

# THE INCLUSIVE HEALTHCARE PARTNERSHIP PROJECT

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

## Removing the Barriers

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

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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)<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>4</sup>

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<sup>1</sup> 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.

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

<sup>3</sup> 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.

<sup>4</sup> 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-advocate<sup>5</sup> 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

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<sup>5</sup> 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.<sup>6</sup>

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;<sup>7</sup> 3) conducted structured telephone interviews with 12 key Vermont stakeholders;<sup>8</sup> 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;<sup>9</sup> 5) analyzed Medicaid data on health care usage by adult Vermonters with I/DD;<sup>10</sup> 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

<sup>6</sup> Addendum 1, The Inclusive Healthcare Partnership Project, Planning Team Members and Staff.

<sup>7</sup> Addendum 2, National Experts Interviewed for The Inclusive Healthcare Partnership Project.

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

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

<sup>10</sup> 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%).<sup>11</sup> 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.<sup>12</sup>

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

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<sup>11</sup> Kessler Foundation and the National Institute on Disability. *The ADA 20 Years Later*, July, 2010. See: [www.2010disabilitysurveys.org/pdfs/surveyresults.pdf](http://www.2010disabilitysurveys.org/pdfs/surveyresults.pdf).

<sup>12</sup> 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.<sup>13</sup> 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.<sup>14</sup> 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.

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<sup>13</sup> 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.

<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup> 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!”

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<sup>15</sup> 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.

<sup>16</sup> 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.<sup>17</sup>
- 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.<sup>18</sup>
- 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%).<sup>19</sup>
- 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.<sup>20</sup>
- 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.<sup>21</sup>

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

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

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

<sup>20</sup> 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.

<sup>21</sup> 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.<sup>22</sup>

- 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

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<sup>22</sup> 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.<sup>23</sup> 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.

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<sup>23</sup> 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.<sup>24</sup>
- 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.<sup>25</sup> 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.<sup>26</sup>
- 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.<sup>27</sup>

*“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

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

<sup>25</sup> 42 United States Code, §15001(a)1.

<sup>26</sup> 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).

<sup>27</sup> 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.<sup>28</sup>
- 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

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<sup>28</sup> 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.<sup>29</sup>

- 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.<sup>30</sup>
- 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.<sup>31</sup>

## 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.

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<sup>29</sup> 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.

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

<sup>31</sup> 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 risk<sup>32</sup>
- 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

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<sup>32</sup> “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.<sup>33</sup>

- 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.

<sup>33</sup> 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.<sup>34</sup>
- 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.<sup>35</sup>
- 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

<sup>34</sup> 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.

<sup>35</sup> *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.<sup>36</sup>

- 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.<sup>37</sup>
- 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.<sup>38</sup>
- 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

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<sup>36</sup> 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.

<sup>37</sup> Addendum 3.

<sup>38</sup> 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.<sup>39</sup> 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.<sup>40</sup> 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.<sup>41</sup>

## 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.

<sup>39</sup> 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.

<sup>40</sup> 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.

<sup>41</sup> 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.<sup>42</sup>

- 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.

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<sup>42</sup> 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.<sup>43</sup>
- 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.<sup>44</sup>
- 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.<sup>45</sup>
- 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.<sup>46</sup>
- 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.<sup>47</sup>
- In reviewing over 80 tools related to health care (curricula, apps, worksheets, etc.)

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

<sup>44</sup> 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.

<sup>45</sup> 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.

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

<sup>47</sup> 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.<sup>48</sup>

- 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.<sup>49</sup>

## 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

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

<sup>49</sup> *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.<sup>50</sup>

- 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.<sup>51</sup> 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

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<sup>50</sup> Addendum 4 — IHPP Community Allies.

<sup>51</sup> 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

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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

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- **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

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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

# THE INCLUSIVE HEALTHCARE PARTNERSHIP PROJECT

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

## **From a Personal Perspective:**

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**Adults with Developmental Disabilities and Parents Share their Experiences  
With Vermont's Health Care System**

Supporting Documentation for  
*Removing the Barriers, Improving Health Care for Adult Vermonters with Intellectual  
and Developmental Disabilities*

Prepared By  
**Susan Covert, Project Coordinator**  
August, 2015

*Funding for this report was provided by the State of Vermont, Vermont Health Care Innovation Project, under Vermont's State Innovation Model (SIM) grant, awarded by the Center for Medicare and Medicaid Services (CMS) Innovation Center (CFDA Number 93.624) Federal Grant #1G1CMS331181-03-01."*

## Introduction

Individuals with intellectual and developmental disabilities, as a group, experience poorer health than the general population. Once considered an intrinsic feature of having a disability, poorer health is now recognized as an inevitable consequence of the significant disparities in health care and health promotion for individuals with disabilities.<sup>1</sup> To consider how to address these disparities, the Vermont Health Care Innovation Project (VHCIP) awarded the Vermont Developmental Disabilities Council a one-year planning grant for the Inclusive Healthcare Partnership Project (IHPP). The council is working in collaboration with Green Mountain Self-Advocates to develop recommendations for improving the health care experience and outcomes for adult Vermonters with intellectual and developmental disabilities (I/DD) while reducing high healthcare costs for this population.

In order to hear directly about people's health care experiences, IHPP held three focus groups for self-advocates and one focus group for parents supporting an adult son or daughter with developmental disabilities and complex medical needs.

The four focus groups took place in June and July 2015; each group met for 90 minutes. The three self-advocate focus groups were held at the Green Mountain Self-Advocates (GMSA) office in Montpelier. A staff member from GMSA attended these groups and provided support to participants. The focus group for parents was held at the Vermont Family Network office in Williston.<sup>2</sup>

The self-advocate focus groups were structured around a standard list of questions. Questions for self-advocates covered access to health care, utilization of health care services, relationship with their health care providers, use of accommodations and barriers to health care. The same questions were asked of all three groups; the focus group with women self-advocates included additional questions related to women's health care. (See Appendix 1 for questions for the self-advocate focus groups.)

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<sup>1</sup> Krahn, G., Hammond, L., Turner, K., 2006. Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities. *Mental R. and Developmental Disabilities Research Reviews* 12: 70-82.

<sup>2</sup> IHPP is grateful to Karen Topper, Administrative Director of Green Mountain Self-Advocates, and Joanne Wechsler, Family Support Specialist at Vermont Family Network, for their ongoing support of the project and their help in recruiting participants and hosting focus groups.

While questions were developed for the family focus group, parents attending the group chose to engage in a more free flowing interchange about their families' experiences with the health care system. Topics covered in their discussion included: The transition from pediatric to adult care, difficulties finding qualified health care providers, the need for care coordination, challenges working with the Medicaid Program, inadequate state funding for developmental services, and concerns about what will happen when they are no longer able to advocate for their children.

Given the different format for the focus groups and the differences in perspective and experience that parents and self-advocates have in their dealings with the health care system, the findings from the self-advocate focus groups and the family focus group are reported separately.



## Self-Advocates' Health Care Experiences

Three focus groups were conducted with self-advocates; the groups included:

- Self-advocates who receive services through Vermont's developmental services system — Participants in this group included four men and three women whose ages ranged from early-20s to mid-40s.
- Self-advocates who do *not* receive state-funded developmental services — This included three men and two women, aged late-teen to late-20s.
- Women self-advocates — Five women, including a grandmother and young mother with a year-old daughter, participated in this group. Three women in this group receive services through Vermont's developmental service system; two participants receive no developmental services or supports.

It should be noted that in Vermont, approximately 25% of adults with I/DD qualify for state developmental services. From a medical perspective, the health challenges and barriers to care faced by those without developmental services are no different from those of Vermonters who receive developmental services, which may include assistance with care coordination and transportation.

### ACCESS TO HEALTH CARE

All 17 of the self-advocates participating in the three focus groups reported that they had a primary care physician and a dentist whom they saw regularly; participants were current with their annual physicals and dental check-ups. All participants had health care coverage either through Medicaid, Vermont Health Connect (Vermont's subsidized exchange created under the Affordable Care Act), Medicare, or through their families' private health insurance policy.

The majority of participating self-advocates have families actively involved in their support; nine individuals still live with their parents. The oldest participant is in her 60s and now lives with her sister who is contracted by the state to be her shared living provider. Two other individuals receive state-funded residential services; one participant lives with a shared living provider and the other in a group home. Six individuals live independently.

Who makes the decision to see a doctor?

Asked who they talked to when they were not feeling well, most participants reported that they spoke with their parents or a family member. Those receiving services through a designated agency said they also spoke with their support staff or their case manager. Lori lives independently and does not receive services; she has a close relationship with her neighbors and consults with them when she is sick.<sup>3</sup>

The majority of participants said they were usually the ones who decided whether they needed to see a doctor or not. Ian, who is in a residential program, said the agency nurse decides when someone in the residence should see a doctor. Four participants said their parents made this decision for them.

Who makes the decision to go to the emergency room?

The majority of self-advocates said that they would talk to their family or staff first, but that ultimately they would decide for themselves if they needed to get emergency care. Ian commented that it all depended on the situation, “If I’m unconscious and bleeding from the head, someone else would have to do that.” Four advocates who live at home said that their parents would make the decision about whether to go to the emergency room or not.

In the past year, two self-advocates have gone to the emergency room. Nina who is in the process of changing home providers talked about how she recently ended up calling for an ambulance, “I’m getting really sick. I don’t know what to do, so I called (the agency’s) on-call. They said, ‘Come in the morning if you can’t get somebody to help you.’ I went up to my temporary SLP (shared living provider) and said, ‘I need help. It’s the middle of the night. I can’t sleep. I need to get some medicine or something. I’m feeling really sick.’ She said, ‘Oh, I can’t really help you, I’ve been up all night.’ I called 911 because I felt like no one could help me.”

Several people talked about past emergency room visits. Tessa who has a chronic health condition said she has been going to the emergency room her whole life for a variety of issues and that she has always received good care. Two other self-advocates shared their experiences with emergency care:

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<sup>3</sup> The names of the focus group members have been changed to protect their confidentiality

- “One summer I went four different times in a week because I had gallstones and they couldn’t figure it out. The emergency room takes forever. I would check in, wait like five or ten minutes until the triage nurse comes out and gets you. Then I would be in there for hours on end waiting for the doctor ... I think emergency rooms speed things up, when people go up there by ambulance, instead of just walking in. It seems like it goes a lot quicker when an ambulance shows up and you’re coming in through that, instead of going in by yourself and just checking in.”
- “I took a nasty fall and they rushed me off to hospital. It was a lot of stress — believe me. I was working with different kinds of people. Some people that I worked with were a little bit pushier. They were a bit more, you know, like ‘I want to get this done. I want to get this over with.’”

### Problems Getting Needed Health Care

Asked if they had any problems getting the health care that they needed, only four people said they have had no problems. Charlie commented, “I think that I have been lucky because my mom is such a great advocate!”

One of the most common problems for self-advocates was finding transportation to their doctors. Those using public transportation were at the mercy of bus schedules and often arrived at their doctor’s office much earlier than necessary. Those relying on support staff to provide transportation talked about their difficulties coordinating their medical appointments with staff schedules. They shared the following examples of transportation problems:

- “I only have staff three days a week; my appointments have to fall on the days that my staff is there. It’s very difficult when they try to give it (appointment) on Monday or Tuesday and I only have staff on Wednesday, Thursday, Friday.”
- “I had to catch a bus, up there, where my doctor’s is. I can never remember what the bus schedule is. What time do they leave? How long does everything take?”
- “I have to tell the people (at the doctor’s office) the nurse at home, that’s unreliable because sometimes she forgets to write it down and then it doesn’t happen. It’s like five days later and I get a call, ‘Hey, why weren’t you here five days ago?’”

