

Preliminary Report on Health Equity in Vermont

HEALTH EQUITY ADVISORY COMMISSION

February 7, 2022

SUBMITTED TO THE SENATE COMMITTEE ON HEALTH AND WELFARE AND THE HOUSE COMMITTEES ON
HEALTH CARE AND ON HUMAN SERVICES

INTRODUCTION

The Health Equity Advisory Commission (the “Commission”) submits this preliminary report to the Senate Committee on Health and Welfare and the House Committees on Health Care and on Human Services pursuant to 18 V.S.A. §252. It is accompanied by a plain-language summary and an audio format available [here](#).

Standup & Composition of the Commission

Pursuant to 18 V.S.A. §252, there are currently 29 members on the Health Equity Advisory Commission. These members represent diverse communities in their personal and professional lives, and include members of the Black, Latino, Asian, Indigenous, and LGBTQIA+ communities, and the Deaf and Disability Community. This diversity in Commission membership is a key part of ensuring process equity in the state’s ongoing work related to public health and health care. By including a broader cross section of voices, we are more likely to be successful in developing solutions that are genuinely inclusive of all residents and visitors.

Public health and healthcare regulation are immense and complex policy areas. Thousands of professionals around the country perform this work as full-time, decades-long careers. Because of the breadth and depth of these topics, the Commission has chosen to perform its work at a pace that allows for thorough research and meaningful community input. To assist with this goal, the Commission has established seven subcommittees, each focused on a core component of the group’s statutory mandate:

Subcommittee 1 - Access to Care

Subcommittee 2 - Policy & Programming

Subcommittee 3 - Training

Subcommittee 4 - Engagement & Communication

Subcommittee 5 - Data

Subcommittee 6 - Prevention, Upstream Services, & Social Determinants of Health

Subcommittee 7 - Grants & Funding

Practices & Protocols

The Commission believes that process equity is an important component of inclusive policymaking, but also acknowledges that each member organization may hold a different stance on a given health policy. To this

end, the Commission has adopted decision-making practices that respect disagreement while striving for consensus.

The Commission has also adopted a meeting accessibility policy¹ to support members of the Commission and members of the public who attend Commission meetings.

PRELIMINARY FINDINGS

While the Commission is still early in its substantive deliberations about health equity in Vermont, the members have already identified dozens of issues and topic areas that require deeper focus. Each of these issues is important, and each one is urgent. These topics are listed below, but the Commission reminds the reader that this list is *preliminary* and *partial*. In other words, these are the first priorities identified, but not necessarily the top priorities. The Commission looks forward to engaging more with the public and the healthcare delivery system to refine and better understand these issues.

Data Needs & Availability

There are many health-related datasets and sources already available, many of which have been maintained by reputable entities for decades. The Commission will rely on these datasets for a large portion of its research and deliberations.

However, there are several limitations to these existing datasets that must be acknowledged:

- In Vermont, historically marginalized communities often represent small percentages of an already small population. This creates barriers to data aggregation and analysis due to the risk of personally identifiable information and lack of statistical power. Further, the public's trust in data collectors is fragile, particularly for those communities against whom those data have been used in harmful ways. This includes communities of color, people living with disabilities, the LGBTQIA+ community, and more.
- Until recently, most health research has focused solely on able-bodied individuals and their healthcare experiences. Research specific to people with disabilities and to various types of disabilities (developmental, sensory, mental health, etc.) has been

¹ <https://aoa.vermont.gov/sites/aoa/files/HEAC%20accommodation%20List%202010-16-21.pdf>

- conducted from an ableist perspective. This would include studies that: seek to quantify the degree or impact of specific impairments; use research methodologies that fail to include the perspective of those who live with disabilities; and assess interventions designed to modify perceived deficits so that they appear closer to a “typical” presentation.
- The barriers with respect to Vermont’s available data outlined above are compounded by:
 - inconsistencies in program, state, and federal definitions used to define membership to historically marginalized communities (e.g., disability status);
 - the reliance on antiquated or ill-suited data infrastructure, systems, and resources; and
 - the lack of qualitative data to provide insight into the experiences of individuals that is not otherwise captured in quantitative datasets.
 - Throughout the history of biological, medical, and behavioral health sciences, most clinical and empirical research has included participants who were male, able-bodied, and of European descent. This practice informs what is known about only a subset of the broader population.
 - Much of the public messaging about common health issues centers on the male experience (for example, widely repeated signs of a heart attack include symptoms such as numbness in the left arm, which is not a symptom associated with female-assigned people who experience heart attacks. Symptoms specific to this population tend to be different but are less widely known²).
 - Much of the data regarding health and other systems are collected and analyzed within a system that still perpetuates systemic racism and other forms of discrimination. Because of this, our collection systems and procedures are still likely tainted by implicit and explicit biases at each step of the data journey.
 - The history of medical research and experimentation has come at catastrophic cost to communities of color, creating cascading intergenerational trauma and a reluctance to engage with the professional, westernized health care system. This trauma has

