered is IRC Section 119. Under IRC Section 119 and Treasury Regulation 1.119-1, if an employee is required to live in a particular residence and have meals on premises, then the value of the lodging and meals is not imputed taxable income to the employee. Nor is there imputed taxable income for the value of lodging or meals provided to the employee's spouse and children.
   - This is the tax code provision that is utilized by many of the Camphill Communities – Householders live in the community 24/7 and receive free room and board as part of the employment, and there is no "phantom income" that is subject to income taxation – in the same way that there is total cost savings under the adult foster care payments under IRC 131 with no FICA taxes to be paid by an employer or employee.

4. **33 V.S.A., Chapter 71 Needs to be Revisited.**
   - The licensing requirements for any residential care provider, whether a Residential Care Home or a Therapeutic Community Residence, kick in when there are 3 or more individuals being supported under one roof. I recall looking years ago, and the 19 Group Homes owned & operated by the DAs are split about equally in being licensed as either Res Care Homes or TCRs. Heartbeet and Yellow House are both licensed as TCRs.
   - Obviously, health and safety are paramount, but it needs to be considered whether the licensing requirements are a significant barrier to the creation of alternative housing models that will provide stable, long-term, residences (even if the care providers change).
   - In addition, or alternatively, consideration should be given to whether there should be a permanent position within the DDSD of a Residential Program Developer (which is currently contemplated as a 3-year limited service position under H.720), who could assist families and individuals, DAs, SSAs, and any independent service contractors that come along (in addition to Heartbeet and Yellow House) to provide stable, long-term, residential supports for adults with ID/DD in compliance with any licensing requirements.

5. **"No More Than Four" Is Not Law.**
   - This line has been stated as though it is legally binding by various people within the Vermont DS System for as long as I can remember. That is simply not true.
   - There is no prohibition on housing more than four individuals under one roof in the DD Act, 18 V.S.A., Chapter 204A, or under the licensing requirements of 33 V.S.A., Chapter 71.

    - There is no legally binding prohibition under the Current (outdated) System of Care Plan, Chapter Four, Section IV.D.14.a (page 62): https://ddsd.vermont.gov/sites/ddsd/files/documents/Vermont_DS_State_System_of_Care_Plan.pdf

        14. Developmental disabilities HCBS services funding cannot be used to:

            a. Increase the availability of residential settings that provide supports to more than four adults (age 18 and over). Any exceptions to this limitation must be approved by the Division.

- Alas, the Division currently has the authority to allow more than 4 under the expire SOCP. Therefore, if there were 5 or 6 families, whose adult children had similar challenges and communication modes (e.g., communicating with American Sign Language), there is no legal prohibition under the Vermont DD Act, the DD Regulations, or even the non-binding, expired SOCP, that would prohibit those families from working together to create a stable, long-term living community that utilizes Medicaid HCBS money to support those individuals.
- It has been a while since I read them, but there is nothing in the 2014 CMS Regulations that would prohibit such a living community either.

6. **Remove the Prohibition on Family Management of 24-Hour Home Supports.**
    - When the Self & Family Management Program started, a family could manage 24/7 home supports. That ability was removed by a 2005 Policy Memo (see attached), and then that 24-hour Home Support management was inserted into the System of Care Plan in 2010 (I think) and then the 2011 DD Regulations over the universal objection of every public comment filed for those 2011 DD Regulation changes (I know that is true because I filed a Public Records Request for those public comments and DAIL ignored them all).
    - The fact that some families' 24-hour management was "problematic" is not a reason to prohibit every family from doing so.
    - See SOCP, Chapter Four, Section IV.D.14.a (page 62):

        13. Individuals who chooses to self/family-manage or share-manage cannot manage 24-hour home supports (i.e., shared living, staffed living, group living). Individuals may self/family-manage up to 8 hours per day of paid home supports. However, individuals who need 24-hour home supports may receive them from their local DA, or an SSA of their choice.

- See current DD Regulation, Part 5, and proposed renumbered Regulation 7.100.6. https://ddsd.vermont.gov/sites/ddsd/files/documents/DDAct_Regulations_Draft_Revisions_2022.pdf
- The DD Regulations are currently clear: "In order to self/family-manage services, the individual or family member must be capable of fulfilling the responsibilities set forth in Section 5.2" (*soon to be Section 7.100.6(b)*.

7. **Remember Where DDSD Came From.**

In my written testimony to the House Human Services Committee on February 15, 2022 (copy attached), I pointed out that in both the FY 2005-2007 and FY 2008-2010 System of Care Plans, there were 12 Funding Priorities for Developmental Services. In the 2018-2020 (extended to 2022) System of Care Plan, there are only 6 Funding Priorities.

- Conversely, trending in the opposite, but also wrong direction, the FY 2005-2007 System of Care Plan contained only 7 "Limitations for Funding", and by the 2018-2020 (extended to 2022) System of Care Plan, the "Limitations for Funding" had exploded up to 20.
- It would appear to be a safe bet that funding priorities going south and funding limitations going north over the last 20 years is how Vermont arrived at the current "System of Crisis".
- There is a Maya Angelou quote that says: "If you don't know where you've come from, you don't know where you're going." While the families involved in the DDHI are looking for a future in which the Vermont DD SOCP encourages and truly promotes "meaningful [residential] choices" for the first time, the DDSD should also be mindful of how the SOCP has changed (and not for the better) since its inception.

If you are still reading at this point, I will end this by saying that I, and other members of the DDHI, are looking forward to meaningful engagement in the various DDSD projects that will result in meaningful residential choices for our adult children.

Jim Caffry

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STATE OF VERMONT
AGENCY OF HUMAN SERVICES
Department of Aging and Independent Living

Division of Disability and Aging Services
103 South Main Street
Waterbury, VT 05671-1601

MEMORANDUM

TO: **Developmental Services Program Directors**

FROM: Theresa A. M. Wood, Deputy Commissioner, DAIL/DDAS

DATE: March 9, 2005

SUBJECT: Self- and Family-Managed Twenty-four Hour Home Supports

There are relatively few self- or family-managed twenty-four (24) hour home support arrangements across Vermont Although some of these arrangements have worked for people, a number of them have been problematic. These concerns have led us to question the advisability of self- and family-managing twenty-four (24) hour home supports.

Effective immediately, I am placing a moratorium on any new self- or family-managed twenty-four (24) hour home supports until, a number of issues can be addressed. It is our intent to have discussions regarding our concerns with a variety of sources, including the Developmental Services State Standing Committee.

At the current time, individuals and families may continue with any *existing* twenty-four (24) hour home support arrangements. Additionally, individuals and families may manage intermittent, hourly home supports which are less than twenty-four (24) hours.

The Division of Disability and Aging Services continues to be committed to providing the option to self- or family-manage services. We are also committed to Insuring the health, safety and rights of individuals. Please share this information with your staff and call if you have any questions.

All who now Self- or Family- Managed Twenty-four hour Home supports are now grandfathered into this new non-choice option.

/s
CC: DS Leadership Team
Community Alternatives Specialists
Maryann Wilson, ARIS

From: Annie Galloway
To: AHS - DAIL DDSD SOCP & Regulations
Subject: Cannabis medicine and Residential programs
Date: Friday, October 21, 2022 9:00:02 AM

Hello,

I’m writing as a family member and worker in the system of care. I’m writing as an advocate for healthy life choices for our families.

Now that we have legalized cannabis medicine in our state and we know many people who have disabilities or medical conditions that benefit from this medicine are using it daily to heal and restore their health.

We need to be at the forefront of creating change that allows our family members who are using cannabis medicine to have access to both residential programs and their cannabis medicine.

A woman in St Albans had to give up her life saving cannabis medicine in order to enter into a residential program. This is unethical.

As more and more people enter into this system this will become an issue. It already is an issue.

I hope you will be part of making a change so that we can move forward together in justice for all people.

Anne Galloway

Live by faith not by sight

From: Jim Caffry
To: McFadden, Clare; Garabedian, Jennifer
Cc: "Elizabeth Campbell"; Karen Price; "Collins Reading Twing"; "Barbara Lee"; "Marla McQuiston"; "Lauren Arcuri"; "LAURIE MUMLEY"; "Jenn Townley"
Subject: Comments on Proposed Changes to the Developmental Disabilities Services Regulations
Date: Friday, October 28, 2022 2:33:08 PM

Clare and Jennifer:

The following are written comments to the Developmental Disabilities Services Division (“DDSD”), within the Vermont Department of Disabilities Aging and Independent Living (“DAIL”) regarding the proposed changes to the regulations, now to be referred to as the Developmental Disabilities Services Regulations.

I am filing these written comments individually. However, as you know, I have been part of the parent-led Developmental Disabilities Housing Initiative (“DDHI”), and my comments on the proposed Regulations are made with the goal of encouraging positive changes in the Vermont developmental services system, particularly in the area of providing stable, service-supported housing for Vermonters with developmental disabilities and high support needs.

Most of the changes needed to move forward will come through the development and adoption of new State System of Care Plan for Developmental Disabilities Services.

The comments in this communication are focused on the proposed Developmental Disabilities Services Regulations.

As a starting point, DAIL and DDSD need to acknowledge that the State had fallen short of meeting one of the key principles of service in the Vermont Developmental Disabilities Act of 1996 – specifically the State has not met its obligation to provide meaningful choices when it comes to providing residential living situations for individuals requiring 24-hour supports.

