Disability Core Competency Tool Kit

Resources and Information

Vermont Health Care Innovation Project

People with disabilities experience dramatic disparities in health and healthcare, including barriers to accessing needed care, a markedly greater risk of preventable health problems, and poorer overall health than the general population.

These unique training materials have been designed to support a wide range of health professionals in providing care that is attuned to the needs of adults with disabilities.
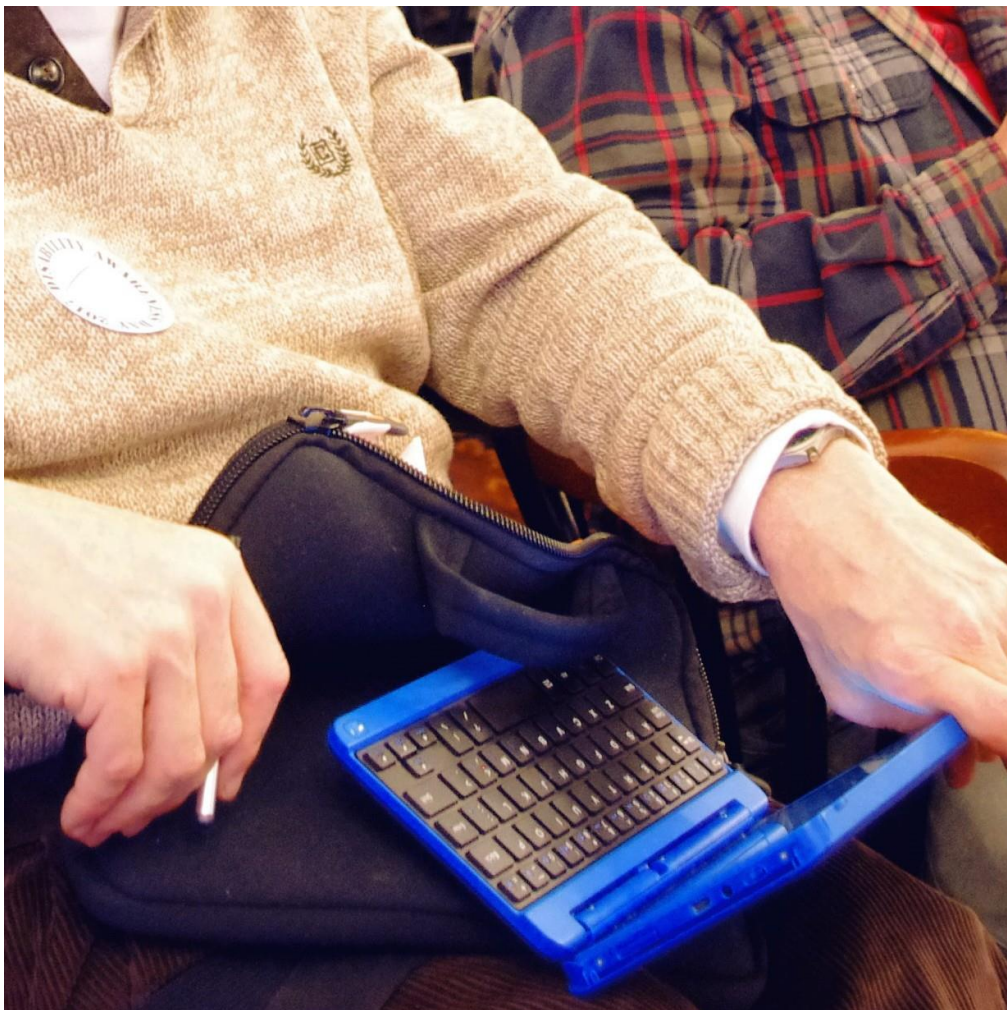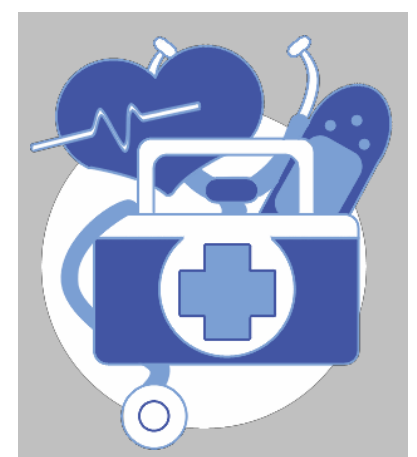
Materials and Trainings by

Vermont Developmental Disabilities Council

Green Mountain Self-Advocates

Vermont Family Network

Vermont Federation of Families for Children's Mental Health

Table of Contents:

Part I:

Key Concepts in Coordinating Care for People with Disabilities

Introduction to
Disability Core Competency Training

Health begins where we live, learn, work, and play. This powerful message, crafted by the Robert Wood Johnson Foundation, points to the many influences on individual wellbeing that lie outside of traditional healthcare. *Healthy People 2020* defines these "social determinants of health" as "the conditions in the social, physical, and economic environment in which people are born, live, work and age. They consist of policies, programs, and institutions and other aspects of the social structure, including government and the private sectors, as well as community factors." Social determinants weave a complex web of influences that the Care Managers must consider to successfully optimize a client's health. Three stories are shared in this unit to illustrate the complex and elusive link between good health and having a meaningful role in one's community.

Social determinants are also the drivers of "health disparities." These are the differences in health and the health care experience between population groups that reflect a longstanding history of unfair treatment and/or unequal access to resources. People with disabilities in general --and developmental disabilities in particular -- experience marked disparities across many aspects of health. These include higher rates of chronic disease and the health behaviors that contribute to disease, lower rates of recommended screenings, and higher utilization of emergency room care and of hospitalizations.

There is some evidence that poverty alone does not explain differences in health outcomes: For example, even when one controls for socio-economic factors, infant mortality among African Americans is twice that of Caucasian babies. Is it possible that racism itself – and other types of prejudice, including ableism – contribute to poor health? Again, the Care Manager is asked to consider not only the role of community but the quality of community supports: Access to transportation has little value if you have nowhere to go. Housing is not the same thing as a home. Someone can work, but their contribution may not be valued by customers or co-workers.

Watch a video of Presentation 1, which is approximately 1 hour and 17 minutes.
https://youtu.be/aQyYmT3Ba-U?list=PLtncqwjB2vuXQOklpkpZtUBRtZvfy1F9-

Introduction to
Disability Core Competency Training
Resources and Handouts

Disability Core Competency Briefs

- **Introduction to Disability Awareness** (June 2015)
  http://healthcareinnovation.vermont.gov/sites/hcinnovation/files/DLTSS/Disability%20Awareness%20Brief%20-%20Introduction%20to%20Disability%20Awareness%20-%20June%202015.pdf
- **Disability Competency for Providers** (June, 2015)
  http://healthcareinnovation.vermont.gov/sites/hcinnovation/files/DLTSS/Disability%20Awareness%20Brief%20-%20Disability%20Competency%20for%20Providers%20-%20June%202015.pdf

Healthcare Disparities for People with Disabilities

- **American Journal of Public Health**, Supplement 2 (2015, Vol 105, No. S2), *Persons with Disabilities as an Unrecognized Health Disparity Population,* G. Krahn, *et. al.:* http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2014.302182
- **National Council on People with Disabilities***, The Current State of Health Care for People with Disabilities* (2009):
  http://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f973d.pdf
- **New England Journal of Medicine** (September, 2015). *Health Care for Americans with Disabilities – 25 Years after the ADA,* G. Peacock, MD,PhD, L. Iezzoni, MD, and Thomas Harkin, JD:
  http://www.nejm.org/doi/full/10.1056/NEJMp1508854?af=R&rss=currentIssue&
- **Office of Disease Prevention and Health Promotion, Healthy People 2020**, Disability and Health: https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health
- ***Removing the Barriers, Improving Health Care for Adult Vermonters with Intellectual and Developmental Disabilities*** (2015) by S. Covert, a project of the Vermont Developmental Disabilities Council and Green Mountain Self-Advocates:
  http://healthcareinnovation.vermont.gov/sites/vhcip/files/documents/VT%20DDC%20-%20VHCIP%20Provider%20Sub-grant%20Final%20Report.pdf

Introduction to
Disability Competency Training

Kirsten M. Murphy

Executive Director

Vermont Developmental Disabilities Council

1

Overview of our Training Team

Four Vermont disability organizations with shared beliefs in ….

- The central importance of individual and family voices
- The need for advocacy at *both* the personal and at the systems level
- Collaboration trumps difference

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The Values of the Federal DD Act

Self Determination

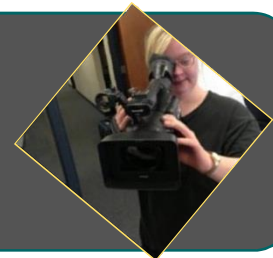*Being your own boss.*

Independence

Adventuring out on your own.

3

The Values of the Federal DD Act

Community Inclusion

I have a role to play.

Independence Productivity

Adventuring out on your o Working hard and achieving your goals.
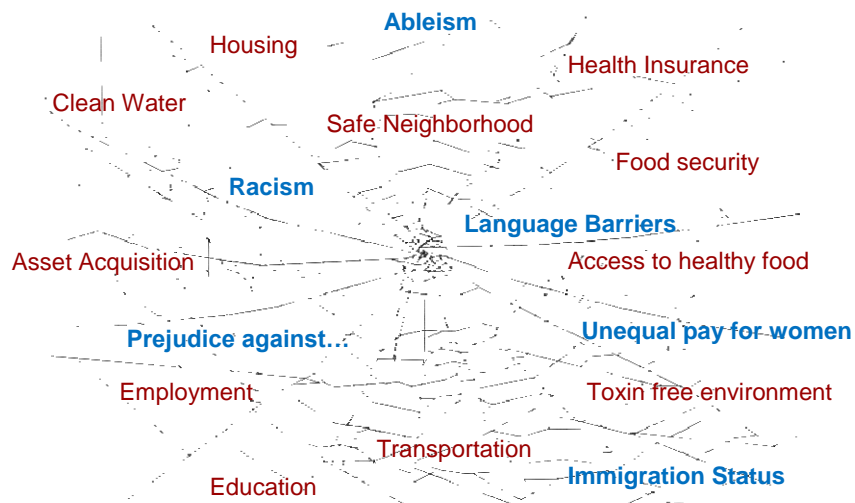
4

Three Stories

A MEANINGFUL ROLE IN COMMUNITY

Activity: the social determinant of health

Ableism

Housing

Health Insurance

Clean Water

Safe Neighborhood

Food security

Racism

Language Barriers

Asset Acquisition

Access to healthy food

Prejudice against...

Unequal pay for women

Employment

Toxin free environment

Transportation

Education

Immigration Status

Review: the social determinant of health

Built Environment 10%

Genes & Biology 10%

Social and Economic 40%

Clinical Care 10%

Health Behaviors 30%
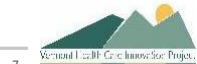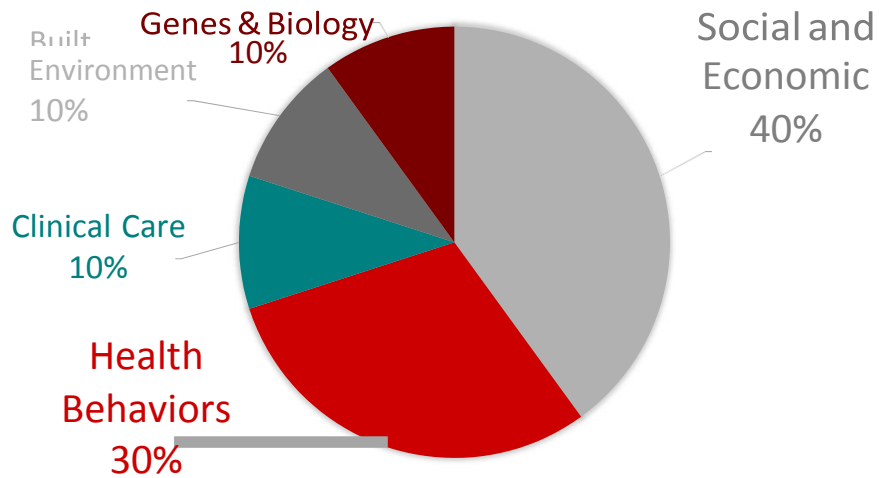
7
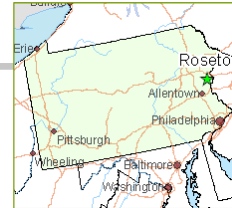
The Roseto Effect

How a small Pennsylvania town enjoyed unexpected good health
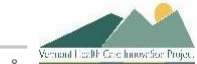
8

The Roseto Effect, *cont.*

How can we explain rates of heart disease that were only half the national average?
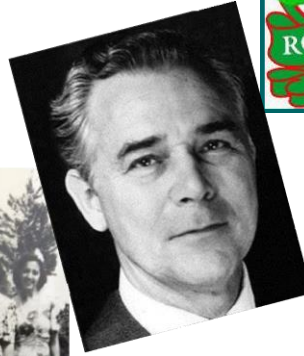
The Guinea Pig Club
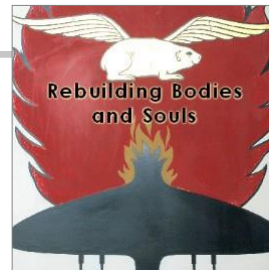
East Grinstead, England "The Town that Didn't Stare"

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Lessons from Grinstead, Sussex, England

For Video, See YouTube: "The Town that Didn't Stare"
https://www.youtube.com/watch?v=NfwP6vs6rCo

First 4 minutes, 21 seconds

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Lisa from Bennington, VT

Finding community in Vermont

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Why Introduce Care Managers to Disability?

