

THE INCLUSIVE HEALTHCARE PARTNERSHIP PROJECT

*The Vermont Developmental Disabilities Council
In Partnership with
Green Mountain Self-Advocates*

Removing the Barriers

*Improving Health Care for Adult Vermonters with
Intellectual and Developmental Disabilities*

Prepared By
Susan Covert, Project Coordinator

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Dear members of the Green Mountain Care Board, the Vermont Health Care Innovation Project, and the general public:

We are pleased to deliver this final report from the Inclusive Healthcare Partnership Project (IHPP). It is our hope that the findings, recommendations, and opportunities for action presented here will spark further consideration, investment, and innovation in the delivery of quality health care to adult Vermonters with intellectual and other developmental disabilities (I/DD).

When the IHPP Planning Team first came together, we struggled to wrap our arms around the enormity of the health care challenges confronting this population. Why were adults with I/DD, even those well supported in their community, experiencing ill health in ways unrelated to their disability? Why were pediatricians routinely providing primary care for adults with I/DD well into their twenties and even their thirties? Where could we find health information and care models to address the needs of what former Senator Tom Harkin has dubbed “the ADA generation” — young people with disabilities whose experiences, expectations, and aspirations closely mirror their peers who do not have disabilities?

We owe a tremendous debt of gratitude to the many Vermont stakeholders and national experts who shared their insights and ideas with us. Based on their input, the project chose four areas of inquiry to better understand how and why adults with I/DD face dramatic disparities in access to and utilization of health care and, consequently, experience such poor health outcomes. IHPP focused its efforts on the following: (1) transition services from pediatric to adult primary care; (2) medical education and provider training; (3) care models and practice transformation; and (4) supports for health and wellness. We recognize that other significant health issues — dental care being an obvious example — are deserving of attention, but we were unable to include them in the scope of this planning project.

Vermont is not unique in having a health care system that has largely overlooked the disparity in health status and care delivery experienced by adults with I/DD. Rather, what sets Vermont apart is our state’s willingness to tackle this longstanding problem and to take advantage of opportunities for making both large and small practical changes to improve health care for this vulnerable population. Each of us on the Planning Team and the IHPP staff look forward to working with you to realize the goals of health care reform — better health through improved health care delivery at a sustainable, lower cost — for people with intellectual and developmental disabilities.

Yours Sincerely,



Kirsten Murphy

Executive Director, Vermont Developmental Disabilities Council
Project Director, Vermont Inclusive Healthcare Partnership Project

INTRODUCTION

*Of all the forms of inequality, injustice in health care
is the most shocking and inhumane.*

Martin Luther King, Jr.

While our nation has seen transformational changes for individuals with disabilities, access to quality health care has remained elusive. The first national legislation guaranteeing a free and appropriate public education for all children was signed into law in 1975, and in 1990 the passage of the Americans with Disabilities Act significantly expanded civil rights for people with disabilities. These landmark pieces of legislation, along with the closing of state-run institutions, like Vermont's Brandon Training School in 1993, have brought individuals with intellectual and developmental disabilities (I/DD)¹ out of the shadows. Increasingly, people with I/DD are fully included in school, in the workplace, and in the community. In spite of these advances, however, there are dramatic disparities in health and health care for people with disabilities, including significant barriers to accessing needed care, a markedly greater risk for preventable health problems and poorer overall health than the general population.

Adults with developmental disabilities are frequent users of emergency rooms, have longer hospital stays, and are more likely to suffer from chronic illnesses.² Compared to the general population, they have higher rates of chronic diseases, including diabetes, hypertension, and cardiovascular disease, yet they are significantly less likely to receive preventive care. For example, adults with intellectual disabilities are up to five times more likely to have diabetes than the general population and are at greater risk of receiving less than adequate care management.³ In addition, public health and wellness programs typically do not consider the needs of individuals with I/DD. This is especially troubling, as obesity, physical inactivity, and smoking are much greater health problems for this group as compared to the general population.⁴

¹ For the purposes of this project, "developmental disability" is defined by criteria set out in the 2000 federal Developmental Disabilities Assistance and Bill of Rights Act as "a severe, chronic disability that manifests before the age of 22 and results in substantial functional limitations in 3 or more areas of major life activity." The federal definition is broader than that used by the State of Vermont. It includes not only those who receive home and community based services through the Developmental Disability Services System of Care, but also some individuals served under Vermont's Choices for Care program, as well as other Vermont Medicaid recipients who do not receive community-based supports and services.

² Centers for Disease Control and Prevention. "Health disparities and inequalities report." *Morbidity and Mortality Weekly Report*, Vol. 62, Nov. 22, 2013.

³ Krahn, GL, Walker, DK, Correa-De-Araujo, R. "Persons with disabilities as an unrecognized health disparity population." *American Journal of Public Health*: Vol. 105, No. S2, April 2015.

⁴ Krahn G, Drum CE. "A cascade of disparities: Health and health care access for people with intellectual disabilities." *MRDD Research Reviews*. 2006; 12:70-82.

To begin addressing these health disparities, the Vermont Developmental Disabilities Council was awarded a one-year planning grant for the Inclusive Health Care Partnership Project (IHPP) through the Vermont Health Care Innovation Project (VHCIP). The Council, in collaboration with Green Mountain Self-Advocates (GMSA), has engaged in an inclusive planning process to identify barriers that adult Vermonters with I/DD face in accessing quality care and engaging in health promotion activities and to make recommendations for improving their health care experience and outcomes, while reducing the high cost of care for this population.

AN INCLUSIVE PLANNING PROCESS

In conducting this project, the Vermont Developmental Disabilities Council and its partner, Green Mountain Self-Advocates, were committed to a fully inclusive planning process. Both IHPP staff and the nine-member Planning Team that oversaw the work of the project included adults with I/DD and individuals who have family members with I/DD. GMSA helped recruit the self-advocate⁵ participating in the project and provided them with support throughout the planning process. IHPP's Planning Team met monthly from April through December 2015. Prior to meetings, GMSA met with self-advocates to review the agenda, explain terms and concepts that might not be familiar, and answer questions. GMSA also created cognitively accessible Planning Team agendas and meeting handouts. This preparation helped to ensure that self-advocates were able to fully participate in the Planning Team meetings. The contribution of self-advocates and family members and their willingness to share their personal experiences were invaluable in understanding the challenges adult Vermonters with I/DD face when accessing health care.

The IHPP Planning Team included: Three self-advocates, two parents of children with developmental disabilities, three physicians (an internist, a family practitioner, and an emergency medicine doctor), and a registered nurse from a designated agency. (In Vermont, state-funded mental health and developmental services are provided at the county level through a designated agency.) Several individuals

“I was able to give my input and people thought it was important.

We were looked at as a resource.

I felt like they listened to me and I was valued.

They understood me when I had input.

At the end of every meeting, they asked how we could make the meetings even better.”

— Self-Advocate members of the IHPP Planning Team

⁵ Self-advocacy refers to the civil rights movement for people with developmental disabilities. Self-advocates are individuals with I/DD who take control of their own lives by knowing their rights, speaking up for themselves, and making choices and decisions that affect their lives.

approached their work with the project from both a personal and professional perspective. One of the physicians on the IHPP Planning Team has a daughter with Down syndrome and the parent representative on the team is also an occupational therapist. Two members of the IHPP staff have adult family members with I/DD.⁶

To better understand health disparity for this population and to identify opportunities for improving the health of adult Vermonters with I/DD, the project engaged in the following activities: 1) researched national best practices in health care and health promotion for adults with I/DD; 2) interviewed national experts in developmental medicine, health care policy, and promotion of health and wellness;⁷ 3) conducted structured telephone interviews with 12 key Vermont stakeholders;⁸ 4) conducted three focus groups with self-advocates and one focus group with parents of adult children who have multiple disabilities and complex medical conditions;⁹ 5) analyzed Medicaid data on health care usage by adult Vermonters with I/DD;¹⁰ 6) conducted a health care survey with self-advocates attending GMSA's annual conference; 7) invited presenters with expertise in developmental medicine, medical education, and care coordination to participate in Planning Team meetings; sent the Project Director to attend the annual conference of the American Association of Developmental Medicine and Dentistry; and 8) connected with allies in medical education, health care administration, special education, and public health to explore options for improving the health care experience and outcomes for adult Vermonters with I/DD.

A MEDICALLY UNDERSERVED POPULATION

“The state of Vermont must ensure universal access to and coverage for high-quality, medically necessary health services for all Vermonters. Systemic barriers, such as cost, must not prevent people from accessing necessary health care. All Vermonters must receive affordable and appropriate health care at the appropriate time in the appropriate setting.”

— Vermont Act 48, §1a (1)

Although there is a growing body of evidence indicating significant differences in both the health status and the utilization of health services by adult with I/DD, this population has been largely overlooked by programs designed to reduce health disparities. The reasons are complex. Gains in life expectancy for people with I/DD are relatively recent, as seen dramatically in the case of

Down syndrome, where the life expectancy has risen from 25 years in 1983 to 60 years today. Medical education has been slow to integrate this reality into already overburdened curricula, with the result that allied health and medical students are still introduced to developmental disability solely as a pediatric issue. Until recently, insufficient data

⁶ Addendum 1, The Inclusive Healthcare Partnership Project, Planning Team Members and Staff.

⁷ Addendum 2, National Experts Interviewed for The Inclusive Healthcare Partnership Project.