² For further exploration, see more about low dose aspirin usage for prevention purposes.
<https://heart.bmj.com/content/101/5/369>

been inflicted by private and public entities, and includes such shameful experiences such as

- the work of J. Marion Sims³;
- the experience of Henrietta Lacks⁴;
- forced sterilizations by the U.S. government in Puerto Rico⁵, in carceral facilities⁶, and most recently at the southern border per a whistleblower report⁷;
- Vermont's role in eugenics⁸;
- and many more.

All of this points to one clear conclusion: The data we have are limited in their representation and are generally collected from a Westernized or settler perspective that often disregards traditional healing and causes harm.

Future recommendations from the Commission will likely discuss ways to improve the state's data collection and analysis processes.

Process Equity & Community Input

The Commission has identified several barriers to participation in statewide and regional dialogues on health equity. These barriers include

- language access,
- lack of physical and content accessibility,
- logistical and financial opportunity costs, and

³ Owens, D. C. (2017). *Medical bondage: Race, gender, and the origins of American gynecology*. University of Georgia Press.

⁴ United Nations. (2021). *UN honours Henrietta Lacks, whose cells transformed medical research worldwide*. United Nations. <https://news.un.org/en/story/2021/10/1102962>

⁵ de Malave, L. (1999). *Sterilization of Puerto Rican Women: A Selected, Partially Annotated Bibliography*. <https://www.library.wisc.edu/gwslibrarian/bibliographies/sterilization/>

⁶ Perry, D. M. (2017, July 27). *Our long, troubling history of sterilizing the incarcerated*. The Marshall Project. <https://www.themarshallproject.org/2017/07/26/our-long-troubling-history-of-sterilizing-the-incarcerated>

⁷ Project South, Georgia Detention Watch, Georgia Latino Alliance for Human Rights, & South Georgia Immigrant Support Network. (2020, September 14). *Re: Lack of Medical Care, Unsafe Work Practices, and Absence of Adequate Protection Against COVID-19 for Detained Immigrants and Employees Alike at the Irwin County Detention Center*. Project South. Retrieved from <https://projectsouth.org/wp-content/uploads/2020/09/OIG-ICDC-Complaint-1.pdf>.

⁸ Charlene Galarneau. (2021). *Eugenics in Vermont: A Chronology of "State-sanctioned eugenics policies and practices."* <https://legislature.vermont.gov/Documents/2022/WorkGroups/Senate%20Government%20Operations/Bills/J.R.H.2/Public%20Comment/J.R.H.2~Charlene%20Galarneau~Chronology%20Update%20-%20VT%20Eugenics~4-22-2021.pdf>

- a sense of safety or welcoming in discussion and decision-making spaces.

While the Commission is proud of its membership diversity, its 29 members still cannot fully reflect the needs and nuances of Vermont’s residents and visitors. For this reason, additional public input will be a critical component in the group’s research and in the state’s continued trust-building efforts.

Future recommendations from the Commission will likely discuss ways to reduce these and other barriers to ensure we are building robust and meaningful community participation.

Resourcing & Sustained Support

Members of the Commission represent a wide variety of stakeholders with different access to resources. One clear point of consensus among the group is that health equity initiatives must be resourced appropriately and sustainably. This means proper staffing, funding, and pacing. Part of the Commission’s statutory mandate is to distribute grant funds to the extent those funds are available, and they remain available in subsequent years; the year-over-year availability of those funds remains uncertain.

Future recommendations from the Commission will likely discuss ways to establish an ethical and predictable funding structure to support the work that will need to occur in communities, in government, and in healthcare delivery.

FURTHER EXPLORATION (ISSUE MAPPING)

The topics highlighted above represent a small portion of the Commission’s preliminary findings, which themselves represent a small portion of the health equity landscape. The table below lists additional areas of focus for the Commission’s ongoing deliberation.