HEALTH DISPARITIES & DISABILITY

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Disability is Common

Prevalence of disability 2013: 22% of adults

1 in 5 or 53 million Americans

Vermont prevalence: 17.8%
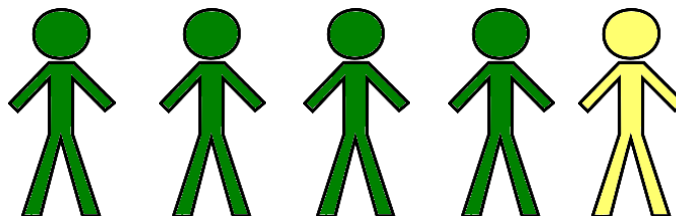
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Disability is Common, *Cont.*

AGE RANGE OF PEOPLE WITH DISABILITIES

Children
7%

Ages 65+
40%

Ages
18-65
52%
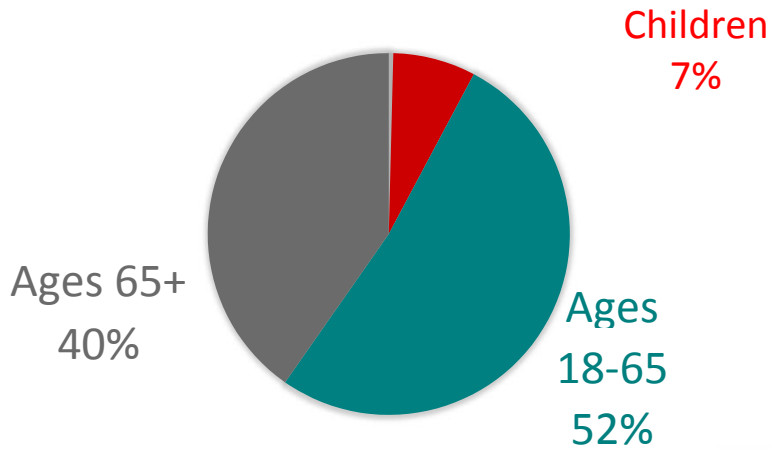
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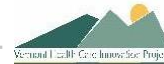
Disability leads to health disparities

Health disparity: Differences in health and health care between *population groups* that reflect a longstanding *history of unfair treatment and/or unequal* access to resources.

Examples

Health Status	Pattern of Utilization
Access to Care	Adherence to Treatment
Experience of Care	Mortality Rate

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Disability and Health Disparities

- Adults with disabilities are 4x more likely to report poor health status than adults without disabilities;
- Adults with disabilities are at a 2.5x greater risk for developing chronic diseases;

  - 71% of adults over 40 with intellectual disabilities have at least 2 chronic diseases;

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Disability and Health Disparities, *Cont.*

WHO CARES ABOUT **KELSEY?**

A new documentary film by Dan Habib

- Adults with intellectual disabilities are 6x more likely to be hospitalized than their peers;
- The risk of developing mental illness or suicidal tendencies is 3x higher in adults with intellectual disabilities compared to adults without disabilities;
- Students with disabilities are more likely to smoke cigarettes, use marijuana, or drink alcohol than students without disabilities.

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Health Status

On a team of 10 athletes.

6 are obese or overweight

4 have obvious tooth decay and 1 needs an urgent referral to a dentist

3 fail a hearing test

4 need glasses and 2 have an eye disease

5 have a significant problem with flexibility.

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Health Status: Vermont's 3 → 4 → 50

3 Health Behaviors that Contribute to 4 Chronic Disease that account for 50% of deaths

	Do NOT eat recommended fruits and veggies	Do NOT get recommended physical activity	Currently smoke
All VT Adults	79%	42%	18%
VT Adults with Disabilities	85%	51%	29%

☐ All VT Adults ☐ VT Adults with Disabilities

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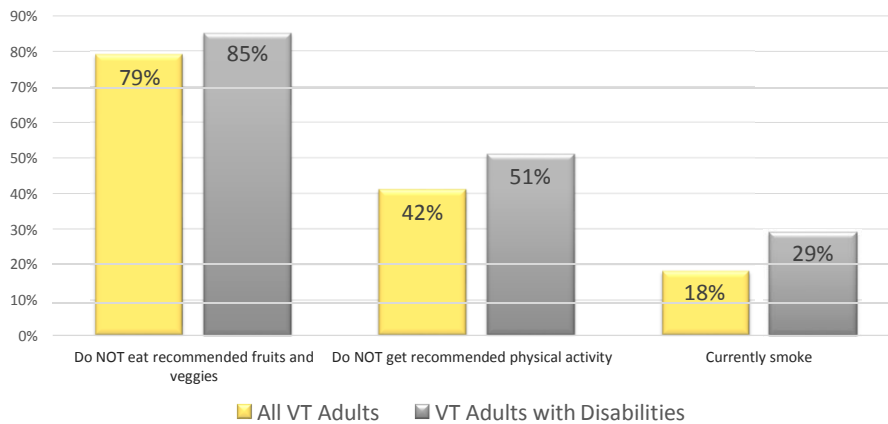
3 → 4 → **50**, *cont.*

4 Chronic Diseases

Chronic Disease Diagnosis	All VT Adults	All VT Adults with Disabilities
Lung Disease *(Asthma/COPD)*	15%	28%
Diabetes & Pre-Diabetes	13%	25%
Cardiovascular Disease	7%	16%
Cancer	7%	12%

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Utilization: ED Visits by Adults with I/DD

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
Total	.74	1.27	.96

Cohort 1
People with HCBS*
N= 2719

Cohort 2
People w/out HCBS*
N= 1906

Average Vermonter used ED .48 x/year
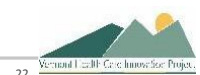
*HCBS = Home and Community Based Supports

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Expense: ED Visits

D   ED use by Cohort 1, 38.8% non-emergent
D   ED use by Cohort 2, 44.0% non-emergent

D   Mean cost of ED visit, Cohort 1: $ 40.27
D   Mean cost of ED visit, Cohort 2: $279.01

Almost 7x more

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Beyond socio-economic factors…

FIGURE 3

Infant mortality rate: deaths per 1,000 live births, by race and ethnicity

- Total
- White
- Black
- Hispanic
- Asian
- American Indian and Alaskan Native
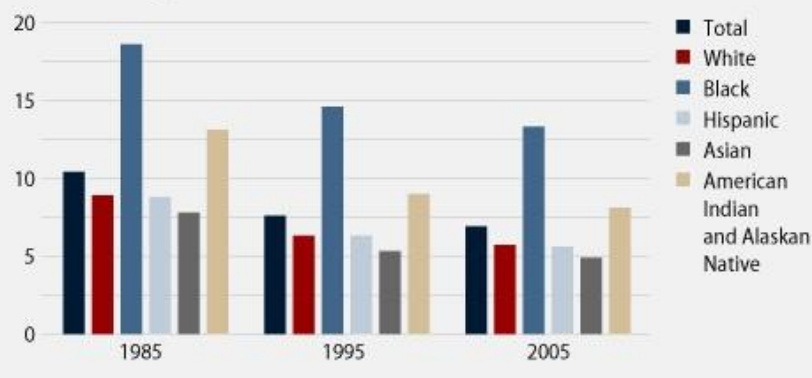
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Social Role Valorization

HEALTH AND COMMUNITY INCLUSION

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Social Role Valorization

JM,
*   High School Athlete*

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Social Role Valorization

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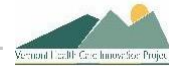
Social Role Valorization

Lois Curtis, Artist

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Review: The social determinant of health

Ableism

Housing

Health Insurance

Clean Water

Safe Neighborhood

Food security

Racism

Language Barriers

Asset Acquisition

Access to healthy food

Prejudice against...

Unequal pay for women

Employment

Toxin free environment

Transportation

Immigration Status

Education

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Final Thoughts

Housing that is a Home
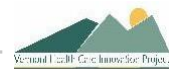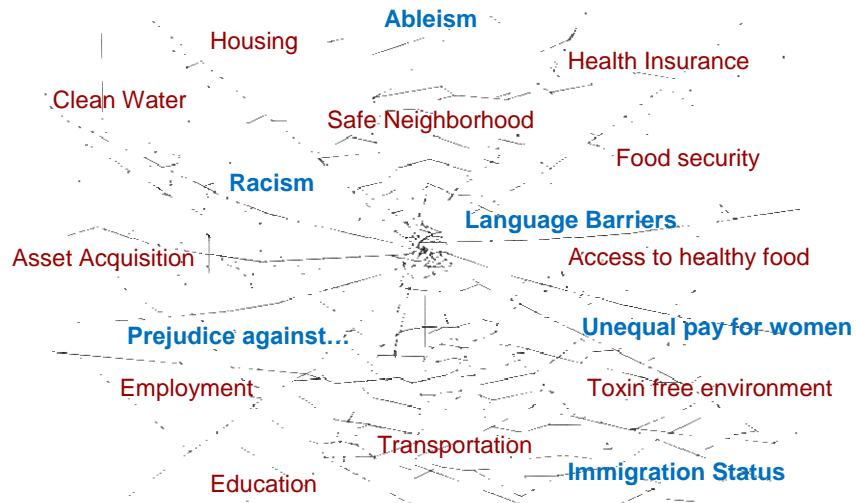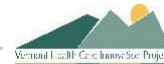
Work that is valued by Customers and Co-workers

Transportation because I have somewhere to go

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Understanding Disability
and the Intersection with Wellness

Disability has been understood in different ways throughout history. In some cultures, certain disabilities were thought to elevate a person's moral character or to imbue them with special powers. In other times and places, disability was thought to be an outward sign of inner depravity, a judgement by God. These belief-based models of disability set people – whether saint or sinner -- apart from society. They were the basis of practices like forced sterilization, the eugenics movement, and the segregation of people with disabilities in asylums, training schools, and other institutions.

Another common model of disability reflects an emphasis on diagnostic labels. Known as the "medical model," this paradigm emphasizes disability as something to be cured. Again, the effect of this understanding is to narrow our view of a person to just one aspect of their life. The medical model sees people with disabilities as broken and disability as something that needs to be fixed by experts with special skills and knowledge.

The disability rights movement takes a different view. Rather than focusing on static labels, disability is understood as a dynamic interaction between a person, their functional abilities, and the environment around them. In this "social model" of disability, a person is more or less disabled based on their interaction with the community and environment. When barriers are removed and appropriate accommodations are put in place, disability is diminished, and in fact, all people are better supported to engage in everyday activities.

Despite this new understanding of disability, many myths continue to shape our response to people with disabilities. For example, people with disabilities are often not offered counseling about birth control during routine medical visits, because of an assumption that they are not sexually active. Similarly, we may assume that someone who is non-verbal has nothing to say. It is important for Care Managers to challenge such ideas. One way to do this is to practice disability etiquette and to use people first language.

Three core assumptions underlie these respectful practices. The first of these is the need to **presume competence**. Parents of children with disabilities often hear the phrase, "he'll never…" before anyone has explored what their child needs to be successful. The **dignity of risk** refers to the idea that just like the rest of us, people with disabilities grow through trying new things; they are entitled to make mistakes. The third value is that of **self-determination**. Adults with disabilities have a right to make important life decisions for themselves and to be present when decisions that impact them are being discussed. This includes decisions made in the public policy arena. Disability rights teaches that there is "nothing about us, without us."

Watch a video of Presentation 2, which is approximately 1 hour and 55 minutes.
https://youtu.be/zg3NxLzuDQU?list=PLtncqwjB2vuXQOklpkpZtUBRtZvfy1F9-

Understanding Disability and the Intersection with Wellness
Resources and Handouts

Self-Advocacy and Self-Determination

- National Gateway to Self-Determination: http://www.ngsd.org
- Self-Advocates Becoming Empowered (SABE): http://www.sabeusa.org
- Green Mountain Self-Advocates (GMSA): www.gmsavt.org

Presume Competence

- *Wretchers and Jabberers*, **film and blog**: http://www.wretchesandjabberers.org/

People First Language

- **Syracuse University Disability Cultural Center**, *An Introductory Guide to Disability Language and Empowerment*: http://sudcc.syr.edu/LanguageGuide/

Common Courtesies & Disability Etiquette

- **United Spinal Association, Disability Etiquette**, *Tips on Interacting with People with Disabilities* (2008): https://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf

Supported Decision-Making

- **National Resource Center for Supported Decision-Making**, http://supporteddecisionmaking.org
- **The Jenny Hatch Justice Project**, http://jennyhatchjusticeproject.org

People First Language
Group Activity

Small Groups: Break into groups of 4 people.

Part #1 – 5 Minutes

Use your phones to go on Google to find news articles/ stories about people with disabilities. Notice if the stories use Person First Language. (5 minutes)

Reflection Question #1: Why you think it is important for reporters to use respectful and Person First Language?

Part #2 – 5 Minutes

Think about your own workplace. On a scale of 1-10 (10 is terrific, 1 is poor), circle how you think your office environment ranks in using People First Language.

1   2   3   4   5   6   7   8   9   10

Don't use   Always!
It much

Brainstorm ways you can encourage people in your office to use People First Language more often.

Activity Adapted From:
http://iris.peabody.vanderbilt.edu/wp-content/uploads/pdf_activities/group/IA_People_First_Language.pdf

**Understanding Disability
and the Intersection
with Wellness**
April 2016

GMSA Mission Statement

ACTIVITY

Look
Through
Our Eyes

Partnership

Learning Goals

1. Demonstrate basic knowledge of what disability is and how understanding disability has changed over time.
2. Identify the unique personal and cultural barriers people with disabilities face when accessing healthcare
3. Embrace the need for and promote self-determination, supportive decision-making and dignity of risk
4. Know where you can access more resources on this topic

Let's talk about Numbers Quickly

56,672,000

19%

88,400

14%

Source: http://www.disabilitycompendium.org/docs/default-source/2014-compendium/annual-report.pdf;
https://www.disabilitystatistics.org/reports/report.cfm?fips=2050000#prev-all
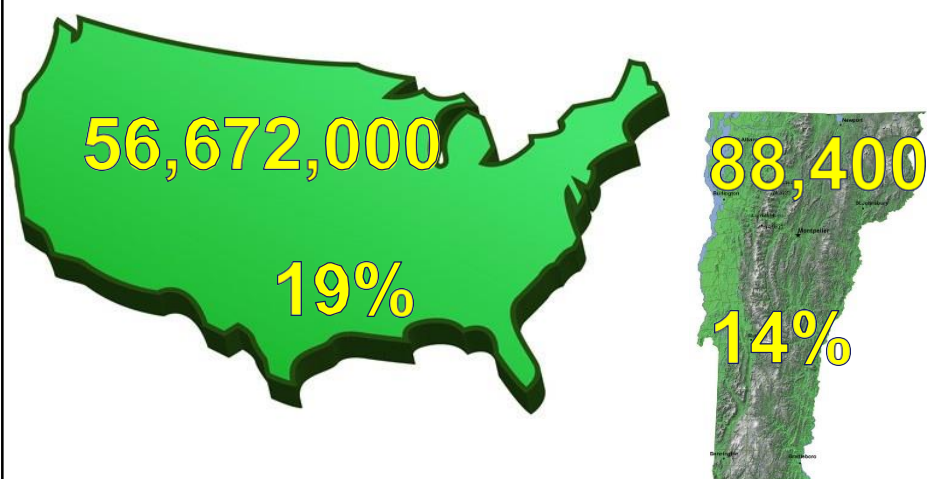
People First Language

People First Language

Say this…

Instead of this…

7

Myths and Attitudes about PWD

People who are non-verbal are unable to communicate.

People with disabilities can't live independently.