⁸ The Inclusive Healthcare Partnership Project, “Stakeholder Interviews: Findings and Recommendations.”

⁹ The Inclusive Healthcare Partnership Project, “From a Personal Perspective: Adults with I/DD and Parents Share their Experiences with Vermont’s Health Care System.”

¹⁰ Addendum 3, The Inclusive Healthcare Partnership Project, Findings from Vermont Medicaid Claims Data.

collection for subpopulations, including individuals with disabilities, also has played a role in obscuring the health differences between people with I/DD and the general population.

Perhaps most importantly, there has been a lack of clarity about what constitutes a health disparity for people with disabilities in general and, more specifically, for those with developmental disabilities. Although definitions vary, there is widespread agreement that health disparities are not simply differences, but rather differences that stem from a history of social, economic, and environmental disadvantages, and as such, they are avoidable. While differences in the health status of adults with I/DD in certain cases may be related to the underlying disability — for example, the early onset of dementia associated with Down syndrome — for the vast majority of conditions it is entirely inappropriate to dismiss poor health as the inevitable result of disability. A review of the socio-economic status of people with disabilities would indicate that poor health is much more likely to be attributed to other significant disadvantages. For example, as compared to the general population, people with disabilities are significantly less likely to be employed (21% vs. 59%). People with disabilities are much more likely to have an annual household income under \$15,000 (34% vs. 15%), have inadequate transportation (34% vs. 16%), and lack access to the Internet (46% vs. 15%).¹¹ Vermont, in fact, ranks third in the nation, surpassed only by Maine and the District of Columbia, in the gap between the poverty rate for people with disabilities and the poverty rate for people without disabilities.¹²

While health disparities for people with disabilities have been largely ignored, considerable attention has been focused on other populations that experience health disparities, including racial and ethnic minorities, migrant farm workers, and members of the LGBTQ community. Medical education has incorporated curricula that address the unique needs of these groups, hospital certification boards ask specifically about care for underserved groups, and a wide variety of federal programs target resources to projects that reduce health disparities for certain populations. The fact that the health disparities experienced by people with I/DD have gone unnoticed is not simply a matter of academic interest, but rather a critical issue that must be addressed if we are to have a just and equitable health care system. One means of securing this recognition and the resources that are tied to being designated as medically underserved, comes through the federal Health Resources and Services Administration (HRSA), which oversees the Index of Medical Underservice.

The concept of medical underservice first entered the public health lexicon in the Health Maintenance Organization Act of 1973. Designed to promote access to primary care, the Act defined certain geographic locations as medically underserved areas (MUA) based on a formula created by HRSA. By the 1990s the number of federal programs and benefits tied to the MUA designation had grown to more than 20. A second category, medically underserved populations (MUP), was created to reflect the fact that certain concentrated

¹¹ Kessler Foundation and the National Institute on Disability. *The ADA 20 Years Later*, July, 2010. See: www.2010disabilitysurveys.org/pdfs/surveyresults.pdf.

¹² Annual Disability Statistics Compendium, 2014. See: <http://disabilitycompendium.org/home>.

groups — for example, residents of public housing — face similar barriers to care, but are too small in number to trigger an MUA designation. In granting both MUA and MUP designations, HRSA uses a formula that weighs four variables thought to be key indicators of poor access to health services and, therefore, indicative of poor population health: The ratio of primary care physicians to the total population; the infant mortality rate; the poverty rate; and the percentage of the population age 65 or over at the time of application. This formula has remained remarkably stable over time, despite criticism in both the academic literature and by the Government Accountability Office.

In the past decade, the American Academy of Developmental Medicine and Dentistry (AADMD) has led an effort to obtain formal designation of people with I/DD as a medically underserved population by HRSA and other federal agencies. Their goal, whether by special exemption, a revision of the HRSA formula, or a favorable interpretation of the Index of Medical Underservice as it applies to people with I/DD, is to obtain for those with developmental disabilities the same consideration, benefits, opportunities, and assistance provided to other medically underserved populations.¹³ The American Medical Association and the American Dental Association have both endorsed this campaign.

IHPP has compiled and reviewed a considerable body of qualitative and quantitative data indicating that in both health and health care, Vermont adults experience significant disparities similar to those documented nationally.¹⁴ HRSA's reluctance to award a formal designation notwithstanding, by any common sense meaning of the term, adults with developmental disabilities are, indeed, medically underserved. Adopting this framework is important for two reasons: First, it acknowledges the fact that suboptimal care is largely rooted in historical inequalities and unexamined attitudes. Second, and more importantly, it immediately suggests a way forward. Medical practitioners are increasingly familiar with the complex social determinants that underlie health disparities. Training programs, practice guidelines, and other creative solutions already exist to address these challenges as experienced by other marginalized groups. To improve the health of adults with I/DD, Vermont does not need new programs or added regulations, but rather to work with community partners in weaving the unique needs of this group into the fabric of established educational, clinical, and public health programs.

¹³ Executive Director of the AADMD, Matt Holder, MD, MBA has persuasively argued that the Index of Medical Underservice, if properly interpreted, results in a score that clearly qualifies people with I/DD for designation as a MUP. For a summary of this argument, see Rick Rader, MD, "Satchel Paige on Being Medically Underserved," *Exceptional Parent Magazine*, May 14, 2007.

¹⁴ The Inclusive Healthcare Partnership Project, Addendum 3.

FINDINGS AND RECOMMENDATIONS

“We have regular occasions where there is some significant thing that would not have been diagnosed without the advocacy of the family or our case manager. In our small agency, we have had several instances — six or more in a year — where we had to insist on follow-up and some of those things have been life-threatening. There have been times when it has been something as simple as asking for an x-ray but the doctor doesn’t see the need, and when you finally get the x-ray, it turns out that there is a problem. This is not due to bad medical care. It’s due to a lack of ability to communicate with the person and not enough time.”

— Designated Agency Executive Director

In all, more than 100 individuals from across Vermont provided input to the Inclusive Health Care Partnership Project (IHPP). Self-advocates, family members, developmental service administrators, and health care providers all shared their frustrations with the significant health disparities experienced by adult Vermonters with intellectual and developmental disabilities (I/DD). There was remarkable agreement in their assessment of the challenges Vermont faces as it looks to improve health for this population:

1. Persistent problems with the transition from pediatric to adult health care;
2. A lack of health care providers who have training or experience caring for adults with I/DD;
3. Inadequate care coordination, especially for individuals with I/DD who qualify for Medicaid but do not meet the more stringent criteria for home and community-based services (HCBS);
4. Lack of inclusion in public health initiatives and other wellness programs;
5. Difficulty in obtaining private insurance or Medicaid coverage for specialized equipment and long-term therapies;
6. A health care financing system that does not reimburse providers for the additional time needed to deliver quality care to patients with I/DD.

From the outset, IHPP made a conscious effort to go beyond documentation of the problem and asked what can be done to make things better and who can help. Planning Team members, participants in the initial stakeholder interviews, and leaders in health care, special education, and developmental services sought out during the course of the project have been exceedingly generous in sharing their time and expertise. These allies were unflinchingly honest in detailing the many challenges faced by adults with I/DD in obtaining quality health care, and they made concrete, practical recommendations to address health

disparities for this population. More importantly, they identified opportunities within their own organizations and networks to improve the health care experience and outcomes for adult Vermonters with I/DD and offered to help make these changes happen.

SECTION 1: TRANSITION FROM PEDIATRIC CARE TO ADULT-FOCUSED MEDICINE

“We received a letter that he would no longer be seen by his pediatrician. It was a nightmare. It took us eight years to find a good primary care doctor. One doctor who came highly recommended refused to touch my son. He was intimidated by him.”

— Mother of a son who has Angelman syndrome

GOAL: All young adults with intellectual and developmental disabilities in Vermont will experience a seamless transition from pediatric to adult health care.

In making the transition from pediatric to adult care, young adults with disabilities and their families often encounter health systems that are unprepared to provide the level of care to meet their complex needs.¹⁵ For youth aging out of pediatric practices, the availability of adult health care providers who are willing to accept new patients with intellectual and developmental disabilities is limited. Health care providers cite lack of training and experience and inadequate reimbursement for the additional time required to provide quality care for this population as major barriers to transition.¹⁶ As a result, patients with I/DD often remain under the care of their pediatrician long beyond the transition period, which typically occurs between the ages of 18 and 21.

The Inclusive Health Care Partnership Project repeatedly heard from self-advocates, family members, and health care providers that youth with I/DD and their families need substantially more information and support to navigate the transition to adult health care than is currently being provided. In particular, parents and self-advocates wanted pediatric practices to be more engaged in the transition process and to assist with referrals to adult care providers. Care coordination seems especially important in this process because school special education records often include a long history of clinical information from years of evaluation. As one practitioner explained, “When asked to assess whether a young woman with Down syndrome is showing signs of early onset dementia, I need to know what her functional skills were years earlier. School records are a gold mine of information!”

¹⁵ Krahn, GL, Walker, DK, Correa-De-Araujo, R. “Persons with disabilities as an unrecognized health disparity population.” *American Journal of Public Health: Vol. 105, No. S2*, April 2015.

¹⁶ American Academy of Pediatrics Clinical Report. “Supporting health care transition from adolescence to adulthood in the medical home.” *Pediatrics* Vol. 128, No. 1, 2011.