- “I’ll try to make the appointment, but then I might have to call back because I got to check to see if that works or not ... Right now it’s just so frustrating ... The agency just varies — who’s available or if you have a person and then say all of a sudden, ‘I need to be somewhere else’ ... Sometimes my case manager will jump in. It just depends. So it’s very, very challenging.”

For Derek taking time off from his job to see his doctor has been a problem. While his employer is good about giving him unpaid time off for appointments, having a smaller paycheck is a hardship. Derek has dental work that needs to be taken care of, but with his Medicaid dental coverage maxed out, he won’t be able to see his dentist again until 2016<sup>4</sup>. Derek commented, “The insurance won’t cover it and it’s over \$300. That’s why I just take the pain.”

Raymond, one of the older focus group participants, said he had trouble finding a new doctor, “It’s hard to change doctors — there’s a lot of paperwork and it can be hard to find doctors who have an opening in their practice.”

Lori talked about a problem she had been dealing with that morning, “I’ve been having pains for six months straight and they haven’t figured it out. They referred me to the orthopedics ... The referral was to the wrong place. Instead of referring me to a rheumatologist, they referred me to the orthopedic surgeon. I called them today and I was like, ‘Did you get my referral?’ ... They looked at the referral, they’re like ‘Sorry, we can’t do this. We’re sending it back to your primary.’ I need another referral to a rheumatologist, because right now my neighbors think that I might have fibromyalgia.”

Self-advocates who do not receive services from a designated agency were asked if they would like extra help getting the health care that they needed. Tom said he would like help in finding health care coverage when he goes off his parents’ insurance policy. Derek, who regularly drives from his home in Barre up to Burlington to see a specialist, said he could really use help paying for gas for his truck. Nina would like help finding a new doctor.

Sara lives independently and is not receiving any home and community-based services. Her mother lives in a nearby town and checks in with her every day to make sure she has taken her medication. Her mother also helps make doctors’

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<sup>4</sup> For adults, Vermont Medicaid has a \$500 annual cap for the coverage of dental services.

appointments and is there if she gets sick. When asked what is her biggest problem in getting health care, Sara answered, “What happens when my mother isn’t around anymore?”

## **RELATIONSHIP WITH THE PRIMARY CARE PROVIDER**

Most self-advocates reported that they had a good relationship with their primary care provider. Tessa, who is 32 and still in a pediatric practice, said, “I’m the oldest patient ... They know me really well. I’ve been to the hospital and they were always there.” Other participants had this to say about their doctor:

- “My primary doctor knows me well and everybody that works under him knows me pretty well ... They make me comfortable whenever I go into the room. It’s great.”
- “The relationship we have is long standing and positive.”
- “We just got to know each other, but we get along very well.”
- “I went to elementary school and high school with his daughter, plus he knows all the results of all my blood labs and all that, so I think he knows me very well.”

Derek appreciated that his primary care doctor found a dietician to work with him. “My doctor really cares about my weight. Before I started this program I was almost 400 pounds and now I am down to 312. I have a partner in crime — my trainer,” Derek pointed to his friend Sam who was sitting next to him. “We run 5-Ks; that’s how we got these shirts.” (Sam and Derek had competed in a 5-K charity race the previous weekend.)

There were several self-advocates, however, who did not have good feelings about their primary care provider.

- “I see so many doctors in that building. It’s hard to know if my doctor even knows me that well. He’s always out, so I’m always seeing whoever is on call.”
- “They have you see the nurse practitioners and other people in my doctor’s office. I don’t like it. I would rather see one person.”

- “I only saw the primary provider doctor — I met her like once and then I’ve seen the person that helps her out. I haven’t seen the regular doctor except for once.”
- “At this point I don’t really think that she’s listening to what I need. She referred me to someplace else and they can’t deal with the problem, so they’re referring me back to my primary doctor. It’s just confusing right now.”

A number of self-advocates said they were uncomfortable when their doctor was unavailable and they needed to see a nurse practitioner or another doctor in the practice. Ian has a good relationship with his primary care provider, but said unexpected changes in the routine are difficult, “It’s very upsetting when the doctor goes out and doesn’t tell anyone. It’s always right when I get there, like, ‘By the way, your doctor isn’t in today.’ It’s like why the hell didn’t you tell the person who called (to make the appointment). It makes it very hard. I don’t like change that much. Change is a behemoth to me.”

Many of the self-advocates said they had a hard time getting their doctor to listen to them. Helen talked about her decision to change doctors, “They didn’t really listen. I can be in there for about five minutes and I’m out. I was trying to get another doctor’s name. I just barely got her in November and she listens to me.”

Raymond had similar feelings about his former doctor, “He definitely could have done a little bit better about communication. He just could have listened to me and explained it to me a little bit more in detail.”

*When you see a doctor in an examining room, does anyone go with you?*

Self-advocates were asked whether a staff or family member were with them in the examination room when they see their doctor. A number of participants said that they were more comfortable having someone with them who could help them to understand what the doctor was saying. Michael summed up the sentiments of many of the self-advocates, “It’s always my parents going with me for backup ... Some of the things that they get into can be very complicated for me to understand and also I just forget about them all. I think it’s a matter of just making sure that my parents have the information as well as me — Then my parents can remind me of when to do this and when to do that to take care of myself.”

Ian generally goes in by himself to see his doctor, but there are times he wants a staff person with him. "It depends, if there are needles involved or not, which I always ask. If they say, 'Yes.' I'm like 'OK I'm going to bring someone in with me.' And if there isn't, I go, 'OK I can handle this on my own.'"

Five self-advocates have recently requested that their parents no longer come with them to see the doctor.

- "I feel like I'm more responsible with my mom not being there in the room when he's asking me questions and it makes me feel a little bit happier that I get that choice."
- "I like to go in alone in my doctor's, because if my father's with me, he'll go in, he'll start doing jokes and all that. When I had my gallbladder surgery, he cracked the surgeon up. I'm like, 'Dad, come on now ... you're embarrassing.'"
- "I do the appointments myself, because I like my doctor to talk to me instead of my parent."
- "My original doctor didn't talk to me at all. I was just kind of there. Like 'Oh, here's a lollypop' and then (the doctor) explained to my parents what's going on with me. I don't go with my parents for this reason ... I decided when I turned 18 I'm done with having my parents decide for me. I'm making all my decisions for me, medically."
- "My mom used to make a lot of decisions for a lot of stuff and now I'm starting to learn to have a say in what I need and to explain different problems. I'm just learning how to advocate better at the doctor's office."

### *Does your doctor talk directly to you?*

While many self-advocates relied on support from a parent or staff person at their doctors visits, having another person with them at times was a source of tension. Sara reported that her mother accompanies her in the examination room whether she wants her to or not. While she appreciates her mother's concern and support, she said that in regards to her health care, "I want to be more involved."

Charlie uses alternative communication and needs to have his mother accompany him in the exam the room to do facilitated typing. He said there are times his doctor talks to his mother and not to him. When this happens he "protests through typing."

Katie shared her frustration about being left out of the conversation, “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 — ‘Yoo-hoo! I’m like right over here too. I’m not invisible.’”

## **MEDICATIONS**

Most of the participating self-advocates regularly take prescribed medications. Several people said they were often confused about their medication and a number of people reported that they’ve had problems with their medications.

- “I’m actually on one medication right now that I’m like — it’s not actually really helping me — why am I on this?”
- “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.”
- “Some medication just took a toll on me -- Really took a big toll, and I said, ‘What is going on here?’ Finally we decided to bring it up to the doctor, so we tried different kinds of medicine ... It took a while, but we finally got it worked out.”
- “You know what else confuses me? Where it says one of the side effects on the bottle, it says like death — probable cause of death. “

Helen talked about the problem she had with medication after the birth of her daughter, “I was on five Dilantins when I was carrying Amy and then Dr. W. put me up to six. Till this day, I don’t even know how I got through ... I don’t even know how I even took care of my daughter. I remember bending down; she fell right out of my arms. I thought I’d broke her back ... It was like I was high on pot.”

Melanie also had a serious issue involving medication. For fifteen years, before seeing her current neurologist, she took anticonvulsants for seizures. Melanie explained how these came to be prescribed, “You know how all kids when they get mad at their parents they can tune them out by staring through them ... I could stare at my mom until I was blue in the face, like she wasn’t there. She brought me to the doctor ... He put me on Tegretol and then he switched me to Topamax ... Years later I was found out not to have seizures at all. I have been retested and I do not have seizures.”



## ACCOMMODATIONS

The majority of self-advocates said their doctors made accommodations for them. By far, the most important accommodation for those participating in the focus groups was getting their doctors to slow down and take the time needed to explain things in a way they could understand.

- “The only accommodation I have is to have people talk to me directly and just to be open and give me eye contact.”
- “They are really calm when they talk to me. If the doctor starts getting hyper, the patient is going to start to get hyper and nothing is going to work.”
- “The one thing he does is listen.”
- “They were calm and kept me calm, even if I didn’t feel calm.”
- “Sometimes they talk really fast, or they’re in and out ... I just have to say I’m having trouble processing you know, can you repeat it.”
- “I went to see a gynecologist, I had a guy one, but it wasn’t working very well. I ended up getting this doctor who helped me out with the situation and was very patient and very helpful to me with the problem. I had to have an IUD. She was very patient because I had a hard time with it.”

Several people talked about not having enough time at their appointments:

- “Sometimes my doctor gets overbooked and when I go he's got another appointment — another patient — before me ... You do a lot of waiting and then when you see him the appointment is rushed.”
- “I feel like she’s not listening. I feel like it goes in one ear and out the other.”
- “They do it like you quickly have to leave. You come in and you’re confused through the whole appointment. You’re explained something and then it’s like my brain can’t process as quick as the doctor’s.”
- “Usually my doctor talks fast just so she can leave.”

People offered ideas about how health care providers could improve communication and make their doctor’s visit a more positive experience:

- “Just (give) a little more time and not be in such a hurry ... Be patient and give people more time to process and understand what’s going on.”
- “I have autism and, you know, sometimes I have to remind them about that and why I’d rather be warned before you stick a needle into me.”
- “I feel sometimes like they treat you like a kid ... They look at me sometimes like I don’t know; I don’t understand things. Say it — just have a regular conversation — like with anyone else.”
- “I tell them to translate what they are saying into English please.”
- “Having a list of accommodations that you could choose from would be helpful.”
- “(At) my doctor’s office, they have a sign up with a bunch of smiley faces and underneath they ask you to write the pain you’re in from a one to 10. (That’s) a lot easier for people who can’t read to be able to point it out.”
- “Have things a little easier to understand, you know, like have a piece of paper written *very* clearly so we know exactly what to do. (For doctor’s written instructions.)”

In the women’s focus group, participants were asked if their doctor talked to them about doing a breast self-exam. Nina replied, “They do, but I never can do that, 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.”