18 V.S.A. § 8724 (Principles of service) states:

> Services provided to people with developmental disabilities and their families shall foster and adhere to the following principles:
>
> ***
>
>> (6) Meaningful choices. People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values, and needs and assure that each recipient is directly involved in decisions that affect that person’s life.

Additionally, the passage of Act 186 requires the DDSD to take affirmative steps to expand housing and residential services for individuals with developmental disabilities.

In some of the materials recently produced by DDSD regarding housing arrangements, the DDSD has stated that of the roughly 1,800 people receiving Home Supports, 76% percent live in Shared Living:

https://ddsd.vermont.gov/sites/ddsd/files/documents/Considerations_of_New_Housing_Options.pdf.

As has been expressed numerous times, that figure is very misleading. The 15% of people in Supervised Living have the independence skills that they do not require 24/7 supports. The 4% in Staffed Living and the 5% in Group Living generally have either significant medical needs or behavioral challenges that those 158 individuals have been unsuccessful in one or more Shared Living placements.

With some *very* limited exceptions, Shared Living is the *only* residential option for individuals who require 24/7 supports, but who do not have the medical or behavioral needs that result in Group or Staffed Living arrangements.

With those considerations in mind, turning to the proposed Developmental Disabilities Services Regulations, the DDSD is respectfully requested to consider the following:

1. **<u>7.100.1 (Purpose and Scope)</u>**
   See above. The purpose of the Regulations is to implement the DD Act (18 V.S.A., Chapter 204A), and not be a barrier to implementing the Act.

2. **<u>7.100.2(v) (Definitions – Home Supports)</u>**
   See above.
   "Home Supports" means services, supports and supervision provided for individuals in and around their residences up to 24 hours a day, seven days a week (24/7). Services include support for individuals to acquire and retain life skills and improve and maintain opportunities and experiences for individuals to be as independent as possible in their home and community. Services include maintaining health and safety and home modifications required for accessibility related to an individual's disability, including cost-effective technology that promotes safety and independence in lieu of paid direct support. Home supports must be in compliance with HCBS rules which emphasize choice, control, privacy, tenancy rights, autonomy, independence and inclusion in the community.
   Currently, there really is no choice for Home Supports if an individual requires 24-hour supports.

3. **<u>7.100.2(ff) (Definitions – Resident)</u>**
   In subsection (ff)(1) a "facility" is not defined, but the Regulations should clearly permit individuals to reside in an out of state residential community (e.g., Visions in New Hampshire) in an adjoining state just as the Regulations allow for a person to remain a Vermont resident if the person lives with a Shared Living Provider in an adjoining state.

4. **<u>7.100.4 (Recipient Criteria)</u>**
   Subsection (c) cross-references 7.100.2(ff)(1). Again, if an individual is considered to maintain Vermont residency when the individual resides in an adjoining state, that individual should have that same consideration for a residential community in an adjoining state.

5. **<u>7.100.5(j) (Choice of Provider)</u>**
   Subsection (j)(1)(E) states: A recipient or family may request that an agency sub-contract

with a non-agency provider to provide some or all of the authorized services; however, the decision to do so is at the discretion of the agency.

This language is currently in Subsection 4.10(a)(5) of the 2017 Regulations. This subsection should include language that makes it clear that an agency's consent to a family's request to have services provided through a subcontract with a non-agency provider must not be unreasonably withheld.

The Regulations should be clear that if an individual or family wants services provided through a non-agency provider, then the presumption should be that the agency will enter such a subcontract, and the agency's discretion not to subcontract should only be exercised in the event that there is a reasonable basis to conclude that the sub-contractor is unable to comply with the applicable programmatic requirements.

Additionally, there should be clear language that if an agency refuses to enter a contract with a non-agency provider, then the individual or Authorized Representative (e.g., parent/guardian), may appeal the refusal to subcontract to the DDSD Director.

6. **7.100.6 (Self/Family Management)**

As expressed in my October 20, 2022 email to the two of you, the prohibition on Self/Family Management of 24-hour home supports should be eliminated. That 8-hour limitation is an arbitrarily imposed barrier to creating alternative, sustainable housing options for individuals and families.

Whatever the "problematic" situations were that led to the 8-hour limitation being imposed by a memo in 2005, and then jammed into the 2011 DD Regulations over the unanimous objection of all public commenters, are not a legitimate basis to prohibit all individuals or families from managing 24-hour Home Supports.

The fact that there was a recent horrible situation of abuse and neglect in the Shared Living Provider Program (https://vtdigger.org/2022/09/13/4-caregivers-for-vulnerable-adults-charged-with-abuse-and-neglect/) does not mean the DDSD is going to ban all Shared Living Providers.

It is the DDSD's job, and the Supportive ISO's job, to administer the Self/Family Management Program. There is a process to terminate individuals or families from the management of services. If the individuals or families are not up to the task, then those individuals or families can have their ability to manage services taken away. It should be no different when it comes to management of 24-hour services.

Because the 8-hour Home Support limitation should finally be eliminated, and the ability to manage 24-hour Home Supports should be restored as it existed before March of 2005, then the requirement in the current 2017 Regulations, Section 5.2(m) should be reinstated ("Follow the requirements of the Housing Safety and Accessibility Review Process to ensure that the individual is living in a safe and accessible home.").

7. **7.100.11 (Certification of Providers)**

See Comment #5 above. The language of Subsection (f)(1) (Status of non-designated providers) should mirror Subsection 7.100.5(j) and be made clear that there is a presumption that the agency will enter a subcontract with a non-designated

> organization, and the discretion not to subcontract with a non-designated organization will only be exercised if there is a reasonable basis to conclude that the subcontractor is unable to comply with the applicable programmatic requirements.

In short, the Regulations should encourage the expansion of housing and residential service options for individuals with developmental disabilities, and any impediments to new and creative housing options should be removed from the Regulations. This is a requirement of both the DD Act of 1996 and of Act 186.

Thank you for your consideration of these comments.

Jim Caffry

118 Graves Farm Road
Waitsfield, VT 05673

From: j.e.townley1@gmail.com
To: McFadden, Clare; Garabedian, Jennifer
Subject: Comments on Proposed Changes to the DSD Regs
Date: Friday, October 28, 2022 3:59:06 PM

Hi Jennifer & Clare,

After reviewing the Draft of the DSD Regulations, I would like to see the Regulations encourage the expansion of housing and residential service options for adults with developmental disabilities, and any barriers/obstacles to new and creative housing options should be removed from the Regulations. The Regulations should align with the HCBS Settings Criteria and provide meaningful choices for residential living situations for individuals requiring 24-hour supports. Although Act 186 is noted, changes could easily be incorporated as part of the current update of Regulations to support housing choice.

My family would like to see:

1. Federal law allows up to five adults with ID/DD to live together under the same roof. We would like the Vermont policy that no more than two adults with developmental disabilities can reside together in the same home under the Shared Living arrangement be changed to align more with Federal law. Also, would like to see that housing could be created for more than 3 individuals residing together without requiring licensure and have DAIL/DSD work with licensure to change this requirement. Perhaps licensure shouldn't be based on # of people being served within a residence, but on level of need of the clients residing together.

2. Self and family management only allows for 8 hours/day of paid in-home supports and we believe the state should allow for family management of 24/7 paid in-home supports.

3. Eliminate the provision that a DA/SSA can refuse to subcontract with a family or recipient who desires that their authorized services be provided by a non-agency.

4. The state should allow for HCBS funding to be used for out-of-state authorized services, including housing, if there are no options to meet the client's needs within the state.

5. Expand the definition of individuals that qualify for the HCBS Wavier to include those individuals that fall on the Fetal Alcohol Spectrum like the Federal government defines today. This is a developmental disability and many students leave high school with no supports and services which are greatly needed. Fetal Alcohol in utero is organic damage to the brain and often these clients plateau and will never achieve independence.

6. Provide services including housing options that are based on a client's needs and not

just on the lowest cost option of providing a specific service.

Thank you for your consideration.
-Jenn, Ed, Ben & Noah Townley

Vermont Developmental Disabilities Council

100 State Street, suite 342
Montpelier, Vermont 05633-0206

(802) 828-1310
vtddc@vermont.gov
www.ddc.vermont.gov

TO: Department of Disabilities, Aging, and Independent Living

RE: Proposed changes to Vermont's Developmental Disabilities Regulations

FROM: Vermont Developmental Disabilities Council

Susan Aranoff, Senior Policy Analyst and Planner

DATE: October 28, 2022

Thank you for the opportunity to comment on the proposed changes to Vermont's Developmental Disabilities Regulations. The Vermont Developmental Disabilities Council (hereafter "VTDDC") is a statewide board created by the federal Developmental Disabilities Assistance and Bill of Rights Act (hereafter "the DD Act"), first adopted by Congress in 1970. An estimated 86,000 Vermonters experience a developmental disability as defined by the DD Act, with approximately 5,100 receiving Medicaid-funded, home and community-based support (HCBS) through the Developmental Disabilities Services System of Care or in some cases, the Choices for Care Program.

VTDDC is charged under federal law with engaging at the state level in "advocacy, capacity building and systems change activities that… contribute to the coordinated, consumer-and-family-centered, consumer-and-family directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families."[1]

In addition to our federal mandate, we are commenting in our unique role within the Agency of Human Services (AHS). As per our signed assurances with AHS, the VTDDC advises AHS on quality strategies as they pertain to people with developmental disabilities.[2]

Introduction

VTDDC applauds the Developmental Disabilities Services Division (the Division) for providing robust opportunities for public engagement as part of the rule-making process. The Division provided the State Program Standing Committee (SPSC), the advisory board established in 18 V.S.A. §8733, with an initial draft of the proposed rule, seeking for advice and recommendations in March 2022. A plain language document explaining the proposed changes was developed and shared with the board. DAIL staff and the SPSC members reviewed and discussed the draft. The SPSC members offered comments and suggested some changes to the proposed draft. The process is described in DAIL's filing with the Secretary of State's office[3] and could serve as a model for the Department going forward.