KEY FINDINGS

- In 1989 the Surgeon General set forth a national agenda in training, research, and program development to establish a seamless health care system to support youth with special needs to successfully transition to adult-centered care. Decades later, transition planning is still not the standard of care for most pediatric practices. Only in the past few years has it even been acknowledged that adult care providers also need to be partners in supporting the transition to adult care.¹⁷
- With advances in care, children with conditions that 50 years ago would have meant a drastically reduced life expectancy are now living well into adulthood. While there are developmental pediatricians for children with disabilities, in the world of adult medicine there is no equivalent to the developmental pediatrician.¹⁸
- The American Academy of Pediatrics 2008 Adolescent Health Care Survey found that less than half of pediatricians assisted their patients with a referral to family or internal medicine (47%) or to adult specialists (45%).¹⁹
- In a 2007 survey of New Hampshire adult primary care providers, of the 180 providers who responded, 46% rarely or never communicated with the previous health care provider, 57% rarely or never received a written transfer summary, and 48% thought young adults entering their practice had experienced a gap in medical care. Asked what would help, 95% wanted a written transfer summary, 95% wanted support from specialists, 84% wanted written information about a particular disability, and 91% wanted to talk with the previous primary care provider about the needs of their new patient.²⁰
- The difficulty in making the transition to adult care is exacerbated by the increasing reluctance of health care providers to accept Medicaid, the health care coverage for nearly all adult Vermonters with I/DD. Medicaid's reimbursement rates are significantly lower than both Medicare and private insurance payments for the same outpatient services. In addition, the administrative process associated with Medicaid is complex and time consuming; Medicaid's reimbursement for services is unacceptably slow.²¹

¹⁷ North Carolina Division of Public Health. "A health care provider's guide to helping youth transition from pediatric to adult health care." 2010.

¹⁸ *Infectious Diseases in Children*, "Transition from pediatric to adult care 'takes a village' for patients with developmental disabilities." June 2015.

¹⁹ American Academy of Pediatrics. "Periodic Survey #71." *Adolescent Health Care*. 2008.

²⁰ NH Department of Health and Human Services. "Survey of adult health care providers about health care transition for youth with special health care needs." 2008.

²¹ Long, SK, "Physicians may need more than higher reimbursement rates to expand Medicaid participation." *Health Affairs*, Vol. 32, No. 9, Sept 2013.

RECOMMENDATIONS TO IMPROVE TRANSITION TO ADULT CARE

“I am the oldest patient at my doctor’s office. They know me really well.”

— 32-year-old woman with Down syndrome who is still seen in a pediatric practice

“I would like to see pediatricians give more help to families with the transition to adult medicine. They have to know about other doctors who would be good. It’s all left up to me. I would like to have a little more hand-holding.”

— Mother of a 22-year-old son with I/DD

“There isn’t anywhere to go once you get out of the pediatric medical home — it just doesn’t work that way in adult care settings.”

— Vermont pediatrician

“There is nobody else. I have to outlive my son to be sure he gets what he needs. It’s scary.”

— Mother of an adult son with I/DD

Recommendation 1

The Vermont Child Health Improvement Program, in collaboration with a group of physicians from the Burlington area, will develop and promote practice guidelines to ensure a seamless transition from pediatric to adult care. These will include criteria for identifying and monitoring transitioning youth, a model plan of care for transitioning youth, transition readiness checklists and timelines, and provider protocols for the transfer of care.

Recommendation 2

Supporting an individual in transition planning across age-specific service delivery systems will be included as a disability competency for Care Management Practitioners. The Vermont Health Care Innovation Project will highlight the importance of a smooth transition from pediatric to adult care to long-term health outcomes and include it in future trainings based on the Disability Awareness Briefs.

Recommendation 3

Vermont Family Network will continue to provide young adults with I/DD and their families with information, training, and support to make a successful transition to adult health care. As practice guidelines and other best transition practices are developed Vermont Family Network will share this information with youth and their families.

Recommendation 4

The Vermont Department of Education will establish a process for special education students or their guardians to receive upon graduation, or when the student turns 22, a summary of their school records pertaining to functional abilities and health-related services (i.e. occupational, physical, and speech therapy

services). Students and guardians will be encouraged to provide this information to the student's primary care physician.

Recommendation 5

The Vermont Department of Education will include health care transition as a required component of the adulthood transition planning process for special education students. This aspect of transition planning will focus on achieving optimal health and wellness and include the development of skills needed to be an effective health care consumer.

Recommendation 6

Vermont's state budget is finalized in late spring. This timing means that special education students do not know until just before graduation if they will meet a funding priority under the state's System of Care Plan, thereby qualifying for disability long-term supports and services. In its work on payment reform, the Vermont Health Care Innovation Project will address this longstanding problem and will consider viable options that disentangle service eligibility from dependence upon immediate availability of new caseload funding.

OPPORTUNITIES AND ALLIES

The Inclusive Healthcare Partnership Project has reached out to key organizations and professionals to help address the challenges confronting youth with intellectual and developmental disabilities and their families in making the transition from pediatric to adult health care. Leaders at the Vermont Council of Special Education Administrators; Vermont Medical Society; Vermont Department of Education; Vermont State School Nurses' Association; Vermont Department of Disabilities, Aging, and Independent Living; as well as private pediatric and adult health care practices have committed to doing what they can within their organizations and networks to improve the transition process.²²

- Four Vermont health care practices (internal medicine, family medicine, and two pediatric practices) in Chittenden County are engaged in a pilot project, the ABCs of Transitioning, to develop an effective transition process for 40 at-risk young adults who have anxiety disorder, depression, attention deficit hyperactivity disorder, or asthma. The goal of the project is to foster effective collaborative relationships between referring and receiving practices to ensure a successful transition to adult care. Once the pilot is completed, the project will be expanded through personal contacts to other pediatric and adult practices. Transition forms vetted through the pilot process will be shared with sending and receiving practices. Lessons learned from the pilot will be presented at the annual conference of the Vermont Chapter of

²² Addendum 4, IHPP Community Allies.

the American Academy of Pediatrics and Vermont Academy of Family Practice, the annual Family Medicine Review Course, and at Grand Rounds at Vermont hospitals.

- A survey on transition protocols will be sent to Vermont adult primary care physicians on behalf of the Vermont Academy of Family Physicians, the Vermont Academy of Pediatricians, and the Vermont Medical Society.
- The Vermont Council of Special Education Administrators and Vermont Developmental Disabilities Council will work on expanding the transition process for special education students to include making the transition to adult health care.
- Vermont Developmental Disabilities Council and Green Mountain Self-Advocates will work with the Transition Specialist at the Vermont Department of Education to include transition to adult health care in the department's transition materials and presentations for Vermont's special educators.
- Vermont Family Network will provide families with transition guidelines and other emerging best practices for making a successful transition from pediatric to adult-focused care.
- Dartmouth-Hitchcock Medical Center has a strong quality improvement process. The issue of improving the transition from pediatric to adult care could be put forward as a focus for a quality improvement project.
- The Vermont State School Nurses' Association is in the process of revising its *Standards of Practice: School Health Services Manual*. The Vermont Developmental Disabilities Council will reach out to the association to discuss the role of school nurses in supporting students' transition from pediatric to adult-focused care in the manual.

SECTION 2: MEDICAL EDUCATION AND PROVIDER TRAINING

“Our staff has no special training on the best way to care for people with intellectual disabilities — whether it’s how to communicate or how to feel comfortable — nobody has had that training.”

— Director of a federally qualified health center

GOAL: All medical students, medical residents, other health care students, and health care providers will have access to medical education and training to attain competency and comfort in caring for adults with intellectual and developmental disabilities.

Adults with intellectual and developmental disabilities experience multiple barriers to accessing appropriate health care. Key among these is a significant lack of health care providers with adequate medical training and practical experience in caring for this population. Too often, patients with I/DD encounter providers who are uncomfortable working with them, demonstrate a lack of respect for them, and make inappropriate assumptions about their health care needs.²³ The Inclusive Healthcare Partnership Project heard from a number of self-advocates who expressed frustration that their health care providers did not take the time needed to explain things in ways that they could understand. This is unfortunate, as poor communication between the patient and the provider make it less likely that medical advice will be followed or preventative measures taken.

It should not be surprising that adult health care providers have difficulty communicating with individuals with I/DD and are ill-prepared to address their health care needs. Throughout the course of their medical education and training, almost no time has been devoted to learning about developmental disabilities and there has been little, if any, clinical training focused on treating adult patients with I/DD. Every stakeholder interviewed for the project cited the lack of adult providers with expertise and experience in working with persons with I/DD as one of the biggest challenges to improving health care for this population. Stakeholders repeatedly emphasized the importance of providing additional training at pre-service and practice levels on how to effectively communicate with and respectfully care for individuals with intellectual and developmental disabilities.

²³ Sharby, N, Martire, K, Iverson, MD, “Decreasing health disparities for people with disabilities through communication strategies and awareness.” *International Journal of Environmental Research and Public Health*, 12(3):3301-3316, 2015. See also: The Autistic Self Advocacy Network. *Our Lives, Our Health Care*. April, 2014. (<http://autisticadvocacy.org/our-lives-our-health-care-self-advocates-speaking-out-about-our-experiences-with-the-medical-system/>).

