



## Stakeholders' Perspective on Autistic Healthcare Transition from Youth to Adult Services in Vermont

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## Introduction

Vermont Family Network hears regularly from families and caregivers with autistic loved ones, and autistics themselves, about how difficult it is to find a provider that meets their health care needs. These are difficult stories to hear when there are limited resources to share with families. This is why we were enthusiastic partners in this project that worked diligently to engage multi-stakeholders including providers, community organizations, autistics, and family members. Many of the autistics who participated were of transition age themselves. Hearing from those with lived experiences brings powerful focus to the gaps in healthcare for autistics across the lifespan. Our hope is that the insights and recommendations presented in this summary provide concrete steps to close the gaps in healthcare access for so many vulnerable Vermonters.

Marie Fetterhoff  
Family Support Consultant  
Vermont Family Network

It's been increasingly difficult to access medical care for my 20-year-old son who was diagnosed with autistic disorder (now ASD level 3) at age 3. He has significant communication challenges and high levels of anxiety which leave him with little tolerance for any invasive medical procedure. It sometimes feels like he's being "written off" by the medical community... Nobody really seems to know what to do with him or how to help him. I'm excited to be part of the UVM Autism Collaborative. The Healthcare Transition project follows in the footsteps of the [Inclusive Healthcare Partnership Project](#), identifying similar priorities but from a research point of view. I feel optimistic that these efforts will lead to concrete actions towards achieving higher quality, more accessible healthcare for my son and other young people like him with complex healthcare needs.

Jennifer Lagro  
Co-chair UVM Autism Collaborative

## Table of contents

Introduction	2
Executive Summary	4
Important topics for healthcare transition research	5
Training for providers	6
Accessibility of healthcare	7
Individualized transition planning and supports	8
Autism-informed mental health support	9
Starting early to prepare for adulthood	10
Inclusion in communities of interest	12
Building trust with healthcare providers	13
Healthcare system supports for transition	14
Measuring important research outcomes	15
Opportunities and allies	16
Stakeholders engaged in the project	19
References	22
Acknowledgements	23

## Executive summary

Pediatric to adult healthcare transition has been identified as a national and local priority.<sup>1,2</sup> For autistic\* youth, there are many challenges associated with healthcare transition. In Vermont, like in the rest of the country, transition services are rarely available. Autistic adults and families are clear that there is a high need for supports.<sup>2-4</sup>

The UVM Autism Collaborative (UVM-AC) is a group of autistic and non-autistic research partners. We conducted this project to talk with more autistic and non-autistic community members representing different stakeholders: youth, caregivers, professionals and healthcare leaders about healthcare transition. We wanted to hear their ideas on the research needed to improve healthcare transition for autistic youth. We also wanted to meet champions and future research partners.

Healthcare transition is complex. Our stakeholders shared with us a road map to start addressing these healthcare transition challenges.

In this report, you will find:

- The 8 important research topics that future healthcare transition research should address.
- Outcomes to measure to make sure future research efforts are having an impact.
- Ideas for collaborations to get this work done.

Liliane Savard

Co-chair UVM Autism Collaborative  
Healthcare Transition project Co-leader

\*Note: We are using identity-first language in place of person-first language, as this is the preference of our team and Board members.

## Important topics for healthcare transition research

During a first series of focus groups and during individual interviews we talked about [5 research articles](#) and their models for healthcare transition.

Some of the guiding questions were:

- How do these models compare with your experience in Vermont?
- Which models or aspects of these models would be applicable to Vermont?

### **Vermont stakeholders identified 8 important research topics for healthcare transition research:**

1. Training for providers
2. Accessibility of healthcare
3. Individualized transition planning and supports
4. Autism-informed mental health support
5. Starting early to prepare and empower autistic children for adulthood
6. Inclusion in communities of interest
7. Building trust with healthcare providers
8. Healthcare system supports for transition

For information on how we came to these results visit the [method page](#) on the project website.

One interesting finding was that the important research topics were similar across the focus group discussions and the interviews. They were also similar between autistic and non-autistic participants.