In its summary of the proposed changes, the Division acknowledges its need to align the rules regarding eligibility with the ruling in *In re: R.R.*. VTDDC participated in the R.R.

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[1] Developmental Disabilities Assistance and Bill of Rights Act of 2000. 42 USC 15001 et. seq.

[2] "Section M. The Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities." Signed by AHS Secretary Samuelson.

[3] Developmental Disabilities Proposed Rule Filing

case as an Amicus Curiae and commends the clarifying amendments that align with the holding in R.R.

Likewise, VTDDC commends the State for adding transportation to the definition of support services.[4] Transportation is critical to accessing the community. It has long been a point of confusion for individuals supported by direct support providers (DSPs) and by home support providers, as to whether they can expect their DSP or their home provider to transport them to planned activities.

Proposed Additions

1. Supported Decision Making

VTDDC is working with several statewide organizations including DAIL to increase the use of Supported Decision Making in Vermont. VTDDC supports in full the recommendations made by Vermont Legal Aid's Disability Law Project, one of our partners in the Supported Decision-Making project.

In its April, 2022, Comments on the pre-filed proposed rules, the Vermont Legal Aid's Disability Law Project recommended the following:

> "The core principles of the Department for Disabilities, Aging, and Independent Living (DAIL) and of the Developmental Disabilities Services Division closely align with the principles of Supported Decision-Making (SDM). As outlined in the Developmental Disabilities Act for Vermont, these principles include that supports and services are person-centered, that they promote personal and economic independence, self-determination, and flexibility, and that individuals benefit from collaboration. While the concept

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[4] See 7.100.2(q).

> of Supported Decision-Making pre-dates the current System of Care Plan, and most recent DD regulations revisions, the role of DAIL and of Designated and Specialized Services Agencies in enabling SDM as an alternative to guardianship is not mentioned anywhere within either document, nor is it part of the quality review process.
> We recommend that the rules on Training, Certification of Providers, and Evaluation be amended to incorporate the use of supported decision-making approaches for beneficiaries with and without guardianships in place.
>
> The training section can be amended so that, in addition to ensuring employees have training on abuse reporting, health and safety, individual specific information, and values, employees and contractors receive training on formal and informal methods of supported decision making and serving as supporters in a more formal supported decision-making agreement if they so choose."

Excerpt from Letter from VT Legal Aid Disability Law Project to DAIL, April 18, 2022

The certification section can be amended so that the guidelines for quality review incorporate adoption of supported decision-making approaches, and providers report on how supported decision making is incorporated into ISAs, and how many beneficiaries served are using some form of supported decision making, just as ISAs reflect supervision needs and communication support.

2. Incorporate CMS Rules

Overview

The definition of Home and Community-based Services (HCBS) references the need for Vermont's HCBS to be provided in a manner consistent with Medicaid's HCBS Rules.[5]

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[5] See 7.100.2 (u).

> (u) “Home and Community-Based Services” (HCBS) means an array of long-term services developed to support individuals to live and participate in their home and community rather than in an institutional setting, ***consistent with Centers for Medicare and Medicaid Services (CMS) federal HCBS Rules.*** (Emphasis added).

The definition of Home Supports also references the need for Vermont’s Medicaid-funded services to be in compliance with CMS Rules.[6]

> (v) “Home Supports” means services, supports and supervision provided for individuals in and around their residences up to 24 hours a day, seven days a week (24/7). Services include support for individuals to acquire and retain life skills and improve and maintain opportunities and experiences for individuals to be as independent as possible in their home and community. Services include maintaining health and safety and home modifications required for accessibility related to an individual’s disability, including cost-effective technology that promotes safety and independence in lieu of paid direct support. ***Home supports must be in compliance with HCBS rules which emphasize choice, control, privacy, tenancy rights, autonomy, independence and inclusion in the community.*** (Emphasis Added).

It is VTDDC’s understanding that the proposed rules will be in place in early 2023. The Council notes that the HCBS Settings rule, which has been anticipated since 2014, will be in force March 2023. It is therefore especially timely that the Settings Rule be incorporated in Vermont’s regulations now.

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[6] See 7.100.2 (v).

Recommendation: VTDDC recommends embedding the core elements of CMS' HCBS Settings into Vermont's DS Regulations.

The CMS Settings Rule is designed to ensure that people with disabilities living in the community have access to the same kind of choice and control over their own lives as those not receiving Medicaid HCBS funding. The requirements that should be specified in the Vermont's rules come directly from the 2014 HCBS Settings Rule. They require that any setting where Medicaid funded HCBS are delivered be:

1. Integrated in the greater community.
2. Support the individual's full access to the greater community, including opportunities to seek employment, work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community.
3. Selected by the individual from among different setting options, including non-disability specific options and an option for a private unit in a residential setting.
4. Ensures an individual's rights to privacy, dignity, respect, and freedom from coercion and restraint.
5. Optimizes individual initiative, autonomy, and independence in making life choices, including in daily activities, physical environment, and personal associations.
6. Facilitates individual choice regarding services and supports and who provides them.

A "provider-owned or controlled residential setting" is one in which the service provider also owns or controls the real estate where the individual lives, as distinct from a setting owned or controlled by the person receiving services or their family where the provider merely arrives to deliver support services. The residences of shared living providers are considered provider-owned or controlled residential settings, as are group homes.

The 2014 Settings Rule contains specific requirements for provider owned and controlled settings. Vermont provides HCBS services to over 3000 individuals residing in provider owned or controlled settings, including the residences of shared living providers and other adult foster care providers. There have been no efforts to date to educate the residents of these settings as to their rights under the CMS Settings Rule, including the right to a lease or lease-like protections.

All shared living residences could be settings that isolate because in most cases, the residents in a shared living residence do not control their own access to the community. The Settings Rule requirements for provider owned or controlled residential settings should also be included in the Rules.

Individuals in provider-owned or controlled residential settings must have:

1. A lease or other legally enforceable agreement providing similar protections.
2. Privacy in their unit, including lockable doors, choice of roommates, and freedom to furnish or decorate their space.
3. The right to control his/her own schedule including access to food at any time.
4. The right to visitors at any time.
5. A setting that is physically accessible.

VTDDCD further recommends that the State include in its rules a model agreement for state-funded shared living providers that contains the lease-like protections required by CMS' HCBS Rules. If each of the 14 designated agencies creates its own lease agreements, there will be confusing differences between beneficiaries receiving the same services.

Recommendation: VTDDC recommends that the Person-Centered Planning Rule Plan of Correction Should be Incorporated in the rules by Reference

Vermont lacks person-centered planning processes that are free from undue conflicts of interest. VTDDC notes that the Vermont Agency of Human Services submitted a proposed plan of correction to CMS to address the lack of conflict-of-interest free case management in Vermont. When the Plan of Correction is approved by CMS it will be added to the Global Commitment to Healthcare waiver as Attachment Q. The Plan of Correction should be incorporated in the new Rule by reference. VTDDC further recommends that knowledge of Person-centered planning and settings rules requirements be added to training requirements.

ADDITIONAL RECOMMENDATIONS

The Council recognizes that the Division of Developmental Disabilities Service is facing a time of unprecedented change. For this reason, we anticipate that there will be opportunities to revise the rule again in the near future. We want to take this opportunity to anticipate some of these changes.

1. Embed an Independent Ombudsman in the Rules: Vermonters with disabilities who are receiving home and community-based services for a developmental disability need an outside independent entity to address complaints and conduct independent investigations. These beneficiaries should have access to a service that has been embedded in Choices for Care since its inception
2. Quality reviews and monitoring of compliance with HCBS rules should be increased to significantly more than a 15% review every 2 years and set out in the Rules.

3. The State must provide a Notice of Rights for HCBS recipients – in plain language – detailing the rights enumerated in the settings and person-centered-planning rules and include it in the Rules.

From: Bascom, June
To: McFadden, Clare
Subject: Regs Edits - Communication and Waiting List
Date: Thursday, November 3, 2022 8:39:22 AM
Attachments: DD Act Regs_Training_Communication Updates_v2.docx
DD Act Regs_Waiting List Edits_v2.docx

I thought I sent this to you yesterday. Got delayed by your DD Act email – which is good as it got me rethinking about the waiting list wording.

Re: Communication edits – I removed the new language on AAC from 9.5(a)(2) as it didn't really fit there. Being knowledgeable about AAC was the intent behind the new wording in that section so it should be good as is.

Re: Waiting List – The way section 4.9 reads, it just references the DA and the requirement to only put people who do not meet a funding priority on the waiting list. The edits to 4.18 were made to better reflect this original intent. I don't think this change in wording takes anything away from HCBS recipients since they have the right of a periodic review and a new needs assessment if their needs change. However, the wording still requires agencies to follow-up "at least annually" with people on the list, which doesn't really make sense in most cases and doesn't currently happen. This was a concern expressed by the DS Directors and what you brought up as well. It makes more sense to remove (b.)(1) and depend on applicants to let the agency know when their needs have changed (b.)(3). I've proposed that in the attached version for consideration.