KEY FINDINGS

- In its 2009 report on the current state of health care for people with disabilities, the National Council on Disability found health care provider misinformation, stereotypes about disability, and lack of appropriate provider training to be significant barriers preventing people with disabilities from receiving appropriate and effective health care.²⁴
- Few medical schools include disabilities in their curricula, and those that do teach what is often called “the medical model” of disability. In this paradigm, disability is viewed as an impairment to be cured or overcome, rather than as a natural part of the human experience, as set out in the Developmental Disabilities Assistance and Bill of Rights Act.²⁵ To create a better understanding of the disability experience, the University of Michigan Medical School, in a collaborative effort with disability advocates, developed a curriculum for first- and second-year medical students. Students reported an increased awareness of issues affecting individuals with disabilities, a better understanding of how disability can function as part of one’s identity, and an ability to view disability within the context of both medical and social models.²⁶
- All third-year medical students at the University of South Florida are required to participate in a primary care clerkship that includes a disability-focused module. In addition to classroom lectures, students have community-based learning experiences with individuals who have physical, sensory, or intellectual disabilities. Medical students completing this module demonstrated improved knowledge, attitudes, and comfort in caring for people with disabilities.²⁷

“Has anyone else had the experience of having a doctor say essentially that you should let your child die? When my daughter was diagnosed with cancer one of the doctors she saw suggested that we shouldn’t bother with treatment; that it could be painful and confusing because of my daughter’s disabilities. The doctor we saw was pregnant and I wanted to say to her, ‘Is this the advice that you would want a doctor to give to you if your baby was sick?’”

— Family focus group participant and parent of an adult daughter with I/DD

²⁴ National Council on Disability. “The current state of health care for people with disabilities.” 2009.

²⁵ 42 United States Code, §15001(a)1.

²⁶ Sarmiento C, Miller SR, Chang E, Zazove P, Kumagal, AK, “From impairment to empowerment: A longitudinal medical school curriculum on disabilities.” *Academic Medicine*, Sep 25, 2015. (Epub ahead of print).

²⁷ Woodard LJ, Havercamp SM, Zwygart KK, Perkins EA, “An innovative clerkship module focused on patients with disabilities.” *Academic Medicine*, 87(4), April 2012.

- The institutions that accredit medical schools and residency programs (the Liaison Committee on Medical Education and the Accreditation Council for Graduate Medical Education) do not have requirements specific to intellectual and developmental disabilities.
- There are very few medical school faculty members with expertise in the care of adult patients with I/DD; typically, pediatricians are the faculty members most familiar with developmental disabilities.
- At the University of Vermont College of Medicine and Dartmouth’s Geisel School of Medicine, as is true nationwide, preclinical curricula devoted to developmental disabilities is nearly absent. At UVM, medical students touch on disability in the Generations course, which includes a one-hour lecture on intellectual disabilities, a one-hour lecture on autism, a one-hour lecture on cerebral palsy, viewing the documentary *Unforgotten: 25 Years After Willowbrook*, and a half-day disability awareness practicum. UVM College of Medicine has a pediatrics course on developmental disabilities; family medicine and internal medicine have no content courses on developmental disabilities. At Geisel, chromosome abnormalities are covered in first year biochemistry, and in year two there is an hour session on autism and a problem-based learning case on a patient with Down’s syndrome. The first-year Psychology of Illness, Patients and Providers course includes a video about the dehumanizing treatment of people with developmental disabilities.
- In 2014–2015, two Schweitzer fellows from UVM College of Medicine developed a program to help adults with I/DD be better health care advocates. In reflecting on their project, the fellows reported that they should have devoted more time to educating physicians and hospital staff about the health care challenges this population faces.
- Factors contributing to health disparities for people with disabilities include inaccurate or inadequate knowledge, as well as stigmatizing attitudes still held by some clinicians about disabling conditions. For individuals with mental health or intellectual disabilities stigma is especially problematic.²⁸
- A study of nursing, physician assistant and medical students whose clinical training included a virtual patient module involving the case of a woman with intellectual disabilities found that this training improved the students’ knowledge and reduced

²⁸ Peacock MD, Iezzoni, LI, Harkin TR, “Health care for Americans with disabilities – 25 years after the ADA.” *New England Journal of Medicine*, July 30, 2015.

their perception of difficulty in providing care to patients with intellectual and developmental disabilities.²⁹

- Volunteering with the Special Olympics Healthy Athletes program, which conducts health screenings, has a profoundly positive impact on health care professionals. Research found that after volunteering 84% of health care professionals reported a better understanding of how to work with patients with intellectual disabilities, 72% indicate a need to learn more about the specific health needs for this population, and 90% expressed a desire to pursue additional education about health issues and management of patients with intellectual disabilities. Significantly, 73% of health care professionals plan to actively seek out more patients with intellectual disabilities.³⁰
- The Affordable Care Act specifically targets disability; Section 5307 authorizes federal funding for training health care professionals in disability-related competencies and development of model curricula on needs of people with disabilities. Of critical importance is training to address the cervical- and breast-cancer screening needs of women with disabilities.³¹

RECOMMENDATIONS TO IMPROVE MEDICAL EDUCATION AND PROVIDER TRAINING

“My doctor talks directly to my mother and not to me. Sometimes it annoys me. I want to know the information he is giving to my mother. I feel really, really bad, because I am the person — the patient — that is sitting right there. I feel like saying, ‘Yoo-hoo! I’m like right over here too. I’m not invisible.’”

— Young woman with I/DD

Recommendation 1

The Vermont health care system and institutions of higher education will provide opportunities throughout the training continuum, from pre-clinical curricula to continuing medical education for physicians, nurses, and other allied health professionals to work directly with and learn from individuals with I/DD and their family members who may serve as mentors, standardized patients, presenters, panel participants, or other types of trainers.

²⁹ Boyd MS, Sanders CL, Kleinert HL, Huff MB, Lock S, Johnson, S, Clevenger K, Bush NA, Van Dyke E, Clark TL, “Virtual patient training to improve reproductive health care for women with I/DD.” *Journal of Midwifery and Women’s Health*, Vol. 53, Issue 5, Sept-Oct 2008.

³⁰ *Special Olympics*, “Serving athletes, families, and the community – The universal impact of Special Olympics: Challenging the barriers for people with intellectual disability.” 2009.

³¹ Peacock MD, Ienzzoni LI, Harkin TR, “Health care for Americans with disabilities – 25 years after the ADA.” *New England Journal of Medicine*, July 30, 2015.

Recommendation 2

In pre-clinical education, the University of Vermont, College of Medicine and the College of Nursing and Health Sciences and the Geisel School of Medicine at Dartmouth will embed training in disability competency and the care of individuals with I/DD in the broader context of teaching cultural competency and the delivery of care to medically underserved populations. Training that supports the delivery of appropriate, person-centered care to adults with I/DD includes, but is not limited to:

- History and physical examination of individuals with complex needs
- Communication skills, especially communication with people who have limited oral language and/or use augmentative and alternative communication
- Health literacy for patients with intellectual disabilities
- Non-medical determinants of health
- Care coordination, care transitions, and working within a patient-centered medical home
- Ethical issues related to decision-making, assumptions about quality-of-life, pregnancy planning, parenting capacity, and the dignity of risk³²
- Soliciting ongoing feedback from patients with I/DD and their families to assess quality of care and identify areas in need of improvement

Recommendation 3

Health care providers in Vermont will receive disability competency training and information about best practices in easy-to-access formats, including electronic media that use provider time efficiently. Incentives such as continuing medical education credits or enhanced reimbursement will be linked to acquiring skills through these training options. Opportunities to teach explicitly about delivering appropriate, person-centered care to adults with I/DD include, but are not limited to, training in:

- History and physical examination of patients with I/DD
- Disability etiquette and culture
- Accommodations for people with cognitive differences and communication challenges, including people who have limited oral language and/or use augmentative and alternative communication
- Systems of care and social supports available to adults with I/DD, including peer support and self-advocacy
- Supported decision-making with adults with I/DD and related legal and ethical issues

³² “Dignity of risk” refers to the right to take risks when engaging in life experiences and the right to fail in taking these. The dignity of risk acknowledges that life comes with risk and part of living a full life includes experiencing both success and failure.

- Principles of universal design and the use of tools that support health literacy for people with I/DD
- Soliciting ongoing feedback from patients with I/DD and their families to assess quality of care and identify areas in need of improvement

Recommendation 4

The Vermont Medical Society and other professional health care associations will vigorously promote training and education opportunities for health care providers at all levels to acquire disability competencies, including those outlined in the Vermont Health Care Innovation Project’s six Disability Awareness Briefs.

OPPORTUNITIES AND ALLIES

“I never can do that (a breast self-exam), because I don’t understand the instructions. I wish they would do a visual example with me while I’m at the doctor’s, so that I can understand it when I go home. They just explained the instructions; they didn’t really show me anything. So it’s hard for me to learn.”

— Self-advocate with intellectual disabilities

The Inclusive Healthcare Partnership Project has been fortunate to connect with key leaders at the University of Vermont College of Medicine, University of Vermont Medical Center, Dartmouth Geisel School of Medicine, Dartmouth-Hitchcock Medical Center, Vermont Medical Society, Vermont Family Network, and Vermont Special Olympics who have offered to work within their respective institutions and organizations to improve medical education and provider training in communicating with and caring for adults with intellectual and developmental disabilities.³³

- There are a number of opportunities at the University of Vermont, College of Medicine and within the University’s Medical Residency and Fellowship Programs to work with existing curricula and programs to include a focus on caring for patients with I/DD.
 - The Clinical Simulation Laboratory, a collaborative effort of UVM College of Medicine, UVM College of Nursing and Health Sciences, and the University of Vermont Medical Center, provides hands-on learning interacting with standardized patients in settings that reflect actual health care settings. Adults with I/DD could be recruited and trained to be standardized patients. Transition of care communication skill exercises could also be integrated into this experience.