Each of these topics are discussed below with quotes from participants in our focus groups.

1. Training in autism is necessary for healthcare providers and staff, including mental health providers. Not enough time is spent on autism during medical school. Participants noted many topics to be included in training, such as:

- Support needs and the unique challenges of autism
- Conditions that co-occur with autism
- Gender-affirming care in the context of autism
- Early autism diagnosis
- Diagnosis in gender and age diverse populations
- Identification of autistic traits in those who choose not to disclose or do not know they might be Autistic
- Healthcare transition framework to support transition to adult care from pediatrics

One autistic youth described some of the training issues he has experienced:

"Because the people working for such a thing [healthcare] have not gone through the study of those on spectrum [or have] learn[ed] how to teach them [autistics] these skills in the right way to make sure their minds can keep up with the lesson that they're trying to teach . . . forcing me to believe I need to be self-taught rather than taught by a professional."

A parent shared their concerns on training needs:

It's the training too, for people that are providing the care. How do we get that to the folks so it becomes more automatic, not a freeze-in-place situation, and they don't know what to do with your individual with these complex needs.

A physician added their perspective on training:

"I know I don't have too many patients who are like autistic, but I do have a few that I've met with and I mean, I have education from school, but I have no further training outside of just didactic work."

2. Accessibility of care is important. This includes available trained providers, accommodations, and being able to find providers and resources.

Examples of accommodations noted include:

- Telehealth
- Visual supports
- Environmental changes to address sensory sensitivities
- Limiting waiting time
- Plain language

An autistic adult described important aspects of accessibility that were missing from her experience:

"I agree with [...] having as much predictability is ideal and opportunity for easily accessible written communication with health care provider[s] instead of having to jump through hoops to get answers, like my process of being diagnosed."

Another autistic youth described her need for being heard. Lack of accessibility resulted in her avoiding going to her doctor:



"I feel like they don't totally listen or like I feel like I'm not taken seriously when I talk about like concerns, so I really just try to go to the doctor as little as possible, because it can definitely be an issue. And then a lot of doctors sometimes like put things as oh, it's because of a mental illness. It's like, No, no, it's not so. It definitely can be hard feeling like they're not fully getting what I'm saying."

A parent shared her experience with lack of sensory accessibility in healthcare:

"And once you move into adult care, especially if you're raising a male, you really lose any sensitivity to the challenges that this individual is having moving through all of the sensory overload that they already have on top of the pain that they're experiencing, and they present differently, because they get into that fight or flight mode, and it's really hard to calm the panic down."

3. Use an individualized, wrap-around approach with a transition framework. Includes the autistic youth in making their transition plan.

This transition plan would include healthcare, mental health, education, employment, and community connection services/resources. Important parts of the transition plan include:

- Someone serving in a role of transition coordinator or supporter
- A warm hand-off to the new provider
- Help understanding how insurance and medical billing works
- Partnering with schools, designated agencies, and community organizations.



A parent talked about her experience compared to transition support mentioned in the articles reviewed for the discussion:

"But, just there's so much stuff, and I just, I don't know anybody else's experience, any of it. But I, there's so much good stuff that could happen, and pre-planning, and I just haven't seen any of it."

One professional offered her view on the benefit of a transition manager:

"I think that there might be a role for something like a transition manager. But I'm not sure if situating it in just health care would be the best choice."

4. All autistic youth and adults should have universal access to mental health support by autism-trained providers.

- Mental health care is also important for parents/caregivers.
- The parent-child relationship changes during the time of transition to adulthood requiring additional mental health support.

An autistic adult talked about the importance of specialized mental health supports:

"Access to different kinds of mental health services is sorely needed. Too often the only option on state insurance is CBT, which isn't the most helpful for a lot of types [of] neurodivergence. We need access to specialized care for the many conditions that are often comorbid with autism, like OCD."

An autistic youth described their need for mental health support:

"I have had both negative and positive experiences [with mental health therapists]. And I do need a therapist to manage some of my issues, because I do not wish to trauma dump here, but I have been through some intense past experiences which I cannot process on my [own] or I prefer to process with someone else to talk to and filter through."