The issues below were identified by the Commission as relevant to the discussion and resolution of barriers to health equity. They form a framework from which the Commission may base ongoing recommendations.

Relationship between the Commission and Related Entities

- What are the best ways to engage with other relevant entities and not to work in silos?

- Consider predominant research methodology. Quantitative *and* qualitative data are important.

Public and Stakeholder Engagement

- The Commission seeks to understand differences/disparities in health outcomes.
- The Commission will engage individuals whose areas of specialty may not be health-specific (i.e. housing, education).
- The Commission will implement “process equity” including plain language and other accommodations.

Demographic-Specific Concerns

- The Commission seeks to serve all groups together; no one group is more worthy than another.
- There needs to be clear policy around treatment for the LGBTQIA+ community
 - Some of this policy exists in Vermont for the white LGBTQIA+ community, but not for LGBTQIA+ people of color.
 - Still, basic access to primary and other types of care is difficult, especially for the Trans community.
- The Indigenous community experiences several disparities, which contributes to reduced trust in public health and healthcare delivery.
- Youth and those who serve youth tend to be limited to acute care in school settings.
- Policy and treatment decisions must account for the trauma that refugee communities have experienced, and the mental health implications of that trauma.

Pandemic Response

- Recovery and response must consider the barriers for people living with disabilities.
- Homelessness is a barrier because of inconsistent access to spaces needed for quarantine, hygiene practices, remote gathering, and more.
- LGBTQIA+ people are almost entirely excluded from COVID-19 data collection.

- To accommodate remote gatherings, many services switched to phone/internet format, but many people didn't have phone or internet.

Access

- The Commission will explore the use of Safe Use sites and other harm reduction practices.
- For people living with disabilities, it is difficult to find dentists with accessible offices and who practice trauma-informed care.
- The Commission will explore biases held against people with psychiatric disabilities at hospitals, and model approaches to mental health treatment.
- Access to health care in rural areas is more difficult.
- The Commission will explore technology and coaching that support the use of technology for telemedicine, reviewing health records, and tracking personal health information like blood pressure.
- The Commission will explore possibilities for transportation to healthcare appointments and to wellness activities like exercise facilities or classes. Some areas of the state have micro-transit pilot programs that will pick up people from their homes, but these are mainly focused on traditional medical appointments. They do, for example, include transportation to opportunities like an exercise class at the local senior center, practice sessions for Special Olympics, or a visit to the Wing Sensory Center in Rutland.
- There is a need for expanded physical access to healthcare facilities and medical equipment. For example, wheelchair accessible scales, mammography equipment with staff trained to accommodate someone who uses a wheelchair, and bathrooms that accommodate a Hoyer Lift.
- There is a need for expanded accommodations for sensory issues in healthcare settings to reduce stress for individuals with Intellectual and Developmental Disabilities. These accommodations include adjustable lighting, quiet spaces, and even use of fidget devices or special techniques when administering minor procedures like shots.

- The Commission will explore the current offerings in health education in schools, including sex education. This education is withheld from some special education students.
 - There is also a need for health education materials in plain language for people of all ages who have disabilities.
- The Commission will learn more about longer appointments to accommodate patients with developmental disabilities who may process conversation and information more slowly, or who need concepts explained more than once.
- The Commission will explore transition supports for young adults moving from pediatric care to adult medicine.
- The Commission will study the role of insurance coverage, including
 - The need for more healthcare providers that accept Medicaid payment (this includes specialty providers such as dentists); and
 - The need for more affordable coverage for lower income residents and visitors with disabilities who do not qualify for Medicaid.

Regulatory Challenges

- The Commission sees opportunities to serve more family structures by re-imagining HIPAA and other regulations.
- To ease the challenges of recruiting healthcare workers in Vermont, the state can consider changes to the licensure process and develop a strategic way to recruit and retain people who may be attracted to Vermont.
- The Commission will explore the idea of a Mental Health Peer Support certification.
- This certification can be used for services that allow for Medicaid payments.

Upstream Factors

- Transportation remains challenging, especially during nighttime hours when the few public transit options are no longer running.
- The Commission will explore the connections between healthcare systems and other carceral systems.

- Decriminalizing sex work could improve health and other outcomes for people who are stigmatized because of it.
- Food insecurity impacts individual and community health and negatively affects academic and job performance.

