

## Inclusive Healthcare Partnership Project - IHPP Plain Language Summary [IHPP White Paper](#) March 2016

**Introduction:** People with intellectual and developmental disabilities (I/DD) have a hard time getting good health services and are sicker than other people.

- ❖ They use the emergency room a lot and many people have lifelong diseases like diabetes and heart disease.
- ❖ Doctors and other health providers don't get much training about how to work with people with I/DD.







GMSA and the VT Developmental Disabilities Council got money to work on making this better in Vermont by creating the Inclusive Healthcare Partnership Project (IHPP). When we say “inclusive,” this means that people with I/DD were speaking up in the project from start to finish. We wanted to learn about the good and the bad of what happens when Vermonters with disabilities need health services. We did this by:



- Giving a survey to over 90 people (self-advocates, families, agency staff, and doctors)
- Talking with experts from all over the US
- Looking at websites, written tools, and trainings
- Learning about what doctors learn when they go to school
- Holding a Planning Team meeting every month

The Planning Team **found four main areas** where Vermont needs to make changes and people who can help fix these problems.

-  Transition from Pediatric Healthcare to Adult Healthcare
-  Medical Education and Provider Training
-  Care Delivery and Practice Transformation
-  Health and Wellness

## **Transition:**

Lots of self-advocates, family members, and health care providers said that youth with I/DD and their families need more information and help when it is time to move from a pediatric (or kid's) doctor to an adult doctor. It is tough to find a doctor who will take a patient who has I/DD so many adults keep seeing their childhood doctor after they become an adult. Also, many doctors won't take Medicaid. Doctors said they haven't been trained to work with people with disabilities. One solution we found is to have schools teach students about health transitions as they are getting ready to graduate. Another solution is to have doctors work together to share information about new patients. Lots of teachers, doctors, and state workers have agreed to help make this better.

## **Medical Education and Provider Training:**

One reason people with disabilities have poor health is that doctors don't learn empowering messages about disability. When doctors and nurses are in school they spend almost no time learning about people with I/DD. Sometimes there is a little bit of information but it focuses

on the more “medical model” and curing medical problems. Doctors who are part of programs like Special Olympics Healthy Athletes say that it helps them work better with people with I/DD and makes them want to learn more and have more patients with I/DD. One solution is to include more training about disability and accommodations in medical schools. We also think it is important for doctors to be able to take trainings that are easy to find and use online. The UVM and Dartmouth medical schools will be partners in working on this problem, as well as the Department of Health.



### **Care Delivery and Practice Transformation:**

People with I/DD need better health care but they also need someone to coordinate their care to make sure the person’s family, doctors, and support staff are all on the same page. If people with I/DD can’t get help from their normal doctor, they will go to the Emergency Room even if it is not an emergency. It is hard for people with I/DD to follow through on their medical next steps without help and support. One idea to solve this problem is have nurses do home visits before annual physical exams. This could help figure out what issues they have and help the doctor plan for their appointment. Another issue is that lots of doctor offices are not accessible. For example, most offices do not have a weighing scale for someone in a wheelchair. We will ask partners like the Department of Health to help clinics evaluate their physical accessibility.



## Health and Wellness:

Adults with I/DD are healthier if they exercise, don't smoke, and eat a nutritious diet. When there are campaigns to help people quit smoking or get healthy, they are not always made accessible to people with I/DD even though people with I/DD want to learn about living healthy lives. People with I/DD sometimes have a hard time joining wellness activities in their communities because they feel alone or don't know what is going on. People should make a real effort to include people with I/DD when they are planning health and wellness activities and to make them accessible. There are lots of ways for peer advocates to train their peers about living a healthy lifestyle and there are programs we can use to teach people to be trainers. Direct support staff can also help people with I/DD to learn more about health lifestyles and health activities in the community.



**Conclusion:** To sum up, the Planning Team decided that people with I/DD should be considered a “Medically Underserved Population.” This means that people with I/DD are more likely to fall through the cracks of the health care system - they have a hard time getting the health care services they need and health care staff don't know how to take care of them. We have asked lots of partners to team up with people with I/DD to help solve the problems found during the IHPP project so we can make health better in Vermont for everyone.