9.4 **Pre-Service Training**

Before working alone with an individual who receives support funded by the Department, each worker shall be trained and demonstrate knowledge in (a) through (e) of this section. The employer of record, whether recipient, family, shared living provider or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(a) Abuse reporting requirements:

(1) The requirements of Vermont law to report suspected abuse or neglect of children; and

(2) The requirements of Vermont law to report suspected abuse, neglect, or exploitation of vulnerable adults.

(b) Health and Safety:

(1) Emergency procedures, including where to locate the emergency fact sheet;

(2) What to do if the individual is ill or injured;

(3) Critical incident reporting procedures; and

(4) How to contact a supervisor or emergency on-call staff.

(c) Individual specific information. (The provisions of this subsection apply each time a worker works with a different individual or family.)

(1) Whether the individual has a guardian, and how to contact the guardian;

(2) The individual's behavior, including the individual's specific emotional regulation support requirements and behaviors which could place the person or others at risk;

(3) Health and safety needs of the individual;

(4) ~~How to~~ Methods of communicationi~~e~~ used by ~~with~~ the individual including tools, technology, and effective partner support strategies; and

(5) The individual's ISA, including the amount of supervision the individual requires.

(d) Values:

(1) Individual rights, including those specified in 18 V.S.A. § 8728;

(2) Confidentiality;

(3) Presumption of Competence: a strength-based approach that assumes all people have abilities to learn, think, and understand;

(~~3~~4) Respectful interactions with individuals and their families; and

(~~4~~5) Principles of service contained in the Developmental Disabilities Act of 1996.

(e) How to access additional support, training, or information.

9.5 **In-Service Training**

(a) Within three months of being hired or entering into a contract, workers shall be trained in and demonstrate the knowledge and skills necessary to support individuals in (a)(1) and (2) of this section. Workers shall be trained in or demonstrate knowledge and skills necessary to support individuals, in (a)(3) and (4) of this section. The employer of record, whether recipient, family, shared living provider, contractor, or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(1) The worker's role in developing and implementing the ISA, including the role and purpose of the ISA, and working as part of a support team;

(2) The skills necessary to implement the recipient's ISA (including facilitating inclusion, teaching and supporting new skills, being an effective communication partner to support~~ing~~ methods of communication used by the recipient). For self/family-managed services, the employer of record is responsible for providing or arranging for this training for their workers. For share-managed services and respite the agency is responsible to ensure the employer of record has provided the training and the worker demonstrates knowledge in the areas trained;

(3) Vermont's developmental disabilities service system (including Department policies and procedures) and agency policies and procedures as relevant to their position in order to carry out their duties; and

(4) Basic first aid.

(b) Workers shall be trained in blood-borne pathogens and universal precautions within time frames required by state and federal law.

Proposed Changes to Regulations Implementing the DD Act of 1996
Submitted by J Bascom and endorsed by the DS Directors – amended 11/2/22

4.9(b)(4) – Notification of decision on application – Consent of notices

If the assessment determines the person has a developmental disability but does not meet a funding priority to receive Home and Community-Based ~~s~~Services ~~or~~ funding, the notice shall state that the DA shall continue to offer information and referral services and shall place the person's name on a waiting list (Section 4.18).

4.18 – Waiting list

A person with a developmental disability whose application for Home and Community-Based ~~s~~Services ~~or supports~~ is denied~~, in whole or in part,~~ because the person's needs do not meet the funding priorities outlined in section 4.7 shall be added to a waiting list maintained by the designated agency ~~or Supportive ISO, as applicable~~. The designated agency ~~or Supportive ISO~~ shall notify an applicant that his or her name has been added to the waiting list, and explain the rules for periodic review of the needs of people on the waiting list.

(a) Each designated agency ~~and Supportive ISO~~ maintains a waiting list for services they provide, including:

(1) Individuals eligible for HCBS based on their developmental disability~~, including those already receiving services~~, but whose request for services is denied~~, in whole or in part,~~ because the individual's needs do not meet a funding priority.

(2) Individuals eligible for, but denied, FFF because of insufficient funds (including people
who receive partial funding and/or one-time funding).

~~(3) Individuals eligible for, but denied, TCM because of insufficient funds.~~

(3~~4~~) Individuals eligible for, but denied, FMR funds because of insufficient funds.

~~(5) Individuals eligible for, but denied, PSEI funds because of insufficient funds or lack of capacity of the PSEI program to support additional students.~~

(b) Each designated agency ~~and Supportive ISO~~ shall notify individuals when they have been placed on a waiting list and review needs of all individuals on the waiting list, as indicated below, to see if the individual meets a funding priority, and if so, to submit a funding proposal and/or refer the individual to other resources and services. A review of the needs of all individuals on the waiting list shall occur:

~~(1) At least annually; and~~

(1~~2~~) When there are changes in the funding priorities or funds available; or

(2~~3~~) When notified of significant changes in the individual's life situation.

From: Bascom, June
To: McFadden, Clare
Subject: RE: Regulations and State System of Care Plan Recommended Edits
Date: Monday, October 31, 2022 12:44:04 PM
Attachments: DD Act Regs_Communication Updates_2022_updated_31Oct2022.docx

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Before the public comment period ends, I'd like to amend a section of the Vermont Communication Task Force's recommended edits to the Pre-Service Training section of the Regulations. See highlighted section in attachment. We can discuss when we meet to go over these recommendations. I sent you an invite for Wednesday to discuss the recommended changes from the DS Directors and VCTF.

From: Bascom, June
Sent: Friday, October 07, 2022 5:37 PM
To: McFadden, Clare <Clare.McFadden@vermont.gov>
Subject: Regulations and State System of Care Plan Recommended Edits

Clare,
Attached are the following public input into the DD Act Regulations:

- Waiting List – submitted by me and endorsed by the DS Directors
- Pre-Service/In-Service Training – submitted by the Vermont Communication Task Force

Related to the Waiting List changes to the Regulations, attached are relevant edits to the State System of Care Plan.

Please let me know if you have questions about these recommended changes.
Thank you.
June

9.4 **Pre-Service Training**

Before working alone with an individual who receives support funded by the Department, each worker shall be trained and demonstrate knowledge in (a) through (e) of this section. The employer of record, whether recipient, family, shared living provider or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(a) Abuse reporting requirements:

(1) The requirements of Vermont law to report suspected abuse or neglect of children; and

(2) The requirements of Vermont law to report suspected abuse, neglect, or exploitation of vulnerable adults.

(b) Health and Safety:

(1) Emergency procedures, including where to locate the emergency fact sheet;

(2) What to do if the individual is ill or injured;

(3) Critical incident reporting procedures; and

(4) How to contact a supervisor or emergency on-call staff.

(c) Individual specific information. (The provisions of this subsection apply each time a worker works with a different individual or family.)

(1) Whether the individual has a guardian, and how to contact the guardian;

(2) The individual's behavior, including the individual's specific emotional regulation support requirements and behaviors which could place the person or others at risk;

(3) Health and safety needs of the individual;

(4) ~~How to~~ Methods of communication~~e~~ used by ~~with~~ the individual including tools, technology, and effective partner support strategies; and

(5) The individual's ISA, including the amount of supervision the individual requires.

(d) Values:

(1) Individual rights, including those specified in 18 V.S.A. § 8728;

(2) Confidentiality;

(3) Presumption of Competence;

(~~3~~4) Respectful interactions with individuals and their families; and

(~~4~~5) Principles of service contained in the Developmental Disabilities Act of 1996.

(e) How to access additional support, training, or information.

9.5 In-Service Training

(a) Within three months of being hired or entering into a contract, workers shall be trained in and demonstrate the knowledge and skills necessary to support individuals in (a)(1) and (2) of this section. Workers shall be trained in or demonstrate knowledge and skills necessary to support individuals, in (a)(3) and (4) of this section. The employer of record, whether recipient, family, shared living provider or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(1) The worker's role in developing and implementing the ISA, including the role and purpose of the ISA, and working as part of a support team;

(2) The skills necessary to implement the recipient's ISA (including facilitating inclusion, teaching and supporting new skills, being an effective communication partner to support~~ing~~ methods of communication used by the recipient including basic knowledge of Augmentative and Alternative Communication). For self/family-managed services, the employer of record is responsible for providing or arranging for this training for their workers. For share-managed services and respite the agency is responsible to ensure the employer of record has provided the training and the worker demonstrates knowledge in the areas trained;

(3) Vermont's developmental disabilities service system (including Department policies and procedures) and agency policies and procedures as relevant to their position in order to carry out their duties; and

(4) Basic first aid.

(b) Workers shall be trained in blood-borne pathogens and universal precautions within time frames required by state and federal law.

From: Elizabeth Campbell
To: Garabedian, Jennifer
Cc: McFadden, Clare
Subject: DDHI Input to Proposed SOC Plan and DD REGULATIONS
Date: Monday, October 24, 2022 3:35:16 PM

Dear Jennifer and Clare,

As you and your colleagues at DAIL are aware, the parent-led Developmental Disabilities Housing Initiative's (DDHI) primary focus is advocating for and supporting the development of stable, service-supported housing communities for our adult daughters and sons, many of whom have significant support needs and would benefit from the option of living with peers.

Given this, many DDHI parents have expressed disappointment that the current draft SOCP (2023-2025) and the proposed 2022 DD Regulations do little to remove barriers to expanding housing options for adults with ID/DD who benefit from the HCBS waiver.