Health Care Profession(s)

- The Commission commits to hearing more from nurses.
- The Commission will consider how regional differences impact treatment and access to healthcare. For example, some people in decision-making positions relocate to Vermont from other regions where religion plays a different/greater role, which can sometimes worsen or reduce services for the LGBTQIA+ community.
- There is wage disparity in healthcare professions.
- Representation matters. Patient should see themselves reflected in the healthcare workforce.
- Recruitment and retention are key to the strength of Vermont's healthcare system. The Commission will explore ways to create tracks for people to enter the health field.
- Healthcare facilities must address incidents in which patients are abusive to staff from historically marginalized groups.
- People living with disabilities experience greater risk of being incarcerated or fined when in crisis.

Mental and Emotional Health

- There needs to be more meaningful conversation about mental health.
 - The Commission will explore the intersection of mental health outcomes and race/ethnicity.
- The Commission commits to hearing more from psychiatric survivors, specifically about approaches to mental health services.
- There is a need for more peer support services in all systems.
- The Commission will explore practices in Emergency Departments, specifically involuntary hospitalizations and their connection to mass incarceration.

Cultural Factors

- Access to care is more difficult for Limited English proficient communities when there is insufficient language access.
 - This includes access to American Sign Language and accommodations for the Deaf community.
 - The Commission will learn more about Deaf Culture training.
 - The Commission is interested in learning more about access for people who use alternative and augmentative communication, including supported typing and people who communicate through gesture.
- Ableism is a form of bias that leads to many assumptions about the type of care that is appropriate for people with disabilities.
- Cultural Understanding is an important factor in healthcare.
 - Traditional and Indigenous healing: Providers and public health officials must acknowledge what people perceive as their healing process and change perceptions in the profession.
- The Commission will study whether and how traditional and Indigenous healing fit alongside the existing licensure model.
- Training on disability etiquette is needed for healthcare providers. Examples include:
 - Speaking to an individual's parent/guardian rather than speaking directly to the individual
 - Touching someone's wheelchair without asking
 - Failing to use person-first and other preferred language when speaking about disability.

PLAIN-LANGUAGE SUMMARY

Introduction

This is the first report of the Health Equity Advisory Commission (the “Commission”). It is being submitted to the state legislature's health committees. The law that requires this is 18 V.S.A. §252. This is the plain-language summary. There is also an audio format available [here](#).

Organizing the Commission

The law that created the Commission requires it to have 29 members. These members represent diverse communities. These include people who are Black, Latino, Asian, Indigenous, LGBTQIA+, and/or have a disability. Diversity is important to health equity work. This is because more voices mean more inclusion in health policy.

Public health and healthcare regulation are big topics. Many people do this work full-time for many years. Because these are big topics, the Commission will take its time to research and talk to the community. That is why the Commission created seven (7) subcommittees focused on different parts of this work. These subcommittees are:

Subcommittee 1 - Access to Care

Subcommittee 2 - Policy & Programming

Subcommittee 3 - Training

Subcommittee 4 - Engagement & Communication

Subcommittee 5 - Data

Subcommittee 6 - Prevention, Upstream Services, & Social
Determinants of Health

Subcommittee 7 - Grants & Funding

Practices & Protocols.

The Commission believes that everybody's opinion is important. The Commission knows that not everyone will agree on everything. That is why the Commission tries to get as much agreement as possible. But the Commission is also okay with disagreement.

The Commission has a meeting accessibility policy to support members and the community. Find the accessibility policy [here](#).

Early Findings

The Commission is just starting to talk about health equity in Vermont. The group has found some areas to think more about. These topics are below. This is not a complete list of all the important issues. The Commission will talk to the community more to learn about more topics.

Data

There are a lot of health data that the Commission can use. Not all the data are inclusive. Western medicine has a strong focus on some communities and not others. In Vermont, there are smaller numbers of communities of color, so the data are hard to use. Some data systems still use outdated technology. Some of the health information we know is the result of harm and trauma. Some examples are:

1. The work of J. Marion Sims.
2. The experience of Henrietta Lacks.
3. Forced sterilizations by the U.S. government. This happened in Puerto Rico. It also happened in jails, detention centers, and institutions for people with disabilities.
4. Vermont's role in eugenics.
5. And many more.

All of this means that we need more data, and we need to find better ways to collect it.

The Commission plans to make more recommendations about data collection and analysis.

Community Input

Not everybody can participate in conversations about health equity. This is because of reasons such as:

- Not speaking the same language.
- lack of accessibility.
- challenges in going to a particular place.
- having to pay or lose money in order to participate.
- not feeling safe or welcome.