A mother described difficulties in finding a mental health provider who was comfortable working with an autistic youth:

"But we had a whole string of counselors, social workers who really didn't know how to interact with her or help her, and [they] tell me that they didn't know anything about autism. Some providers didn't want to see her when they heard that she had an autism diagnosis, and others just had no idea how to approach her."

5. Preparing Autistics for adult healthcare should start as early as kindergarten. The autistic youth should be empowered in their autistic identity, disability rights, and making their own decisions.

- Autistics need to develop skills to take care of their healthcare needs.
- Education should include developing relationships, and understanding sexual health:
  - Sexual health information should come from a source other than parents/caregivers.
  - Social, mental, and physical health aspects of adult relationships should be addressed.
  - Social safety and the prevention of relationship trauma is important.

One autistic youth described what he would like to see early on in health classes:

"So, sharing my opinion on how sex should be discussed. I am a sexually active trans gay man . . . I think that they should really talk about [it] in health class like how different relationships work safely with different contraception as well as just you know safety with actions and relationships... talking to other people and communicating openly about sexual, nonsexual [behavior]... I don't think that being quiet about it, or hush, hush about it, or only talking about it with your parents and your very special teachers. I don't think that's smart or healthy."

A professional explained how empowering autistic children to make decisions should start early:

"Transition starts at preschool. Transition starts with a paradigm of how do I empower my patient to learn about their brain, to learn about their access needs, to learn about self advocacy skills."

A professional and disability advocate talked about the importance of knowing your identity to advocate for your rights for reasonable accommodations:

"We have that discussion about how we have to [help] our children to know who they are, because disability is part of our identity. Nobody can take that out from us, and the more we embrace it that we have it, the more we can move forward because it's just one step you see. I have a disability. And that's part of me, it's just 1%. As I always say, the 99% has to be what's developed by you yourself. [...] we draw from having what we call reasonable accommodation because that is how the ADA [American with Disability Act] defines it. And then that makes you qualify to actually have all the services."

6. Increase opportunities for both inclusive and autism-specific community engagement for Autistics.

- There is a need to increase understanding and visibility of autism across other identities: BIPOC (Black, Indigenous, and People of Color), disability, neurodiversity, and LGBTQ+ (Lesbian, Gay, Bisexual, Trans, Queer and more) communities.

An autistic youth shared their desire for connection:

“... just have like a way to get people together and socializing with people similar to them in a way that's like really accommodating towards other people's needs because everybody's needs aren't the same . . .because I know I've struggled personally with finding and making friends, especially because I'm online school and Vermont is just not a place with a bunch of different things like that.”

An autistic adult described opportunities for creating inclusive communities:

“I think we really need to tap into groups like Outright and the local Pride organizations. They have special groups for transgender people. They have special groups for gay men. They have special groups for other subculture parts of the LGBTQ community. And I think that it will be a really positive thing if these organizations actually catered also to the autistic community as a part of the subculture, because we're six times more likely to be a part of that community than the neurotypical population.”

A mother described an additional benefit of promoting inclusive communities:

“The other thing is, our kids help educate their community if they're included.”

7. Developing a trusting relationship with providers is essential. It takes time. Autistics want to feel like their provider cares about and understands them.

- Beginning the transfer of care early or to a family practitioner would help develop a relationship by the time youth become adults.
- Options to build initial relationships could include telehealth, home visits, open houses, or co-visits with their pediatrician.

One autistic youth described his approach to building a relationship with his healthcare provider:

“One idea I have right now is to start off by having a long-distance conversation with the doctor until you feel more comfortable around them. . . I would prefer to be seen from a long-distance video chat. And then, and once you've gotten to know that person a little, well get to know them in person: before reaching out to your more medical and mental needs like basically take it like one saying, I have, take it like I haven't used this one in a really long time. But like on some, on rare occasions I used, like to say, take it as slow as a sloth.”