## **DISCRIMINATION**

Self-advocates were asked if they ever had experienced discrimination. Three people in the focus groups reported that they had been personally discriminated against. Lori said, “I have a lot of discrimination, in general like agencies ... We're never allowed to have our own life. Everybody had to know about everything ... We can’t get supports to help us grow, or to help us with getting together, and making our own choices in general. It’s really frustrating.”

Tom said when he was much younger he saw a doctor for a vision problem, “I was telling him I couldn’t see. He didn’t believe me. He started slapping me.” Even though this happened years ago, it was clear that talking about this experience was still upsetting to Tom.

Katie talked about what happened when she questioned a phlebotomist who was preparing to draw blood from her upper arm, “It’s suppose to be going down here, not up here, right? She was like ‘Oh you’re just stupid.’ She called me stupid and I was like, ‘Really? In front of my mother!’ ... And then she called me psychotic ... I stuck up for myself and I told the other people (at the doctor’s office) ... She’s not there anymore. They kicked her out.”

The most serious case of discrimination involved Sara’s fiancé James who died two years ago. With Sara’s permission, the GMSA staff member who was attending the focus group talked about what happened when James went to the hospital with pneumonia, “They didn’t want to treat him; they were making a judgment ... James was pretty independent and well known around here, but he had a pretty obvious disability ... In the hospital they put a Do Not Resuscitate order in his file ... When he went to the nursing home his family and friends and loved ones saw what was in his file and said, ‘Who put that on there?’ and made them take it off.”

## Parents of Adults with Multiple Disabilities

Seven parents of adults with multiple disabilities and/or complex medical needs, ages 19 to 42, participated in the family focus group. All parents in the focus group are actively involved in coordinating care for their sons and daughters. Three parents still have their family member living at home; another parent has a son who just completed his first year of college and is home for the summer. Three participants have adults who no longer live at home; two have young adult who reside with shared living providers and one has a daughter in a developmental home.

While the self-advocate focus groups went through a standard list of questions, parents in the family focus group engaged in a free flowing discussion about the challenges they have encountered in their efforts to find quality health care for their sons and daughters. The topics covered in their conversation included: health care transitions, problems finding health care providers, the lack of care coordination, health care coverage, issues with the state's developmental service system, and concerns about their children's future.

### HEALTH CARE TRANSITIONS

Reflecting on their children's transition from pediatric to adult care, only two parents had positive experiences. One father reported that the transition process for his daughter went smoothly and she receives great care. The family gets their health care through the University of Vermont Medical Center; when his daughter aged out of pediatric care, she transferred into his primary care provider's practice. The mother of a 19-year old said that while her son is still with his pediatrician, he no longer sees a pediatric neurologist. His current neurologist has a special interest in muscular dystrophy and wanted her son in his practice. His mother noted, "It was a positive energy we hadn't seen before."

Five of the seven parents in the family focus group reported that their children encountered significant problems in making the transition to adult care. One mother, whose 41-year-old son has Angelman syndrome, talked about her family's struggle, "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."

Discussing the transition process, other parents had this to say:

- “The transition was really rocky; our pediatrician couldn’t recommend anyone. We finally found a doctor through a neighbor. All her specialists are now adult specialists — those transitions were tough too.”
- “We’ve had transitions to a number of doctors. The only time it really works is when I get my family doctor to see her as a patient.”
- “Our pediatrician gently suggested that we think about finding another doctor for our son (who is now 22), but told us, ‘There’s no hurry.’ So I’m not hurrying. I would like to see pediatricians give more help to families with transition to adult medicine. They have to know about other doctors and who would be good. It’s all left up to me; I would like to have a little more hand-holding.”

Parents said their families could use support with other health care transitions as well. A mother whose son has had a number of major surgeries commented that her son went from the hospital to a rehabilitation facility with no exit plan in place. Another mother said her daughter’s treatment at a mental health hospital did not include a connection to her doctor or a wrap-around approach to put in place the supports her daughter needed when she left the hospital.

## **FINDING QUALIFIED HEALTH CARE PROVIDERS**

All the parents in the focus group talked about the difficulty of finding qualified health care providers for adults with developmental disabilities. As one participant noted, “With medical advances, kids like ours are living longer than expected; adult medicine doctors don’t know what to do with them.” Other parents commented:

- “It’s hard to find a doctor at all. There is a shortage of primary care providers. You get to see residents and then they move on.”
- “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.”
- “Doctors are reluctant to take on Medicaid patients; they don’t get reimbursed at the same rate.”

- “Addressing mental health issues is really challenging. We had to go out-of-state for our daughter’s psychiatric care.”

One mother posed a heartbreaking question to the other parents in the focus group, “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?’”

Parents spoke about the importance of finding doctors who take the time to listen to them and to understand the needs of their child and their family. As one of the parents put it, “The good doctors are the ones that take my input and balance that with their medical knowledge.” This father, a volunteer with Vermont Family Network’s Family Faculty Program<sup>5</sup>, said he regularly speaks to third-year residents, “I talk with them about really listening to families. We are the ones who really know the child. What we have to say is really important.”

## **CARE COORDINATION**

All of the parents in the family focus group have children with significant disabilities and long-term, complex medical needs. They are under the care of multiple specialists and receive therapies and other health care in a variety of home and community-based settings. Effective care coordination is a critical component to maintaining their children’s health. One mother stated, “These are really vulnerable people. In health care situations, you need someone there who can advocate for them.”

Parents reported that the quality of care coordination through the developmental service system left much to be desired. One parent noted that you have to be an incredible advocate to get what your child needs, or you have to have incredible luck and land with a very good agency. All participants expressed agreement with the

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<sup>5</sup> The Family Faculty Program enlists parents to share their experience of having a child with special needs with University of Vermont medical students and residents, and undergraduate and graduate students in health sciences at the University of Vermont and Saint Michael’s College.

mother who said, “I’m the one who is ultimately responsible for coordinating care. You are assigned someone, but they’re young and they move. That’s when all the wheels fall off the bus. I’m the one who is there day in and day out.”

Parents had limited experience with care coordination within a medical home. One mother reported that the pediatrician’s office coordinated care of all her daughter’s specialists and she hoped that she would be able to find this level of coordination when her daughter transitioned into adult care. Another mother who would like support for her son’s transition to adult care said she only recently found out by chance that the pediatrician office even had a care coordinator. She noted, “We’ve never received any help.”

Another parent shared her frustration in trying to get her daughter’s doctors to communicate with one another, “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.”

## **HEALTH CARE COVERAGE**

Regardless of whether their children’s health care was covered under Medicaid or by private health insurance, parents said they experienced significant problems getting the health care, therapeutic services, and specialized equipment that their children needed.

Participants complained that private insurance companies were extraordinarily slow to respond to requests for coverage and that it often took a letter from their child’s doctor to get the insurance company’s attention. One parent said that three different insurance companies had provided coverage for their family and that “none of them were easy to work with.” Other comments from parents about their dealings with their insurance companies included:

- “Insurance doesn't understand developmental disabilities. It’s not like getting injured and getting occupational therapy (OT) or physical therapy (PT) for a

- few weeks and then you get better. This population needs ongoing OT and PT. I finally got regular OT and PT for my daughter, but it took a lot of convincing.”
- “We waited more than a year to get our daughter’s wheelchair replaced; the back was broken on it. It wasn’t until her surgeon finally called the insurance company that they replaced it. Insurance companies will listen to doctors.”
  - “It took us nine months to get our insurance company to pay for a back sling.”
  - “The time it takes to get equipment needs to be expedited. My child uses a lot of adaptive equipment; the *shortest* turn-around time was six months for a communication device.”

Families whose children are covered through Medicaid reported they experienced the same kind of problems as families with private insurance. One mother talked about her family’s experience, “Our son needs a lot of equipment and Medicaid makes it really hard to get what he needs ... We tried to get Medicaid to pay for a track lift that went from our son’s bedroom to the bath. They came out to our house and their treatment was really humiliating. They were only willing to pay for a Hoyer lift, which completely took over his bedroom. I told them he’s a teenager; he has a desk in his room that he needs to use and he has his drum set. This is not a luxury item we are asking for.” When her son went off to college, the family requested Medicaid assistance to pay for a special bed. Medicaid’s denial of this request included the argument that when their son went to camp for two weeks he was able to sleep on that bed.

Understandably, parents whose children are still under their family’s private insurance worry about what will happen when Medicaid is their child’s only health care coverage. One mother whose daughter experiences significant mental health challenges has not been able to find providers in Vermont who can address her daughter’s needs. She wonders if Medicaid will pay for her daughter to continue seeing her out-of-state psychiatrist.

## **ISSUES WITH HOME AND COMMUNITY-BASED SERVICES**

All of the parents in the family focus group supported adults who received home and community-based services through Vermont’s developmental services system. Three parents have adults who are in state-funded living arrangements. For those with adults who still live at home, the developmental services system funds day programs, in-home supports, case management and respite care. Two parents whose children



are now in their 40s talked about the changes that they have seen in Vermont's delivery of developmental services. One mother commented that the current system is set up to deal with crises, rather than providing ongoing supports and preventative care. Another parent said, "Fifteen years ago there was much more flexibility built into the long-term care system; that's been continually eroding. Without flexibility it is very difficult to have individualized services. In Vermont we are losing what made our system great."

Parents shared their frustrations with a lack of adequate services and provided examples of problems they have had with developmental services:

- "My daughter had to be hospitalized with cancer. While she was in the hospital, money for her home provider where she has lived for the past 12 years was stopped. The home provider hung in there and my daughter was able to go back to their home when she got out of the hospital, but not everyone would be able to do that. Who would even want to be a home provider if you can't have financial security?"
- "Support is not there in the way it used to be. Our son came home from the hospital and we needed extra help. It takes him three hours to get up in the morning to use the bathroom and to take a shower and get dressed. That's what burns parents out. We now have a Licensed Nurse Practitioner (LPN) who comes in three times a week for an hour and half each time."
- "There is no money for things like van modifications. There are some funds for home modifications, but you have to figure out who has the funds and how to get them."

Several parents manage their adult child's developmental services budget. While parents appreciate having more control over the quality of supports and services their child receives, taking on this responsibility requires a significant commitment of time and energy. These parents shared some of the systemic problems that have made life more difficult for their families:

- "We manage the budget for our daughter. We had turnover with her personal care attendant and weren't able to use her hours during a period of time when we were looking for a replacement. The state took that money *permanently* out of her budget. We now get \$7,000 less a year for her care."

- “You may have nursing hours in your budget, but you can’t find nurses to do homecare. They are paying \$39 an hour at the hospital and with your budget, you can only pay \$20-something an hour for nursing.”
- “I do a self-management budget for my daughter’s respite. The paperwork has gotten much more complicated. There are new categories for care that you’re expected to check off and there is no guidance or explanation about how to fill it out.”

Parents are worried about the continued erosion of services. Talking about the needs of their children, one mother observed, “We have a population that has much higher risks. We need to start explaining the impact of what happens when vulnerable people aren’t served.”

### **THINKING ABOUT THE FUTURE**

As parents of children who have multiple disabilities and significant health care needs, the participants in the family focus group are acutely aware of their children’s vulnerability. Throughout the focus group, parents spoke about how critical their advocacy has been to their children’s health and well-being. To a person, these parents expressed concerns about what will happen to their children when they are no longer able to fight for them. A mother commented, “There is nobody else. I have to outlive my son to be sure he gets what he needs. It’s scary.”