The specifics of various housing models need not be suggested, at this time, in the Regulations and SOCP; however, given that it was the intention of Act 186 to help promote increased choice and flexibility in housing options as required in the 2014 CMS HCBS Settings Rule, we would expect that these two documents would at least lay the groundwork by removing barriers so that new housing models can emerge.

We suggest the following changes be considered, which would be in keeping with the intent of Act 186:

1. Eliminate the Vermont policy that no more than two adults with developmental disabilities can reside together, in the same home, under the Shared Living arrangement. Federal law allows up to five adults with ID/DD to live together under the same roof.

2. Eliminate the prohibition on family management of 24/7 paid in-home supports. Currently, SFM (self and family management) only allows for 8 hours/day of paid in-home supports.

3. Eliminate the provision that a DA/SSA can refuse to subcontract with a family

or recipient who desires that their authorized services be provided by a non-agency. Currently, granting such a request is “at the discretion of the agency (DA/SSA).”

4. Include and/or clarify that HCBS funding can be used for out-of-state authorized services, including housing, if the recipient’s “needs are so specialized” that no provider within the recipient’s geographic area can accommodate the recipient’s needs.

Thank you both for your work on behalf of our adult children.

Respectfully,

Elizabeth Campbell (on behalf of the 90+ parents behind DDHI)

From: Bascom, June
To: McFadden, Clare
Subject: Regulations and State System of Care Plan Recommended Edits
Date: Friday, October 7, 2022 5:37:23 PM
Attachments: DD Act Regs_Training_Communication Updates.docx
DD Act Regs_Waiting List Edits.docx
SSCP_Waiting List Edits.docx

Clare,

Attached are the following public input into the DD Act Regulations:

- Waiting List – submitted by me and endorsed by the DS Directors
- Pre-Service/In-Service Training – submitted by the Vermont Communication Task Force

Related to the Waiting List changes to the Regulations, attached are relevant edits to the State System of Care Plan.

Please let me know if you have questions about these recommended changes.

Thank you.

June

9.4 **Pre-Service Training**

Before working alone with an individual who receives support funded by the Department, each worker shall be trained and demonstrate knowledge in (a) through (e) of this section. The employer of record, whether recipient, family, shared living provider or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(a) Abuse reporting requirements:

(1) The requirements of Vermont law to report suspected abuse or neglect of children; and

(2) The requirements of Vermont law to report suspected abuse, neglect, or exploitation of vulnerable adults.

(b) Health and Safety:

(1) Emergency procedures, including where to locate the emergency fact sheet;

(2) What to do if the individual is ill or injured;

(3) Critical incident reporting procedures; and

(4) How to contact a supervisor or emergency on-call staff.

(c) Individual specific information. (The provisions of this subsection apply each time a worker works with a different individual or family.)

(1) Whether the individual has a guardian, and how to contact the guardian;

(2) The individual's behavior, including the individual's specific emotional regulation support requirements and behaviors which could place the person or others at risk;

(3) Health and safety needs of the individual;

(4) ~~How to~~ Methods of communication~~e~~ used by ~~with~~ the individual including tools, technology, and effective partner support strategies; and

(5) The individual's ISA, including the amount of supervision the individual requires.

(d) Values:

(1) Individual rights, including those specified in 18 V.S.A. § 8728;

(2) Confidentiality;

(3) Presumption of Competence;

(~~3~~4) Respectful interactions with individuals and their families; and

(~~4~~5) Principles of service contained in the Developmental Disabilities Act of 1996.

(e) How to access additional support, training, or information.

9.5 In-Service Training

(a) Within three months of being hired or entering into a contract, workers shall be trained in and demonstrate the knowledge and skills necessary to support individuals in (a)(1) and (2) of this section. Workers shall be trained in or demonstrate knowledge and skills necessary to support individuals, in (a)(3) and (4) of this section. The employer of record, whether recipient, family, shared living provider or agency, is responsible for providing or arranging for this training for their workers. The agency or Supportive ISO is responsible for verifying that the employer of record has provided or arranged for this training.

(1) The worker's role in developing and implementing the ISA, including the role and purpose of the ISA, and working as part of a support team;

(2) The skills necessary to implement the recipient's ISA (including facilitating inclusion, teaching and supporting new skills, being an effective communication partner to support~~ing~~ methods of communication used by the recipient). For self/family-managed services, the employer of record is responsible for providing or arranging for this training for their workers. For share-managed services and respite the agency is responsible to ensure the employer of record has provided the training and the worker demonstrates knowledge in the areas trained;

(3) Vermont's developmental disabilities service system (including Department policies and procedures) and agency policies and procedures as relevant to their position in order to carry out their duties; and

(4) Basic first aid.

(b) Workers shall be trained in blood-borne pathogens and universal precautions within time frames required by state and federal law.

Proposed Changes to Regulations Implementing the DD Act of 1996
Submitted by J Bascom and endorsed by the DS Directors

4.9(b)(4) – Notification of decision on application – Consent of notices

If the assessment determines the person has a developmental disability but does not meet a funding priority to receive Home and Community-Based ~~s~~Services ~~or~~ funding, the notice shall state that the DA shall continue to offer information and referral services and shall place the person's name on a waiting list (Section 4.18).

4.18 – Waiting list

A person with a developmental disability whose application for Home and Community-Based ~~s~~Services ~~or supports~~ is denied, in whole or in part, because the person's needs do not meet the funding priorities outlined in section 4.7 shall be added to a waiting list maintained by the designated agency ~~or Supportive ISO~~, as applicable. The designated agency ~~or Supportive ISO~~ shall notify an applicant that his or her name has been added to the waiting list, and explain the rules for periodic review of the needs of people on the waiting list.

(a) Each designated agency ~~and Supportive ISO~~ maintains a waiting list for services they provide, including:

(1) Individuals eligible for HCBS based on their developmental disability~~, including those already receiving services~~, but whose request for services is denied, in whole or in part, because the individual's needs do not meet a funding priority.

(2) Individuals eligible for, but denied, FFF because of insufficient funds (including people
who receive partial funding and/or one-time funding).

~~(3) Individuals eligible for, but denied, TCM because of insufficient funds.~~

(3~~4~~) Individuals eligible for, but denied, FMR funds because of insufficient funds.

~~(5) Individuals eligible for, but denied, PSEI funds because of insufficient funds or lack of capacity of the PSEI program to support additional students.~~

(b) Each designated agency ~~and Supportive ISO~~ shall notify individuals when they have been placed on a waiting list and review needs of all individuals on the waiting list, as indicated below, to see if the individual meets a funding priority, and if so, to submit a funding proposal and/or refer the individual to other resources and services. A review of the needs of all individuals on the waiting list shall occur:

(1) At least annually; and

(2) When there are changes in the funding priorities or funds available; or

(3) When notified of significant changes in the individual's life situation.

Proposed Changes to the State System of Care Plan

Submitted by J Bascom and endorsed by the DS Directors

Section Two: Eligibility

IV. Authorization of Services and Funding and Notification

The DA is responsible for determining whether an applicant meets the criteria for financial and clinical eligibility. The DA will conduct or arrange for an assessment to determine clinical eligibility. If the applicant is found financially and clinically ineligible for services, the DA is responsible to provide the individual information and referrals to other services. If an applicant has been found financially and clinically eligible, an Individual Needs Assessment must be completed to determine whether the applicant meets criteria to access any of the services or funding listed in Section Four of this Plan.

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If the applicant is found financially and clinically ineligible for services, the DA is responsible to provide the individual information and referrals to other services. If the applicant is found ineligible to receive Home and Community-Based Services funding for some or all services, the DA will, as soon as possible, notify the applicant and provide information to the individual about the basis for the decision, the process for appeal and where to obtain legal assistance. The applicant's name will be placed on a waiting list maintained by the DA~~/SSA~~. The applicant will be informed that his or her name has been placed on the waiting list~~,~~ and will be given information about the periodic review of the waiting list. (See the Regulations Implementing the Developmental Disabilities Act of 1996, Section 4.9 for more information on notification of decisions and Part 8 on the appeal process.)

Commented [BJ1]: Move this wording to the 3rd sentence of the first paragraph in this section (see above).

Section Five: Management of Home and Community-Based Services

IV. Guidance for Management of HCBS Funding

G. Waiting List

Each Designated Agency~~, Specialized Service Agency and Supportive ISO~~ maintains a waiting list for the following services they provide~~, including~~:

1. Individuals eligible for HCBS (Home and Community-Based Services) based on their developmental disability~~, including those already receiving services~~, but whose request for services is denied, in whole or in part, because the individual's needs do not meet a funding priority.
2. Individuals eligible for, but denied, FFF (Flexible Family Funding) because of insufficient funds (including people who receive partial funding and/or one-time funding).

~~3. Individuals eligible for, but denied, TCM (Targeted Case Management) because of insufficient funds.~~

3~~4~~. Individuals eligible for, but denied, FMR (Family Managed Respite) funds because of insufficient funds.

~~5. Individuals eligible for, but denied, PSEI (Post-Secondary Education Initiative) funds because of insufficient funds or lack of capacity of the PSEI program to support additional students.~~

Each Designed ~~a~~Agency ~~(DA/SSA) and Supportive ISO~~ shall notify individuals when they have been placed on a waiting list and review needs of all people on the waiting list, as indicated below, to see if the individual meets a funding priority, and if so, to submit a funding proposal and/or refer the individual to other resources and services. A review of the needs of all individuals on the waiting list shall occur:

1. At least annually; and
2. When there are changes in the funding priorities or funds available; or
3. When notified of significant changes in the individual's life situation.