An autistic mental health professional shared about lack of trust and the need to feel safe:

“I know that there is a requirement in order to have your first visit for you to transfer your records to a new provider so they have every bit of information they can possibly see about you before they meet you. And that's a role for so many practices right now. We need to be able to know if it's a good fit or if it's going to be a safe space. And we have a lot of private information about ourselves. Doctors, they don't get to have that because they want to.”

8. The healthcare and support service structure does not support providers and patients in meeting their healthcare and mental health needs.

- Lack of a support service structure affects healthcare transition.
- Complex insurance issues and payment structure are barriers to access care and to collaboration for healthcare transition.
- Care coordination has been identified as an important priority for funding.

A parent of an autistic adult, and a community-based professional, described the barriers to healthcare:

"I was thinking about how most providers don't understand the way we bill for health care in the United States. But when you make your appointment it's like you get this approximately 10 to 15 min window . . . You know, as someone who is neurotypical that's not enough time for me to give like the context and the detail to my physician about what I'm experiencing, what are potential solutions and having a dialogue with my physician. And so, if I imagine, my son, as an adult going into those conversations and knowing that he's very detailed-oriented, and he wants to give it a whole context. I think one of the key things to think about is [the] idea of the longer appointment times and making sure physicians are positioned in the healthcare billing system for that, because it is meeting the patient's needs by giving them an extended window of time."

An autistic adult described the need for insurance to cover mental health:

"... I mean health insurance is a whole other beast. But I think, making sure that it's clear that, especially for autistic people, mental health is as essential, mental health care is as essential as like physical care, but that shouldn't be like some extra cherry on top that you get. If your insurance happens to pay for it, or what like that, that needs to be included in the whole package."

## Measuring important research outcomes

During a second series of focus groups, we talked about important research outcomes.

We reviewed the outcomes measured in the [5 research articles](#) discussed in the first focus group as examples to guide our discussion.

Some of the guiding questions were:

- How would we know the transition supports are working?
- How would it make a difference in your experience?

All the research outcomes shared with us were clearly important to the project participants and survey respondents.

- The research outcomes in **green** were rated as **higher priority**.
- Those in **brown** were rated as **medium priority**.
- There was no clear data allowing the identification of lower priority outcomes.

## We would know that healthcare transition research has an impact when...

### Autistic youth and adults would experience:

- **Better quality of life**
- **Better mental and physical health**
- **More physical and mental healthcare needs are met**
- More independence with healthcare
- Improved relationship with provider
- More comfortable with healthcare visits and procedures

### Providers would show:

- **Increased COMPETENCY in working with autistic people.**
- Increased BELIEF in their ABILITY to work with autistic people.
- The use of a menu of autism-informed accessibility options.



- Active work to improve autistic people's healthcare experience.

## The healthcare system would have:

- **More autism-trained providers available to take patients**
- **More autistic youth and adults with insurance coverage that meets physical and mental health needs**
- Improved access to autism-informed transition PLANNING
- Improved access to autism-informed transition SUPPORTS
- More specialized clinics in autism/neurodiversity or in “complex care” for adults with autism
- More autistic-informed training options for providers

For details on the related measures described by our stakeholders under each of these outcomes, visit the [Important Outcomes](#) page on our project website.

## Opportunities and allies

The Autism Collaborative has been fortunate to connect with key stakeholders in our efforts to understand their perspectives on research needed to address healthcare transition in Vermont. Autistic and non-autistic leaders, researchers, clinicians, caregivers and youth have identified a number of opportunities and allies for taking the next steps to improve healthcare transition for autistic youth and young adults.

- Vermont Child Health Improvement Program (VCHIP) is spearheading several healthcare transition projects. They are implementing the Got Transition recommendations. They have established transition collaboration projects with 7 clinics including pediatrics, family practice and internal medicine providers.

Tools developed:

- Materials to support patients and families.
- Chatbot to guide youth through the transition journey.
- Transition assessment added to the electronic health records.

- o A “complex care” information section in the electronic record.

The lessons learned, tools and strategies put in place in their projects may have relevant applications for transition planning for autistic youth.