One of the older parents in the focus group shared a conversation she recently had with her physician, “My doctor said he needed to talk about advanced directives for me. I told him, I want heroic measures. I have a child with special needs and I have to live as long as possible.”

## **Summary**

To better understand the health care challenges confronting adults with intellectual and developmental disabilities and their families, the Inclusive Healthcare Partnership Program held three self-advocate focus groups and one family focus group. A total of 24 individuals -- 17 self-advocates and 7 parents -- participated in the 90-minute focus groups. In talking about their experiences with Vermont’s health care system, focus

group participants shared a number of common problems in accessing and utilizing health care. These included:

- Lack of a thoughtful transition process from pediatric to adult care
- Difficulty finding qualified primary care providers who have experience working with adults with I/DD
- Difficulty finding health care providers willing to accept Medicaid patients
- Problems finding transportation to and from medical appointments
- Appointment schedules that do not allow the additional time that is needed to provide adequate care and treatment for a patient with I/DD
- Health care providers who do not know how to effectively communicate with individuals with I/DD
- Absence of care coordination for individuals who have multiple disabilities and complex medical needs
- Confusion on the part of self-advocates about their medications
- Unacceptably long waiting periods to obtain coverage — either through private insurance or Medicaid — for needed care, therapies and specialized equipment
- Significant issues with the state’s developmental services system, including diminished services, problems with continuity of care, and extremely narrow eligibility requirements. (In Vermont, only 25% of adults with I/DD qualify for state developmental services.)

Focus group participants were clear about what would improve their health care experience. Self-advocates wanted their medical appointments to be less rushed and their doctor and other health care workers to take more time and slow down when they talked with them. They wanted information presented in plain English and, where appropriate, the use of visual materials and hands on demonstrations. Self-advocates who have someone accompany them to their medical appointments, wanted their doctor to speak directly to them, rather than to their parent or support staff.

Parents wanted better support during health care transitions. They especially wanted a smoother transition from pediatric to adult care that included recommendations from the pediatric practice to adult medicine providers who would be able to meet the complex needs of their children. Families also wanted better communication and

care coordination among the doctors and health care workers who treat their children. In their dealings with insurance, Medicaid and the state's development services, families want to be treated with respect, to have their child's needs addressed in a timely fashion and to have the systems they rely on adopt a common sense approach to problem solving.

The Inclusive Healthcare Partnership Project is grateful to focus groups participants for being so open in sharing their personal experiences with the health care system and in identifying the problems that people with disabilities and their families face in accessing quality health care. The Vermont Developmental Disabilities Council and its partner, Green Mountain Self-Advocates, are committed to including self-advocates and their families in their work to eliminate health care disparities and improve health care outcomes for adults with intellectual and developmental disabilities.

## Focus Group Questions for Self-Advocates

### General questions asked of all self-advocates

1. Who do you talk to if you don't feel well or have a health care problem?
2. Have you had any problems seeing a doctor or getting the medical care you need? If yes, what problems did you have? Is there anything else that gets in the way of seeing your doctor?
3. Who decides if you need to see a doctor?
4. Do you have a primary care or main doctor who you usually see?
5. When you're in the room with the doctor, is anyone with you? If yes, who is with you?
6. Have you had an annual physical/check up in the last year?
7. Tell me about your relationship with your doctor. Does he/she know you well?
8. Does your doctor talk directly to you and treat you with respect?
9. Are you able to tell the doctor what YOU need? What happens if the person who is with you says something you don't agree with?
10. Does your doctor make accommodations for your disability or provide extra help to meet your needs? If yes, what does your doctor do?
11. What happens if your doctor doesn't understand what you need for accommodations?
12. If you take medication every day that is prescribed by a doctor, have you ever been confused about your medications? If you are confused who do you talk to?
13. Does anyone remind you to take your medication or help you with your medication?
14. Have you had a dental check up in the last year?

15. Who decides if you need to go to the emergency room?
16. Have you gone to the emergency room in the past year? If yes, how often have you gone?
17. Have you had any problems with the way people in the emergency room treated you? If yes, what were they?
18. Do other health care workers — people who draw blood, take X-rays, do mammograms – understand your needs and make accommodations?
19. Have you had any problems with these health care workers?
20. What does your doctor tell you about how you can stay healthy?
21. Does your doctor give you information about staying healthy? (Examples: Online, brochures, made an appointment with a nutritionist?)
22. What do you do to keep yourself healthy?
23. What do you see as the biggest problems in getting the health care you need?
24. Have health care workers ever treated you unfairly or discriminated against you? Can you please tell me what happened?
25. Is there anything else you would like to say about your health care or your experience with doctors?

#### Additional questions for the women's focus group

1. Do you have a gynecologist? How often do you see your gynecologist?
2. Do you get regular Pap smears? Do you get regular mammograms?
3. Does your doctor talk with you about these women's health issues — birth control, how to do a breast self-exam, how to avoid sexually transmitted diseases?
4. If you have children, did you see a doctor regularly when you were pregnant?

5. If your children were born in a hospital, were you happy with the care you received? If not, what could have made your stay in the hospital better?
6. Before you left the hospital did you get information about nursing, how to care for an infant, etc. Was this information presented in a way you could understand?
7. Did a visiting nurse or other health care worker come see you and your baby after you went home? If yes, was this visit helpful — in what ways?

## Introduction

*“ 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*

More than 20 years after the passage of the Americans with Disabilities Act, people with disabilities have poorer overall health, lack access to adequate health care and have a greater risk of preventable health problems than the general population. Adults with developmental disabilities are often frequent users of emergency rooms, have longer hospital stays and are more likely to suffer from chronic illness.<sup>1</sup> As a beginning step in addressing these health care disparities, the Vermont Council on Developmental Disabilities (the Council) was awarded a one-year planning grant for the Inclusive Healthcare Partnership Project (IHPP) through the Vermont Health Care Innovation Project (VHCIP). The Council is working in collaboration with Green Mountain Self-Advocates to develop recommendations for improving the health care experience and outcomes for adult Vermonters with intellectual and developmental disabilities (I/DD) while reducing health care costs.

To better understand health care disparities for individuals with I/DD and their families, as well as the challenges for those who are providing their health care, the IHPP Project Coordinator conducted structured interviews with 12 key stakeholders. These represented a wide range of organizations, including: developmental service designated agencies, University of Vermont Medical School, Center on Disability and Community Inclusion, Vermont Medical Society, Vermont Division of Disability and Aging Services, Vermont Blueprint for Health and a federally qualified health center. (See addenda 1 for a complete list of those interviewed.) The telephone interviews were conducted in April and May 2015; interviews ranged from 30–60 minutes with most running an hour. With the exception of a conference call with the IHPP Director and Coordinator and a Vermont Blueprint administrator and two

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<sup>1</sup> Centers for Disease Control and Prevention, 2013 Second Health Disparities and Inequalities Report.



community health team leaders, all other interviews were one-to-one conversations between the IHPP Coordinator and the interviewee.

Interviews were structured around a standard list of questions; representatives from designated agencies were asked additional questions specific to their role in supporting health care for their clients. Questions included assessment of the current delivery of health care, transition from pediatric to adult health care, barriers to health care, training and supports for health care providers, care coordination, opportunities to improve the quality of health care and recommendations to improve the health care experience and outcomes for adult Vermonters with I/DD. (See Appendix 2, Stakeholder Interview Questions.)

## Assessment of Current Delivery of Health Care for Adults with I/DD

Stakeholders interviewed described the current delivery of health care for adults with I/DD as fragmented, patchwork, lacking care coordination and needing improvement. Those affiliated with designated agencies serving individuals with complex needs reported that individuals in their programs are receiving high-quality health care and that their agencies have forged strong working relationships with the health care providers in their region. They noted, however, that the majority of adults with I/DD are not served by Vermont’s developmental services system and individuals who are not receiving care coordination have a vastly different health care experience.

The consensus of those interviewed was that the adult care system was not designed for people with intellectual and developmental disabilities. A health care administrator summed it up, “Before this interview, I met with my staff and asked, ‘How to do we deal with people with intellectual and developmental disabilities?’ The answer was, ‘We do the best we can.’ We work with Heartbeet Farm in Hardwick and regularly see their folks who primarily have Down syndrome. Our staff has no special training on the best way to care for them — whether it’s how to communicate or how to feel comfortable — nobody has had that training.”

### 1. Transition from Pediatric Care to Adult Medical Care

*“ 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. ”*

*Pediatrician*

Asked about the challenges that individuals with I/DD and their families face in making the transition from pediatric care to adult medicine, stakeholders identified a number of problems, including:

- A significant lack of adult practices that have openings and are accepting new patients.
- A health care system that does not foster a seamless transition for young adults aging out of pediatric care.

- An extremely limited number of practitioners who are experienced in treating adults with I/DD.
- Very few practices that have the capacity to provide the level of care coordination that this population needs.
- Reluctance of families to leave the warm environment of a pediatric practice where their child is well-known and cared for.

The pediatricians interviewed offered the following thoughts about improving the transition process.

- We need to share information from the pediatric offices that are doing this well.
- More information and support should be provided to families on what they can do to help make the transition to adult care successful for their child.
- The national Got Transition website has valuable information and links to resources; the website should be promoted to families and health care providers. (See <http://www.gottransition.org/>).
- There is a new effort underway with representatives from internal medicine, family medicine, and pediatric practices to develop an effective transition process for special populations. The group is piloting the process with young adults who have anxiety disorder, depression, ADHD and asthma. The practices participating in this project are working to make successful transitions for specific patients from a pediatric practice to an adult health care provider. Lessons learned from this model could be used to improve transitions for young adults with I/DD.

## 2. The Medical Home and Care Coordination

*“ There is a patient-centered medical home and then there is effective care coordination. Practices can have the title ‘medical home’ and have done the things needed to get certified and still not do care coordination. ”*

*Health Care Provider*

Vermont has an exceptionally high percentage of practices that are certified as medical homes. However, stakeholders were quick to point out that having the title ‘medical home’ is not a guarantee that the practice understands or accommodates the needs of patients with intellectual and developmental disabilities. Stakeholder comments included:

- It's become a catchword in the last two to three years. People are talking about the medical home for all populations, but really understanding what it takes to make a medical home for people with developmental disabilities is another thing.
- At least on paper 75% of primary care doctors in Vermont say they are medical homes, but that doesn't mean every one of these is a fully functional medical home.
- Many adult practitioners and pediatric practitioners are qualifying as medical homes under the National Committee for Quality Assurance (NCQA), but the NCQA standards are not very conclusive for what you need for people with I/DD. They are focused more on chronic care issues like diabetes or obesity. You could qualify to be a medical home and still have little experience that translates into supporting people with developmental disabilities.
- Medical homes have become the thing, but there is the name and then there's the practice. A lot of it is in name only. People try to get qualified and certified as a medical home, but it's a lot of checking boxes for insurance purposes. There are very few adult practices that are truly functional medical homes.

Stakeholders were in agreement that quality care coordination is a critical determinant in whether or not a practice is able to meet the needs of its patients with I/DD. Medical homes should include a care coordinator who interacts with the person, the family, the doctors and all those who provide support to ensure that the needs of the whole person are identified and addressed. As one of the physicians interviewed put it, "Care coordination is key. If there is not a designated coordinator at the practice, you cannot be effective. There has to be someone identified at the practice to do that."

