



JOHN SNOW, INC.
Promoting and Improving Health

Green Mountain Care Board

Vermont SIM State-Led Evaluation Focus Group Report

**Vermont Health Care Innovation Project State-led
Evaluation**

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Introduction

Between fall 2016 and spring 2017, five focus groups were conducted with individuals who receive care coordination services in geographically distinct areas of the state to gain insight to consumer experiences with these services and the best practices which support consumer driven care.

Care coordination, as defined by the Agency for Healthcare Quality and Improvement, “involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care. This means that the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and that this information is used to provide safe, appropriate, and effective care to the patient.”¹ Care coordination is recognized as instrumental for possibly improving the effectiveness, efficiency and safety of the healthcare system—three of the six domains that constitute healthcare quality.¹ Thus, to aid in the examination of care coordination and facilitate subsequent analysis of qualitative data, focus groups questions were structured to explore care coordination as it relates to four of the six healthcare quality domains. The four domains include:

- Effectiveness in improving access to and coordination with multiple healthcare and social service providers
- Patient centeredness (provider communication and consumer engagement)
- Timeliness (obtaining the appropriate care when it is needed)
- Equity (receiving health care of equal quality to those who may differ in personal characteristics other than their clinical condition or preferences for care).

The remaining two domains, safety and efficiency, were not specifically explored in the focus groups however participants did touch upon these domains in the discussion.

Priority populations identified for this research were those who would most benefit from care coordination services. Populations included:

- *Individuals dually eligible for Medicaid and Medicare.* This population includes individuals with disabilities and individuals 65 and over.
- *Adults and older adults enrolled in care coordination.*
- *Families receiving care coordination through Integrated Family Services (IFS).*

¹ Agency for Healthcare Research and Quality. <https://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/index.html>

Methodology

Organizations providing care coordination, case management and/or advocacy services to the priority populations in each of the five regions of the state were approached by JSI staff to gauge their interest in assisting in the research project. Only one organization (in Washington County) declined the opportunity due to the extreme vulnerability of the population. The remaining five organizations worked closely with JSI to review and tailor the focus group moderator’s guide to the specific population ensuring that the questions reflected the scope of services consumers received (see Appendix for Focus Group Moderator Guide). Organization staff also assisted in tailoring the recruitment letter (see Appendix for Recruitment Letter). Recruitment letters included a description of the focus group, its purpose and stipend amount (\$50 cash) as well as the contact information for the JSI staff to address any questions or concerns. Staff disseminated the letter directly to eligible clients and assisted in reminding clients of the date and time of the focus group.

A total of five focus groups were convened with an average of ten participants attending each group (see Figure #). Focus groups lasted approximately 90 minutes with breakfast/lunch provided as well as a \$50 cash stipend per participant. A care coordinator/case manager or advocate was present at all but one of the focus groups. The presence of this individual helped to reassure participants that it was a safe environment. These staff also assisted in answering questions raised by clients during the focus group discussion about services as well as providing examples to clients when there was confusion about a question being posed to them.

Table 1: Focus Group Profiles

Region	Organization/Site	Population	No. of Participants	Service Delivery Model
Addison	Counseling Services of Addison County	Families who receive care coordination via IFS	12	Case Management
Caledonia	Community Connections of Northeastern Vermont Regional Hospital	People with chronic conditions	10	Care Coordination
Chittenden	Cathedral Square: Healthy Homes, Caring Communities, Positive Aging	Dually eligible for Medicaid and Medicare	10	Residential Care Coordination
Rutland	Vermont Center for Independent Living	Individuals with disabilities	9	Advocacy
Windsor	Senior Solutions – Council on Aging for Southeastern Vermont	Individuals 60 years of age and older	10	Case Management

Findings

Service Delivery Models by Agency

The service delivery models implemented by each agency have several features in common. Variations in the service delivery model are most likely a result of the population the agency serves as it tailors services to the population's unique needs and the agency's affiliation in the community (e.g., Community Connections is affiliated with its regional hospital).

- **Senior Solutions (Case Management):** Senior Solutions, Council on Aging for Southeastern Vermont, provides case management through the Medicaid-funded, long-term care program, Choices for Care, which pays for care and support for older Vermonters and people with physical disabilities who are eligible for nursing home level of care.^{2,3} The program assists people with everyday activities at home, in an enhanced residential care setting, or in a nursing facility.³ Support includes hands-on assistance with eating, bathing, toilet use, dressing, and transferring from bed to chair; assistance with tasks such as meal preparation, household chores, and medication management and increasing or maintaining independence. Other services may include Adult Day, financial support for assistive devices, respite, and Emergency Lifeline. For individuals who need minimal assistance to remain at home, the Choices for Care Moderate Needs program offers the aforementioned support services as well as limited case management.