³³ Addendum 4 - IHPP Community Allies.

- Learning about medically underserved populations (racial minorities, LGBT, refugees) and how to care for patients who experience health disparities is a thread that is woven throughout medical education at UVM. Meeting the needs of patients with I/DD, who are also part of a medically underserved population, could be integrated with the College of Medicine’s existing clinical skills training. For example, adult patients with I/DD could be included in Doctoring Skills, a clinical skills development course, and as part of Doctoring in Vermont, a longitudinal primary care experience in the first year and a half of medical school.
 - Completion of a community-based public health project is a requirement for UVM medical students. Projects are designed to teach students about public health issues facing communities and include students working side by side with groups, organizations, and individuals in the community. Working to improve health care access and outcomes for adults with I/DD could be an option for a public health project.
 - Exploring critical ethics issues is already a part of UVM’s medical education. In the provision of care to patients with I/DD there are a number of complex ethical issues to consider, including: challenging hidden assumptions about disabilities, assessing decision-making capacity, addressing sexuality and pregnancy planning issues, including child-rearing capacity, and fostering appreciation for the individual’s quality of life.
 - The Albert Schweitzer Fellowship is dedicated to preparing the next generation of professionals to address the underlying causes of health inequities. Two UVM College of Medicine Schweitzer Fellows for 2014–2015 worked with adults with I/DD and offered to help in whatever way they could to alleviate health disparities for this population.
 - Clerkships in Pediatrics, Family Medicine, and Outpatient Internal Medicine could integrate training on the transition from pediatric to adult care as a general theme, as well as including a specific focus on caring for adult patients with I/DD.
- Within Geisel School of Medicine at Dartmouth and Dartmouth-Hitchcock Residency and Fellowship Programs there are opportunities to enhance existing curricula and clinical training to include both information about intellectual and developmental disabilities and personal interactions with individuals who have I/DD.
 - The Patient Partner Program pairs first year medical students with an older person struggling with illness or the difficulties of aging (occasionally students are paired with children with chronic diseases). Partners meet at least five times a year in the patient’s home or in the community; this provides medical students with an opportunity to understand how illness or disability affects the daily life of their partner. Adults with I/DD could be included in the group

of patient partners. Throughout the program students meet to talk collectively about what they are learning; including just a few adults with I/DD as partners in this program would have a significant impact on the whole class.

- On Doctoring is a two-year course that provides medical students with their first exposure to clinical medicine. Students learn the basics of interviewing patients, taking medical histories, performing physical examinations, and understanding the patient/physician relationship. The course includes sessions on shared decision-making and health literacy and numeracy.
- The Psychology of Illness, Patients, and Providers includes two years of required content that is synergistic with the On Doctoring curriculum. These sessions assist students in understanding responses to illness from the perspective of patients, families, health care providers (including themselves), and communities.
- Reflective rounds which occur in most third year required clerkships offer opportunities to reflect on both joyful experiences and difficult issues that students encounter with patients.
- Schwartz Compassionate Care Rounds in pediatrics and adult services offer an opportunity for care providers from all disciplines and stages of training to share discuss, and process challenging or emotionally difficult problems encountered in providing clinical care. A Compassionate Care session involves a single case and features a small panel of providers who were involved in the case or who have relevant expertise and a facilitated discussion with the audience.
- Patient Support Corps trains medical students from Geisel School of Medicine to support patients at Dartmouth-Hitchcock Medical Center in issues of shared decision making. These student volunteers assist patients in a highly structured process to develop question lists prior to appointments and provide support during the appointment by taking notes and doing an audio recording for patients. After the appointment, students debrief with patients to make sure all questions are answered and that patients have a good understanding of any health care decisions resulting from the visit.
- Albert Schweitzer Fellowship programs offers opportunities for medical students to engage in mentor-directed service projects to improve health outcomes for underserved populations.
- Dartmouth-Hitchcock Medical Center's Patient Safety Training Center offers multidimensional learning experiences in a simulation environment, which includes working with standardized patients.
- Geisel School of Medicine has a curricular review and renewal process that charges small vertical integration groups comprised of faculty and students to develop school-wide recommendations on specific topics. These groups are charged with integrating material over the four-year curriculum and defining

competencies that all graduates should demonstrate. A vertical integration group could be requested on care of patients with intellectual and developmental disabilities.

- The library at Geisel has produced compendiums of educational materials on specific topics. A request could be made to compile a compendium on intellectual and developmental disabilities.
- The Vermont Developmental Disabilities Council, in collaboration with the Vermont Family Network, Green Mountain Self-Advocates, and the Federation of Families for Children’s Mental Health has been awarded a \$175,000 grant through the Vermont Health Care Innovation Project to develop 20 hours of on-line training curricula for care coordinators and health care providers. The trainings, which will expand upon the VHCIP’s six Disability Awareness Briefs developed by the Pacific Health Policy Group, will cover a wide range of disability issues, including accessibility and universal design, communicating with people with I/DD, trauma-informed care, and working with culturally and linguistically diverse populations.
- Dartmouth-Hitchcock Medical Center has a corps of trained Patient Navigators; these volunteers provide patients and their families with information, connections to resources, and emotional support. The Medical Center could train Patient Navigators to support adults with I/DD. These Navigators could provide valuable feedback to Dartmouth-Hitchcock about the health care experiences and challenges for this population.
- Dartmouth-Hitchcock Medical Center regularly captures patients’ stories about their experiences with the Medical Center. These stories provide important information for quality improvement; selected patient stories also are featured on the Center’s website. Stories from adult patients with intellectual and developmental disabilities could be solicited.
- The Office of Continuing Medical Education at the University of Vermont Medical Center sponsors a full series of annual postgraduate medical conferences. The majority of these conferences (Women’s Health, Obesity, Patient and Family Centered Care, Transforming Primary Care, Emergency Medicine, Family Medicine) would benefit from including presentations on care for adults with I/DD. The office is also a sponsor of the Accreditation Council for Continuing Medical Education (ACCME) and provides assistance in preparing the CME Application for Credit to organizations delivering health care provider training.
- There are opportunities within the UVM’s Office of Primary Care and Area Health Education Centers Program to provide medical students, residents and health care providers with training on caring for adults with I/DD.

- Green Mountain Self-Advocates can help to identify and provide support to adults with I/DD who could serve as standardized patients, share their personal stories in a classroom setting, or be co-presenters at Grand Rounds or other trainings for practicing physicians.
- Vermont Family Network could broaden the scope of its Family Faculty Program beyond pediatrics to include presentations to medical students who are pursuing careers in adult medicine.
- Vermont Special Olympics Healthy Athletes program offers health screenings for audiology, vision, dental, physical therapy, and overall health and well-being. Healthy Athletes screenings are scheduled for the Special Olympic Summer Games in Burlington. The Vermont Developmental Disabilities Council and Vermont Special Olympics will work with University of Vermont College of Medicine and College of Nursing and Health Sciences and the Vermont Medical Society to recruit practicing health care providers and medical and nursing students to conduct health screenings.

SECTION 3: CARE DELIVERY AND PRACTICE TRANSFORMATION

“I was involved with a woman who had breast cancer that had gone into her bones. She woke up with a compound fracture to her arm and went to her local hospital. When I went to see her, they had taken care of her arm and wanted to release her. I kept asking questions about whether it was safe to send her home. Her home provider had no training on how to do transfers safely and how to move her. Finally, they agreed to keep her and she ended up staying a week in the hospital while things got put in place. They were treating the symptom that was the arm and not treating the underlying problem or doing what was needed to ensure she could get home and be safe.”

— Developmental Services Nurse

GOAL: All adult Vermonters with intellectual and developmental disabilities will have access to coordinated quality health care that accommodates their cognitive, physical, and communication needs.

Adults with intellectual and developmental disabilities struggle with a health care system that is not responsive to their needs. A lack of health care professionals with training and experience in caring for people with disabilities, inaccessible health care facilities and medical equipment, and payment mechanisms that do not reimburse providers for the additional time needed to deliver culturally competent care all contribute to poor health outcomes for this population. Preventable health problems go unaddressed and secondary conditions such as pain, fatigue, and depression that may be associated with disability are exacerbated. In addition, the failure to provide accessible and effective primary care results in the inappropriate and excessive use of hospital emergency care by adults with I/DD.

In addition to improved access to high quality, culturally competent care, adults with I/DD would also benefit from care coordination. An effective care coordinator works with the patient, family, involved health care providers, and community-based services to ensure that the needs of the whole person are identified and addressed. Stakeholders interviewed for the IHPP were in agreement that quality care coordination is a critical determinant in whether or not a practice is able to meet the needs of patients with I/DD. In the absence of coordinated care, it is much more difficult for individuals with intellectual disabilities to follow through on medical advice and maintain the positive practices needed for good health.

KEY FINDINGS

“Our son Patrick has cerebral palsy, an intellectual disability, and is totally blind. He requires total care and relies on others to transfer him in and out of bed from his wheelchair, on and off his shower chair, etc. Ever since he’s gotten “big” (he now weighs close to 175 pounds), I am unable to get him onto a doctor’s examining table. For the last 10+ years, Patrick has remained in his wheelchair for all his exams, including those done by his family doctor and all of his specialists. In my opinion, this compromises the medical examination. A high/low adjustable height table would make the transfer very quick and easy.