Individuals with I/DD often see a number of doctors with each specialist looking at one slice of the person without talking with one another or sharing information. In addition, there is limited communication between health care providers and the social service agencies that support the person. The absence of coordinated care presents real challenges for an adult with I/DD in terms of following through on medical advice and maintaining the positive practices needed for good health. A leader of a community health team spoke about this problem, "We need support with medication management. A lot of ER admissions come from people being isolated and struggling to manage multiple meds on their own and not being successful."

Stakeholders offered the following recommendations regarding care coordination:

- Pediatric practices have experience in creating shared care plans with a focus on care coordination. The Vermont chapter of the American Academy of Pediatrics (AAP-VT) can share this knowledge with the health care community for adults.
- Practices need to commit to care coordination by designating a social worker or a nurse practitioner in their office to take on this responsibility.
- The Pediatric Care Coordination Learning Collaborative, which includes representation from VCHIP, AAP-VT, LEND and Title V social workers, is an excellent source for information about best practices.
- Some community health teams and other regional health initiatives 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 individual’s Designated Agency for developmental services should have responsibility for providing care coordination for those they serve. Agency commitment to a person-centered process and its ongoing role in the person’s life make it better suited to provide care coordination than a clinical provider.
- Care coordination needs to be a team approach. It is important that systems not put too much burden on the primary care providers (PCPs). PCPs can provide education, open doors and help make connections, but they shouldn’t be solely responsible for coming up with solutions.

### 3. Education and Training for Health Care Providers

“ Precious few doctors or nurse practitioners have the training or special knowledge needed to work with people with intellectual disabilities. ”  
*Health Care Administrator*

Every stakeholder interviewed cited the lack of adult health care 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. To a person, 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 I/DD. Comments included:

- If you look at curriculum for medical students around attention to the unique characteristics of people with I/DD, it is really, really small. I don’t know of a

- strong curriculum in any medical school about how you communicate with or treat people with I/DD.
- It's a national issue, a lot more resources have gone into educating health practitioners on how to work with children with disabilities than have gone into training doctors who work with adults with disabilities.
  - Providers in adult medicine need a better understanding of this population. They need to know about augmentative communication, secondary conditions and effective ways of interacting with people with developmental disabilities and their families. They especially need to know about the value of using strength-based approaches.
  - Providers need to recognize that most families have knowledge about their family member's health care needs and that the individual with a disability also has knowledge about his or her own health. Providers need to give them the respect they deserve and allow them to be a part of their care.

Stakeholders offered a wide range of recommendations to improve the capacity of the adult health care system to adequately care for persons with I/DD.

- We need to strengthen training in medical schools, residencies and programs for allied health professionals to include caring for individuals with I/DD and this training should be required.
- Training at the pre-service level has to be embedded in the curriculum, rather than restricted a few specific lectures. There should be residencies that provide hands-on experience working with adults with I/DD.
- It will be a very tough sell to get medical schools to voluntarily add new requirements to the curriculum. It may have to be dictated by the legislature.
- The Wagner Chronic Care Model, originally developed for managing chronic diseases, could work with this population. The goal for utilizing this model is to have a prepared health care practice and an empowered patient.
- The voices of people with disabilities and families should be embedded in training tools.
- As health care providers, we need to be very welcoming to community agencies. We need to have training teams, a person with I/DD and support staff, who can come in and train us on the best way to work with individuals.
- The focus for training shouldn't just be on the physician; it should target the whole practice — the intake desk, billing, everyone.
- Practices need a supermarket of concrete, practical tools and resources that are off the shelf and easy to use. We need tools that identify different situations and provide specific steps to help the practice develop a comfort level in working with people who have different disabilities.

- Training for practitioners should utilize an adult learning model. It should offer training where people learn something and use it right then and there.
- Avoid making training one more administrative burden for a medical practice. The approach should be, “Here is a tool that can help you.” If there is any additional burden, then it has to be clear why it has value.
- Create a high-level marketing campaign that alerts practices to the need for better training and work in partnership with the Vermont Medical Society to get the word out.
- The University of Vermont College of Nursing and Health Sciences has excellent simulation labs for physicians and nurses working with trauma, stroke, palliative care and mental health issues. There are currently no simulations for working with individuals with I/DD. We need to create scenarios around caring for people with I/DD and work with Green Mountain Self-Advocates to identify people who could to be trained to act as ‘standardized patients.’

#### 4. Support and Resources for Health Care Providers

“ Doctors are spending less and less time with people. It’s , ‘get them in. Get them out. Send them home. ‘ ”

*Health Care Provider*

Asked if Vermont health care providers have the support and resources they need to effectively serve this population, stakeholders talked about problems with Medicaid and Medicare reimbursement levels for services. One provider expressed his frustration with the situation, “The measure of success is on how quickly you can see patients. This doesn’t measure the quality of care. With patients who have disabilities, more time is needed; where are the resources for that?” Stakeholders underscored the need to change current financing mechanisms to allow doctors to be reimbursed for the additional time needed to provide quality care for patients with intellectual and developmental disabilities.

Stakeholders gave the following recommendations to improve supports and resources for providers:

- For doctors and other health care providers (occupational and physical therapists, nurse practitioners, etc.) — change the financing mechanisms to ensure there is reimbursement for the time it actually takes to provide quality consultation, assessments and clinical care for this population.

- Provide reimbursement for care coordination.
- Provide primary care providers with information about the resources and services that are available to individuals with I/DD. Vermont has lots of services, but there is not a clear pathway guiding a provider to the right contacts or outlining the right questions to ask.
- Improve the electronic health records; these are a great resource, but EHR systems don't always talk to one another and things fall through the cracks.
- Quality care requires a lot of good prep work. In order to establish a good relationship with the doctor and the practice, it is helpful for the individual with I/DD and, if needed, a family member or staff person to come into the office for a get-to-know-you visit prior to the first medical appointment.
- The typical doctor or nurse practitioner will benefit from having an expert staff member (someone who knows the person well) accompany the person in the exam room.

## 5. Need for Patient Advocacy

*“ Residents and other doctors were all coming in and talking to him in increasingly loud voices and asking multiple questions all at the same time. My brother’s anxiety and confusion just escalated. I finally stepped in and said, “This isn’t working.” I told them there were three things they could do – One, talk in a normal voice; my brother has Down syndrome; he’s not deaf. Two, ask one question at a time, then pause and wait for an answer. Or three, ask me, ask his mom, or ask his brother. We all know J. very well. They put my instructions in his chart and that did change how they dealt with him. ”*

*Health Care Educator*

Without strong advocacy, many individuals with developmental and intellectual disabilities are at risk of not getting the care they need. Physicians, whether in a practice or hospital setting, are under time pressure and may not take the additional time necessary to communicate effectively with an individual with I/DD. In addition, the service system maze is intimidating for everyone. Without a guide, a person with I/DD is unlikely to obtain the services and supports they need to maintain good health. Stakeholder comments included:

- Similar to frail elders and other vulnerable populations, it is critical that the person with I/DD have a strong advocate to help tell their story. Especially in a large facility like Dartmouth where there are lots of residents, staff,



- specialists and people everywhere, it is critical that the person has a strong advocate and a good communication system.
- We need to support a level of advocacy for this population to ensure that they are able to access health care. Our agency worked with a man who needed to enroll in an exercise program that he couldn't afford. In order to qualify for a scholarship, he needed to have an IQ test. It took a long time for us to arrange this; eventually, we were successful in this situation.
  - People need the resources and assistance to get recommended follow-up care after they have been seen. They need a parent or an advocate who can help arrange follow-up care. Even someone who is very independent still needs help with this.
  - 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 into Rutland Regional Hospital. When I went up to the hospital, 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.

## 6. Staying Well

*“ It would be great if we could do more to empower the people we are serving to know about how to care for themselves. ”*

*Service Agency Administrator*

Stakeholders talked about the importance of individuals with developmental disabilities taking responsibility for their own health. Like the general population, adults with intellectual and developmental disabilities will be healthier if they exercise regularly, watch what they eat and don't smoke. Those who were interviewed recognized that more needs to be done to effectively communicate this message to individuals with I/DD and to support their adoption of good health habits.

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

- Individuals with intellectual and developmental disabilities need training on how to communicate and advocate during their health care visits. This includes learning how to interview the provider and ask for what they need from that medical home.
- It would be extremely helpful if those with experience working with people with I/DD looked at general population health maintenance advice and tailored it for this population.
- There are good models that we can learn from. The Global Campus Foundation (GCF) now in the Howard Dean Technology Center is an inclusive community setting. This is very different than day programs — people go to GCF in the manner they want to and can participate as a teacher or student. They work with a facilitator and propose the classes they want. They have covered sexuality and other topics related to health. Their focus this year is *Healthy Planet - Healthy You*. They did a session on localvore eating and looking at what is good nutrition.

## 7. Other Concerns

“ One of our challenges is how to close the gap between practice and policy. How do you have the people doing the work dictate the policy, as opposed to the waterfall where it’s all coming down from above? ”

Health Care Provider

In addition to the broader topics already covered, individual stakeholders raised other issues that are worth noting. These included:

### ***Health care Reform and Disability***

- In my position, I attend a lot of meetings about health care reform. There is no one in this current climate that has been able to answer my questions about the future of long-term services. When I ask how people with disabilities fit into this health care process, I don't usually get an answer at all. Though recently, I got what I thought was an honest answer. I was told, “We don’t know and we’ll figure it out when we get there.” All of this is happening at the highest levels in government. I find this very troubling.
- A lot is going on at the state level behind the scenes — that could be good or bad. For example, there is the formation of Accountable Care Organizations (ACOs).... How do you convince them that this population is important and get them to pay attention?

- I'm worried about the growing role of the hospitals and their leadership and ACOs, which are really the big hospitals. There is a huge risk that services to this population will be under the control of the medical establishment and that has *never* worked for this population. You have only to look at our history to know this.

### ***Aging and End of Life Care***

- Putting aging factors into the care of the DD population is fairly new. In years past, people with developmental disabilities were not living as long. You are used to dealing with typical things and now you also have to deal with aging issues.
- In the developmental service world, you don't see people leaving and going into nursing homes. They age with us and those supports stay with them. We are partnering with hospice to come into the person's home. Our people die surrounded by people who know them and who care about them.
- We are seeing a whole new realm of hospice care and learning how we can make that happen, so people can stay in their homes at the end of life.
- Hospice has been helpful working with us. How you die is as important as how you live. You need dignity and choice at the end of your life.
- At the end of life, nobody should be more frightened than they need to be and that certainly applies to the folks we support. They have difficulty interpreting the world and fewer close primary supports.

### ***Funding and Access to Care***

- First and foremost, it's not always easy to find a primary care provider for anybody, and if you're on Medicaid it's even harder. There's no requirement that a primary care provider serve anybody (with the exception of Federally Qualified Health Centers). There are a lot of ways that a practice can find to not serve someone.
- There are times when services that can result in better outcomes are not fully funded or not funded at all.
- In reviewing programs, we are seeing more aspiration and pneumonia. These are huge red flags that people need to be evaluated and that precautionary measures need to be put in place.
- Two years ago, there were two nurses for the state and we had two review teams with six people on each. Now we don't have half of what we used to have. When there were two teams, we split the state and were in the agencies on a regular basis. We got to know them and know what was going on. When you are there once a month, it works better and you have better collaboration. The agencies will tell you things and ask for your advice.