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Case management via Senior Solutions consists primarily of assessments and development of a consumer driven care plan. Case managers work closely with the consumer/surrogate (i.e., employer) responding to each consumer's unique needs. As a result, some case managers are more involved in the lives of consumers than others yet all case managers share the overarching goal of empowering clients to direct their own care if not themselves then by their surrogate. To ensure that the changing needs of the consumer are met, case managers meet with consumers on a monthly basis, however additional ad hoc meetings also take place.

- **Community Connections (Care Coordination).** Community Connections of Northeastern Vermont Regional Hospital has a team of Community Health Workers (CHW) who provide care coordination activities. The CHW team work closely with clients to determine the needed supports and services and then link clients to the appropriate community-based agencies and State agency district offices that can provide financial and other tangible resources such as vouchers for heating and transportation assistance.⁴ The CHW team's unique familiarity with area agencies and organizations facilitates this process.⁵ The CHWs can also provide support for

² <http://www.seniorsolutionsvt.org/services/>

³ <http://www.ddas.vermont.gov/ddas-programs/programs-cfc/programs-cfc-default-page#programs>

⁴ ICF International. The St. Johnsbury Community Health Team Evaluation: Final Report. February 28, 2014

⁵ Community Connections. <https://nvrh.org/community-connections>

people with chronic conditions by reinforcing treatment plans from their primary care office or other health care professionals as well as assistance with finding safe, affordable ways to be more physically active and/or finding and preparing affordable healthy foods.⁵ The Community Connections Team is managed by the Care Integration Coordinator to promote integration with the larger St. Johnsbury Community Health Team.⁴

- **The Vermont Center for Independent Living (Advocacy).** The Vermont Center for Independent Living works to promote the dignity, independence, and civil rights of Vermonters with disabilities.⁶ Like other independent living centers across the country, VCIL is committed to cross-disability services, the promotion of active citizenship, and working with others to create services that support self-determination and full participation in community life.⁶
- **Counseling Services of Addison County (Case Management/Integrated Family Services).** Counseling Services of Addison County (CSAC) Youth and Family Services provides therapy, community supports and case management to youth, children and their families in school, office, home and community-based settings.⁷ Substance abuse treatment and adventure-based programs are offered along with a youth employment program, a school-based intensive support program, and an educational treatment program for young people struggling with emotional disorders.⁷ Partnerships with local agencies help to provide mental health services to youth of transition age (16 – 22) and to pre-school age children.⁷ Case managers often work as a team with parents and caregivers, primary care doctors and specialists as well as schools and other agencies to develop coordinated service plans to help to make services more effective.⁷ CSAC is one of the agencies piloting the **Integrating Family Services (IFS)** approach. IFS provides flexible funding which allows service providers to meet family needs, enabling families to access supports and services based on need rather than program eligibility criteria.⁸ State partners shift their focus from counting clients and service units to measuring the impact of those services.⁸
- **Cathedral Square Independent Living (Care Coordination/Support and Services At Home).**⁹ Cathedral Square Corporation offers affordable, service-enriched housing communities for seniors and individuals with special needs.⁹ Cathedral Square's Support and Services At Home (SASH) is designed to provide personalized coordinated care to help adult participants stay safely at home regardless of their age or residential setting.⁹ SASH, part of the Blueprint for Health, helps Vermont's most vulnerable citizens, seniors and individuals with special needs, access the care and support they need to stay healthy while living comfortably and safely at home.⁹ SASH is available in many communities throughout Vermont and primarily serves persons 65 and older and persons with disabilities. Participation is voluntary and free of charge.⁹

⁶ Vermont Center for Independent Living. <http://www.vcil.org/about>

⁷ Counseling Services of Addison County. <http://www.csac-vt.org/>

⁸ Integrating Family Services. <http://humanservices.vermont.gov/Integrating-Family-Services>

⁹ <https://cathedralsquare.org/housing/>

SASH communities include a care coordinator and wellness nurse who work in partnership with a team of community providers to assist SASH participants.⁹

Service Delivery Models and Quality Domains

All of the above service delivery models reflect aspects of the four quality domains of patient centeredness, effectiveness in improving access to and coordination with other providers, timeliness and equity of care. Because these service delivery models are in community or residential settings the issues shared by focus group participants largely revolved around social issues such as food, housing and transportation and access to the services that would meet these needs.