- The Emergency Department (ED) at the University of Vermont Medical Center (UVMHC) has a physician champion for improving the care of individuals with disabilities in that setting.
  - o Preparing for ED visits when needed for autistic patients, their families and providers should be part of the transition planning process.
  - o A model and planning tools exist for preparing families, autistic patients or patients with cognitive or communication differences and providers for ED visits to improve the experience of the autistic patient.
- A model of care using designated scheduling for children with complex care needs and the establishment of a pediatric ‘Comfort Zone’ for medical procedures have been used at UVMHC.
  - o For many pediatric patients there is a need for coordination of dental work, blood work and vaccines that are done under sedation but there are limits to how often and when this should be done.
  - o The Comfort Zone helps reduce the level of sedation required for medical procedures but there is currently no equivalent for adults with IDD/complex needs.
  - o A physician champion for individuals with IDD has submitted a proposal to fund the equivalent of a ‘Comfort Zone’ for adults with IDD including those with autism.
- Creating a directory of autism-informed providers and their different specialties would make it easier to make referrals, and for autistic individuals and caregivers to find a good match for the care needed.
- The Vermont Family Network (VFN) can be leveraged to provide information and education to parents. They have been a consistent partner in our PCORI projects and with VCHIP. The Vermont Center for Independent Living (VCIL), Green Mountain Self-Advocates (GMSA) and All Brains Belong VT are other excellent resources for educating autistic youth and their caregivers on disability and neurodiversity identity and on their protected rights.

- There is a model for patient navigators that has been established in the Cancer Center at Central Vermont Medical Center. This model is promising for transitioning from pediatric to adult care for autistic patients and could be funded by insurance if the provider was a licensed social worker.
- The role of current transition and care coordinators and transition plans that occur through schools, HireAbility, the designated developmental agencies and community health centers could be leveraged to facilitate healthcare transition. This would require greater collaboration and coordination among these agencies. Adding healthcare transition to those plans and making it easier to share information while respecting the different rules is needed.
- Apple Tree Bay is a UVM nurse practitioner faculty practice providing healthcare to patients 12 years and older through a certified medical home model. They provide a holistic, integrative health approach with care coordination, functional medicine, motivational interviewing, acupuncture, and massage among many services. They would be an ideal partner to initiate education for their practitioners and the students who participate as learners in the practice about autism specific accommodations and transition support.
- Currently, there is a hub and spoke model for opioid treatment in Vermont that has been very successful in meeting patients' and providers' needs in rural communities. Lessons learned from the model and the experience with implementation could help with future efforts to develop and disseminate autism specialized care across the state of Vermont.
- Vermont has many Federally Qualified Health Centers where providers work together and use the "medical home model" of care. The federal certification requires that these practices provide care coordination. It also requires training for providers. The Bi-State Primary Care Association provides technical assistance to these practices. Collaborating with this organization and with champions in this network would provide opportunities to disseminate training on autism friendly practices and implement transition supports.
- Got Transition has excellent guidelines for implementing a [value-based payment initiative](#) for transitioning from pediatric to adult primary care that can be a roadmap for Vermont's efforts to develop a robust healthcare transition plan for autistic youth and adults.
- Got Transition also has a [resource on ways to strengthen the adult healthcare workforce](#) to support adults with complex care needs: Three models of complex care for adults are mentioned which have relevance and could be implemented in Vermont:

- 1) Enhanced primary care where current primary care practices increase their provision of interdisciplinary primary care, case management and disease self-management;
  - 2) Transitional care focusing us on episodic care during transitions between the hospital and rehabilitation or home care; and,
  - 3) Integrated care where there are cross disciplinary providers integrating their services for social, behavioral, medical, and overall health care.
- Finally, Vermont is rich in community resources such as the Youth Service Bureaus/Boys and Girls clubs, Outright Vermont, Pride, Umbrella (a violence and abuse prevention group), advocacy groups, recreational communities, etc. who do wonderful work with youth. They could be leveraged so they are part of a larger network or system of transition support that autistic youth and adults could access.

## Stakeholders engaged in the project

A total of 56 stakeholders joined this project:

- 39 stakeholders attended the focus group discussions.
- 17 professionals were interviewed separately.