“Weight management and control are important for Patrick’s health and important for all his caregivers’ health. Currently, we are working very hard to decrease his calories while trying to increase his activity level. Keeping track of his weight is critical. His doctor’s office does not have a scale that will accommodate Patrick in his chair. In order to weigh Patrick, I have to take him to our veterinarian and ask to use the large dog scale. I wheel him onto the scale in his chair, and then take the total weight minus the weight of the chair. It’s no easy task. Let’s just say Patrick doesn’t get weighed very often!”

— Patrick’s mother and member of the IHPP Planning Team

- While it has been 25 years since passage of the Americans with Disabilities Act (ADA), many health care settings and most medical equipment remain inaccessible. Individuals with disabilities often do not receive thorough examinations because scales, examination tables, mammography systems, and other medical equipment cannot accommodate a patient’s disability. Disparities in accessing health care can be reduced by implementing standards for accessible medical equipment and close monitoring of ADA and ACA compliance for health care facilities and medical equipment.³⁴
- The Centers for Disease Control and Prevention emphasizes that accessibility to health care applies to both physical access and communication. Health care providers need to know how to effectively communicate with a wide variety of patients with disabilities, including those with intellectual disabilities.³⁵
- The U.S. Access Board, in collaboration with the Food and Drug Administration, is in the final stages of promulgating standards for accessible medical equipment. Availability of accessible equipment should increase the use of preventive services

³⁴ Krahn, GL, Walker, DK, Correa-De-Araujo, R, “Persons with disabilities as an unrecognized health disparity population.” *American Journal of Public Health*, Vol. 105, No 52, April 2015.

³⁵ *Center for Disease Control website* — <http://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html>.

and improve safety for health care staff by reducing the risk of injury during patient transfers.³⁶

- Adults with significant developmental disabilities who need anesthesia and other supports when receiving routine tests or preventative care do not have access to a specialty clinic equivalent to what children and youth access at the Pediatric Sedation Comfort Zone at the University of Vermont Medical Center or the Pain Free Clinic at the Children’s Hospital at Dartmouth-Hitchcock Medical Center. Staff at the Comfort Zone estimate that they receive four to six inquiries per month by families seeking this level of care for an adult with complex disabilities.
- Unable to access routine health care from community-based primary care providers, individuals with I/DD turn to the hospital emergency room for their health care. A review of Vermont Medicaid claims data finds that Vermonters with developmental disabilities visit the emergency room twice as many times per year as Vermonters without I/DD. Moreover, 38–44% of those visits were for non-emergent issues where care could have been delivered in a primary care setting.³⁷
- Individuals with complex chronic health conditions that require a variety of medical and social services are responsible for a large share of the overall cost of health care and social supports, yet often have the worst outcomes. Typically, their care is fragmented with agencies and health care providers failing to communicate with one another about the patient’s history or plan of care. The result is patient confusion, poor patient compliance, unnecessary tests, duplication of services, and uncontrolled costs.³⁸
- CareConnect, a pilot program in southern New Hampshire, provides intensive, coordinated care management for adults with I/DD. Five participants in the program met the criteria as high utilizers of hospital emergency rooms (criteria being more than three ER visits in a six-month period that did not result in a hospital admission). Eighteen months after enlisting in CareConnect, emergency room visits for four participants in a six-month period were reduced from 4 to 0, 10 to 3, 22 to 14, and 36 to 28. (The fifth participant moved midway through the project. Prior to leaving the state, his emergency room admissions in a six-month period fell from 36 to 5).
- Studies in the United Kingdom, New Zealand, and Australia have found incorporating regular health-check interventions as part of primary care for adults with I/DD has

³⁶ Peacock, MD, Ienzzoni, LI, Harkin, TR, “Health care for Americans with disabilities — 25 years after the ADA.” *New England Journal of Medicine*, July 30, 2015.

³⁷ Addendum 3.

³⁸ Vermont Program for Quality in Health Care, “Assisting communities in providing better coordinated care: The integrated communities care management collaborative.” *VPQHC, Annual Quality Report*, 2015.

been effective in identifying unreported and unmet health needs.³⁹ Furthermore, adults with I/DD who received in-home health-check interventions were found to have lower health care costs as compared to their peers who received only standard care.⁴⁰ Dr. Clarissa Kripke, a national leader in the emerging field of developmental medicine, has identified home-based evaluation prior to a primary care visit as the single most effective strategy in improving health for this population.⁴¹

RECOMMENDATIONS TO IMPROVE CARE DELIVERY FOR ADULTS WITH I/DD

“We need support with medication management. A lot of emergency room admissions come from people being isolated and struggling to manage multiple meds on their own and not being successful.”

— Community Health Team leader

“It can be, you know, too much information ... If it’s more than one medication that has so many different ways of when you have to take it. That can be a little bit too much in your head.”

— Self-advocate

“The measure of success is on how quickly you can see patients.”

— Vermont Health Care Provider

Recommendation 1

Vermont Medicaid will support health checks by a registered nurse who makes a home visit for screening and assessment prior to an annual physical for adults with intellectual and developmental disabilities who are at high risk for multiple health issues.

Recommendation 2

As a medically underserved population, Vermont adults with I/DD will have access to comprehensive care management provided by professionals trained in the disability competencies outlined in Vermont’s Disability Awareness briefs. Vermont’s health care system will provide adults with I/DD care coordination that is consistent, sustained over time, and provided regardless of whether or not the individual qualifies for community-based supports and services. Preventative health care is a critical component of care management; adults with I/DD will be referred for and receive routine screening exams such as mammograms and colonoscopies that are consistent with clinical practice guidelines.

³⁹ Felice, D, Baxter, H, Lowe, K, Dunstan, F, Houston, H, Jones, G, Felice, J, Kerr, M, “The impact of repeated health checks for adults with intellectual disabilities.” *Journal of Applied Research in Intellectual Disabilities*, 21, 2008.

⁴⁰ Romeo, R, Knapp, M, Morrison, J, Melville, C, Allan, L, Finlayson, J, Cooper, SA, “Cost estimate of health-check intervention for adults with intellectual disabilities in the UK.” *Journal of Intellectual Disability Research*, Vol. 53, Part 5, May 2009.

⁴¹ Kripke, Clarissa, MD. “Supporting Successful Community Living: the CART Model of Health Service Delivery,” presentation at the annual meeting of the American Academy of Developmental Medicine and Dentistry. July 28, 2016.

Recommendation 3

Vermont’s health care system will develop the capacity to offer specialty care to adults with significant intellectual and developmental disabilities who need sedation and other supports for routine preventative care, including dental procedures, as well as for episodes of acute care. The specialty clinic will serve as a teaching site for medical students and residents and a focal point for expertise in the delivery of care to adults with I/DD.

Recommendation 4

The Vermont Agency of Human Services, in collaboration with Vermont Independent Living, Green Mountain Self-Advocates and other agencies, will assess the accessibility of health care settings in Vermont. Their review will include physical accessibility of facilities and medical diagnostic equipment such as examination tables, weight scales, radiological and mammography equipment, and the availability of health records and health information in cognitively accessible formats.

Recommendation 5

Medicaid and private carriers will ensure that health care providers are reimbursed for the additional time it takes to provide quality consultation, assessment, and clinical care for adults with intellectual and developmental disabilities.

OPPORTUNITIES AND ALLIES

The State of Vermont is committed to health care reform and has devoted considerable time and resources to making improvements in health care access and delivery, while reducing the cost of care. The Inclusive Health Care Partnership Project is part of this effort and has made connections with other state initiatives including, Community Health Teams, Health Care Learning Collaboratives, and the Vermont Chronic Care Initiative, to explore

“There can be a lot of ego involved. My daughter was in the local hospital to have surgery on her back. After surgery she was having three to five seizures a day, way more than usual. I asked the doctors at the hospital to talk with her neurologist at Dartmouth. They refused to do that. I was even told, ‘Why didn’t you go there for her back surgery?’ even though this is our local hospital.”

— Mother of an adult daughter with I/DD

“It is really hard to find a dentist to see my son. He has to be under anesthesia for any dental care. The dentist he has now keeps saying, ‘He’s fine. Let’s wait before we do anything.’ I don’t think he is getting the level of care that he needs.”