- The lack of access to dental care is a major problem. This is often how many people with disabilities will present to Emergency Room. They are in excruciating dental pain to the point they need dentures.
- I come from a rehabilitation background and everything was a functional assessment. You don't see that much here; I think it would be helpful.
- We are seeing individuals with I/DD who have a combination of mental health issues and physical conditions. The presence of comorbid conditions is very challenging and impacts outcomes.
- When it comes to hospital care or specialty care, how people access that is important. Gynecological care or being admitted to a hospital can be very, very traumatic for people with I/DD. This is a system-wide problem that is not well addressed.

## Opportunities and Allies

Asked where they saw opportunities to improve the quality of health care for adult Vermonters with I/DD, stakeholders had a wealth of ideas, including ways their organization could help make a positive difference. These offers and ideas included:

- It would make a lot of sense to have the Center on Disability and Community Inclusion involved in ongoing efforts to provide effective training, technical assistance or evaluation services. Vermont's UCED (University Center of Excellence in Developmental Disability) has experience in best practices in interdisciplinary training.
- The case manager model we presently have in Vermont is exceptionally strong and needs to be looked at and preserved. And not only preserved, but expanded. We are skilled in the developmental services world in supporting people through case management. We can provide a model for those in the health care system to learn how to bring the cost of care down.
- We need to sit down with families, Green Mountain Self-Advocates and Vermont Family Network to develop a public awareness campaign and address health care barriers. We need to use families' and individuals' voices and do a campaign to change policy.
- The person-centered planning process should include health care. What does the person want and need, and who should be providing that. These should be laid on the table and addressed in the personal plan.
- I would love to see something like the Voices and Choices conference, but with a focus on health care. This could be an annual conference that has separate components geared to professionals, people who get services and people doing home care.
- Under the Blueprint there are community health teams; for every 20,000 insured covered lives you can create a five-person community health team. Regions can choose what their teams look like depending on the needs in their community. Have any of these teams looked at how to improve health for people with developmental disabilities? Training could be delivered to these community health teams so they recognize the needs of this population and are able to connect them to resources.
- The maintenance of certification process for primary care doctors, pediatricians and family doctors includes an option to implement a quality improvement project in their practices. If you developed a certification

activity that was easy to do and relevant, that could be a carrot for practices to make improvements to better serve this population. I would recommend developing it with practices that have done this before.

- The state’s Health Care Learning Collaboratives are good resources and could be tapped. There is one focused on people who have high emergency department users. It would be interesting to find out if they are addressing the needs of people with I/DD. (Contact Reba Porter for general information about these and Nancy Abernathy VCHIP Project Manager and Pat Jones and Ginny Samuelson from Blueprint about the collaborative on Emergency Room use.)
- Vermont Medical Society Research and Education Foundation is planning on having a consumer/patient education focus on its website. This could be a resource for sharing information.
- Vermont Medical Society helps make connections to medical doctors and physician assistants.
- The Vermont Chronic Care Initiative (VCCI) serving Brattleboro and Bennington is a good resource. Our Community Health Team collaborates with VCCI and we share patients; they have more resources to serve this population. If we could identify individuals with I/DD who are in need, we could connect them to VCCI.
- It would be great to have a specialized position on the Community Health Teams that is responsible for serving this population.
- Partnerships at the local level can be especially valuable for special populations. There are a number of communities — St. Johnsbury, Rutland, St Albans — working on local initiatives. The state of Vermont has grant money for different projects. Northern Counties Health Care is in the beginning stages of working with Northeastern Vermont Regional Hospital on a project around the dually eligible population; for adults with developmental disabilities, that is about 50% of that population.
- Northern Counties Health Care would be willing to have people with I/DD and people from developmental services come in to do training for our staff.
- We need to work with hospital emergency departments to be a point of access to connect people to providers. Emergency department admissions should be asking, “Do you have a primary care doctor?” And if the answer is no — “Here’s how you get one.”

- We need to take this grant and call a meeting with Vermont Medical School Residential Coordinators for pediatrics, family medicine and internal medicine to explore how we can build more training to work with this population into their programs.

Stakeholders also offered examples of individuals and programs that were doing exemplary work and could be allies in working to improve the health care experience and outcomes for adults with intellectual and developmental disabilities.

- The Aging and Disability Resource Center, Vermont Center for Independent Living, Brain Injury Association, and Vermont Family Network could all be part of this effort. Creating an ongoing training collaborative would help build capacity.
- In each designated agency or specialty care agency there are agency nurses — boots on the ground type people — who should be involved. A lot of time it's the executive director, but you need to involve the people who have direct contact with the individual.
- The Vermont Practice Manager Association is a resource for independent practices and could be helpful.
- The Frail Elders Project may have information about care models and innovative payment models.
- Community Health Teams can be valuable allies.
- Green Mountain Self-Advocates peer mentoring movement is doing empowering and important work. GMSA has a huge reach and could help meet the goal of supporting people to get and stay healthy.
- The people on the Vermont Statewide Ethics Committee are respectful, sensitive and have great values. When you are in the forest and struggling as a team, they can be very helpful.
- Vermont Federation of Families for Children's Mental Health would be willing to help with this project moving forward.
- The Vermont Children's Health Improvement Project (VCHIP) is often the unsung hero in good things that are happening in health care.
- Our Federally Qualified Community Health Centers have a model of care that is ideal for working with populations whose care is not easily accessed.

## Moving Forward

All of those who participated in the stakeholder interviews for the Inclusive Healthcare Partnership Project were in remarkable agreement in their assessment of the challenges Vermont faces as it looks to improve health care for adults with intellectual and developmental disabilities. These include significant problems with the transition from pediatric care to adult medicine, inadequate care coordination, few adult health care providers who have training or experience working with this population, and 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.

Stakeholders offered concrete, practical recommendations to address these issues and identified opportunities to make changes that would improve the health care experience and outcomes for adults with I/DD. They shared strategies, recommended programs and individuals that could be allies in this effort and volunteered to help make those connections. The stakeholders looked to their own organization and saw ways that they could be part of the solution.

The stakeholder interviews are a beginning step in the Inclusive Healthcare Partnership Project. The stakeholders have helped define the scope of the problem, clarified the issues that will need to be addressed, and offered ideas for making needed changes. Their input has been invaluable and will help to guide the Project Planning Team as it moves forward.



## Appendix 1

### Participants in Vermont Stakeholder Interviews

William Ashe, Ed.D.  
*Executive Director, Upper Valley Services*

Joy Barrett, R.N.  
*Nurse Surveyor, Vermont Department of Disabilities, Aging, and Independent Living*

Stephen Contompasis, M.D.  
*Professor Department of Pediatrics, University of Vermont College of Medicine*  
*Program Director, Vermont Leadership Education in Neurodevelopmental Disabilities*

Wendy Cornwell, R.N.  
*Director Community Initiatives, Brattleboro Memorial Hospital*

Patrick Flood  
*Chief Executive Officer and Executive Director, Northern Counties Health Care, Inc.*

Trevor Hanbridge, M.A.  
*Community Health Team, Springfield Medical Care System*

William Cyrus Jordan, M.D., M.P.H.  
*Director, Vermont Medical Society Education and Research Foundation*

Deborah Lisi-Baker  
*Disability Policy and Health Consultant*  
*Associate Director Center on Disability and Community Inclusion, University of Vermont*

Patricia Prelock, Ph.D.  
*Dean, College of Nursing and Health Sciences, University of Vermont*

Jill Rinehart, M.D.  
*Pediatrician, Burlington, Vermont*  
*Clinical Associate Professor of Pediatrics, University of Vermont College of Medicine*

Beth Tanzman, M.S.W.  
*Assistant Director, Vermont Blueprint for Health*

Cheryl Thrall, M.A.  
*Executive Director, Lincoln Street, Inc.*

## Stakeholder Interview Questions

### General questions, asked of all stakeholders

1. How would you characterize Vermont's current delivery of health care for adults with I/DD?
2. What do you see as the challenges for individuals with I/DD and their families in making the transition from pediatric care to adult medicine?
3. Among Vermont's primary care physicians for adults, how widespread is the Medical Home approach to care?
4. What do you see as the greatest barriers to improving health care for adult Vermonters with I/DD?
5. Do Vermont health care providers have the training they need to serve adults with I/DD? If not, what could be done to improve this?
6. Do you believe that Vermont health care providers have the support and resources they need to effectively serve this population? If not, what could be done to improve this?
7. In addition to those you've already mentioned, what other recommendations would you make to improve health care for adults with I/DD?
8. Where do you see opportunities to improve the quality of health care for adult Vermonters with I/DD?
9. Are there programs/individuals doing exemplary work that could be allies in the effort to improve health care for this population?
10. What can your organization do to help improve the health care experience and outcomes for adults with I/DD?
11. Is there anything I haven't asked that would be important to include?


### Additional questions for representatives from designated agencies

1. What role do designated agency staff play in ensuring that adults receive support from their agency to obtain high quality health services?
2. What type of staff are involved in providing this support? (For example, nursing, direct support providers, home providers, case managers)
3. Should the role of agency staff in health care delivery be strengthened? If so, how? (That is, what additional duties would agency staff have? Examples might be care coordination, ensuring that recommended follow-up occurs, or promoting wellness activities).
4. Should care coordination reside with the Designated Agency or with a community clinic or other traditional health care provider?
5. What are the barriers to agency staff expanding their role in supporting health and access to health care for adults with I/DD?
6. How uniform across the State are agency-based supports for access to health care and wellness activities?
7. What is the role of designated agency staff when individuals receiving developmental services become seriously ill or near the end of life? (For example, if a person is hospitalized or receiving hospice care, is their one-on-one able to provide support?)
8. Do the current *Vermont Guidelines for Health and Wellness* provide an up-to-date and complete framework for supporting the health of adults in the DD System? If not, what would you change or add?
9. Do agency staff have the training they need to ensure that the *Vermont Guidelines for Health and Wellness* are followed?



*Inclusive  
Healthcare  
Partnership  
Project*

**VHCIP Summit**  
October 7, 2015



*Of all the forms of  
inequality, injustice in  
healthcare is the most  
shocking and inhuman.*

*-- Martin Luther King, Jr.*

# The Inclusive Healthcare Partnership Project will...



...identify and recommend a set of innovative best practices in the delivery of health services to adult Vermonters with intellectual and developmental disabilities (I/DD) that will support the triple aims of healthcare reform – improving the experience of care and population health while reducing the cost of high quality, effective health services.