The stakeholders included 20 autistic participants:

- 9 autistic participants were youth aged 16 to 25 years.
- 11 autistic participants were adults aged 26 and older.

Some autistic participants were also parents/caregivers and professionals:

- 2 autistic participants were professionals;
- 1 was an autistic parent/caregiver, and
- 2 were both autistic parents/caregivers and professionals.

There were 26 non-autistic participants:

- 19 were part of the focus groups.
- 17 were interviewed.

## Focus group participants

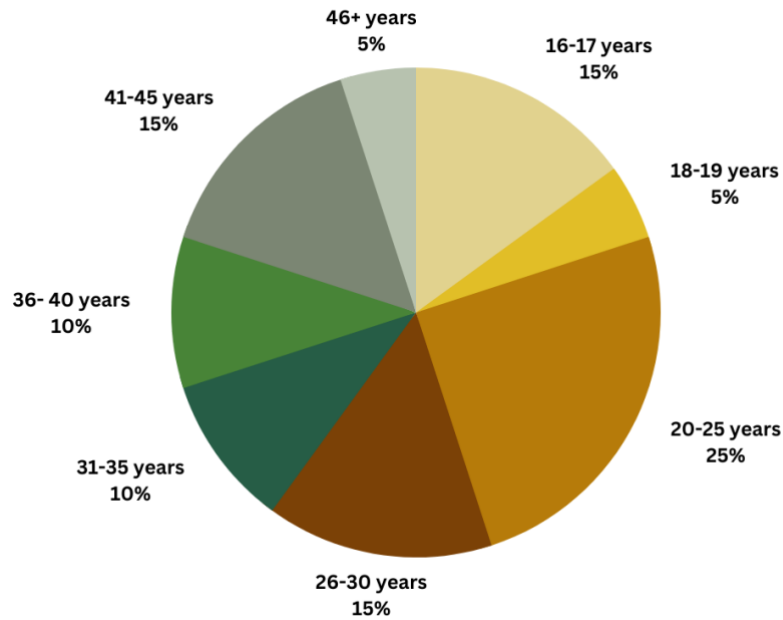
Figure 1.

39 focus group participants

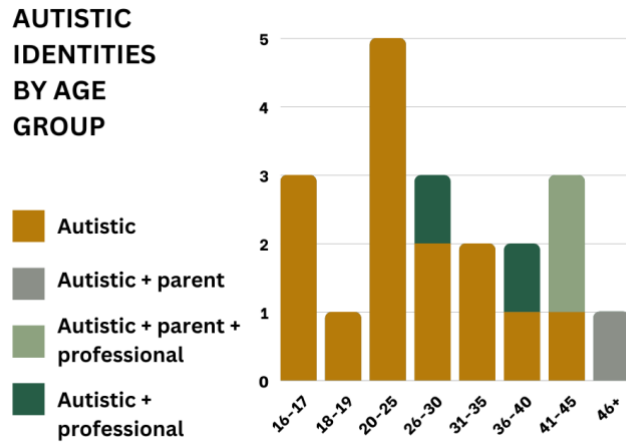


Figure 2.

Ages of autistic participants



**Figure 3.**



**Table 1.**

**Professions represented in the focus groups**

Professions	Number	Works with children	Works with adults	Works with both
Mental health providers	4	1	1	2
Psychiatrist	1			1
Nurse practitioner	1		1	
Family physician	1			1
Special educator	2			2
Healthcare experience specialist	1		1	
Home health provider	1			1

## Interviews

The 17 non-autistic professionals interviewed included:

- Physicians representing:
  - Pediatrics
  - Family practice
  - Internal medicine
  - Emergency department
  - Anesthesiology
  - Pulmonology
  - Gender affirming care
- Professionals from the Vermont Child Health Improvement Program (VCHIP).
- Patient-centered care support service specialists
- Healthcare navigator
- Representative from a designated developmental agency
- HireAbility transition specialist
- Vermont Center for Independent Living (VCIL) representative

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