— Mother of an adult son with I/DD

how they can address the needs of adults with I/DD within the scope of their work. IHPP partner agencies, the Vermont Developmental Disabilities Council and Green Mountain Self-Advocates, are collaborating with University of Vermont Medical Center and Dartmouth-Hitchcock Medical Center on a number of projects to improve care for their adult patients with I/DD.⁴²

- University of Vermont Medical Center is considering how to more appropriately address the need for adults with I/DD, who often seek care at their Pediatric Sedation Comfort Zone. In April 2016, the Medical Center is bringing Dr. Matt Holder, Executive Director of the American Academy of Developmental Medicine and Dentistry and founder of the Lee Specialty Clinic in Lexington, Kentucky, to provide consultation on how to address this issue.
- Some Vermont Community Health Teams have begun working with hospitals to have the intake/patient assessment process include questions to identify the agencies and services that are providing supports to the individual.
- The Community Health Team in Windham County has found that making home visits has enabled them to serve their patients more effectively. Having home visits available through all Community Health Teams would improve health outcomes for vulnerable individuals, including adults with I/DD.
- Northern Counties Health Care, Vermont's largest system of Federally Qualified Health Centers, is interested in piloting a program for adults with I/DD that would include a home visit by a nurse prior to the patient's annual medical appointment.
- The Vermont Chronic Care Initiative, a statewide program through the Department of Health Access, provides care coordination and intensive case management services to non-dually-eligible Medicaid beneficiaries with one or more chronic conditions. The program is focusing on improving care and reducing costs for the top 5% of Vermont Medicaid beneficiaries with the highest utilization.
- The Integrated Communities Care Management Learning Collaborative is a pilot program to implement integrated care management in Rutland, Saint Johnsbury, and Burlington. These participating communities are testing promising models for improving care coordination and services, reducing duplication and gaps in services, and improving the health care experience and outcomes.
- Dartmouth-Hitchcock Medical Center's Emergency Department is developing and piloting a Health Passport for emergency department patients with intellectual and developmental disabilities.

⁴² Addendum 4 - IHPP Community Allies

SECTION 4: HEALTH AND WELLNESS

“My doctor really cares about my weight. Before I started this program (working with a dietician) I was almost 400 pounds and now I am down to 312. And I have a partner in crime – my trainer (my good friend and running partner). We run 5-Ks; that’s how we got these shirts.”

— Participant in a self-advocate focus group

“Many things that public health pays for and promotes like healthy living practices are not designed for people with disabilities to participate in — things like wellness programs and exercise programs.”

— Administrator, University Center for Excellence in DD

GOAL: All adult Vermonters with intellectual and developmental disabilities will be able to benefit from State and local health promotion initiatives and be supported to fully participate in community health and wellness programs.

As compared to the general population, individuals with disabilities have higher incidences of obesity, are less likely to engage in regular exercise, and experience significantly higher rates of preventable health problems including heart disease, diabetes, and hypertension. In spite of being in poorer overall health, people with disabilities are excluded from public campaigns to promote wellness and are not supported to take greater responsibility for their own health.

Adults with intellectual and developmental disabilities, like the general population, are healthier if they exercise regularly, eat a balanced diet, and don’t smoke. More needs to be done to communicate this message effectively to adults with I/DD and to support their adoption of good health habits. Successful health promotion includes providing cognitively accessible information, tailoring community health and wellness programs to meet the needs of this population, and training direct care staff on how to effectively support the individual to make healthier choices. Vermont’s strong self-advocacy network can play an important role in helping adults with I/DD develop greater self-determination in taking control of their health.

KEY FINDINGS

- For adults with disabilities, the biggest challenge is not the disability itself, but rather the experience of being socially isolated, which may lead to anxiety, obesity, diabetes, and depression.⁴³
- There is no reason that poor physical and mental health should be a common feature of disability. Many of the health problems encountered by individuals with disabilities are preventable given access to medical care, attention to health promotion and disease prevention, and improved social circumstances.⁴⁴
- People with disabilities should be included in public health programs, practices, and research. Instituting specific policies and practices for including people with disabilities into mainstream programs often improves the ability for *all* people to participate. Facilities should be wheelchair accessible, and information should be accessible to people who have trouble with vision, hearing, or understanding complex information.⁴⁵
- Self-advocacy is good for your health. Becoming knowledgeable about one's own health, informed about health resources, and participating in health promotion activities leads to improvements in health and well-being for adults with I/DD. Acquiring health advocacy skills not only increases people's ability to change their own behavior, it also makes them effective role models for their peers. Developing a collective approach to health advocacy can promote social change to improve health care for people with I/DD.⁴⁶
- Smart devices such as iPhones, iPads, and other touch screen tablet computers, with built in scheduling and multimedia capabilities, offer many ways to use technology as a support for a variety of self-directed health care activities by persons with I/DD. These include dietary management and meal preparation, coached exercise programs, and self-management routines for chronic and episodic health conditions such as taking your own blood pressure.⁴⁷
- In reviewing over 80 tools related to health care (curricula, apps, worksheets, etc.)

⁴³ Hanks, C, "Transition from pediatric to adult care 'takes a village' for patients with developmental disabilities." *Infectious Diseases in Children*, June 2015.

⁴⁴ Krahn, GL, Hammond, L, Turner, A, "A cascade of disparities: Health and health care access for people with intellectual disabilities." *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 2006.

⁴⁵ Krahn, GL, Walker, DK, Correa-De-Araujo, R, "Persons with disabilities as an unrecognized health disparity population." *American Journal of Public Health*, Vol. 105, No. 52, April 2015.

⁴⁶ Marks, B, Sisirak, J, "Health matters for people with intellectual and developmental disabilities: Take charge!" *National Gateway to Self-Determination*, Issue 3, Sept 2012.

⁴⁷ Stock, SE, Davies, DK, O'Hara, D, "Self-determination, technology, and health." *National Gateway to Self-Determination*, Issue 3, Sept 2012.

Green Mountain Self-Advocates found that, while promising, many of these resources would need to be adapted in order for individuals with intellectual and developmental disabilities to use them effectively. In particular, there is very little health information that is written and graphically designed to meet the needs of people with I/DD.⁴⁸

- A project conducted by 2014–2015 Schweitzer Fellows to improve health for adults with I/DD through education and self-advocacy training, found project participants had a strong interest in health and were excited about learning how to make effective lifestyle changes, such as increased exercise and healthier diets. The Schweitzer Fellows also reported that developmental services staff wanted concrete advice on how to support their clients to better manage their health and to be more aware of preventative health measures.
- Special Olympics Healthy Athletes program offers free health screenings and information about health services. 2015 health screenings found that nationally 60% of Special Olympic athletes were obese or overweight, 40% had untreated tooth decay, 40% needed eyeglasses and 20% had an eye disease, and 30% failed a hearing test. Vermont Special Olympic athletes fared worse than their national counterparts in obesity, hearing, and vision screening. Of the 65 Vermont athletes screened for vision, nearly 90% failed the screening and 32% had eye diseases. Special Olympic organizers provided 38 Vermont athletes with prescription eyewear.⁴⁹

RECOMMENDATIONS TO IMPROVE HEALTH AND WELLNESS FOR ADULTS WITH I/DD

“Experiences at the local and state levels suggest that the key ingredients for success are building strong and long-lasting collaborations with diverse stakeholders and partners, identifying common goals, and integrating persons with disabilities into all facets of public health activities.”

— CDC Grand Rounds

Recommendation 1

The Green Mountain Care Board and the Vermont Health Care Innovation Project will recognize adults with intellectual and other developmental disabilities as a medically underserved population. As such, adults with I/DD should receive the same consideration, benefits, opportunities, and assistance provided to other populations with this designation.

Recommendation 2

⁴⁸ For a working document that lists the tools reviewed by GMSA, see: [link](#)

⁴⁹ *Special Olympic Health Research*, June 23, 2015.

The Vermont Department of Health will consider the unique needs of adults with intellectual and developmental disabilities in all of its health promotion and disease prevention efforts.

Recommendation 3

The Vermont Department of Health will include disability as a demographic (similar to sex, age, gender, race, etc.) in periodic public health surveillance activities. Vermont's All Payer Claims Database will have the capacity to track the health status of Vermonters with I/DD.

Recommendation 4

Green Mountain Self-Advocates will create and promote the use of a Health Passport to help adults with intellectual and developmental disabilities communicate with health care providers in clinic and hospital settings. The Health Passport, available either in paper format or as a digital app, will include concise information about accommodations and communication preferences; contact information for key people (family, friends, support providers) and the primary care physician; and critical personal health information, including diagnoses, allergies, and pertinent past medical history.

Recommendation 5

Green Mountain Self-Advocates will recruit strong peer leaders (self-advocates) to participate in the *Health Messages* program, which teaches people with I/DD to become Healthy Lifestyle Coaches. These trainers will take the lead in developing and promoting a Vermont *Health Messages* campaign and will collaborate with local GMSA groups to present *Health Messages* workshops throughout the state.

Recommendation 6

The Vermont Department of Disability, Aging, and Independent Living will require that direct support professionals working with adults with I/DD receive training in how to support an individual with I/DD to achieve a healthy lifestyle and to become a well-informed health care consumer.