People with disabilities are asexual.

People with disabilities are broken and need to be fixed.

Some people with disabilities are "higher functioning" than others.

People with disabilities can't work.

People with disabilities can't give consent.

Disability is a personal problem that is the person's fault.

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Myths and Misconceptions PWD

When given the right support a person with a disability can achieve the same goal and dreams as someone without a disability.

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Models of Disability

Medical Model

Belief-Based Model

Social Model

World Health Organization

How Have Experiences Been Framed by History

Eugenics Congress Announcement
Number 1. History and Purpose of the Congress.

EUGENICS

EUGENICS IS THE SELF DIRECTION OF HUMAN EVOLUTION.

LIKE A TREE EUGENICS DRAWS ITS MATERIALS FROM MANY SOURCES AND ORGANIZES THEM INTO AN HARMONIOUS ENTITY.

Third International Eugenics Congress
New York City, August 21-23, 1932.
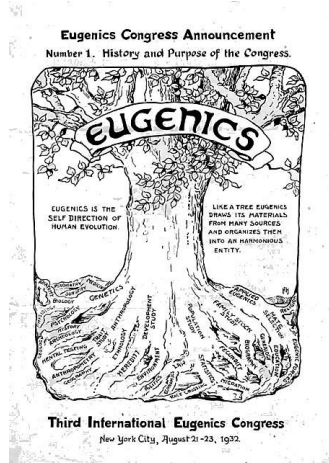
Sterilization Bill Is Passed by House on Roll Call Vote

Vote Is 142 to 75—Measure Will Become Law When Signed by Governor Wilson Who Sponsored It

-- Vermont, 1931

WHO Model of Disability

- Disability is a natural part of the human experience.
- The environment matters!

World Health Organization

Why Talk about This?

Because you are agents of change and helping us to shift the culture!

Core Values of Disability Community

NOTHING ABOUT US WITHOUT

- Disability is natural
- Control and informed choice over our lives
- Fully participate in and contribute to our communities
- Full integration and inclusion in an individualized manner
- Lead meaningful and productive lives
- Have interdependent friendships and relationships
- Live free of abuse, neglect, financial and sexual exploitation
- Presume competence
- Nothing about us without us!

Self-Advocacy and Self-Determination

Nothing About Us, Without Us!

Presume Competence

If you want to see competence, it helps if you look for it.

- Douglas Biklen

WHEN YOU SEE, MEET, OR THINK ABOUT A PERSON WITH A DISABILITY PRESUME COMPETENCE

Being an Ally

Dignity of Risk

Common Courtesies & Disability Etiquette

Videos shown during Presentation

Ask me First:
https://www.youtube.com/watch?v=VH0To4_kXwfs (captioned)

Talk to me please:
https://www.youtube.com/watch?v=8YXyTN_Idux4 (captioned)

It's Common Courtesy:
https://www.youtube.com/watch?v=ImICLUi_g7AM (captioned)

What are you saying?"
https://www.youtube.com/watch?v=FJDb6o_nmfew (captioned)

Disability etiquette gone wrong:
https://www.youtube.com/watch?v=yivppJvj_Mho (captioned)

Green Mountain Self-Advocates

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http://www.gmsavt.org

Person- and Family-Centered Care, Planning, and Thinking

Person-and-family-centered thinking is at the heart of care management. As defined in the Disability Core Competency Briefs, it is:

> *The ability to engage, communicate effectively with, and take direction from the individual in decisions affecting the design, delivery and evaluation of care management activities and service delivery, including honoring and respecting the individual's choices to take some risk in engaging in life experiences.*

Historically, this movement began in pediatrics, with family-centered care at the foundation of the primary care medical home. Today it refers to an approach to planning across many areas of life, including school, community-based support, healthcare, or a combination of these. Person-centered thinking reflects many of the core values of the disability rights movement, especially respect for personal autonomy and the dignity of risk. It requires seeing the whole person and respecting the desires, resources, and vision that they bring to the planning process.

Fundamental to person-centered thinking, is the distinction between what is important *to* someone and what is important *for* someone. What do these terms mean? Historically, services provided to people with disabilities have focused on what is important *for* them – in other words, what will keep someone healthy and safe. In the medical model discussed in Presentation 2, a plan was devised by experts, often without the individual participating or even in the room. In contrast, a person-centered approach requires exploring what someone cares about and finds motivating. A plan that emphasizes doing only those things that are important for you (for example, taking medicine, quitting smoking) -- but ignores the things that are important to you -- is likely to fail. When the two work together, there is momentum toward success. For example, when I take my medicine I am more successful in school, which means I am more likely to be accepted into the training program that I want to pursue.

When working with an individual, especially someone who has not been supported in making their own decisions, they may not readily identify, or tell you, what is important to them. Person-centered thinking tools are a set of easy to use templates that give structure to these conversations. Several are introduced in this presentation and many more are available on the resource page.

Another important skill in person-and-family-centered thinking is the ability to distinguish between a service and an outcome. Someone may start by saying, "I want to go to a day program." This immediately limits options. A good question to ask is, "what would be different in your life if you were at a day program?" The desired outcomes can emerge from this conversation – more friends, access to better food, a warm place to be during the day, for example. Ultimately, the goal of care management is to help people have better lives, not better plans.

Watch a video of Presentation 3, which is approximately 32 minutes, followed by a panel.
https://youtu.be/o3vUuFZefuQ?list=PLtncqwjB2vuXQOklpkpZtUBRtZvfy1F9-

Person- and Family-Centered Care, Planning, and Thinking
Resources and Handouts

- **Helen Sanderson Associates:** http://www.helensandersonassociates.co.uk/

- **Institute for Patient-and Family-Centered Care:** http://www.ipfcc.org/

- **The Learning Community for Person-Centered Practices**: http://www.learningcommunity.us/

- **Supported Development Associates (SDA):** http://sdaus.com/

Vermont Health Care Innovation Project

Person- and Family-Centered Care, Planning, and Thinking

Presentation by Vermont Family Network
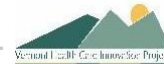
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Vermont Family Network

- Our mission is to empower and support all Vermont families of children with special needs.

Learning Goals

- Define what person- and family-centered care means
- Communicate the benefits of person- and family-centered care
- Understand the importance of trust, communication, and respect to the process
- Understand that each family is a unique cultural unit

Activity: Who is your chosen family?

Person-Centered Care

- The ability to engage, communicate effectively with, and take direction from the individual in decisions affecting the design, delivery and evaluation of care management activities and service delivery, including honoring and respecting the individual's choices to take some risk in engaging in life experiences (i.e., the concept of "dignity of risk").
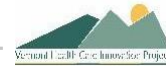
Core Values

- Seeing the whole person
- Self-determination and control
- Active participation
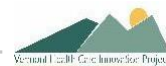
Activity: Speed Sharing
Person- and Family-Centered Practices
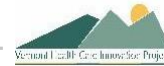
Differences in Terms

- Person- and Family-Centered Approach
- Person- and Family-Centered Plan
- Person- and Family-Centered Thinking

Person- and Family-Centered Thinking

- Set of tools to help discover and organize information that will help a person get the life they want
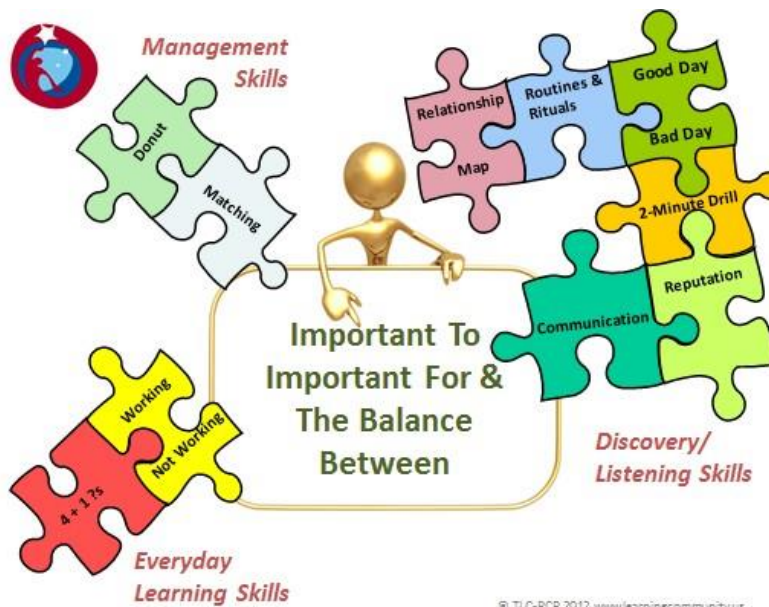
Important To

- Those things in life which help us be satisfied, content, comforted and happy

Important To   Important For
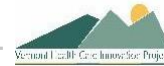
Important For

- Issues of health or safety (physical and emotional)
- What others see as important to help the person be a valued member of their community

Important To   Important For
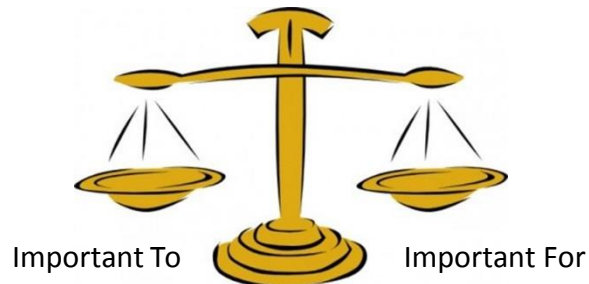
Finding a Balance

- If something is *important for* us and is also *important* to us, we will do it

- If something is *important* for us is not *important to* us, we have no interest in doing it

- If we want people to attend to what is *important for them* there has to be an aspect of it that is *important to them*
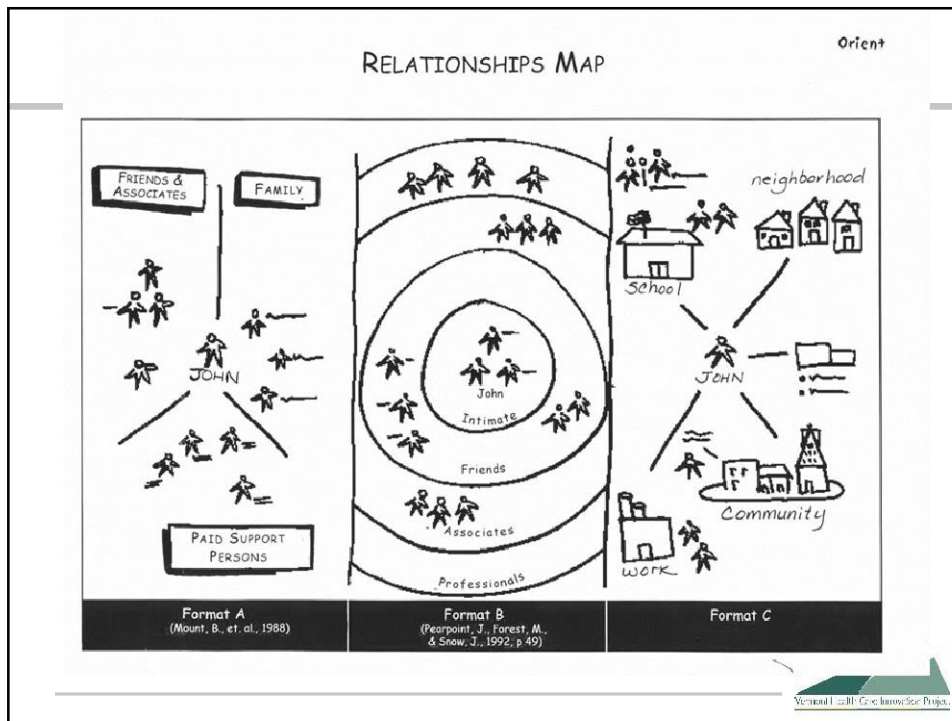
Personal Profile

| What People Like and Admire about ___ | Insert Photo Here | What is Important to ___ |
| Supports   Needs To Stay Happy, Healthy & Safe | | For a good match: characteristics needed to be present or absent |

4 + 1 Questions

What have you done to improve_____?

What have you tried? 1	What have you learned? 2	What are you pleased about? 3	What are you concerned about? 4

+1 – Given your learning what will you do next?

Good Day Vs Bad Day

Good Day	Bad Day
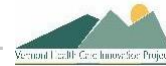
Focus on Outcomes
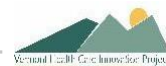
Building Strong Relationships

- Show them they can trust you
- Keep your word
- Try to be empathetic and compassionate
- Make an effort to understand their background, and respect their culture and community - your ability to help depends on it
- Try and "stand in their shoes"
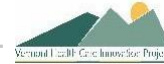
Panel Discussion
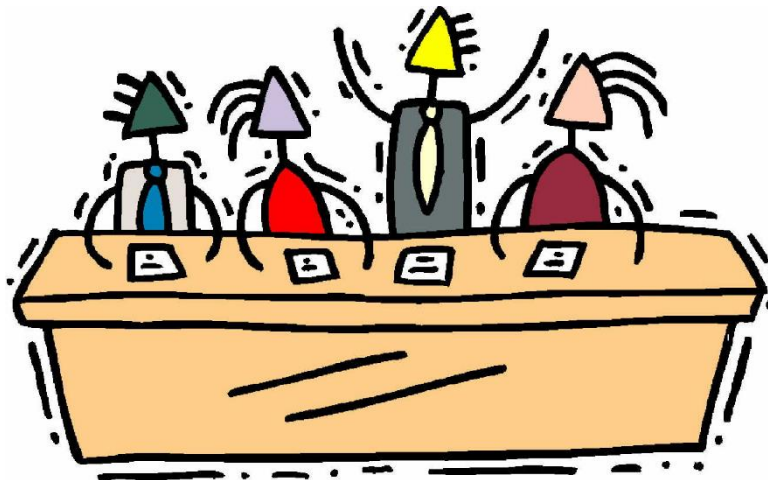
Activity: Discuss Benefits

- For individuals
- For families
- For your organization
- For you personally

Thank You!

Help people get better lives

Not just a better plan

Part II:

Strategies to Improve Communication & Access for People with Disabilities

Cultural Competency & Cultural Humility

The demographics of Vermont and our nation are changing. By 2044 the United States will be a "majority-minority" nation, meaning that people of color will outnumber non-Hispanic white people. With 94.8% of residents identified as Caucasian, Vermont lags behind the US in diversity, but here too there are significant changes, especially in the cities and towns that have participated in the Refugee Resettlement Program. Fourteen percent of students in the Burlington School District are identified as English Language Learners. Like people with disabilities, minority groups experience significant health disparities.