Each Designated Agency~~, Specialized Service Agency and Supportive ISO~~ shall submit waiting list data according to instructions established by the Division. The waiting list for Flexible Family Funding and Family Managed Respite are reviewed by the Division annually. Information regarding the utilization of each Designated Agency's allocation and waiting lists for the FFF and FMR programs is used in determining the following fiscal year allocations.

Information regarding waiting lists will be included in the DDSD annual report.

From: Garabedian, Jennifer
To: McFadden, Clare
Subject: FW: DD Act Feedback
Date: Monday, October 10, 2022 12:53:30 PM

Here is some feedback re: Regs.

From: Feddersen, Melanie <Melanie.Feddersen@vermont.gov>
Sent: Thursday, October 6, 2022 4:36 PM
To: Garabedian, Jennifer <Jennifer.Garabedian@vermont.gov>
Subject: DD Act Feedback

I meet with Jessica Stehle, Dylan Devlin, Marc Carpenter and Anna Hutton yesterday to walk through a handful of eligibility situations.

Marc also wanted me to pass on some additional feedback.

1. The highlighted section- is this still a requirement we want in place? Honestly, I don't think we specifically check this clinical requirement is met for this age group.

Page 13 of DD act
(e) Clinicians shall follow the ethical guidelines for their profession regarding practicing within their area of expertise and referring to other professionals when needed. When a single clinician is conducting the assessment, he or she should determine whether other professionals need to evaluate the person to gain additional information before rendering a diagnosis. Additional evaluators may include psychologists, speech language pathologists, medical sub-specialists, developmental[1]behavioral or neurodevelopmental disabilities pediatricians, occupational therapists, psychiatrists, and neurologists. For evaluations of children from birth to age six, a developmental-behavioral or neurodevelopmental disabilities pediatrician or pediatric neurologist shall perform the assessment or be part of the assessment team.

2. The highlighted section- what if there are not multiple sources available to give a comprehensive history. For example the person is new to VT , has no available family to provide historical info and schools/other sources do not respond to records requests. Can they find the person eligible?

Page 14 of DD act
2.10 (a) Comprehensive review of history from multiple sources, including developmental history, medical history, psychiatric history with clarification of prior diagnoses, educational history, and family history;

3. Require Adult assessment tools to be used when determining eligibility for adult services. This usually happens but if someone was assessed at age 16 with a WISC, we currently find them eligible. Marc argued, the WISC and WAIS has certain differences where the WAIS is more

clinically appropriate.

Melanie Feddersen

Developmental Disabilities Services Specialist Supervisor
Department of Disabilities, Aging and Independent Living
Office: (802) 289-0015
Cell: (802) 760-0915

From:	Donna Savage
To:	McFadden, Clare
Subject:	Fwd: Changes to the VT State System of Care Plan DDS
Date:	Friday, October 28, 2022 4:56:02 PM

Donna Savage
cell: 802-503-5690

---------- Forwarded message ---------
From: **Donna Savage** <donnasavagevt@gmail.com>
Date: Fri, Oct 28, 2022 at 4:49 PM
Subject: Changes to the VT State System of Care Plan DDS
To: <ahs.DAILDDSDSOCPRegulations@vermont.gov>, <clare.mcfadden@vt.gov>, <Jennifer.Garabedian@vermont.gov>

Dear DDSD,

The purpose of our email is to request changes to the draft VT State System of Care Plan for Developmental Disabilities Services.

Our son, Jack, is now 21 years old and has significant life-long disabilities. Jack is profoundly deaf (with a cochlear implant), visually and cognitively impaired, developmentally delayed, and on the Autism Spectrum Disorder. He is also completely non-verbal and needs full-on personal care support as he is incontinent and wears diapers. Another thing very concerning about our son is his lack of understanding and awareness of danger. All of this has meant that throughout his life Jack has needed 1:1 care and support in all aspects of daily living - as well as eyes on him at all times! We, as his parents, lovingly care for him now, but of course realize that when we are no longer able to do so Jack will need to reside in a safe, stable home that provides round-the-clock care for him.

We are so grateful for the development of the DDHI group of VT parents and the work they are so diligently advocating for. We enthusiastically join them in being a voice for our son, who is completely unable to be a voice for himself. Jack, like others with I/DD with high support needs, deserves to live in a safe, service-supported residential community that offers opportunities to live among friends and enjoy supervised outings. We know this is no small undertaking for the state. It will necessitate the highest quality and competent staffing - and that too will need to be laser-focused on: for training, improved wages and benefits, and overall support to hire and *retain* the best!

Ideally, we'd see transportation be provided and the cost covered for trips back and forth to favorite activities, such as biking along the Burlington bike path, skiing with VT Adaptive Ski & Sports at Sugarbush, and bowling at Spare time (to name a few of Jack's favs!).

We have read the draft Vermont State System of Care Plan for Developmental Disabilities Services, to become effective Jan 1, 2023, and in order to allow our son to live in a permanent, supported home with a few friends, it is our desire to see the following barriers to housing projects changed in the SOCP:

1. C**hange the DRAFT SOCP Section Five IV.(B) 9. (page 56) AND DRAFT Regulations 7.100.5 (j)(3) (A)** so that if an individual chooses to receive services from an agency other than the DA, or an agency agrees to subcontract with a provider, the provider shall submit a budget to the DA and the DA shall determine its costs to serve the individual, **the individual will have the choice of which of the services they would prefer not based completely or only, on the lowest possible cost.**

Notes:

a. The previous rule wording does not support the individual having choices in housing because the lowest possible housing cost is the SLP, and the cost is so low that it does not provide adequate financial support for any other housing choices.

b. This is particularly true for any individual needing 24/7 service and supports.

c. One reason that 90% of adults receiving Home Supports are in Shared Living is because it is the least expensive to the DAs and the State. The Adult Foster Care payments to Shared Living Providers are exempt from income taxation under Section 131. Additionally, the “operations and maintenance” costs of the real estate is not the responsibility of the DAs.

d. Creating new, sustainable, housing options has to recognize that the current lack of choice is directly tied to inadequate funding for DD services for decades.

e. The fact that Group Living and Staffed Living are more expensive ignores the fact that they are more expensive because the people served in those models have the highest needs. They are also more expensive because both of those models operate entirely on shift-staff.

2. Change Family Management of 24-Hour Home Supports in draft SOCP 2023, , Section Two, III Intake Process Choice of Provider, Family Managed Services so that the Family management can be for 24 hrs of home supports.

Notes:

a. The fact that some families’ 24-hour management was “problematic” is not a reason to prohibit every family from doing so.

b. The DD Regulations are currently clear: “In order to self/family-manage services, the individual or family member must be capable of fulfilling the responsibilities set forth in (Regulations DRAFT, Section 7.100.6 (b)Self/Family-Managed Services - page 36)

3. Approval by the DDD to provide HCBS Medicaid funding for services to more than 4 adults living in a dwelling unit in a residential setting. in Draft System of Care Plan, Section FIVE, IV.(D)15.a (page 66)

4. Change Licensing requirements in 33 V.S.A., Chapter 71.

The licensing requirements for any residential care provider, whether a Residential Care Home or a Therapeutic Community Residence, start when there are 3 or more individuals being supported under one roof.

Note: The licensing requirements create an extra layer of cost and a significant barrier to creating the choice of small homes with a few friends living together in their chosen community.

REQUEST: We would like **change requirements for Therapeutic Community Residence, to be dependent on criteria other than number of individuals in the residence**, for example dependent on the levels of care needed, but less than licensing.

Respectfully,

Patrick D. and Donna T. Savage (on behalf of our son, Jack D. Savage)

Donna Savage
cell: 802-503-5690

From: Barbara Lee
To: McFadden, Clare; Garabedian, Jennifer
Subject: Re: Comments on Proposed Changes to the Developmental Disabilities Services Regulations
Date: Friday, October 28, 2022 3:22:23 PM

Dear Clare and Jennifer,

I wish to offer full support to the written input to the Regulations which you received from Jim Caffry (see below). He articulates well the same concerns that I have, so please consider this email my written “input”, also.

As a parent, an advocate, a member of DDHI, and as a member of the State Standing Committee and the ACT 186 Steering Committee, I believe it is essential that the DDSD implement significant changes, now, in the Regulations and the SOCP so that Vermonters have meaningful choice in their living arrangements. This is clearly the intention of our recently passed Act 186, and would bring Vermont closer to compliance with the CMS Settings Rule of 2014.

Respectfully,
Barbara Lee

64 Oak Hill Drive
Dummerston, VT 05301

> On Oct 28, 2022, at 2:33 PM, Jim Caffry <jim@caffrylaw.com> wrote:
>
> Clare and Jennifer:
>
> The following are written comments to the Developmental Disabilities Services Division (“DDSD”), within the Vermont Department of Disabilities Aging and Independent Living (“DAIL”) regarding the proposed changes to the regulations, now to be referred to as the Developmental Disabilities Services Regulations.
>
> I am filing these written comments individually. However, as you know, I have been part of the parent-led Developmental Disabilities Housing Initiative (“DDHI”), and my comments on the proposed Regulations are made with the goal of encouraging positive changes in the Vermont developmental services system, particularly in the area of providing stable, service-supported housing for Vermonters with developmental disabilities and high support needs.
>
> Most of the changes needed to move forward will come through the development and adoption of new State System of Care Plan for Developmental Disabilities Services.
>
> The comments in this communication are focused on the proposed Developmental Disabilities Services Regulations.