OPPORTUNITIES AND ALLIES

As the lead organizations for the Inclusive Health Care Partnership Project, the Vermont Developmental Disability Council and Green Mountain Self-Advocates are committed to continuing their efforts to improve health and wellness for adults with intellectual and developmental disabilities. They will be working with partners in the Vermont Department of Public Health; Vermont Department of Disability, Aging, and Independent Living; Vermont Department of Health Access; Vermont Department of Education; Vermont

Special Olympics; and the Vermont Medical Society to put in place policies and practices that will improve the overall health and wellness for this population.⁵⁰

- Green Mountain Self-Advocates will promote the use of a Health Passport by providing training to youth and adult self-advocates in a variety of venues including, GMSA’s annual Voices and Choices Conference, the Vermont Special Olympics Healthy Athlete annual Health Promotion event, and state and local GMSA meetings.
- Green Mountain Self-Advocates and the Vermont Developmental Disabilities Council will work with the Department of Public Health to increase the participation of adults with I/DD in health and wellness activities. GMSA will develop cognitively accessible materials that support existing public health initiatives for the Department of Public Health’s website. This accommodation is similar to the Department’s providing information in multiple languages on its website.
- On October 6, 2015 Governor Peter Shumlin signed an executive order to establish the Health in All Policies Task Force across nine state agencies and departments to look at opportunities to include health as a factor in regulatory, programmatic, and budgetary decisions and to promote collaboration across member agencies and departments to improve health for Vermonters while reducing health care costs. The Vermont Developmental Disabilities Council will seek to present the Inclusive Health Care Planning Project findings and recommendations to the task force.
- The US Department of Health and Human Services recently proposed new regulations clarifying protections for people with disabilities in regards to health care and insurance coverage. The proposed rules mandate that health care providers “make reasonable modifications in policies, practices or procedures when necessary to avoid discrimination on the basis of disability.
- Section 4302 of the Affordable Care Act (ACA) calls for enhanced public health surveillance that includes collecting systemic and consistent data on populations affected by health disparities, including people with disabilities.⁵¹ This ACA provision supports IHPP’s recommendation that the State improve its ability to track the health status for Vermonters with disabilities.
- The Vermont Training Consortium or a related group, in collaboration with Green Mountain Self-Advocates, will develop and implement health promotion training for direct support professionals.
- Leadership at the Vermont Department of Public Health has expressed an interest in

⁵⁰ Addendum 4 — IHPP Community Allies.

⁵¹ Peacock, MD, Iezzoni, LI, Harkin, TR, “Health care for Americans with disabilities — 25 years after the ADA.” *New England Journal of Medicine*, July 30, 2015.

periodically measuring the health status and health care utilization of Vermonters with I/DD to track improvements over time. They are particularly interested in looking at rates of mammography for women with I/DD.

MOVING FORWARD

“Largely avoidable chronic illnesses are a growing burden for the state and its people, and negatively affect Vermonters’ productivity, quality of life, life expectancy, and health care costs. Health is an outcome of a wide range of factors, many of which lie outside the activities of the health sector and require a shared responsibility and an integrated and sustained policy across government.”

— Governor Peter Shumlin
Executive order establishing the Health in All Policies Task Force

Adults with intellectual and developmental disabilities in Vermont and across the nation experience immense disparities both in health and health care. As compared to the general population, they have a higher incidence of preventable diseases, face greater obstacles to accessing care, are less likely to receive adequate health services, and have significantly poorer overall health. In looking at the experience for adult Vermonters with I/DD, the Inclusive Health Care Partnership Project found a dramatic absence of transition planning from pediatric to adult care, few providers with formal training or practical experience caring for this population, a lack of accessible medical facilities and equipment, and woefully inadequate care coordination. These problems are exacerbated by a health care financing system that does not reimburse providers for the additional time and attention needed to deliver quality care to patients with I/DD. In addition, public health campaigns and initiatives are not directed to individuals with disabilities and there is little effort to support their participation in community wellness programs.

IHPP partner agencies, the Vermont Disability Council and Green Mountain Self-Advocates, and the project Planning Team understood from the beginning that if they were going to make a difference they would need to go beyond documenting problems and compiling recommendations. Throughout the course of this project, IHPP staff and Planning Team members worked to make connections with leaders in medical education, health care, developmental services, special education, and public health. They asked for help identifying the barriers to care and solicited ideas for what could be done to make things better. Significantly, they invited people to look to their own organizations and networks for opportunities to improve health outcomes for adult Vermonters with I/DD. Almost without exception, people found ways that they could help and have reached out to colleagues to work with them. Committed allies are expanding training for health care providers, developing better transition practices and innovative approaches to care, and supporting participation in community health and wellness programs. Moving forward, Vermont has the opportunity not only to bring about needed changes at home, but to play a leadership role in helping other states improve health care and health outcomes for adults with intellectual and developmental disabilities.

ADDENDA

1. IHPP Planning Team Members and Staff
2. National Experts Interviewed for IHPP
3. IHPP Community Allies
4. Findings from review of Vermont health Medicaid claims data.

ADDITIONAL INFORMATION & RESOURCES

COMPILED BY THE INCLUSIVE HEALTHCARE PARTNERSHIP PROJECT

1. IHPP Stakeholder Interviews: Findings and Recommendations
2. IHPP Report on Self-Advocate and Family Focus Groups
3. Tools and Resources for Improving Care for Adults with I/DD

ADDENDUM 1

STAFF AND PLANNING TEAM MEMBERS

Project Staff

Kirsten M. Murphy, Project Director
Executive Director, Vermont Developmental Disabilities Council

Susan Covert, Project Coordinator
Independent Consultant

Nicole LeBlanc, Project Assistant
Advocacy Director, Green Mountain Self-Advocates

Skye Peebles, MPH, Project Consultant
Program and Development Director, Green Mountain Self-Advocates

Planning Team Members

Kaiya Andrews
Green Mountain Self-Advocates

Dr. Allyson Bolduc
University of Vermont Medical Center, Family Medicine

Rachel Colby
Green Mountain Self-Advocates

Dr. Mia Hockett
University of Vermont Medical Center, Department of Internal Medicine

Dr. Patricia Lanter Dufty
Dartmouth Hitchcock Medical Center, Department of Emergency Medicine

Mary Ann Lewis, OT
Family Caregiver

Carla Manning, RN
Washington County Mental Health

Taylor Terry
Green Mountain Self-Advocates

ADDENDUM 2

NATIONAL EXPERTS INTERVIEWED FOR THE IHPP

- **Val Bradley** — Founder and President of Human Services Research Institute, Past Chair of the President’s Committee on People with Intellectual Disabilities, and President of the American Association on Intellectual and Developmental Disabilities.
- **Alexandra Bonardi** — Medical School, Senior Policy Specialist and Director National Core Indicators Project, Human Services Research Institute, and Clinical Assistant Professor at the University of Massachusetts, and past Director of the Center for Developmental Disabilities Evaluation and Research at the Shriver Center.
- **Carl Cooley, MD** — Medical Office at Crotchet Mountain, Medical Director for the Center for Medical Home Improvement, Co-founder and Co-Director of Got Transition — the National Health Care Transition Center.
- **Martha Hodgesmith, JD** — Associate Director, Kansas University Research and Training Center on Independent Living; Board Member of the National Council on Independent Living; developer and Manager of the Kansas Medicaid Fraud Control Unit; and past Chair of the National Policy Work Group of the National Association of State Directors of Developmental Disabilities Services.
- **Matthew Holder, MD** — President of the American Academy of Developmental Medicine and Disability, CEO of Lee Specialty Clinic, Global Medical Advisor, Special Olympics, Vice President of the Council on Developmental Disabilities.
- **Clarissa Kripke, MD** — Clinical Professor of Family and Community Medicine and Director of the Office of Developmental Primary Care at the University of California San Francisco, School of Medicine.
- **Beth Marks, PhD, RN** — Senior Research Specialist, University of Illinois at Chicago; Associate Director for Research in the Rehabilitation and Training Center on Aging and Developmental Disabilities; President of National Organization of Nurses with Disabilities; and nationally recognized expert in evidence-based practices promoting health and wellness for people with disabilities.
- **Dorothy Nary, PhD** — Research Associate, University of Kansas, Research Group on Rehabilitation and Independent Living; Member Equal Health Opportunity Committee of the American Public Health Association and the Board of the Rehabilitation Engineering Research Center on Recreational Technologies and Exercise Physiology Benefitting Persons with Disabilities.

- **Amanda Reichard, PhD** — Research Assistant Professor, University of New Hampshire Institute on Disability, member of the National Institute for Health (NIH) Expert Panel on Adults with Developmental Disabilities, and through the NIH conducting research on high utilizers of health care.

ADDENDUM 3

COMMUNITY ALLIES FOR THE IHPP

The following individuals are working within their respective organizations and professional networks to improve health care for adults with intellectual and developmental disabilities. This is sample of the many Vermont leaders who have expressed their commitment to this issue.

Green Mountain Self-Advocates

- Nicole LeBlanc, Advocacy Director
- Skye Peebles, MPH, Program and Development Director
- Karen Topper, Administrative Director

Geisel School of Medicine, Dartmouth

- Trisha Lanter Dufty, MD, Department of Emergency Medicine
- Joseph O'Donnell, MD, Department of Oncology, retired

Transition Project, Chittenden County

- Allyson Bolduc, MD
- Barbara Frankowski, MD
- Alison Landry, MD
- Kathy Mariani, MD
- Jill Rinehart, MD
- Aaron Rieter, MD
- David Zigelman, MD

University of Vermont, College of Medicine

- Mark Levine, MD, Associate Dean for Graduate Medical Education, Internal Medicine
- Mia F. Hockett, MD, MPH, Department of Internal Medicine
- Monica Modlinski, MD, Department of Anesthesiology
- Patricia Fisher, MD, Department of Family Medicine
- Stephen Contompasis, MD, Department of Pediatrics

University of Vermont, College of Nursing and Health Sciences

- Patricia Prelock, PhD, CCC-SLP

Vermont Council of Special Education Administrators

- Jo-Anne Unruh, Executive Director

Vermont Developmental Services System

- Cheryl L. Thrall, Executive Director, Lincoln Street, Inc.
- Bill Ash, Executive Director, Upper Valley Services

Vermont Family Network

- Pam McCarthy, President & Chief Executive Officer
- Lisa Maynes, Director, Health

Vermont Special Olympics

- Lisa DeNatale, President and Chief Operating Officer