Cultural and Linguistic Competency is an enormous topic worthy of its own multi-day training. This presentation raises just a few key issues for the Care Manager to explore further in their professional development.

1. Cultural and Linguistic Competency exist on a continuum, ranging from a general awareness of diversity and bias, to increasing levels of personal and/or organizational commitment to self-reflection and actions aimed at addressing the power imbalances of racism and other forms of prejudice and discrimination. Cultural and linguistic competency is best viewed as a process, rather than an end-product.

2. Refugees – as distinct from other immigrant groups – may have significant healthcare needs due to trauma and long separation from familiar settings and support systems. As many as 50-80% may experience mental health issues.

3. Recognizing that cultural and linguistic competency has a direct bearing on health outcomes, the US Department of Health and Human Services, Office of Minority Health has developed national standards for culturally and linguistically appropriate Services in Health and Healthcare. Known as the **CLAS standards**, these guidelines address three areas:
   - The need for provider organizations to reflect the diversity of the population they serve in their governance, leadership, and workforce.
   - The need to provide services and care in the preferred language of the individual served and to make that option highly visible and easy to access;
   - The need for health providers to structure ongoing engagement with the full range of cultures in the community served and to hold their organization accountable for embedding CLAS-related activities and metrics in all aspects of care delivery.

This presentation is complemented by a panel discussion with parents from New American communities and a first-hand account of the complexities of working as an interpreter and cultural broker.

Watch a video of Presentation 4, which is approximately 90 minutes long.
Excerpts of the panel presentation and discussion by an interpreter are also available:
https://www.youtube.com/playlist?list=PLtncqwjB2vuUOnpLxLVwJavDITzMuZ_2O

Cultural Competency & Cultural Humility
Resources and Handouts

Vermont Resources

- **Champlain Valley Area Health Education Center, Cultural Competency for Health Care Providers**: www.cvahec.org/app/wp-content/uploads/2013/10/CulturalCompetencyforHealthcareProviders13.pdf
- **Vermont Health Care Innovation Project, Disability Awareness Brief: Cultural Competency:** www.healthcareinnovation.vermont.gov/sites/hcinnovation/files/DLTSS/Disability%20Awareness%20Brief%20-%20Cultural%20Competency%20-%20June%202015.pdf
- **Vermont Department of Health:**
  - ➢ Health Disparities of Vermonters: www.healthvermont.gov/research/healthdisparities.aspx
  - ➢ Cultural Diversity in Vermont: www.healthvermont.gov/family/toolkit/tools%5CF-1%20Cultural%20Diversity%20in%20Vermont.pdf
- **Cultural and Language Differences – Provider's Tool Kit:** http://www.healthvermont.gov/family/toolkit/CulturalDifferences.aspx
- **Refugee Health Program:** http://www.healthvermont.gov/local/rhealth/refugee.aspx
- **Office of Minority Health & Health Disparities:** www.healthvermont.gov/local/mhealth/minority.aspx

National Resources

- **AUCD (Association of University Centers on Disabilities) Diversity and Inclusion Toolkit:** www.implementdiversity.tools
- **Bridging Refugee Youth & Children's Services:** www.brycs.org
- **Ethnomed, Integrating Cultural Information into Clinical Practice:** www.ethnomed.org
- **Kansas Home Visiting Cultural Awareness Tools:** www.kshomevisiting.org
- **National Center for Cultural Competency:** https://nccc.georgetown.edu/
- **National Council on Interpreting in Health Care:** www.ncihc.org
- **Refugee Seniors in the U.S.** – Cultural Orientation Resource Center Resource Guide for Serving Refugees with Disabilities: www.refugees.org/wp-content/uploads/2015/12/Serving-Refugees-with-Disabilities.pdf

- *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, Anne Fadiman (1979).
- **U.S. Department of Health & Human Services**
    - **Think Cultural Health:** https://hclsig.thinkculturalhealth.hhs.gov/
    - **National CLAS Standards:** https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedCLASStandardsBlueprint.pdf
    - **Guide to Providing Effective Communication and Language Assistance Services:** https://hclsig.thinkculturalhealth.hhs.gov/

The CLAS Standards
Important Tools for Care Coordinators & Providers

The National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (The National CLAS Standards) aim to improve health care quality and advance health equity by establishing a framework for organizations to serve the nation's increasingly diverse communities.

Principal Standard

1. Provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs.

Governance, Leadership and Workforce

2. Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices and allocated resources.

3. Recruit, promote and support a culturally and linguistically diverse governance, leadership and workforce that are responsive to the population in the service area.

4. Educate and train governance, leadership and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.

Communication and Language Assistance

5. Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.

6. Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.

7. Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.

8. Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

Engagement, Continuous Improvement and Accountability

9. Establish culturally and linguistically appropriate goals, policies and management accountability, and infuse them throughout the organizations' planning and operations.

10. Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into assessment measurement and continuous quality improvement activities.

11. Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery.

12. Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.

13. Partner with the community to design, implement and evaluate policies, practices and services to ensure cultural and linguistic appropriateness.

14. Create conflict- and grievance-resolution processes that are culturally and linguistically appropriate to identify, prevent and resolve conflicts or complaints.

15. Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents and the public.

To learn more about the CLAS Standards, see:
https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53

Cultural Competency & Cultural Humility

Presentation by Vermont Family Network

Learning Goals

- Define cultural competency/humility
- Understand that all of us have bias, values, and beliefs that sometimes conflict
- Introduction to national CLAS Standards (Culturally and Linguistically Appropriate Services)

Culture

- Culture can be defined as the *behaviors*, *values* and *beliefs* shared by a group of people.
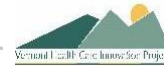
Family Values Activity

- ___tradition, ritual___
- ___hierarchy___
- ___equality/equity___
- ___religion___
- ___independence___

- ___work___
- ___education___
- ___money___
- ___love___
- ___food___
- ___other___

(list)_____

An Iceberg Concept of Culture

dress ⅄ age

race/ethnicity

gender ⅄ language

eye behavior ⅄ facial expressions

Adapted by the NCCC

body language ⅄ sense of self

notions of modesty ⅄ concept of cleanliness

⅄ emotional response patterns ⅄ rules for
social interaction ⅄ child rearing practices
⅄ decision-making processes
⅄ approaches to problem solving

⅄ concept of justice ⅄ value individual vs. group

⅄ perceptions of mental health, health, illness, disability

⅄ patterns of superior and subordinate roles in relation to status by
age, gender class

and much more…

Slide Source: The National Center for Cultural Competence, 2004

Culture

- *Characteristics* that can define cultural groups include:

  - Race
  - Ethnicity
  - Country of origin
  - Language
  - Sexual orientation
  - Gender identity/transgender
  - Age
  - Education

Culture

- *Characteristics* that can define cultural groups include:

  - Disability
  - Family & household composition
  - Class/socioeconomic status
  - Religious/spiritual orientation
  - Political beliefs
  - Geography
  - Refugee status
  - Tribal affiliation
  - Military affiliation

Cultural Barriers

- Mistrust and fear of treatment
- Alternative ideas about disability, illness, health
- Language, ineffective communication
- Access barriers
- Refugee

Language Barriers in Action

- https://www.youtube.com/watch?v=tvArchrsVlo
- https://www.youtube.com/watch?v=UBLuaoGXOBg

An Interpreter's Perspective

Federal Law

- Affordable Care Act of 2010, section 1557
- Prohibits discrimination in health care programs on the basis of race, color, national origin, sex, sex stereotypes, gender identity, age, or disability

Minority Populations in Vermont
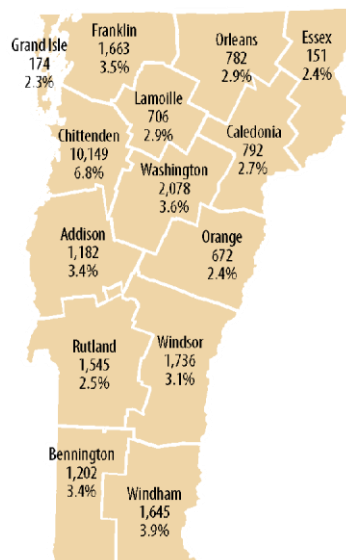
New Americans in Vermont

Children of Refugees

- "I consider all refugee children to have special health care needs because of their experiences."

Dr. Andrea Green, New American Clinic,
Vermont Children's Hospital

Refugees and Mental Health

- "Fifty to 80% of refugees are estimated to have significant mental health issues, primarily post-traumatic stress disorder, and symptoms related to anxiety and depression."

Karen Fondacaro, Director, UVM Behavior Therapy and Psychotherapy Center; founder Connecting Cultures

Cultural Competency/Humility

- Relate effectively to individuals from various groups and backgrounds
- Recognize broad scope of influences on an individual's personal identify

Cultural Competency/Humility

- Respond to unique needs of members of various groups
- Be sensitive to ways others experience the world

Cultural Competency/Humility

- Be curious about other cultures
- Be aware of one's own cultural biases
- Be sensitive to cultural differences while avoiding stereotypes

Stereotyping – We all do it!
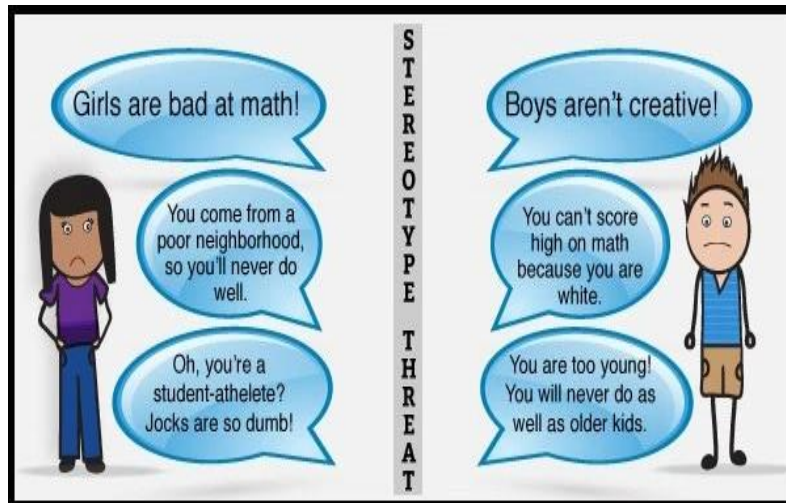
Sharing Stories

Cultural and Linguistic Competence/Humility

- <u>To respond</u> to current and projected demographic changes in the U.S. and Vermont
- <u>To eliminate</u> long-standing disparities in the health of diverse racial, ethnic, and cultural groups
- <u>To improve</u> the quality and accessibility of health and health care services

Find Out How Person Views Condition

- What do you call this problem?
- What do you believe is the cause of this problem?
- What course do you expect it to take? How serious is it?
- What do you think this problem does inside your body?
- How does it affect your body and mind?
- What do you most fear about this condition?
- What do you most fear about the treatment?

Self-Assessment Checklist Activity

- Physical environment, materials and resources - #1
- Communication styles - #6, #13
- Values and attitudes - #16, #25-26, #34

CLAS Standards

- U.S. Department of Health & Human Services, Office of Minority Health
- National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care

CLAS Standards

Principal Standard:

- 1. Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

CLAS Standards

- Governance, Leadership, and Workforce (Standards 2-4)
- Communication and Language Assistance (Standards 5-8)
- Engagement, Continuous Improvement, and Accountability (Standards 9-15)

Examples - CLAS Standards

- Organizations conduct initial and ongoing self-assessments
- Workforce reflects population 7 Recruit, retain, and promote at all levels of the organization a diverse staff and leadership
- Workforce skill development 7 Staff receive ongoing education and training in culturally and linguistically appropriate service delivery
- Data on the individual consumer's race, ethnicity, and spoken/written language are collected in records

Cultural Competency/Humility

- Provide services and care in language preferred by individual and which meets needs of all individuals

Translator Vs. Interpreter
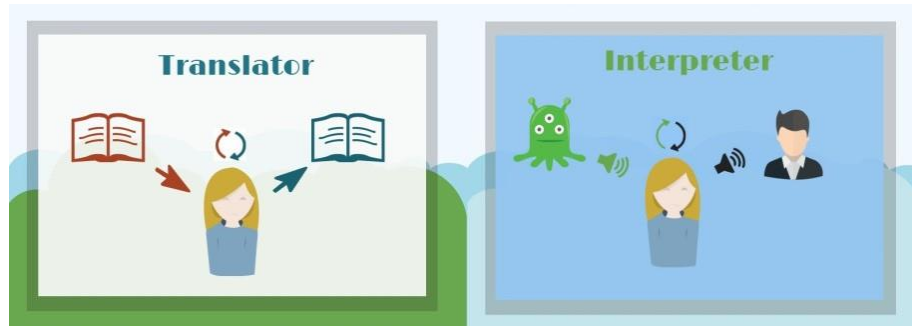
- Remember: this is a shared problem
- Use trained interpreters
- Translate materials into common languages