Patient Centeredness¹⁰ (*provider communication and consumer engagement*)

What is evident across all agencies and populations is that patient centered care is about team work with the team consisting of providers, care coordinators/case managers and the patient. Across all agencies the care coordinators/case managers and advocates encourage patients (consumers) to be active in their care and participate in some of the team's work. VCIL's commitment to the promotion of active citizenship and working with others to create services that support self-determination and full participation in community life is very much in keeping with the concept of patients being active participants of a care team. One VCIL focus group participant shared her story of an abusive care giver and another shared a story of an abusive landlord. In both situations, the VCIL advocate worked closely with the individuals, educating them on their rights, supporting them through a process to issue formal complaints and as a result both individuals were empowered, and now feel they have a voice when it comes to their own care. One focus group participant stated, *"They [the advocates] allow you to help yourself."*

To facilitate and ensure that patients receive patient centered care, the Director of Community Connections has physicians conduct some home visits. She believes these visits increase provider awareness and understanding of the issues the population encounters daily. This understanding also facilitates increasing access to nontraditional services as the physicians need to "sign off"/provide documentation for the necessity of services such as a pass to the swimming pool or an air conditioner. Physician home visits were unique to Community Connections yet all staff providing care coordination, case management or advocacy work to ensure that among health care providers there is a level of understanding of the patient's context—of the social determinants that are impacting their lives. Thus the job of care coordinators/case managers and advocates is to ensure that providers and patients share a mutual understanding of the issues patients/consumers are challenged by that impact their overall

¹⁰ Throughout the focus group process patient centeredness was a term most commonly used however people also used patient-centered care, client-centered care, consumer-centered care, patient-directed care, client-directed care and consumer-directed care. Particular attention was given to using language that focus group participants preferred. For the purpose of the report we've chosen to use patient-centered care to represent the variety of terms used.

health and agree upon possible solutions. One Community Connections focus group participant commented, *“It’s nice to have a community who understands you and willing to work with you and connect you with services.”*

CSAC’s approach to ensuring patient centered care is through a concept called “effective teaming”. CSAC believes that teams benefit from a strong family voice and their contribution to the development of a care plan. CSAC case managers spend a great deal of time facilitating communication among the multiple providers that families have and to help families access various services. One focus group participant shared, *“One thing I found is that when we got our [IFS] case manager it got better. Before then it was really confusing but when things shifted to one person it was a lot less confusing”* Another focus group participant stated, *“Definitely relief that we were not on our own and we had experienced being on our own and this way we felt more connected and that we had options and we could run ideas by.”* And another stated, *“My [case manager] puts the pieces together.”*

Effectiveness in improving access to and coordination

Participants discussed that their care coordinators/case managers not only improved access to and coordination with services, they were also effective at assessing and identifying needs that the participants themselves were not aware of. A focus group participant commented, *“I cannot say enough about my case manager—she is wonderful. She establishes things that I could never have dreamed of and always has a positive result.”*

Sometimes individuals may be connected to services but the connection ends because their circumstances change. One focus group participant shared their experience transitioning from when they were in the hospital back to the community, *“The hospital gives you a case worker but we never heard from them. Once you leave the hospital the help stops. They are not responsive. It is hard to figure these things out by yourself.”* Another focus group participant commented, *“Before [the case manager] it was a series of waiting lists. My children were on six waiting lists in three different counties just to receive services.”* Another focus group participant was engaged in care however was not a fully informed consumer. The individual shared, *“I met the SASH nurse through checking my blood pressure. She looked at my medications and noticed something strange and suggested that I check with my doctor. She went through all my meds and told me what each medication is for. They know more about what the total picture is than I do and they think of questions that I might not have to help me. They help you find the answers to questions.”* Another participant stated, *“The SASH nurse does talk directly to the doctors to help clarify. The SASH nurses help to guide you through the channels to get something.”*

Many needs extended beyond primary care to those that enable focus group participants to live safely and to engage in the community in at large. For example, ensuring access to exercise for one participant with congestive heart failure; or, ensuring access to fresh and free produce (the Care Coordinator would schedule the participant’s physical therapy appointments on the same day the hospital would give out fresh vegetables). One resounding theme across all focus groups was that an unmet need always confronted each participant, such as, food, housing and transportation. Sometimes the unmet need was

less perceptible but still would impede access to services. One participant shared, *“I’m anxious about making the phone calls and [care coordinator] helped me make the phone calls but now I can make them.”*

Timeliness (*obtaining the appropriate care when it is needed*)

The type of services focus group participants accessed ranged from clinical care (accessing a psychiatrist) to very basic needs such as food and housing or completing paperwork. One participant shared her experience living in a house with significant mold which was then “half-gutted” house for more than five years. Community Connections assisted the individual on many levels from mediation to finding new housing including rent, transportation, and a swimming pool pass. Safe and affordable housing as well as transportation was a predominant issue and while not easily resolved in a timely manner (subsidized housing, for example, often has a long waiting list) focus group participants expressed significant relief knowing that they had someone who could assist them in resolving these issues. A Senior Solutions focus group participant commented, *“It doesn’t matter what the issue is she is always there whenever we need her. She always calls back; very friendly. If we have a question, she calls whomever she needs to and finds the answer. It has been really helpful.”*

Equity (*receiving health care of equal quality to those who may differ in personal characteristics other than their clinical condition or preferences for care*).