As a starting point, DAIL and DDSD need to acknowledge that the State had fallen short of meeting one of the key principles of service in the Vermont Developmental Disabilities Act of 1996 – specifically the State has not met its obligation to provide meaningful choices when it comes to providing residential living situations for individuals requiring 24-hour supports.

18 V.S.A. § 8724 (Principles of service) states:

> Services provided to people with developmental disabilities and their families shall foster and adhere to the following principles:
>
> ***
>
>> (6) Meaningful choices. People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values, and needs and assure that each recipient is directly involved in decisions that affect that person's life.

Additionally, the passage of Act 186 requires the DDSD to take affirmative steps to expand housing and residential services for individuals with developmental disabilities.

In some of the materials recently produced by DDSD regarding housing arrangements, the DDSD has stated that of the roughly 1,800 people receiving Home Supports, 76% percent live in Shared Living: https://ddsd.vermont.gov/sites/ddsd/files/documents/Considerations_of_New_Housing_Options.pdf.

As has been expressed numerous times, that figure is very misleading. The 15% of people in Supervised Living have the independence skills that they do not require 24/7 supports. The 4% in Staffed Living and the 5% in Group Living generally have either significant medical needs or behavioral challenges that those 158 individuals have been unsuccessful in one or more Shared Living placements.

With some *very* limited exceptions, Shared Living is the *only* residential option for individuals who require 24/7 supports, but who do not have the medical or behavioral needs that result in Group or Staffed Living arrangements.

With those considerations in mind, turning to the proposed Developmental Disabilities Services Regulations, the DDSD is respectfully requested to consider the following:

1. **7.100.1 (Purpose and Scope)**
   See above. The purpose of the Regulations is to implement the DD Act (18 V.S.A., Chapter 204A), and not be a barrier to implementing the Act.

2. **7.100.2(v) (Definitions – Home Supports)**
   See above.

> "Home Supports" means services, supports and supervision provided for individuals in and around their residences up to 24 hours a day, seven days a week (24/7). Services include support for individuals to acquire and retain life skills and improve and maintain opportunities and experiences for individuals to be as independent as possible in their home and community. Services include maintaining health and safety and home modifications required for accessibility related to an individual's disability, including cost-effective technology that promotes safety and independence in lieu of paid direct support. Home supports must be in compliance with HCBS rules which emphasize choice, control, privacy, tenancy rights, autonomy, independence and inclusion in the community.

Currently, there really is no choice for Home Supports if an individual requires 24-hour supports.

3. 7.100.2(ff) (Definitions – Resident)

In subsection (ff)(1) a "facility" is not defined, but the Regulations should clearly permit individuals to reside in an out of state residential community (e.g., Visions in New Hampshire) in an adjoining state just as the Regulations allow for a person to remain a Vermont resident if the person lives with a Shared Living Provider in an adjoining state.

4. 7.100.4 (Recipient Criteria)

Subsection (c) cross-references 7.100.2(ff)(1). Again, if an individual is considered to maintain Vermont residency when the individual resides in an adjoining state, that individual should have that same consideration for a residential community in an adjoining state.

5. 7.100.5(j) (Choice of Provider)

Subsection (j)(1)(E) states: A recipient or family may request that an agency sub-contract with a non-agency provider to provide some or all of the authorized services; however, the decision to do so is at the discretion of the agency.

This language is currently in Subsection 4.10(a)(5) of the 2017 Regulations. This subsection should include language that makes it clear that an agency's consent to a family's request to have services provided through a subcontract with a non-agency provider must not be unreasonably withheld.

The Regulations should be clear that if an individual or family wants services provided through a non-agency provider, then the presumption should be that the agency will enter such a subcontract, and the agency's discretion not to subcontract should only be exercised in the event that there is a reasonable basis to conclude that the sub-contractor is unable to comply with the applicable programmatic requirements.

Additionally, there should be clear language that if an agency refuses to enter a contract with a non-agency provider, then the individual or Authorized Representative (e.g., parent/guardian), may appeal the refusal to subcontract to the DDSD Director.

6. **7.100.6 (Self/Family Management)**
As expressed in my October 20, 2022 email to the two of you, the prohibition on Self/Family Management of 24-hour home supports should be eliminated. That 8-hour limitation is an arbitrarily imposed barrier to creating alternative, sustainable housing options for individuals and families.

Whatever the “problematic” situations were that led to the 8-hour limitation being imposed by a memo in 2005, and then jammed into the 2011 DD Regulations over the unanimous objection of all public commenters, are not a legitimate basis to prohibit all individuals or families from managing 24-hour Home Supports.

The fact that there was a recent horrible situation of abuse and neglect in the Shared Living Provider Program (https://vtdigger.org/2022/09/13/4-caregivers-for-vulnerable-adults-charged-with-abuse-and-neglect/) does not mean the DDSD is going to ban all Shared Living Providers.

It is the DDSD’s job, and the Supportive ISO’s job, to administer the Self/Family Management Program. There is a process to terminate individuals or families from the management of services. If the individuals or families are not up to the task, then those individuals or families can have their ability to manage services taken away. It should be no different when it comes to management of 24-hour services.

Because the 8-hour Home Support limitation should finally be eliminated, and the ability to manage 24-hour Home Supports should be restored as it existed before March of 2005, then the requirement in the current 2017 Regulations, Section 5.2(m) should be reinstated (“Follow the requirements of the Housing Safety and Accessibility Review Process to ensure that the individual is living in a safe and accessible home.”).

7. **7.100.11 (Certification of Providers)**
See Comment #5 above. The language of Subsection (f)(1) (Status of non-designated providers) should mirror Subsection 7.100.5(j) and be made clear that there is a presumption that the agency will enter a subcontract with a non-designated organization, and the discretion not to subcontract with a non-designated organization will only be exercised if there is a reasonable basis to conclude that the subcontractor is unable to comply with the applicable programmatic requirements.

In short, the Regulations should encourage the expansion of housing and residential service options for individuals with developmental disabilities, and any impediments to new and creative housing options should be removed from the Regulations. This is a requirement of both the DD Act of 1996 and of Act 186.

Thank you for your consideration of these comments.

Jim Caffry

118 Graves Farm Road
Waitsfield, VT 05673

From: Katherine
To: AHS - DAIL DDSD SOCP & Regulations
Subject: Requesting changes to the System of Care Plan
Date: Tuesday, October 25, 2022 1:16:16 PM

To whom it may concern,

I am a mother of an 18 year old daughter who has a diagnosis of autism, schizophrenia, and a receptive language impairment. She currently is attending the private school, Bellcate , where she receives 1:1 support throughout the day. We are working with her DA to find suitable housing options for her, but we have not found any that are suitable, given her complex profile. I am very concerned about her future options for supported housing and ongoing services, based on what is currently available, due to the difficulties in finding/funding alternative housing options, as well as difficulties finding staff to provide home/community supports.

These are the changes that I'd like to see made to the System of Care Plan as it now stands, to reduce barriers to the creation of stable, long-term supported housing options.

1. First of all, there needs to be more housing options presented as choices, beyond SLP's. SLP settings are presented now as the only option. I was told by my DA that other options are only to be considered if a client "fails out" of multiple SLP settings. The practice of "fail out of SLP" is damaging to clients, increases client anxiety, and decreases stability and security. I understand that SLP settings work most of the time, and many clients are happy with this as a choice. However, it should not be the only choice.
2. Ensure that Family Management of 24 hour home supports can be actualized/happen.
3. Increase the number of DD individuals who can live together in the same household/address, and still receive all of their benefits and services. One option might be to allow 2 SLP's two are interested to live under the same roof and job-share 2-3 clients during a week. (job-sharing SLP responsibilities would be part of the contract). Another might be to allow 2 DD clients, who choose to live together, to live in a 2 bedroom Section 8 apartment and still receive all their benefits.
4. Change the requirements for licensing of TCR's, and make those requirements dependent on criteria other than the number individuals in the residence... it should be dependent on the levels of care needed.
5. Ensure that adequate home and community supports are available and are delivered. My daughter is supposed to get 15 hrs/week of after-school home/community supports. However, due to staffing (which we have heard for three years now), she only gets 4 hours. There should be a way to monitor at the state level whether or not clients' services, are being delivered. Also, if these are delivered by people beyond who those managing the household, it allows for "more eyes on a client," in order to help ensure

safety.

Thank you for your consideration. -Katherine Barwin

Sent from Outlook

From: Garabedian, Jennifer
To: McFadden, Clare; Bascom, June; Feddersen, Melanie; Conant, Hilary
Subject: FW: SDM and the System of Care
Date: Tuesday, September 27, 2022 6:03:23 PM
Attachments: Revisions to SOC for SDM Ver 1.5 final.pdf

Here is the feedback from the Guardianship and SDM group. We have talked a little about how this would be a group that we would be receiving input from and possibly an area that we could include a Special Initiative around.

From: Murphy, Kirsten <Kirsten.Murphy@vermont.gov>
Sent: Tuesday, September 27, 2022 11:37 AM
To: Garabedian, Jennifer <Jennifer.Garabedian@vermont.gov>
Cc: McFadden, Clare <Clare.McFadden@vermont.gov>; Rachel Seelig <rseelig@vtlegalaid.org>
Subject: SDM and the System of Care

Dear Jennifer,

Attached please find comment regarding the System of Care Plan written on behalf of the Committee on Guardianship and Supported Decision Making.

My apologies that it is late due to a miscommunication between Rachel and I. Still, I believe you have been aware to these comments.

I hope this is helpful and look forward to seeing the Division's new draft System of Care.