Cultural Competency for Health Care Providers

Provider Toolkit
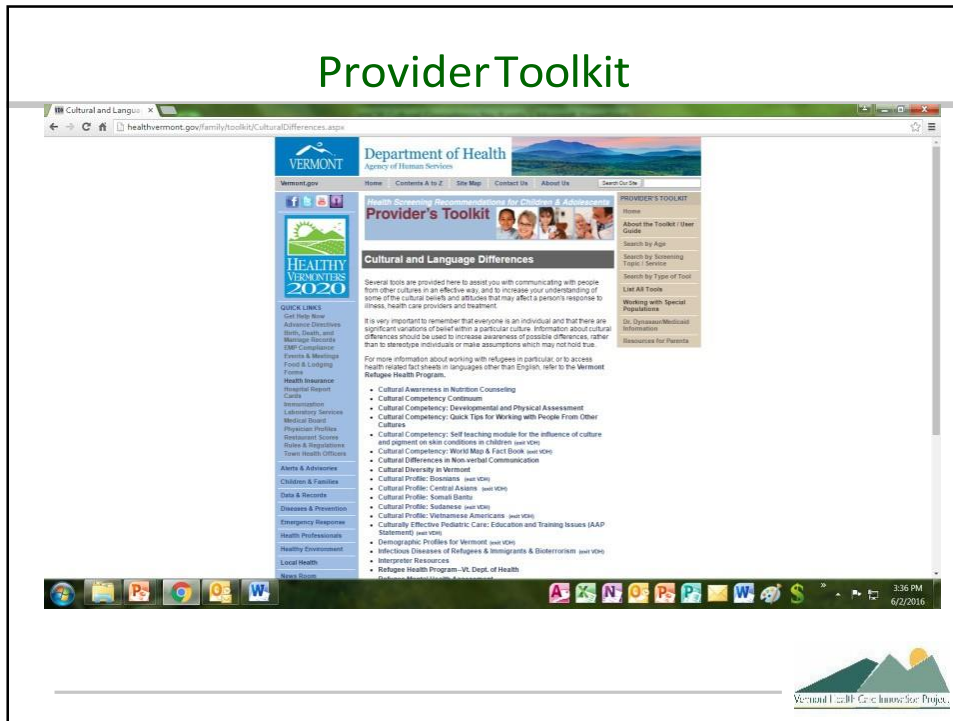
Translated Fact Sheets
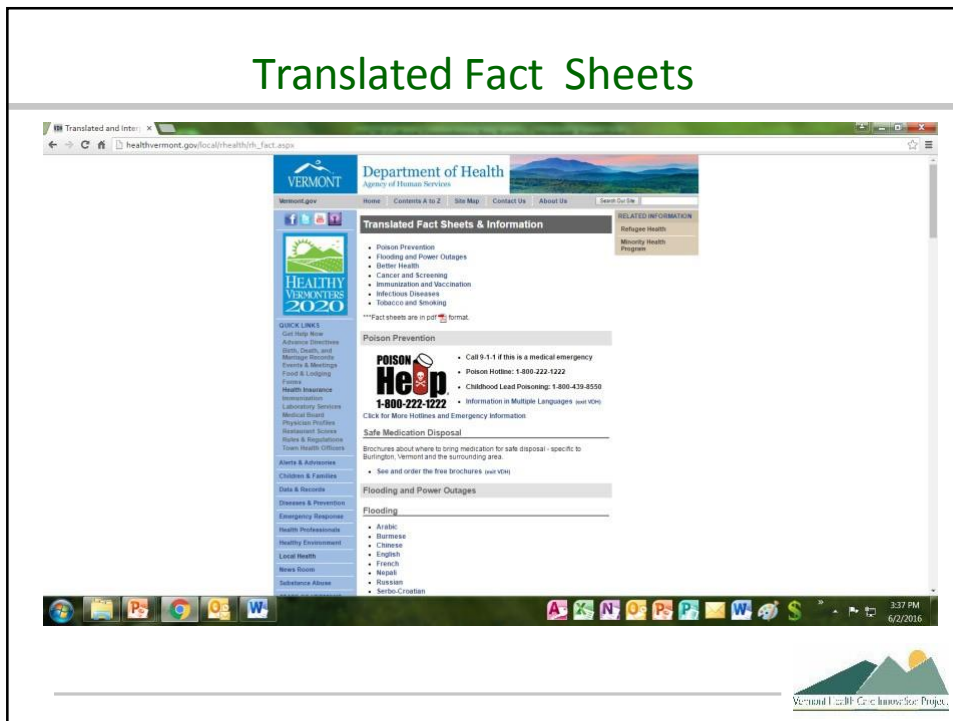
Appointment Reminder Translation Tool

Deaf and Hard of Hearing

- Vermont Telecommunications Relay Service (Dial 711)
- Vermont Interpreter Referral Service (VIRS)
- Vermont Registry of Interpreters for the Deaf (VTRID)

Panel Discussion
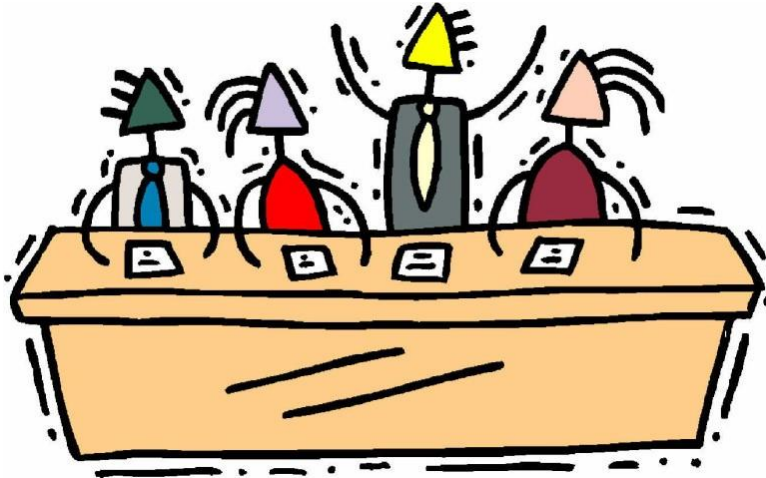
Final Thoughts

- Check-in with yourself
- Be curious
- Get to know people
- Be a voice
- Speak up
- Help build better systems

The Cultural Competence Journey

Cultural Humility

Cultural Competence

Cultural Sensitivity

Cultural Awareness
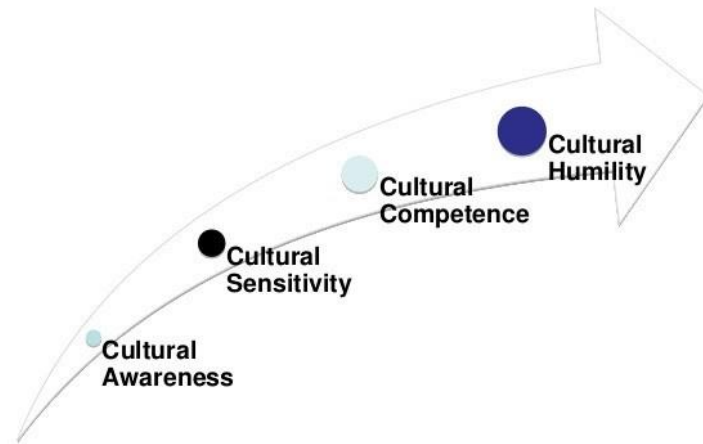
Thank You!

Strength lies in differences,
not in similarities.

Dr. Steven Covey
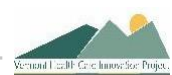
Communication and Interaction

In healthcare settings, good communication builds relationships, prevents medical errors, and can lead to higher level of care provision. Communication takes many forms. People with disabilities may not rely as much on speech as people without disabilities. They may use gestures, symbols, eye pointing, typing, and/or a range of assistive technology.

This highly interactive presentation introduces several tools that Care Coordinators and other providers can use to help improve communication with people with disabilities, depending upon the specific needs. For example, there are many excellent personal summaries like *My Health Passport*, that individuals can bring with them to scheduled appointment or use in emergency situations to convey critical health information. Provider checklists are useful in assessing whether you have considered a full range of possible accommodations, like slowing down, using visual supports, and simply asking your communication partner how they prefer to receive information. Being a good communicator takes time and practice.

Special attention should be paid to creating written health information that is accessible. Only 12% of the US population has sufficient health literacy skills, so accessible health information benefits not only people with disabilities but all of us. Three instructions for the treatment of "pinkeye," illustrate the differences between presenting information at an eighth-grade level, a fifth-grade level, and a level below first grade. The vocabulary is simpler, bullets are used to guide the reader, and pictures help reinforce the meaning. Most health information specialists recommend that written communication be no higher than a fourth-grade reading level.

Finally, the presenters discuss how communication is enhanced or hindered by the environment around the communicator. A cluttered, chaotic, or overstimulating space may make it more difficult for someone to pick out information around them like signage and it may distract an individual with sensory differences from focusing on an important conversation.

Bottom line: Communication with people with disabilities needs to be equally effective as communication with people without disabilities.

Watch a video of Presentation 5, which is approximately 90 minutes long:
https://www.youtube.com/playlist?list=PLtncgwjB2vuUOnpLxLVwJavDITzMuZ_2O

Communication and Interaction
Resources and Handouts

Generic Communication and Interaction Resources

- **Getting Your Message Across: Communicating with People with Intellectual Disabilities**
  GMSA's comprehensive guide to successful communication.:
  http://www.gmsavt.org/wp-content/uploads/2010/12/Getting-Your-Message-Across-Communicating-With-People-With-Intellectual-Disabilities.pdf

- **Simply Put: A Guide for Creating Easy-to-Understand Materials.**
  The CDC's handbook for creating written materials that are accessible.:
  https://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf

- **Heath Care Tools for Patients, Providers, Family Members, and more**
  GMSA's list of tools and resources for patients, providers, family members, and others (see **Communication and Interaction Resources for Providers and Care Managers** below).

Communication and Interaction Resources for Patients

- **My Health Passport**
  A form for communicating information about YOU to your health professionals.
  http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

- **Making an Appointment Worksheet**
  Worksheet covering information needed to make an appointment.
  http://autismandhealth.org/inc/forms/hc_appointment_worksheet.pdf

- **What to Bring to a Healthcare Visit Checklist**
  Checklist to get organized for health care appointments.
  http://autismandhealth.org/inc/forms/hc_prep_checklist.pdf

- **Symptoms Worksheet**
  Worksheet to help explain your symptoms to a health professional.
  http://autismandhealth.org/inc/forms/hc_symptoms_worksheet.pdf

- **After the Visit Worksheet**

  Worksheet to help you make a follow up appointment, schedule an x-ray or lab, and pick up medications.

  http://autismandhealth.org/inc/forms/hc_aftervisit_worksheet.pdf

- **Assortment of Charts and Forms**

  An assortment of charts and forms such as daily food logs, sleep logs, medication logs, etc.

  http://odpc.ucsf.edu/odpc/html/for_self_advocates/charts_and_forms.htm#overlay-context=odpc/html/for_clinicians/charts_forms_c.htm

- **Prevent, Understand, and Live with Diabetes. A Guide for Individuals with Developmental Disabilities.**

  Accessible guide all about diabetes.

  http://www.thearc.org/document.doc?id=4811

- **My Health Booklet Series**

  Online audio booklets to prepare for procedures such as pelvic exams, mammograms and colonoscopies.

    - **Checking up:**

      http://www.surreyplace.on.ca/documents/Flash/New%20Checking%20Up/Checking%20Up.html

    - **Following Through:**

      http://www.surreyplace.on.ca/documents/Flash/Following%20through/data/swf/engage_257/Following%20Through.html

    - **Examine Yourself:**

      http://www.surreyplace.on.ca/documents/Flash/Examine%20yourself_breast%20health/data/swf/engage_256/Examine%20Yourself-Breast%20Health.html

    - **The M Word:**

      http://www.surreyplace.on.ca/documents/Flash/The%20M%20word/data/swf/engage_257/The%20M%20Word.html

    - **The Big Red Dot:**

      http://www.surreyplace.on.ca/documents/Flash/The%20big%20red%20dot/data/swf/engage_258/The%20Big%20Red%20Dot.html

    - **Checking All of Me (Pelvic Exams):**

      http://www.surreyplace.on.ca/documents/Flash/Checking%20all%20of%20me_F/data/swf/engage_258/Checking%20all%20of%20me-Female.html

    - **Checking All of Me (Men's Health):**

      http://www.surreyplace.on.ca/documents/Flash/Checking%20all%20of%20me_M/data/swf/engage_259/Checking%20All%20Of%20Me%20-%20Male.html

➢ **Count on Your Colon:**
http://www.surreyplace.on.ca/documents/Flash/Count%20on%20your%20colon/data/swf/engage_259/Count%20on%20your%20Colon.html

Communication and Interaction Resources for Providers and Care Managers

▪ **Communicating Effectively with People with Developmental Disabilities (DD)**
Suggested communication tips for primary care providers.
http://www.surreyplace.on.ca/documents/Primary%20Care/Communicating%20Effectively%20with%20People%20with%20Developmental%20Disabilities%20(DD).pdf

▪ **Supported Health Care Decision-Making for Professionals and Policy Makers**
Tips for supporting someone with a disability to make their own health care decisions.
http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/Training%20Materials%20for%20Professionals%20and%20Policy%20Makers.pd_.pdf

▪ **What I Wish My Doctor Knew About Non-Traditional Communicators**
Tips for doctors about communicating with people who are non-traditional communicators.
http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/wiw%20non%20trad%20communicators%20final.pdf

▪ **What I Wish My Doctor Knew About People who Accompany Us to OUR Medical Appointments**
Things to remember when a person with a disability brings a support person to an appointment.
http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/WIW%20Attendants_0.pdf

▪ **What I Wish My Doctor Knew About Me as a Person with Sensory Sensitivities**
Tips for making visits more successful by taking into account sensory sensitivities.
http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/WIW%20Sensory%20Sensitivities.pdf

These materials may also be found at: www.gmsavt.org/health

Communication and Interaction

2:10 to 3:55

June 2016

Learning Goals

1. Learn how to communicate about health in an accessible and welcoming way.
2. Appreciate that there are different styles of communication.
3. Acquire concrete strategies for making your workplace more accessible around communication.

2

What is it like to have difficulty communicating?

Time: 5 minutes

Instructions: Work in groups of 2. Decide who will be the patient and the healthcare provider.

- The patient will attempt to communicate the written message by following the instructions on the slip of paper.

- The healthcare provider will attempt to understand the patient's message.

3

What is it like to have difficulty communicating?

At the end of the activity:

Ask patients… What was it like trying to rely on limited means to communicate your message? How well did your communication partner do with trying to understand your message?

Ask healthcare providers… How easy/difficult was it to understand the person's message? How did it feel to be the listener?

4

Why are we talking about this?

In health care settings, good communication:

1. Builds relationships

2. Prevents mistakes and errors

3. Can lead to higher levels of care provision.

5

Communication with people with disabilities needs to be **equally effective** as communication with people without disabilities.

Bottom Line

6

GROUP BRAIN STORM

What builds clear communication?

?   ?

?

?

7

How Do We Connect with the World?
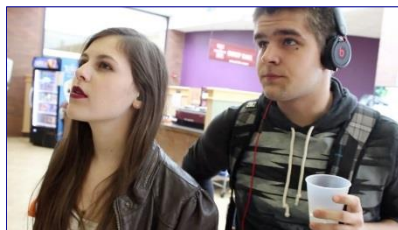
8

Other Forms of Communication

Some speech may be combined with the following to communicate a message:

D gestures
D touching/pointing to
    pictures, symbols, words
    and letters
D writing

D facial expressions
D eye pointing
D headshaking
D drawing
D signing

There is a wide variety of equipment that people use to communicate. They include things as simple as a pencil and paper, tape recorder, computer and text messaging on a cell phone. This also includes more elaborate devices such as:
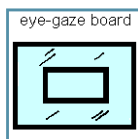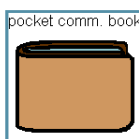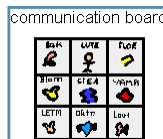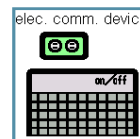
9

Tips for Building Stronger Communication

D Always presume
    competence
D Dignity of risk
D Respectful and Person
    First Language
D Strength-based
D Have a welcoming
    communication
    environment
D Be values-neutral
D Be engaged!