The desire not to be “categorized” by the health care system was a strong theme that ran throughout one focus group. Focus group participants felt that the process of being “categorized” led to not always receiving the care and services they need. One focus group participant commented, *“We are not all the same”* and continued to share that once they found Community Connections they felt a tremendous amount of *“relief, gratitude and surprise”* because their Care Coordinator worked collaboratively with them as unique individuals. One participant commented, *“When I found [care coordinator], he thought outside of the box.”* Another participant shared, *“I was a little reluctant because I did not want to be judged. It was nice to have the support when you are new in the community...”*

A Burlington focus group participant commented about his SASH coordinator, *“Really anything that an older person might be interested in to have a happy healthy living experience they try to make sure those types of events are available. There are constantly new things coming up. Food and diet in particular.”*

Discussion

While the overall analysis of focus group themes demonstrates adherence to the four health care quality domains discussed in the introduction, there are important insights regarding future care coordination activities as health care reform progresses. Primarily this section discusses and emphasizes the expansion of care coordination training opportunities to include a broader array of health care and community based organizations; engaging new partners and incentivizing their participation in care coordination; and using data to improve care coordination activities.

Team oriented approaches are central to the reasons why consumers rated their care coordination and care coordinator highly. As discussed, the inclusion of consumers and promoting their participation in care is an important success factor. When patients/consumers are active participants of the care team, their care and their experience with the care is more positive, appropriate and timely. Focus group participants also underscored the importance of their participation in the community and care coordination efforts to assist them in being engaged in their community. Beyond community based programming focused on health care and self-management we know that engagement in the community decreases isolation, improves mood and outlook and has an overall positive impact on an individual's health. As care coordination activities continue to mature, consideration for all aspects of individual health and wellness such as community engagement should be given. Future trainings and capacity building activities can incorporate community engagement as a priority activity as well as include non-traditional partners with which care coordinators might collaborate in trainings.

Isolation is one of many social determinants which are a predominant issue experienced by all focus group participants and negatively impact their overall health and well-being. Care coordinators, case managers and advocates do their best to mitigate these issues by increasing provider awareness of social determinants via provider education (i.e., communication), arranging for provider home visits, and working with consumers to increase self-advocacy skills. Care coordinators are also aware of the community supports and services to address social determinants and work to facilitate access to these resources. Expanded work in this area under health care reform may require inclusion of a broader array of community based organizations that may assist in addressing social determinants, as discussed in previous paragraph, as well as ongoing exploration of how to incentivize community based organization participation.

Care coordinators, case managers and advocates increase access to and utilization of appropriate care and support services yet consumers and their care coordinators still struggle with certain parts of the health care system. While care coordination has been able to overcome many obstacles, more work to engage specialists and to improve transitions between care settings will need to be done. Data systems that have supported current care coordination systems do not necessarily address the need to communicate and exchange information outside of the primary care setting. In some communities' primary care, hospitals and specialists operate on different EHRs and do not have interfaces to share information. Similarly, community based organizations do not have EHRs yet have important information that is not readily available to be shared with care coordinators and others in the health care system. Data solutions that cut across all members of care teams will need further exploration.

Appendix: Sample Focus Group Guide

CARE COORDINATION CONSUMER FOCUS GROUP FACILITATOR'S GUIDE

- I. Introductions/Role of JSI (2 minutes)
- II. Purpose of the focus group, what to expect & use of tape recorder (4 minutes)
- III. Compensation (2 minutes)
- IV. Ground Rules (confidentiality, respect, etc.) (2 minutes)
- V. Questions (70 minutes)
- VI. Wrap-Up (10 minutes)

Good [morning/afternoon/evening]! Thank you for meeting with us today to talk about your experiences with some of the services you may receive when visiting your doctor's office. My name is Naomi Clemmons and I will be facilitating this [morning's/afternoon's/evening's] discussion. The reason why we are having these discussions with individuals like you is that we are looking for ways to improve families' experiences receiving different types of supportive services. The State of Vermont wants to better understand what your experiences are with the case management services that you receive from CSAC?