Best,

Kirsten
Kirsten Murphy (she/her/hers)
Executive Director
Vermont Developmental Disabilities Council
Kirsten.Murphy@Vermont.gov
OFFICE PHONE: 802-828-1312 (preferred)
CELL PHONE: 603-443-0652

Bringing Vermonters with Developmental Disabilities
Into the Heart of Vermont Communities.

Jennifer Garabedian
Director
Developmental Disabilities Services Division
Agency of Human Services

Via Electronic transmission

Dear Ms. Garabedian,

We write as a group of disability advocates both within and outside of state government who are concerned about the overuse of court-ordered guardianships in Vermont. We seek to promote alternatives, especially Supported Decision Making (SDM). Our community of practice has met monthly for more than five years. It includes representatives from the Agency of Education, the Developmental Disabilities Council, Green Mountain Self-Advocates, the Office of Public Guardian, Vermont Family Network, Vermont Legal Aide, and your division, among others.

We are concerned that the concept of Supported Decision-Making and the role of DAIL and of Designated and Specialized Services Agencies in enabling SDM is absent from the System of Care and the quality review process for developmental services. We provide recommendations below for incorporating SDM into the next System of Care Plan and the standards for quality review.

Introduction

The core principles of the Department for Disabilities, Aging, and Independent Living (DAIL) and of the Developmental Disabilities Services Division (DDSD) closely align with the founding principles of Supported Decision Making (SDM). Specifically, SDM recognizes that all people seek support when making important decisions. People with disabilities should not have their rights and autonomy regarding decision making restricted through a guardianship order. More importantly, they should have access to the same sort of assistance that people without disabilities use when making important decisions. SDM is a means of formalizing that support. Consistent with the Principles of Service outlined in Developmental Disabilities Act for Vermont,[1] SDM promotes personal and economic independence, self-determination, and flexibility. Creating an individualized plan for decision making support also reinforces the individualized, person-centered nature of support that is expected under Medicaid's rules for Home and Community-Based Services.

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[1] V.S.A. Title 18, Section 8724.

Finally, SDM takes a collaborative approach to problem-solving, which echoes the partnerships with families, communities, and providers envisioned by DAIL in its principles.[2]

While we are here focused on the Developmental Services System of Care Plan, the need to incorporate SDM as an approach to case management, direct support, and other services, should be incorporated across programs that assist Vermonters with disabilities, including disabilities associated with aging. Beneficiaries of Choices for Care, the TBI program, and CRT also need the opportunity to use supported decision making to retain their right to fully exercise their legal capacity.

Background

Supported Decision-Making is a practice that helps to ensure that a person with a disability can direct their life choices. An individual using SDM identifies a group of people who can assist them with important decisions. The individual decides what types of decisions (financial, vocational, medical, etc.) he or she wants assistance with, and which supporters will help with each type of decision. SDM may be formalized by using a written agreement and/or scheduling periodic meetings; or it may be established more informally as a verbal agreement. Many states now recognize the legal standing of SDM Agreements in statute.

SDM has grown in popularity since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (entered into force in 2008), which the United States has signed, but not ratified. The CRPD provides for the concept of Equal Recognition in that "State Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Further, it requires that state parties "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." [CRPD Article 12]. The Convention also addresses the way individuals with disabilities have been deprived of their legal right to act on their own behalf, simply because of their disability. The purpose of the Equal Recognition provision is to transform a persistent cultural and legal bias that if a person has a disability they should not be allowed to exercise their own capacity. Instead, the Convention presumes in favor of the person with a disability as their own decisionmaker: "Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise [their] legal capacity to the greatest extent possible, according ot the wishes of the individual."[3] [4]

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[2] See DAIL Mission Statement and Core Principles, https://dail.vermont.gov/DAIL-mission-and-principles

[3] "Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities," Ch. 6, available at http://www.ipu.org/PDF/publications/disabilities-e.pdf (last visited Aug. 2, 2022).

[4] Vermont's guardianship statutory scheme in Titles 14 and 18 of the Vermont Statutes does not empower courts to deprive a person with a disability of their rights to make their own decisions merely because of the existence of a disability. A court must find by the high evidentiary standard of clear and convincing evidence, that a person is

Studies of SDM specifically are limited. However, people with intellectual and developmental disabilities who exercise greater self-determination—who are "causal agents" with more control over their lives—have better life outcomes and a higher quality of life, including being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse.[5] By contrast, when denied self-determination, people can "feel helpless, hopeless, and self-critical,"[6] and experience "low self-esteem, passivity, and feelings of inadequacy and incompetency" and a "decrease in their ability to function."[7] Although not generalizable given limited number and size, professionally evaluated pilot programs have found that SDM led to positive outcomes for participants, including greater community inclusion, improved decision making skills, increased social and support networks, and increased self-confidence, happiness, and willingness to try new experiences.[8]

Despite this, there have been challenges in developing and implementing supported decision-making agreements here in Vermont. Some Designated and Special Service Agencies have been reluctant to, or have refused to, allow staff or contracted shared living providers to serve as supporters for beneficiaries of services, even when this is the stated preference of the individual. This practice runs contrary to the principles of DAIL and the DDS program.

<u>Recommendations</u>

To remedy the impact of overly broad guardianship arrangements, we propose revisions to the System of Care Plan and to the quality review mechanisms that explicitly incorporate Supported Decision Making in the following ways:

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unable to exercise the powers and duties of a guardian on their own behalf, in the specific areas of guardianship sought, prior to creating a guardianship. The statutory scheme also prohibits creation of a guardianship if a less restrictive alternative (such as supported decision making) would meet the needs of the individual.

[5] Yves Lachapelle, et al., "The Relationship Between Quality of Life and Self-Determination: An International Study," Journal of Intellectual Disability Research 49 (2005): 740–744, as quoted in National Council on Disability, "Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination" (March 2018), pg. 131.

[6] Shogren, et al., "Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities," 256–267; Schwartz and Wehmeyer, "Self-determination and Positive Adult Outcomes," 245–255, as quoted in National Council on Disability, "Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination" (March 2018), pg. 131.

[7] B.J. Winick, "The Side-Effects of Incompetency Labeling and the Implications for Mental-Health Law," Psychology, Public Policy, and Law 1 (1995): 21, as quoted in National Council on Disability, "Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination" (March 2018), pg. 131.

[8] Office of the Public Advocate, Systems Advocacy, A Journey Towards Autonomy? Supported Decision-Making in Theory and in Practice, 1–32, February 2014, as quoted in National Council on Disability, "Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination" (March 2018), pg. 131.

(1) Add a required assurance that, when requested by a beneficiary, assigned staff and contractors, including Shared Living Providers, who are paid by a Designated or Specialized Services Agency (or through the supportive ISO for self- and family-managed individuals) have the discretion to agree to serve as supporters in formal or informal supported decision-making arrangements.

(2) Amend the Section 4(I) of the System of Care Plan to include a description of the philosophy of and mechanism for creating SDM arrangements. This information may be incorporated into the existing service descriptions or broken out as a free standing section in the list of services. In either case, it is important that SDM be presented as one means of assisting beneficiaries under existing billing codes. For example, if a case manager has agreed to be a supporter as part of an SDM arrangement, then the time spent assisting that individual with decisions is part of, and therefore billed as, case management services.

(3) Embed a quantitative and qualitative assessment of the implementation of SDM arrangements in existing quality reviews. Metrics should include the percentage of beneficiaries with SDM arrangements within and outside of guardianship, consumer satisfaction with the implementation of these arrangements, and an analysis of overall consumer satisfaction that compares individuals with and without SDM in terms of self-determination, personal and economic independence, and person-centeredness.

Thank you for considering these recommendations. If you have questions, please direct them to Rachel Seelig at the Disability Law Project and/or Kirsten Murphy at the Vermont Developmental Disabilities Council.

Yours Sincerely,

Kirsten Murphy
Vermont Developmental Disabilities Council
On behalf of the Committee

Rachel Seelig, Esq.
Disability Law Project, VT Legal Aid
On behalf of the Committee

cc. Commissioner Monica White

Enc. Committee Membership

Committee Regarding Guardianship and Supported Decision-Making

Association of Vermont Special Education Adm.	Darren McIntyre
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Member at large, evaluator	Kim Allshouse
Vermont Agency of Education	John Spinney
Vermont Developmental Disabilities Council	Susan Aranoff Kirsten Murphy
Vermont Family Network	Jamie Rainville

From: j.e.townley1@gmail.com
To: AHS - DAIL DDSD SOCP & Regulations
Subject: SSOCP - Additional Input
Date: Friday, September 16, 2022 10:52:46 AM

Thank you for seeking stakeholder input. A change that I believe is critical to the SOCP and services is for DAIL/DDS to recognize the spectrum of Fetal Alcohol Disorders as a Developmental Disability (like the Federal government does) and services should be available to those that are impacted by this diagnosis. By not including this in the definition of Developmental Disabilities and not providing services / supports to assist, I am aware of many young adults that have transitioned out of high school that have gone off the cliff and are homeless, dealing with significant mental health issues/crises, self-medicating, unemployed, have the potential for committing crimes, and unable to function at a level capable of moving their lives forward in a positive direction. Scaffolding is still needed at 18 and for many years ahead. I strongly suspect that if more services / supports were available in a proactive manner (vs. reactive manner) to those on the fetal alcohol spectrum, there would be improved positive outcomes and a decrease in some of the social-economic issues being experienced today.

Thanks.
-Jenn