D Consider culture
D Avoid closed-ended
    (Yes/No) questions
D Think outside the box
D Consider the baggage in
    the room – yours, theirs
D Be open to feedback
D Commit to being a
    communication partner
D Practice!

10

Issues Related To Communication

Group Activity to Demonstrate Generic Communication Tips and Effective Ways to:

./ Ask Questions

./ Answer Questions

./ Listen

./ Support Decision Making

./ Give Instructions

11

Good Communication Takes Time

Tools to Improve Communication about Health and Wellness

My Health Passport

If you are a *health care professional* who will be helping me,
PLEASE READ THIS
before you try to help me with my care or treatment.

My full name is: _____
I like to be called: _____
Date of birth: ____ / ____ / _____
My primary care physician: _____
Physician's phone number: _____

Attach your picture here!

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/ support is needed)
_____
_____
_____

Created by University of South Florida

http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

Tools to Improve Communication about Health and Wellness

What I need to know about a colonoscopy

Count on Your Colon...

What I need to know about a colonoscopy
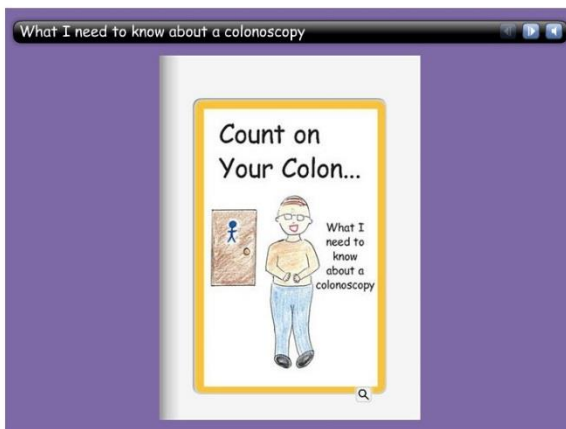
Created by Surrey Place Centre in Ontario, Canada

http://www.surreyplace.on.ca/resources-publications/videos/

14

Tools to Improve Communication about Health and Wellness

MAKING AN APPOINTMENT

Hello, my name is _____ and I'm calling to make an appointment with _____.

2. When you contact the provider's office, tell them what the appointment is for. You may need to give details to a nurse, medical assistant or scheduler–they are an important part of a team and will keep your information confidential.

NOTE: If you are making your first appointment with a new provider, tell them you want to make a **new patient appointment**. See section below for additional information you may need.

The reason that I am making the appointment is:
_____
_____
_____

Created by Autistic Spectrum Partnership In Research and Education

http://aaspire.org/?p=projects&c=hctoolkit

15

Written Communication - Inaccessible -

Conjunctivitis

You have contracted conjunctivitis. This is an inflammation or swelling of the conjunctiva. Often called "pink eye," conjunctivitis is a common eye disease. It may affect one or both eyes. Some forms of conjunctivitis are highly contagious. You have bacterial conjunctivitis which you need to treat with prescription eye drops from the pharmacy. Follow the directions on the bottle. It may improve after three or four days of treatment, but you need to take the entire course of antibiotics to prevent recurrence. Good hygiene is important also.

16

Written Communication
- Accessible -

Pink Eye

You have an **eye infection called pinkeye**. To make it go away:

- You need to get eye drops from the drug store.
- Squeeze eye drops into your infected eye 3 times per day (breakfast, lunch, and supper).
- Use the drops until they are gone.

Pink eye is really **easy to accidentally give to another person**.

- To keep this from happening, wash your hands after you use the drops and before you touch another person (like shaking hands).
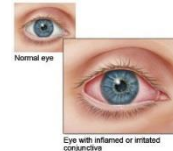
17

Written Communication
-More Accessible -

- **You have pinkeye. To make it go away:**
- **Get eye drops from the drug store.**
- **Squeeze 4 eye drops into your eye.**

- **Use the drops 3 times a day.**
  ◯ **Morning** ◯ **Noon** ◯ **Night**
- **Use the drops until they are gone.**
- **Pink eve is really easy to give to another person.**
- **Wash your hands a lot!**

18

Modify Physical Space to Improve Communication

Look at your checklist:

• What might make this space challenging for communication?

19

Modify Physical Space to Improve Communication

Look at your checklist:

• What makes this space more welcoming for communication?

20

Handouts

We Have a Ton!

www.gmsavt.org/health

Please visit us online for resources, handouts and more!

21

Communication with people with disabilities needs to be **equally effective** as communication with people without disabilities.

→ Bottom Line ←

22

Green Mountain Self-Advocates

2 Prospect Street, Suite 6
Montpelier, Vermont 05602
Toll free in Vermont: 1-800-564-9990
info@gmsavt.org
http://www.gmsavt.org
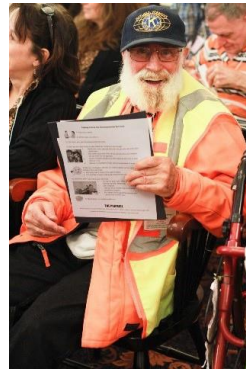
Universal Design and Accessibility

Access to public spaces and services are firmly embedded in two critical pieces of civil rights legislation – Section 504 of the Rehabilitation Act (adopted 1973) and the Americans with Disabilities Act (the ADA, adopted 1990). These rights were hard-won and even today, a great deal of advocacy is directed toward enforcing provisions within these laws.

Under the ADA, healthcare providers must ensure that people with disabilities have "full and equal access to their healthcare services and facilities, and reasonable modifications to policies, practices, and procedures when necessary to make healthcare services fully accessible to individuals with disabilities, unless the modifications would fundamentally alter the nature of the program or services" or "places an undue burden" on the provider. In other words, medical facilities must be designed so that people with disabilities can receive the same level of care as someone without a disability. Providers must plan for and accommodate communication differences, and they must "bend the rules" if a policy creates a barrier to equal treatment. These adjustments are rarely so expensive that they would be considered burdensome or unreasonable.

As discussed in Presentation 2, disability lies in the interface between an individual and their environment. A person is only as disabled as the barriers around them. This presentation includes an original video featuring one of the presenters navigating a typical clinic using his power chair. The film shows places were accommodations have been made, where they have not, and the consequences for the user. The video nicely illustrates how attention to detail is important in preparing an accessible and welcoming environment. The presenters review several helpful online resources that providers can use to determine if they are fully complying with the ADA.

It is also important to know that there limits to what a provider is permitted to ask when granting an accommodation. For example, under the law, a provider may ask what a service animal is trained to do as a support, but they may not ask someone to disclose their diagnosis or type of disability. In employment situations, the employer may ask for documentation of a worker's disability, but they must keep that information confidential.

Universal design is a movement that looks beyond simply accommodating differences to envision spaces that work seamlessly for all. Universal design is based on a set of principles that ensure no single individual or group is placed at a disadvantage or stigmatized by the built environment.

Link here to watch a video of Presentation 6, which is approximately 90 minutes long:
https://www.youtube.com/playlist?list=PLtncqwjB2vuUOnpLxLVwJavDITzMuZ_2O

Universal Design and Accessibility
Resources and Handouts

Peer-To-Peer Resources

- **Deaf Vermonters Advocacy Services** — www.dvas.org
- **Disability Rights Vermont**, judicial systems —www.disabilityrightsvt.org
- **Green Mountain Self Advocates** – www.gmsavt.org
- **National Alliance on Mental Health VT**, mental health advocates — namivt.org
- **Vermont Association for the Blind and Visually Impaired,** blindness and limited sight — www.vabvi.org
- **Vermont Psychiatric Survivors** - www.vermontpsychiatricsurvivors.org
- **Vermont Center for Independent Living**, cross-disability rights –www.vcil.org
- **Central Vermont Council on Aging,** elders & aging — www.cvcoa.org

Technical Assistance Resources

- **ADA.gov**

  (800) 514-0301   Department of Justice

- **Access-Board.gov**

  (800) 872-2253   Wrote the standards

- **ADAChecklist.org**

  (800) 949-4232   Tool to assess spaces

- **AskJAN.org**

  (800) 526-7234   Granting accommodations

- **Barrier Free Healthcare Initiative**

  (800) 348-4232   National collaboration

- **FairHousingFirst.org**

  (888) 341-7781   FHA technical support

Principles of Universal Design
Important Tools for Care Coordinators & Providers

The Principles established a valuable language for explaining the characteristics of Universal Design. They are in common use around the world, sometimes with slight modifications, primarily one or two principles grouped together.

1. **Equitable Use:** The design does not disadvantage or stigmatize any group of users.

2. **Flexibility in Use:** The design accommodates a wide range of individual preferences and abilities.

3. **Simple, Intuitive Use:** Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.

4. **Perceptible Information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

5. **Tolerance for Error:** The design minimizes hazards and the adverse consequences of accidental or unintended actions.

6. **Low Physical Effort:** The design can be used efficiently and comfortably, and with a minimum of fatigue.

7. **Size and Space for Approach & Use:** Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user's body size, posture, or mobility.

Compiled by advocates of Universal Design in 1997. These Principles are copyrighted to the Center for Universal Design, School of Design, State University of North Carolina at Raleigh.

To learn more about these principles or The Institute for Human Design, see:
http://www.humancentereddesign.org/

Universal Design & Accessibility

Presenters:
Ash Brittenham & Kim Brittenham

GMSA

Vermont Health Care Innovation Project

- **The Law Requires**
  ADA & Section 504
- **A Welcoming Environment**
  Universal Design & Physical Access
- **Reasonable Accommodations**
  How to Grant Them
- **Resources**
  Compete for Prizes in Phone Slam

Today We Will Cover   2

?

- Ask the BIG questions that keep you from moving forward

- Write SPECIFIC questions on *blue index cards*

- Use your own devices to look up stuff as we go!

questions

3

LAW

hard-won & long fought for, now our responsibility to implement

4

ADA

- Americans with Disabilities Act 1990 Titles II & III

  Title I employees

504

- Rehabilitation Act 1973, Section 504

These laws require medical providers to provide individuals with disabilities:
full and equal access to their health care services and facilities & reasonable modifications to policies, practices and procedures when necessary to make health care services fully accessible to individuals with disabilities unless the modifications would fundamentally alter the nature of the program or service

5

Accommodation process for employees is different than for people you serve (public)

ADA Title I employees
6

WELCOMING SPACES

elements & short film discussion

7

1 6
2 7
3
4
5

- equitable use
- flexibility in use
  - simple & intuitive
- perceptible information
- tolerance for error
- low physical effort
- size & space for approach and use

universal design

YouTube Link:
http://www.youtube.com/watch?v=M948oEJ9RcU&sns=em

Ash's video

9

What worked well?

10

What worked poorly? 11

Main elements 12

- Accessible Routes
  doorways - around obstacles
- Directional Signage
  entrances – bathrooms – offices
- Open Spaces
  lobby chairs – desk & table clearances
- Maintain those Accessible Elements
  clear snow – stalls aren't storage areas
- Respectful Attitude & Common Sense
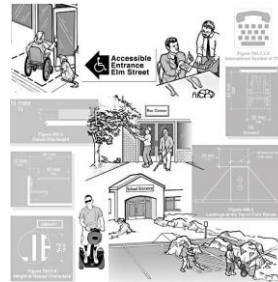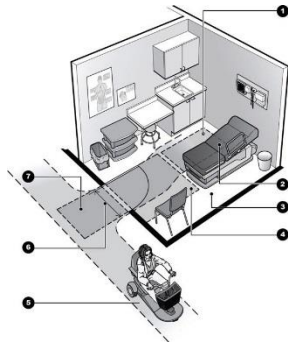
Standards
Checklists
Technical Assistance

ADA for facilities

13

BREAK
mind your chairs

14

ACCOMMODATIONS

15

- An adjustment made in a system to make fair the same system based on an individual proven need

accommodation

16

- **Necessary and appropriate** modification or adjustment not imposing a disproportionate or undue burden

reasonable

17

common requests

18
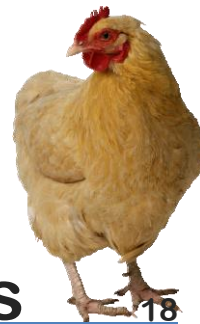
simple process   19

RESOURCES

20

- Using your personal resources, be the first person to find each resource

- All research methods respected

phone slam

21

FIND:

DOJ medical care for people who use mobility devices

22

FIND:

protruding objects animated guide   23

FIND:

Where should I mount way-finding signs   24

FIND:

accommodation support　　25

- **Access to Medical Care for People with Mobility Disabilities**
- **Hospital Access for People who are Deaf**
- **ADA Checklist Assessment Tool**
- **Effective Communication Guide Sheet**
- **Service Animal FAQ from DOJ**
- **Service Animal Matrix**

handouts　　26

- **ADA.gov** (800) 514-0301
  department of justice
- **Access-Board.gov** (800) 872-2253
  wrote the standards
- **ADAChecklist.org** (800) 949-4232
  tool to assess spaces
- **AskJAN.org** (800) 526-7234
  granting accommodations
- **BarrierFreeHealthcareInitiative** (800) 348-4232
  national collaboration
- **FairHousingFirst.org** (888) 341-7781
  FHA technical support

technical assistance 27

- **Deaf Vermonters Advocacy Services www.dvas.org**
- **Disability Rights Vermont – judicial systems www.disabilityrightsvt.org**
- **Green Mountain Self Advocates – www.gmsavt.org**
- **NAMI VT - mental health advocates - namivt.org**
- **VABVI - blindness, limited sight – www.vabvi.org**
- **Vermont Psychiatric Survivors www.vermontpsychiatricsurvivors.org**
- **VCIL - cross-disability rights– www.vcil.org**
- **VCOA- elders & aging – www.cvcoa.org**

peer-to-peer resources 28

"At Your Service: Welcoming Customers with Disabilities"
a self-paced webcourse for people interested in best practices for working with customers who have disabilities.

http://www.wiawebcourse.org

additional learning opportunity

29

Accessible Hospitals & Health Care Facilities
Earleen Sesker & Scott J. Windley
U.S. Access Board webinar (Blackboard)
http://www.accessibilityonline.org/Archives

audio
only: http://128.248.39.58:8080/listen/AudioConference-En/4_2011-07-07.mp3

additional learning opportunity

30

Accessible Hospitals and Medical Care Facilities - "Advanced Session" RexJ.Pace,

"advanced" level discussion on patient room scoping for both medical and long term care facilities, special technical provisions for parking at specialized facilities, alarm systems and toilet rooms in intensive care units

http://www.accessibilityonline.org/archives/session_detail.aspx?id=73

additional learning opportunity

31

Thanks for your time today!