**Partners:** Vermont Developmental Disabilities Council (VTDDC) & Green Mountain Self Advocates (GMSA)

**Amount:** Under \$200,000

**Time:** Calendar 2015



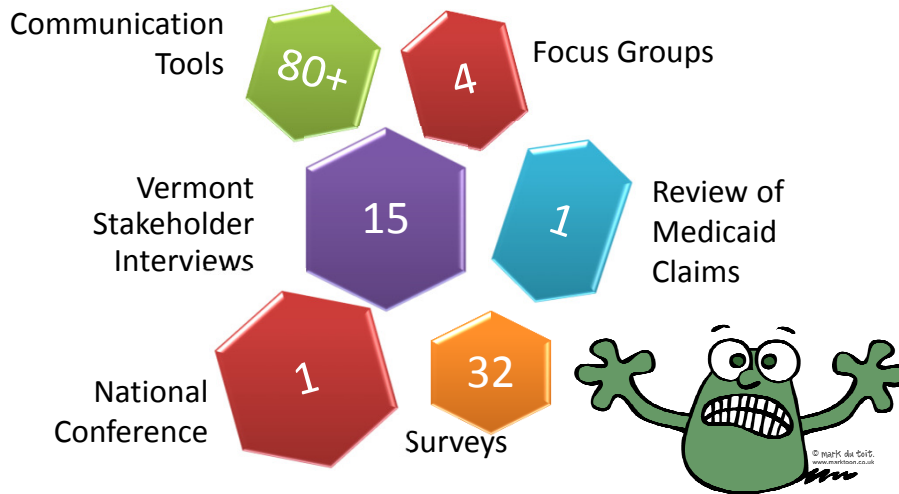
## An inclusive planning process



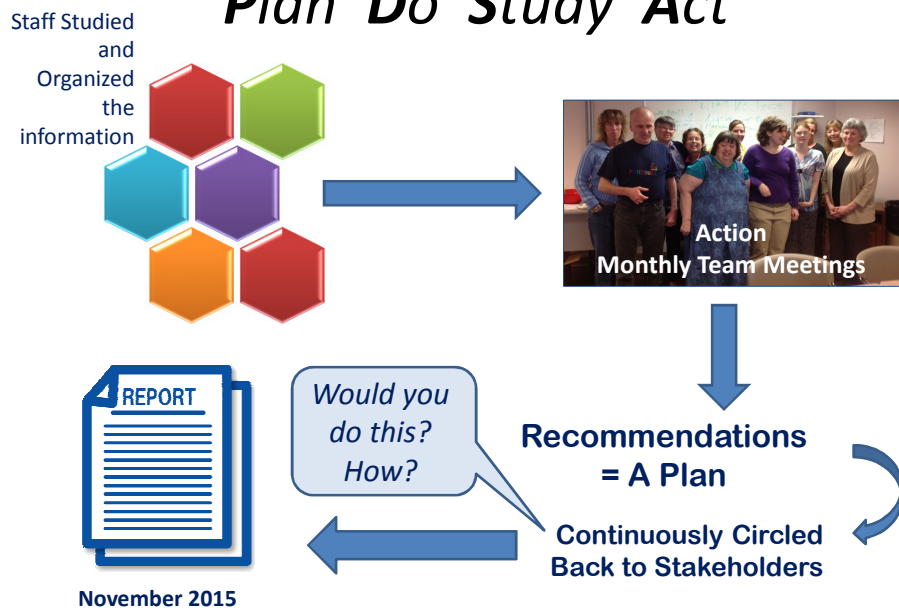
Staff	IHPP Planning Team
Project Director	3 Self-Advocates
Project Coordinator	1 parent
2 GMSA Assistants	3 physicians/ARN
Support provider(s)	1 agency nurse



## Staff collected a lot of information.



## Plan Do Study Act



## A solution-focused approach

### Four Themes:

- Transition from Pediatric Care to Adult-Focused Medicine
- Medical Education & Provider Training
- Care Models
- Health & Wellness

### Report:

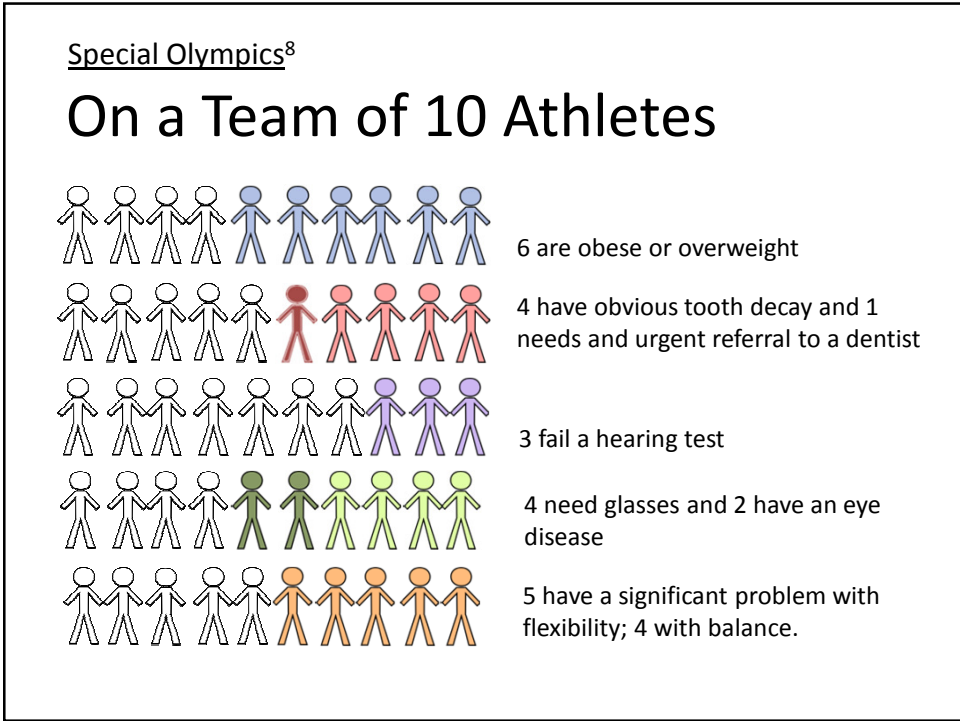
- Findings
- Recommendations
- **Opportunities !**



Inclusive Healthcare Partnership Project

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## **SELECTED FINDINGS**



## Vermont Special Olympics

	All USA	Vermont
Mouth Pain	14.4%	8.2%
Untreated Tooth Decay	36.6%	22.2%
Eye Disease	16.0%	32.3%
Failed Hearing Screening	26.4%	35.7%
Obese (youth)	14.8%	18.8%
Obese (adults)	31.8%	45.7%
Use Tobacco Products	6.5%	5.7%

The logo for Special Olympics Vermont features a red stylized figure with arms raised, surrounded by a circular arrangement of smaller figures. Below the logo is the text "Special Olympics Vermont". To the right of the table is a photograph of a young boy with dark hair, wearing a blue and white Special Olympics Vermont shirt, smiling and holding a green object.



## Emergency Room Use

- In a small survey of self-advocates attending GMSA's annual conference 40% said that they had been seen in an emergency room in the past year. N=35.



## Medicaid Claims for ED visits, 2014

VT HSA	Cohort 1	Cohort 2	Total
Barre	.57	1.80	.99
Bennington	1.95	1.22	1.52
Brattleboro	.53	1.00	.79
Burlington	.60	.78	.66
Middlebury	.39	2.29	1.26
Morrisville	.67	.62	.65
Newport	.38	1.45	.79
Out of State	.62	.96	.76
Randolph	.56	.56	.56
Rutland	.77	1.51	1.10
Springfield	.87	1.54	1.21
St. Albans	1.13	1.41	1.26
St. Johnsbury	.81	.92	.86
White River Jct.	.61	1.11	.84
<b>Total</b>	<b>.74</b>	<b>1.27</b>	<b>.96</b>

**Cohort 1**  
People with HCBS  
N= 2719

**Cohort 2**  
People w/out HCBS  
N= 1906

Average  
Vermonters used  
ED .48 x/year

## *Deeper dive....*



- ED use by Cohort 1, 38.8% non-emergent  
ED use by Cohort 2, 44.0% non-emergent
- Mean cost of ED visit, Cohort 1: \$ 40.27  
Mean cost of ED visit, Cohort 2: \$279.01  
Almost 7x more for adults

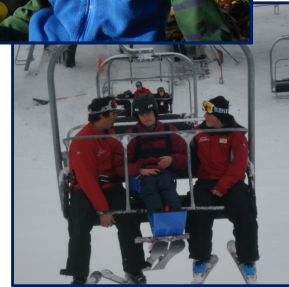
## *Deeper dive....*

- Frequent Fliers – top ten users of ED in 2014
  - Cohort 1 – 734
  - Cohort 2 - 715
- High cost individuals, top 24 in 2014, Cohort 2
  - Average age 29.5, range is 22- 50 years
  - Total cost is \$3,283,086



## Qualitative Data

### *P's Story....*



Inclusive Healthcare Partnership Project

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## **SELECTED RECOMMENDATIONS & OPPORTUNITIES**

## Recommendation:

*Vermont's healthcare system will provide annual pre-appointment nursing checks to certain adults with I/DD.*



- ❖ Evidence-based strategy
  - Randomized Control Trial (2014)<sup>5</sup>.
  - Literature Review (2014)<sup>6</sup>
- ❖ 3-5 health issues identified per visit
- ❖ Impact does not diminish over time (2008)<sup>7</sup>
- ❖ Cost effective (2009)<sup>9</sup>



*What would this look like?*

- Home visit by a nurse prior to an individual's annual visit to the Primary Care Provider (PCP).
- Standardized set of screenings, questions, etc., including anticipating accommodations for upcoming visit.
- Time with PCP can be better targeted to address health issues identified earlier.

*Northern Counties Health Care is interested in piloting this approach.*



## Recommendation:

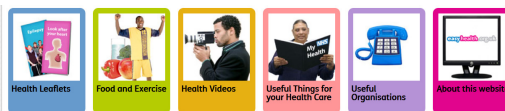
The Vermont Health Department will assess accessibility of health care settings, including accessibility of medical equipment in diagnostic and treatment settings, and promote **physical and cognitive accommodations** for adults with intellectual and developmental disabilities.



**ADA 25**  
AMERICANS WITH  
DISABILITIES ACT 1990-2015

*What would this look like?*

- Compliance with US Access Board standards per the Affordable Care Act
- Improves patient & provider safety
- Increase access to preventative care
- Empowers adults with I/DD to be more independent in managing their health.



*GMSA can help create cognitively accessible health information!*

## Recommendation:

*Provide opportunities throughout the training continuum, from pre-clinical curricula to continuing medical education, 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.*



## *What would this look like?*

- Build on existing curricula focused on medically underserved populations.
- Draw from Vermont's wealth of self-advocates
- Place people with I/DD in simulations that do *not* focus on I/DD.

*Both UVM Medical School and Geisel Medical School have expressed strong interest.*

*An expanded coalition of disability groups has applied to provide in-person and on-line training.*

## Selected References

1. "The Case for Designating People with Intellectual and Developmental Disabilities as a Medically Underserved Population," Kornblau, Barbara L. The Autistic Self Advocacy Network, Policy Brief (April, 2014), [http://autisticadvocacy.org/wp-content/uploads/2014/04/MUP\\_ASAN\\_PolicyBrief\\_20140329.pdf](http://autisticadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140329.pdf).
2. "People with ND/ID should be formally recognized as constituting a 'medically underserved population' by the HRSA and other appropriate Federal agencies and receive the consideration, benefits, opportunities and assistance provided to populations with that designation." Adopted by the American Academy of Developmental Medicine and Dentistry (2004). See: <https://aadmd.org/articles/health-disparities-consensus-statement>
3. "...that the AMA support a simplified process across appropriate government agencies to designate individuals with developmental disabilities as a medically underserved population." Resolution 805-1-10. Council on Medical Service review, 3-1-11.
4. "Resolved, that the American Dental Association support a simplified process across appropriate governmental agencies to designate individuals with intellectual disabilities as a medically underserved population, and be it further Resolved, that the ADA seek to collaborate with the American Medical Association and the American Academy of Developmental Medicine and Dentistry to promote this process to appropriate governmental agencies.." Resolution 96, 2014.
5. "Practice nurse health checks for adults with intellectual disabilities: a cluster-design, randomised controlled trial." Cooper, Sally-Ann *et al.* *The Lancet Psychiatry*, Volume 1, Issue 7, 511 – 521.
6. "The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence." Robertson, Janet, *et. al.* *Research in Developmental Disabilities*, Volume 35 (2014), 2450-2462.
7. "The impact of repeated health checks for adults with intellectual disabilities." Felce, David, *et. al.* *Journal of Applied Research in Intellectual Disabilities*, Volume 21 (2008), 585-596.
8. Special Olympics Health Research, June 23, 2015.