The Commission is diverse, but it needs more community voices. This helps the state do better research and build more trust.

The Commission plans to keep talking with the community about these barriers.

Resources & Sustained Support

There are many people who do health-related work. They do not all have the same funding or staffing. The Commission recommends proper staffing, funding, and timing. The Commission recommends more stability in funding.

The Commission plans to make more recommendations about staffing and funding.

Further Exploration (Issue Mapping)

The topics discussed above are not all the important issues. There is a list below that shows more topics.

The Commission will make more recommendations about the topic areas listed below.

Relationship between the Commission and other groups.

- What are the best ways to work together?
- It is important to collect both data and stories.

Community Input.

- The Commission wants to learn more about differences in health outcomes.
- The Commission wants to hear from people who are experts in areas like housing and education.
- The Commission will make accommodations so the community can participate in its work.

Concerns for Specific Groups.

- The Commission wants to serve all groups. No one group is more worthy than another.

- There needs to be clear policy around treatment for the LGBTQIA+ community.
- Some of this policy exists in Vermont for the white LGBTQIA+ community, but not for LGBTQIA+ people of color.
- Basic access to healthcare is difficult, especially for the Trans community.
- The Indigenous community experiences many disparities. This contributes to reduced trust in public health and healthcare delivery.
- Youth have limited options for care in schools.
- Policy and treatment decisions must be trauma-responsive.

Pandemic Response.

- Recovery and response work must consider the barriers for people with disabilities.
- Homelessness is a barrier. People without a home have inconsistent access to spaces for quarantine, handwashing, remote gathering, and more.
- LGBTQIA+ people are excluded from COVID-19 data collection.
- To accommodate remote gatherings, many services switched to a phone/internet format. Many people do not have phone or internet.

Access.

- The Commission wants to learn more about the use of Safe Use sites.
- It is hard to find doctors and dentists with accessible offices who practice trauma-informed care.
- People with psychiatric disabilities face biases at hospitals.
- Access to health care in rural areas is more difficult.
- The Commission wants to learn more about technology. This includes telemedicine, reviewing health records, and tracking personal health information like blood pressure.
- The Commission wants to learn more about transportation to healthcare appointments.
- There is a need to improve physical access in healthcare facilities.

- There is a need for more accommodations for sensory issues in healthcare settings.
- The Commission wants to learn more about health education in schools. This includes health education for people of all ages who have disabilities.
- The Commission wants to learn more about longer appointments. This could help patients with developmental disabilities. People with developmental disabilities may process information slowly. They may need concepts explained more than once.
- How are young adults with disabilities supported when moving from pediatric care to adult medicine?
- The Commission wants to learn more about insurance coverage, especially Medicaid.

Rules and Laws.

- We can serve more family structures by re-imagining HIPAA and other regulations.
- The state can consider changes to the licensure process to bring more healthcare workers to Vermont.
- The Commission wants to learn more about possible Mental Health Peer Support certification.

Upstream Factors.

- Limited transportation affects people's ability to get to health appointments
- Healthcare systems contribute to incarceration.
- Decriminalizing sex work could help more people have access to care.
- Lack of consistent food access creates negative health outcomes.

Health Care Profession(s).

- The Commission wants to hear more from nurses.
- A provider's backgrounds impacts services. How does this impact the LGBTQIA+ community?
- There is wage disparity in healthcare professions.
- Patient should see themselves reflected in the healthcare workforce.

- The Commission wants to learn more about ways to support people entering the health field.
- Healthcare facilities must address incidents when patients abuse staff from historically marginalized groups.
- People living with disabilities are more likely to be sent to jail or fined when they are in crisis.

Mental and Emotional Health.

- There needs to be more meaningful conversation about mental health.
- The Commission wants to learn more about the intersection of mental health outcomes and race/ethnicity.
- The Commission wants to hear more from psychiatric survivors.
- There is a need for more peer support services in all systems.
- The Commission wants to learn more about involuntary hospitalizations. Does this lead to more people being sent to jail?

Cultural Factors.

- Access to care is more difficult when there is insufficient language access. This includes access to American Sign Language and people who communicate through gesture.
- Ableism may guide what kind of care is offered to people with disabilities.
- Cultural understanding is an important factor in healthcare.
- How do traditional and Indigenous healing fit alongside the existing licensure model?
- Healthcare providers need training about disability etiquette.