32

Ash
- advocate & artist
- ashbrittenham.com

Kim
- access consultant
- kimbrittenham.com
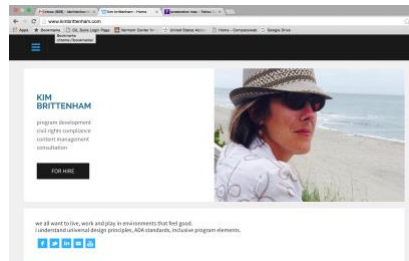
trainers

33

Part III:

Managing Change & Building Resilience

Transition from Pediatric Care to the Adult Medical Home & Beyond

Although this presentation focuses on one important healthcare transition – the shift from a pediatric model of care to an adult model of care – many of the guiding principles apply to managing changing support needs throughout the lifespan.

Change is challenging for all of us, especially for individuals with complex support needs. For individuals with disabilities, life expectancy has risen remarkably in the past two decades. Consequently, providers of adult medical care may not have received training in conditions like Down Syndrome or Duchenne's Muscular Dystrophy, which were once considered to be solely in the scope of practice for pediatricians. Research also suggests that transitions in care increase the risk of medical error. They also represent important opportunities to review how well a person's supports and services align with what is important *to* them and *for* them, as discussed in Presentation 3.

The Got Transition© website outlines six elements of successful transition. These closely mirror a tool used by organizations to support continuous quality improvement – the Plan-Do-Study-Act (PDSA) Cycle. Transition, in other words, is an iterative process, not a single event. It requires sustained attention and tools that facilitate planning, teamwork, and excellent communication over an extended period of time:

- Discovery: Practices serving children and youth make a conscious commitment to engaging patients starting around the age of 12 to 14 and their families in discussing transition. This is a matter of policy, made legible to all patients, perhaps by posting it in the waiting area.
- Tracking: The practice also has in place a means of identifying patients of transition age and of tracking their progress.
- Readiness: The young patient's readiness for transition is periodically assessed. The skills and capacities identified are clear and specific – for example, do you know your allergies and medications? Do you make your own doctor's appointments? This assessment should be repeated over time as new skills are acquired.
- Planning: A plan of care is developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. This plan should be updated regularly.
- Completion: A transfer package is prepared by the medical practice to support a "warm hand off" to the new primary or specialty care provider.
- Follow-up: The practice follows up between 3 and 6 months to make sure the individual is well supported in their new situation.

Watch a video of Presentation 3, which is approximately 32 minutes, followed by a panel.
https://youtu.be/o3vUuFZefuQ?list=PLtncqwjB2vuXQOklpkpZtUBRtZvfy1F9-

Transition from Pediatric Care to the Adult Medical Home
Resources and Handouts

General Information

- **American College of Physicians Pediatric to Adult Care Transitions Initiative,** including disease-specific tools: https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative

- **American Pediatric Association,** Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home: http://pediatrics.aappublications.org/content/pediatrics/128/1/182.full.pdf

- **Got Transition:**
  - General: http://www.gottransition.org/
  - Starting a Transition Improvement Process using the Six Core Elements: http://www.gottransition.org/resourceGet.cfm?id=331

- **Plan-Do-Study-Act (PDSA)**, Template: https://www.cms.gov/medicare/provider-enrollment-and-certification/qapi/downloads/pdsacycledebedits.pdf

- **Vermont Family Network:**
  - **Holistic Transition Guide for Families of Children with Disabilities:** http://www.vermontfamilynetwork.org/wp-content/uploads/VFN_HOLISTIC_FINAL1.pdf
  - **Transition to Adulthood Toolkit**: http://www.vermontfamilynetwork.org/services/transition/transition-to-adulthood-toolkit/

Sample Individual Transition Flow Sheet
Six Core Elements of Health Care Transition 2.0

Patient Name: _____   Date of Birth: _____

Primary Diagnosis: _____   Transition Complexity: _____

Low, moderate, or high

Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver _____

Date

Transition Readiness Assessment

-Conducted transition readiness assessment _____ _____ _____

Date　　Date　　Date

-Included transition goals and prioritized actions in plan of care _____ _____ _____

Date　　Date　　Date

Medical Summary and Emergency Plan

-Updated and Shared medical summary and emergency plan _____ _____ _____

Date　　Date　　Date

Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) _____

Date

-Timing of transfer discussed with youth and parent/caregiver _____

Date

-Selected Adult Provider

Name	Clinic	Phone	Fax	First Appointment Completed

Transfer of Care

-Prepared transfer package including:
- □ Transfer letter, including effective of date of transfer of care to adult provider
- □ Final transition readiness assessment
- □ Plan of care, including goals and actions
- □ Updated medical summary and emergency care plan
- □ Legal documents, if needed
- □ Condition fact sheet, if needed
- □ Additional provider records, if needed

-Sent transfer package _____

Date

-Communicated with adult provider about transfer _____

Date

-Elicited feedback from young adult after transfer from pediatric care _____

Date

Sample Transition Readiness Assessment for Youth
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date:

Name: Date of Birth:

Transition Importance and Confidence   *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

How confident do you feel about your ability to prepare for/change to an adult doctor?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health   *Please check the box that applies to you right now.*

	Yes, I know this	I need to learn	Someone needs to do this… Who?
I know my medical needs.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and medicines I should not take.	☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐

Using Health Care

	Yes, I know this	I need to learn	Someone needs to do this… Who?
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know to show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to go to get medical care when the doctor's office is closed.	☐	☐	☐
I have a file at home for my medical information.	☐	☐	☐
I have a copy of my current plan of care.	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get referrals to other providers.	☐	☐	☐
I know where my pharmacy is and how to refill my medicines.	☐	☐	☐
I know where to get blood work or x-rays if my doctor orders them.	☐	☐	☐
I have a plan so I can keep my health insurance after 18 or older.	☐	☐	☐

My family and I have discussed my ability to make my own health care decisions at age 18. ☐ ☐ ☐

Vermont Health Care Innovation Project

Transition from Pediatric Care to the Adult Medical Home

Presentation by Vermont Family Network

Vermont
Family
Network
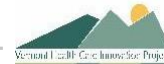
1

Learning Goals

- Learn the pieces of planning a transition policy/statement

- Understand a Plan of Care and how it can be used during transition

- Develop a transfer package for patient and new provider

2

Why is this important?

- CHANGE

- There are many things to be considered

- It's a long process, and preparations often begin far in advance

3

Why is this important?

- Maximize health, wellness, and happiness

- Vulnerable populations are complex and require additional planning

- It's a national priority in the Health and Human Service world

4

Why is this important?

"Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not."[1]

[1]Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home
American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians,
Transitions Clinical Report Authoring Group Pediatrics Jul 2011, 128 (1) 182-200; DOI: 10.1542/peds.2011-0969

5

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got transition

Got Transition/Center for Health Care Transition Improvement has the aim of improving transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

http://www.gottransition.org/index.cfm

6

got transition

Built around Six Core Elements that we will be highlighting throughout this presentation.

1. Transition Policy – "Discovery"

2. Transition Tracking and Monitoring – "Tracking"

3. Transition Readiness – "Preparing"

7

got transition

Built around Six Core Elements that we will be highlighting throughout this presentation.

4. Transition Planning – "Planning"

5. Transfer of Care – "Transitioning"

6. Transfer Completion – "Completion"

8

Practical Suggestions to Lay the Groundwork

The Plan Do Study Act Improvement Process looks at 3 questions:

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What changes can we make that will result in improvement?

9

Practical Suggestions to Lay the Groundwork

10

discovering → tracking → preparing → planning → transferring → completing
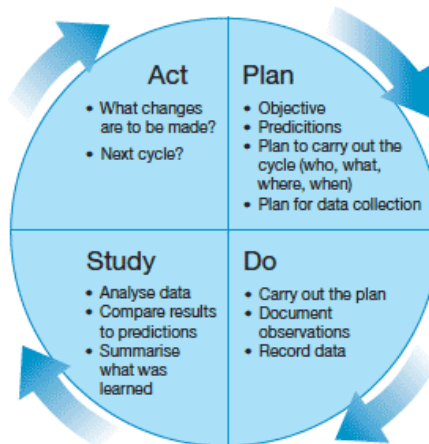
1. Develop a Transition Policy/Statement that describes a practical approach to transition processes.

   - What are some key terms/areas to focus on?

   - Example in Packet for Discussion

*From Got Transition Resources

11

Practical Suggestions to Lay the Groundwork

- Have a plan to ensure staff are all trained to follow the same procedures.

- Plan to have the policy/statement visible and shared with families/individuals you work with as well as staff.
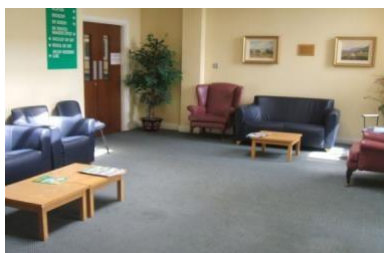
12

discovering → tracking → preparing → planning → transferring → completing

2. Establish Tracking and Monitoring Systems

- Criteria and process to ID transitioning youth/individuals

- Use a flow sheet to track transition progress (sample of this is in your packet!)

- Embed the process into Electronic Record system if possible

13

discovering → tracking → preparing → planning → transferring → completing

3. Transition Readiness
- Regularly conduct readiness assessments – recommend beginning at age 14 for pediatric– adult transitions

- Identify and discuss individual needs and goals

Are you ready?

14

discovering → tracking → preparing → planning → transferring → completing

4. Transition Planning

- Who makes medical (financial, etc.) decisions?

- Is there a directory that would be helpful?

- Update/develop a plan of care – include transition readiness

15

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discovering → tracking → preparing → planning → transferring → completing

5. Transfer of Care

- Confirm date of first new provider appointment

- Complete transfer package, including a letter to confirm details

- Confirm that new provider is ready and responsible

16

discovering → tracking → preparing → planning → transferring → completing

Let me transfer you to my other hand.

NASH

17
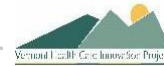
discovering → tracking → preparing → planning → transferring → completing

6. Transfer Completion

- Follow up with individual/guardian 3-6 months after transfer

18

MovieTime

https://www.youtube.com/watch?v=cjXurYrFMZM

Becoming an Adult: Taking Responsibility for Your Medical Care, Published on Dec 6, 2013

Moving out of the pediatric health care world is a major milestone in every young adult's life. This video shows and describes ways for young people to be more involved in their health care, what skills they will need to be successful and how being a patient in the adult health care world will be different from their pediatric experience.

19

Panel – Real Experiences

20

Final Words

THE *secret* OF CHANGE IS TO FOCUS ALL YOUR ENERGY NOT ON THE FIGHTING *the old,* BUT ON BUILDING *the new.* -SOCRATES

www.mivamerchant.com

Everyone Has a Score:
A Resilience-Based Approach to Adverse Childhood Experiences

In 1998, a landmark study from the U.S. Centers for Disease Control and Kaiser Permanente first uncovered the powerful link between Adverse Childhood Experiences – or ACEs -- and harmful physical and emotional outcomes for children and adults. Using a simple questionnaire, researchers scored 17,000 respondents on a ten-point scale, each point indicating that the subject had experiences of abuse, neglect, and serious household dysfunction before the age of 18. Higher scores were strongly correlated with poor health outcomes in adult life, suggesting that early trauma has a significant impact on developing brains and bodies.

The ACEs Study helps us better understand the social determinants of health. Findings include the fact that ACEs are common, with 87% of subjects reporting at least a score of 1 or more. Moreover, ACEs tend to occur in clusters, rather than single occurrences, with a strong, graded relationship to numerous health, social, and behavioral problems throughout their lifespan. Participants who reported a score of 4 or more had 4 to 12 times the chance of increased health risks.

However, the study also has some significant limitations. The subjects were mostly white, middle-class, well educated people with health insurance, and in using a simple design, the 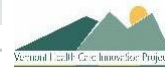study leaves out many types of trauma. More importantly, it does not account for the innate resilience that some individuals have and all people can cultivate. Taken by itself, a person's score can become a self-fulfilling prophecy. It can also be a way of stigmatizing a group that tends toward higher scores.

Resilience is the antidote to toxic stress. People who are resilient do not let failure drain their resolve; they find ways to "bounce back" even in the face of terrible events. People who are resilient share some characteristics: They have a strong sense of purpose that guides their choices. They balance a positive outlook with a realistic assessment of their situation. They have important, close relationships in their lives. They are not aware of their strengths and limitations, and they are skillful in steering toward opportunities that highlight their best self.

This presentation challenges care coordinators to help change public perception of children and adults who have experienced childhood trauma. People who are hurt are not thinking, living, and engaging in their communities in the way that they want to. They have not been supported in the way they needed; but the past does not have to predict the future.

Watch a video of Presentation 8, which is approximately 3 hours long.
https://www.youtube.com/playlist?list=PLtncqwjB2vuXSZek6T-tQnDzeEsN7-i7U

Adverse Childhood Experiences
Calculating your ACEs Score

Prior to your 18th birthday:

1. Did a parent or other adult in the household often or very often… Swear at you, insult you, put you down, or humiliate you? or Act in a way that made you afraid that you might be physically hurt?

    No___   If Yes, enter 1 ___

2. Did a parent or other adult in the household often or very often… Push, grab, slap, or throw something at you? or Ever hit you so hard that you had marks or were injured?

    No___   If Yes, enter 1 ___

3. Did an adult or person at least 5 years older than you ever… Touch or fondle you or have you touch their body in a sexual way? or Attempt or actually have oral, anal, or vaginal intercourse with you?

    No___   If Yes, enter 1 ___

4. Did you often or very often feel that … No one in your family loved you or thought you were important or special? or Your family didn't look out for each other, feel close to each other, or support each other?

    No___   If Yes, enter 1 ___

5. Did you often or very often feel that … You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or Your parents were too drunk or high to take care of you or take you to the doctor if you needed it?

    No___   If Yes, enter 1 ___

6. Were your parents ever separated or divorced?

    No___   If Yes, enter 1 ___

7. Was your mother or stepmother: Often or very often pushed, grabbed, slapped, or had something thrown at her? or Sometimes, often, or very often kicked, bitten, hit with a fist, or hit with something hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or knife?

    No___   If Yes, enter 1 ___

8. Did you live with anyone who was a problem drinker or alcoholic, or who used street drugs?

    No_____   If Yes, enter 1 _____

9. Was a household member depressed or mentally ill, or did a household member attempt suicide?

    No_____   If Yes, enter 1 _____

10. Did a household member go to prison?

    No_____   If Yes, enter 1 _____

Now add up your "Yes" answers:_____This is your ACE Score

Everyone has a Score

A Resilience-based Approach to Adverse Childhood Experiences

Vermont Federation of Families for Children's Mental Health

ACE's Training Vision Statement

"Creating community awareness through dialogue and training to disseminate a deeper understanding of how to better serve our children and their families by dramatically reducing the stigma of a score and by building resilience with strength based philosophy and approaches."