The more we can learn about the answers to these questions the more we can do to make sure that the services, resources and programs available in communities really are meeting individuals' and families' needs. To thank you for the time that you are spending with us today, we are providing you each with \$50 cash. At the end of our discussion, we will ask you to complete some brief paper work and at that time you will receive your \$50.

Today, I am going to ask a few questions that I'd like you to respond to and for us to discuss. I would like to record the conversation to accurately capture what you are saying. However, if any of you do not feel comfortable having the tape recorder on, please let me know and we will not use it.

We hope you feel comfortable saying whatever you think or feel and we want to make sure that everyone who wants to say something gets a chance to talk today. So, we ask that you respect what others are saying; take turns talking; and, what is said in this room stays in the room— in other words, what is said needs to be kept confidential.

We also want to make sure we get a chance to ask all of our questions. So, there may be times during our discussion that I may have to move on to the next question. Please don't be offended if this happens! If at the end we still have time, we can follow up on some of the ideas that we were not able to spend more time discussing.

Once we've conducted all of the discussion groups we will develop a report that describes what improvements could be made to the current programs and services available in your community; what

programs or services should be added; or, how could things be changed to make it easier for people to get the information or services that they need.

Before we begin, do you have any questions?

Now, when I turn on the tape recorder, I am going to ask if there are any objections to this session being recorded. If you do not want this session recorded let me know and we will turn it off. OK, let's begin!

The questions I have for you this [morning/afternoon/evening] are going to focus on the case management services you receive from CSAC. In general, case management involves organizing a families' care and the services and supports that they may need and sharing information among all of the human service and health care providers that may be involved. Sometimes case management involves someone helping you make an appointment with a school staff, specialists or with a service in your community. It can also involve making sure you are getting the information that you need about the care, services and/or support that you need.

I. Family Engagement

1. Describe how you first learned that there is a clinician working with you and who would help you coordinate care, services, information and/or behavior planning?
 - a. *Did you know if there were people who could help you with getting services?*
 - b. *When you learned about how this person could help you, what did you think?*

2. How did the Intake coordinator/CSAC staff person on the phone explain/describe the type of support and services that they could provide to you?
 - a. *Were you confused at any point along the way about how the clinician was going to help you?*
 - b. *What were you most excited about?*
 - c. *What were some things that were unclear?*

3. Thinking back on a time when you were first referred to CSAC for services from a doctor or social service or community program, can you describe how the intake coordinator or CSAC staff person helped you?
 - a. *How did they help guide you through the process of getting services and support? Was it easy?*

- b. *What type of services did you access?*
 - c. *Did you still have unmet needs or questions? If yes, how did you get the help that you needed?*
4. What were/are your initial thoughts/feelings about the kind of help this person provides?

III. Effective communication

5. Sometimes people find it difficult to talk to their doctor, schools, DCF or other providers that they see. And, sometimes people find it difficult to understand what their school, doctor or DCF is saying. In these situations the case manager can help.
- a. *Thinking about your communications with your doctors, school staff, DCF staff or other providers, what about it is working well?*
 - b. *What is hard about the communication?*
 - c. *Have you ever asked the case manager to help you with communicating with your doctor, school staff, DCF staff or other service providers? If so, can you describe how they helped?*
 - d. *Can you describe what gets in the way of good communication that you have experienced?*
 - e. *Does the case manager help to address these problems? If yes, how?*
- a. *What suggestions do you have to improve communication with your clinician or other service providers?*
 - b. *Does the case management help you with coordination and team meetings with all of the different types of providers (including social service providers) involved in your care? If so, how?*
 - c. *What are your suggestions to improve the teaming processes between the different people who provide you services like school staff, DCF staff, doctors and other providers?*

That ends our discussion! Does anyone have anything else they would like to share? Thank you for your time!



What does Service Coordination mean to YOU?!

The Green Mountain Care Board is working on reducing the rate of health care cost growth in Vermont while making sure that the people still get high quality care. They are interested in learning about your experience with services that help you get the services that you need. We invite your participation to a focus group discussion being organized in your local area.

Here is some information about the focus group:

What is a focus group?

A focus group is a planned discussion with a group of people about a specific topic. The group is made up of between 8-10 people and is led by a *moderator* or *facilitator*. The discussion is guided by a set of questions which everyone in the group will have the opportunity to answer.

What is the purpose of this focus group?

We are interested in learning about families' experience with services that may help them get care at home, in school and in the community. We are also interested in learning about what parents think about these services – what have been the benefits as well as set-backs. The information provided will help to make care coordination services better in Vermont.