## References, *continued*

9. "Cost estimation of a health-check intervention for adults with intellectual disabilities in the UK." Romeo, R., *et. al.* *Journal of Intellectual Disability Research*, Volume 53, Part 5 (May, 2009), 426-439.



# TOOLS YOU CAN USE

Information & Other Resources to Improve Health  
Care for People with Developmental Disabilities

Prepared by the Inclusive Health Care Partnership Project



# Health Care Tools

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For questions, comments, or to suggest additional resources, please contact Green Mountain Self-Advocates, [info@gmsavt.org](mailto:info@gmsavt.org); or the Vermont Developmental Disabilities Council, [info@vtddc.vermont.gov](mailto:info@vtddc.vermont.gov)

# Tools for People with I/DD

## ❖ Passports and Accommodations

- [Health Passports from the United Kingdom - there are several different versions](#)
- [My Health Passport \(FCIC\)\\*](#)
- [Sick Kids Health Passport](#)
- [AASPIRE Autism Healthcare Accommodations Letter\\*](#)
- [ODPC What I Wish My Doctor Knew About People who Accompany Us to OUR Medical Appointments](#)
- [ODPC What I Wish My Doctor Knew About Non-Traditional Communicators](#)
- [ODPC What I Wish My Doctor Knew About Asperger's](#)
- [ODPC What I Wish My Doctor Knew About Sensory Sensitivities](#)
- [ICEAutism app\\*](#)
- Surrey Place [What I Need to Know About Going to the Doctor's Office](#)

## ❖ Worksheets - Getting Ready for Visit

- [AASPIRE Making an Appointment Worksheet](#)
- [AASPIRE What to Bring to an Appointment Checklist](#)
- [AASPIRE Symptoms Worksheet\\*](#)
- [ODPC Getting Ready for My Visit Worksheet\\*](#)
- [ODPC Charts and Forms](#) (for example: Medication Log, Daily Food Log, Menstruation Chart, Sleep Log, Vital Signs Log, Durable Medical Equipment Record)

## ❖ Worksheets - After the Visit

- [AASPIRE After the Visit Worksheet](#)
- [ODPC Follow Up From My Visit Worksheet\\*](#)

## ❖ Other Tools for Patients

- [Girls with Nerve - Important Questions to Ask Your Doctors](#)  
(for women with epilepsy regarding sexual/ reproductive health)
- [Philadelphia Coordinated Healthcare Trainings on Numerous Health Topics for People with DD and Family Members](#)
- [AASPIRE Your Rights in Healthcare](#)
- [Image Library](#)
- [Video on Becoming an Adult: Taking Responsibility for Your Medical Care](#)
- [Video for People with I/DD about How to Do Good At-Home Dental Care](#)

# Tools for Health Care Providers

## ❖ Communication Tools

- PA Training about Working with Patients with DD: [includes short disability etiquette and communication tips](#) and [short videos showing many clinical exams for woman with Down syndrome\\*](#)
- ODPC [Exam Room Etiquette\\*](#)
- [United Spinal Do's and Dont's](#)
- [Kathie Snow article on People First Language\\*](#)
- [Handout for Physicians about Communicating Effectively with People with DD](#)
- [Taking the Work out of Bloodwork: A Provider's Guide Toolkit](#)
- [Your Next Patient Has Autism Brochures - A practical guide for the health practitioner for effectively meeting the special needs of patients with disorders on the Autism Spectrum\\*](#)
- [Physician Education in Developmental Disabilities Webinar Series\\*](#)
  - [History and Terminology](#)
  - [The Common Characteristics of Neurodevelopmental Disorders](#)
  - [Communication \(Patient, Parent/Caregiver and Inter-professional\)](#)
  - [Responsiveness, Respect, Self-Determination and Consent](#)
  - [The Patient Support System](#)

- [Assembling Accurate Clinical Information \(Part 1\)](#)
- [Assembling Accurate Clinical Information \(Part 2\)](#)
- [Optimizing Well-being](#)
- [Transitions from Pediatric to Adult Care](#)
- [Identifying Quality Resources and Improving Practice Quality](#)
- [Behavior and Medication Management](#)
- [Healthcare Financing](#)
- [My Health Booklets by Surrey Place\\*](#)
  - [What I Need to Know About Medicine](#)
  - [What I Need to Know About a Colonoscopy](#)
  - [What I Need to Know About Menopause](#)
  - [What I Need to Know about Breast Health](#)
  - [What I Need to Know about Having my period](#)
  - [What I Need to Know about men's health](#)
  - [What I Need to Know about pelvic exams](#)

#### ❖ **Clinical Tools**

- ODPC [Functional Behavioral Analysis](#)
- ODPC [Enhancing Your Interactions](#)
- ODPC [Tips for a Successful Pelvic Exam](#)
- ODPC [Strategies to Organize Care](#)
- ODPC [Communication Simulation Exercise](#)
- [Taking the Fear Out of Doctor's Visits - Practice without Pressure/ Stop Signs](#) Video
- [Mock Clinical Interviews with Nonverbal Standardized Patients](#)

- [ACOG](#) Reproductive Health Care for Women with Disabilities\*

#### ❖ **Basic Information About Disability**

- ODPC [A Brief History of Developmental Disabilities in the United States](#)
- ODPC [Barriers to Care](#)
- ODPC [Rights of People with Developmental Disabilities](#)
- [Fact Sheet: Working with people with intellectual disabilities in healthcare settings](#)
- ODPC [Ability Bias in the Health Professions](#)
- [AASPIRE Caring for Patients on the Autism Spectrum](#)

#### ❖ **Emergency Room Tools**

- [DD Cares - an Emergency Dept. Project from Toronto, Canada to improve ED healthcare for people with I/DD.](#)
- [Webinar - Emergency Healthcare in Adults with IDD; An Introduction to the Issues and Challenges and handouts](#)
- [Webinar: Emergency Healthcare in Adults with IDD; Part 2 Hospital Care and handouts](#)
- [Webinar: Emergency Healthcare in Adults with IDD; Communication of Health Care Needs and handouts](#)

#### ❖ **Other Tools for Providers**

- [Sexuality Resources](#)
- [ODPC Lectures and Workshops](#)
  - Topics include: [Adults with Developmental Disabilities; Ability Bias; Abuse Against People with Mental and/or Developmental Disabilities: Physical, Sexual and Verbal](#)

[Abuse; Constipation in People with Developmental Disabilities; Finding Your Way Home: Managing Inter-specialty Care for Patients with Complex Behavior Needs; Forensic Psychology: Learning Disabilities in Prison \(Student Project\); Health Promotion/Disparities for People with Developmental Disabilities; Is the Use of Problem-Based Learning Cases and Standardized Patients Effective in Teaching Pre-Clerkship Medical Students about; Language Screening; School Problems?: That's Not My Area...; School Readiness](#)

- [Principles of Medical Ethics in Health Care Provision for People with DD: A Case-Based Approach](#)
- [Our Lives, Our Health Care: Self-Advocates Speaking Out About Our Experiences with the Medical System](#)
- [Increasing Physical Activity Among Adults with Disabilities, Centers for Disease Control](#)

# Health and Wellness Tools for People with I/DD

## ❖ Curriculum

- [What's HEALTH Got To Do with TRANSITION? Curriculum](#)
- [Being a Healthy Adult: How to Advocate for Your Health and Health Care by Kathy Toberson, M.S.W.\\*](#)
- [Attainment's Health Advocacy Curriculum\\*](#)
- [Health Matters Curriculum\\*](#)
- [UNC Chapel Hill Curriculum in Women's Health](#)

## ❖ Other Tools

- [List of Online Tools Related to Transition and Healthcare](#)
- [My Health, My Life Toolkit](#)
- [ASAN Webinar About Decision Making in Healthcare\\*](#)



# Tools for parents/ caregivers/ support staff to help support the health of someone with I/DD

## ❖ Tools for Caregivers or Support Staff

- [State of California Dept. of Developmental Services Trainer and Student's Resource Guides for the Direct Support Professional Training](#)
- ODPC [Referral Letters: Samples and Templates For Patients and Caregivers](#)
- ODPC [How to File an Appeal with Your HMO](#)
- [Thinking Ahead Matters - End of Life Planning for People with DD](#)
- [Philadelphia Coordinated Healthcare Trainings on Numerous Health Topics for Provider Staff](#)
- [Sexuality Education for Children and Adolescents with Developmental Disabilities: An Instructional Manual for Parents of and Individuals with Developmental Disabilities](#)

## ❖ Other Tools and Resources

- [Webinar about Improving the patient experience](#)

# Transition Tools

- ❖ [10 Steps to Successful Health Care Transition\\*](#)
- ❖ [Transition Readiness Assessment Tool](#)
- ❖ Got Transition's [Transition Readiness Assessment](#) for Youth/  
Youth Adults\*
- ❖ [Florida HATS Brief Transition Checklist\\*](#)
- ❖ [University of Florida Transition Toolkit](#)
- ❖ [Video Talking With Your Doctor and Other Health Care Providers](#)
- ❖ [This is Healthcare Transition Videos 1-4](#)
- ❖ [Transition Timeline](#)
- ❖ [Transition Health Care Check List: Transition to Adult Living](#)
- ❖ [The Healthy Bodies Toolkit for Girls](#)
- ❖ [The Healthy Bodies Toolkit for Boys](#)
- ❖ [Six Core Elements of Health Care Transition 2.0](#)
- ❖ [Transition Readiness Assessment for Parents/ Caregivers](#)
- ❖ [Medical Summary and Emergency Care Plan](#)
- ❖ [Cultural Competence: Essential Ingredient for Successful Transitions of Care](#)
- ❖ [GotTransition.org Tools](#)
  - Tools for Transitioning Youth to Adult Health Care Providers
  - Tools for Transitioning to an Adult Approach to Health Care Without Changing Providers
  - Integrating Young Adults into Adult Health Care

## **Apps**

- ❖ [My Medical App](#)
- ❖ [ICEAutism app](#)
- ❖ [My Med Schedule app](#)
- ❖ [Apps to Increase Independence](#)

## **Useful Links/ Resources**

- ❖ [USCF Medical Center Office of Developmental Primary Care](#)
- ❖ [GotTransition.org](#)
- ❖ [Florida Health and Transition Services \(HATS\)](#)
- ❖ [American Academy of Developmental Medicine and Dentistry](#)
- ❖ [Public Health is for Everyone](#)