Group Inquiry

What are some other examples of traumatic experiences not reflected in the study?

Everyone has a Score

- Trauma is universal

- No trauma free zones

- Everyone has experienced trauma in one form or another

- Watch out for "us and them"

- Instead think "we"

Experiential Exercise

Debrief

Share one word that captures how you feel right now.

How did it feel to walk with a group?

How did it feel to be left behind?

What do you take away from this activity?

How could this be used in your work or personal life?

Training Modules

- Module One: Adverse Childhood Experiences Study Considerations
- Module Two: The Missing Pieces-Exploring the Dangers of the Data
- Module Three: Adverse Family Experiences Study-The Differences
- Module Four: Trauma and the Brain-Working with Small Steps
- Module Five: Resilience-The Antidote to Toxic Stress
- Module Six: Experiencing Resilience Building Exercises
- Module Seven: Paying it Forward

Module One: The ACE's Study

One of the largest investigations ever conducted by...

Center's for Disease Control & Prevention
Kaiser Permanente's Health Appraisal Clinic

- 17,000 individuals surveyed

- Answer a ten question survey about their childhood

- Physical exam results were included

Group Reflection

What were the demographics of the participants in the original ACE study?

Demographics of Participants

- 54% women

- 46% men

- Median age of 56

- 75% white

- 39% college graduates

- 36% had some college education

- 18% high school graduates

- 7% did not graduate from high school

Adverse Childhood Experience-Defined

Abuse: treat (a person or an animal) with cruelty or violence, especially regularly or repeatedly

Neglect: a form of child abuse, and is a deficit in meeting a child's basic needs, including the failure to provide adequate health care, supervision, clothing, nutrition, housing as well as their physical, emotional, social, educational and safety needs

Household Dysfunction: a family with multiple internal conflicts, domestic violence, mental illness, single parenthood, substance misuse, extramarital affairs, gambling, unemployment; influences that effect the basic needs of the family unit

Five Personal Questions

- physical abuse

- verbal abuse

- sexual abuse

- physical neglect

- emotional neglect

Five Family Member Questions

- a parent who is an alcoholic or substance user

- a mother who's a victim of domestic violence

- a family member in jail

- a family member diagnosed with a mental illness

- disappearance of a parent through divorce, death or abandonment

What is Your Score?

Initial Findings

87% of the 17,000 reported a score of 1 or more

1 or 2 out of every 10 have a score of 5 or higher

*30% of men had been physically abused as boys

*25% women had experienced childhood sexual abuse.

Original Study Results

- 50% of the individuals reported at least one ACE Score

- 25% of the individuals reported two ACE Scores

- Participants that reported 4 or more or more ACE Scores had a 4 to 12 times the chance of increased health risks

Health Risks Identified

With a score of 4 or more there was an 4 to 12 times the chance of having the following:

- Disease of addiction
- Depression
- Suicide attempts
- Sexual assault
- Leading causes of death

Ten Top Leading Causes of Death

- Heart disease.
- Cancer
- Chronic lower respiratory disease.
- Accidents (unintentional injuries)
- Stroke
- Alzheimer's disease.
- Diabetes
- Influenza and pneumonia

Center for Disease Control 2014

Additional Findings

- ACE's are common, in white, middle class, well educated people with great health insurance

- ACE's tend to occur in clusters, rather than single occurrences

- The ACE score captures the increasing risk of negative consequences of traumatic stress

- The ACE score reflects a significant relationship to numerous health, social, and behavioral problems in a person's lifespan

Potential Positive Implications

- A whole health approach to helping people by understanding how trauma can manifest in medical conditions

- Looking at behaviors through a softer lens reducing blame on the individual and the avoidance of referring to "poor choices"

- Technology to visually measure biology affecting the brain structure and function

- A new individual, family, team and community effort approach that reaches beyond traditional boundaries

Module Two:

The Missing Pieces

Group Reflection

What are some key elements that are missing in this study?

Missing Elements

- Other types of traumatic events

- Genetics and other major health issues

- Innate resilience

- A tally of positive experiences in early life

- Experiences post childhood

The ACE Study is not a Magic Eight Ball that Determines your Future.

Potential Dangers of the Data

The Doomsday Effect

Self Fulfilling Prophecy

" A prediction that directly or indirectly causes itself to become true"

Unsupported Access for Youth and Young Adults

Stigma & Group Targeting

"a set of negative and often unfair beliefs that a society or group of people have about something"

Health Condition Assumptions

Synonyms:

- presupposition
- hypothesis
- conjecture
- guess
- postulate
- theory

Trendy Messaging

We have to be cautious about the potential of the ACE's Score becoming a "trendy message".

There could be a tendency to talk about our own or each other's "score" in a way that could be damaging.

Other Considerations

Main focus of the study is about reducing healthcare costs

Potential insurance hikes for those who score high

Assumptions that high ACE scores are linked only to poverty

The deficit-based approach

Module Three: Vermont Sample Study
Adverse Family Experiences

The Differences Between the Studies

- Focus was not on the same age group

- Parents or guardians were asked the questions versus the individuals participating in the study

- Different questions were asked

- Smaller population participation

- Insignificant data due to limited follow up time

Adverse Family Experiences-Defined

- Not having enough to eat
- Not having stable housing
- Having parents who are divorced or separated
- Having a parent who died or went to jail
- Seeing or hearing physical violence between adults in the home
- Being a victim of neighborhood violence
- Living with an adult who was mentally ill or suicidal
- Living with an adult who has the disease of addition

The Findings

1 in 8 Children between age 1-17 have experienced 3 or more AFE

26 % Divorce or separated parents (1 in 4)

25% Family income Hardship (1 in 4)

16% Moved four plus times since birth (1-6)

15% Lived with someone's disease of addiction (1-7)

11% Lived with someone who is mentally ill (1 in 9)

8% Victim of or witnessed neighborhood violence

Findings Continued

8% Victim of witnessed neighborhood violence

6% Incarcerated Parent

6% Witnessed domestic violence

3% Death of a parent of guardian

2% Treated or judged unfairly due to race or ethnicity

The Results

- 1 in 8 kids have 2 or more chronic health problems
- 4 plus AFE is more common than asthma which is 1 in 12
- 1 in 6 kids between 6-17 have two or more health problems

- Youth between 2-17
  - 1-27 currently have depression
  - 1-15 have anxiety
  - 43 % have more than 3 AFE's
  - 1-12 have ADD or ADHD
  - 1-50 have autism
  - 1-33 have behavioral problems

Considerations

How do we know that a child at the age of two is depressed?

The diagnosis of ADD or ADHD could be due to other factors such as diet or environmental factors

The Autism percentage in the study is the same as the national average

Behavioral problems could be due to many different variables not tied to "the score"

The belief that these experiences are adequately dealt with by emergency response systems

For Guidance Only!

ACE's scores don't tally the positive experiences in early life that help build resilience

There are many people with high ACE's scores that do remarkably well

Use the information to view behavioral issues through a new and less blaming lens

There could be many other variables to behavior or medical conditions under the iceberg

Help Change the Mindset

- Children and adults with childhood trauma did not ask for the consequences.
- Most cases they are not aware of it
- Until the linkage between trauma and behaviors (health) are taught there is no awareness.
- Instead the person is blamed for all the consequences.

Some individuals and groups are going to believe ACE's sounds like an excuse for poor health or behavior problems. Educate them. Reduce the stigma.

Break Time

15-Minute Break

Module Four: Trauma and the Brain
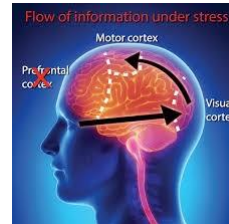
Brains can Heal

- Knowledge is freeing

- Range of promising approaches to help create new neurons

- Promote new patterns of thoughts and reactions

- Be patient with people

- Understand the brain under stress can only handle so much

Group Activity-Peanut Butter and Jelly

Module Five-Resilience

Got bounce?

TheAntidotetoToxicStress

Resilience

is that ineffable quality that allows some people to be knocked down by life and come back stronger than ever. Rather than letting failure overcome them and drain their resolve, they find a way to rise from the ashes.

How do we help our fellow Vermonters to bounce back?

Building Resilience in Adults

Preliminary Thoughts

- Some people seem to be more resilient than others
- Everyone can cultivate resilience on different levels individual to them and based in their experience
- Studies show that the daily repertoire of emotions of people who are highly resilient is remarkably different from those who are not
- Resilient people have an ability to experience both negative and positive emotion in difficult situations
- Resilient people are able to find the "silver lining" in any situation

True Grit-Does is Really Exist?

Being a gritty person means that the one tends to stick to their goals despite numerous issues, problems, setbacks and failures. The person has firmness of mind and unyielding courage.

The synonyms of true grit are: fortitude. determination.

Do you have "true grit"?

Elements of Resilience in Adults

- Sense of Purpose
- Positive Realism
- Relationships
- Determinations *(open-minded and flexible)
- Self Awareness
- Self Management

Sense of Purpose

- Core component of the six
- Foundation of all of the others
- The stronger it is the better you are equipped
- If not clear-leads to feelings of frustration or aimlessness

Positive Realism

"a balancing act between thinking positively and being realistic about what can be achieved"

- Keeping things in perspective
- Avoiding unrealistic expectations
- Practicing the "glass half full"

Relationships

- Other people matter to us
- Supportive and caring relationships are essential
- Being okay with asking for help

Determination

- The ability to see things through
- Being proactive and taking action
- The ability keep going in the face of adversity

"I am not what happened to me, I am what I choose to become."
—Carl Gustav Jung
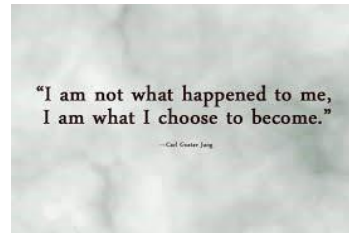
Self-Management

- How well you know your strengths
- How well you use your strengths
- How well you recognize your limitations

Managing Self

Traits and Characteristics	Core Competencies
Integrity & Honesty	Interpersonal skills
Resilience	Communications
Flexibility	Problem Solving
Initiative	Analytical Skills
	Lifelong Learning

Break

Module Six: Time to Bounce

Pick your choice of three stations

Building Resilience in your Community

"People who are hurt are not thinking, living and engaging in their communities in the way they want to. They have not been supported in the way they needed"

Start a "Got Bounce Movement"

You can Make a Difference!

- Talk to each other
- Trail blaze in your community
- Attend trainings
- Share information
- Reach out
- Reduce stigma
- Remove labels
- Talk about the strengths not the score
- It is about "us" not "them"

Love People Back to Life

Thank you!

Please help us to evaluate our training by filling out the post test and comment sheet in your packet. Your input is valued.

Contact us at:
vffcmh.org
or call us at:
(802) 876-7021
(800) 639-6071

We are here for you

Appendix

Curriculum Development and Training Team

Vermont Developmental Disabilities Council (VTDDC)

The Vermont Developmental Disabilities Council is a statewide board composed of people with developmental disabilities, their family members, and representatives from government and service providers. Created under the federal Developmental Disabilities Assistance and Bill of Rights Act, VTDDC uses its federal funding to support advocacy, capacity-building, and systems change activities that strengthen Vermont's ability to fully include people with disabilities in all aspects of community life. VTDDC has acted as the convener of the Disability Core Competency Training Team.

Contact Information: http://ddc.vermont.gov/ or (802) 828-1312,

Kirsten Murphy

Kirsten Murphy is the Executive Director of the Vermont Developmental Disabilities Council where she has worked since 2013. She began her career in non-profit management in the 80's developing programs for high risk youth in New York City and Boston. Her interests turned to disability rights and community inclusion when her two sons were diagnosed on the autism spectrum. Kirsten founded a family support program, ARCH, serving the Upper Valley region of NH and VT, directed the New Hampshire Autism Council, and is credited with securing equitable insurance coverage for NH children who experience the interfering symptoms of autism. She is a 2010 graduate of the Leadership in Neurodevelopmental Disabilities Program (LEND) through the University of New Hampshire. Now a Montpelier resident, she brings over three decades of experience in public policy, systems thinking, and advocacy.

Green Mountain Self-Advocates (GMSA)

Green Mountain Self-Advocates is Vermont's statewide self-advocacy organization. It is composed of 21 regional chapters and governed by a Board made up entirely of people with developmental disabilities. Through peer-to-peer support and training, GMSA helps people with developmental disabilities to take control over their own lives, make decisions, solve problems, and speak for themselves. They provide education to a wide range of groups about the strengths, rights, wants, and needs of people with developmental disabilities.

Contact Information: www.gmsavt.org or (802) 229-2600.

Max Barrows

Maxwell Barrows is a young man with Autism, who works for Green Mountain Self-Advocates, a disability rights organization in Vermont. As the GMSA Outreach Director, Max mentors youth and adults with developmental disabilities to speak up for themselves and become leaders. Max connects with people on all levels, advocating for the true-inclusion of people with developmental disabilities. In his work, he advances the message that when you meet an individual with a disability, presume competence. Max is currently on the board of Self-Advocates Becoming Empowered (SABE), the national self-advocacy organization. His goal is to travel internationally to spread his messages of true-inclusion and self-advocacy. Recently, Max was recognized for his hard work in Disability Advocacy by being selected as a Champion of Change at the White House.

Ash Brittenham

Ash Brittenham is one chill pickle. Informed by his lived experience as a wheelchair-driving artist, Brittenham uses media to educate others. He makes short films and radio stories, and is an audio production student at Full Sail University of Orlando Florida. Over his 18 years, Brittenham has been in front of numerous audiences entertaining or speaking for change. He is a graduate of the Vermont Leadership Series 2015. He is also a member of the newly-formed Youth Caucus for the National Council on Independent Living (NCIL) and will be a panelist for this summer's voting workshop at the NCIL 2016 Solidarity Conference. Follow his work via www.ashbrittenham.com .

Kim Brittenham

Kim Brittenham has been advocating for civil rights and culture-shift all of her professional life. Currently working at the intersection of violence and disability, she serves on the National Council for Independent Living's Violence & Abuse Task Force, and works as a consultant for the Women of Color Network to increase leadership of members of marginalized populations in the sexual and domestic violence movement. For the previous eight years, Brittenham provided technical assistance and training on the Americans with Disabilities Act (ADA) to Vermont. She gets excited about building spaces that work for the communities they serve.

Nicole LeBlanc

Nicole LeBlanc is a person with Autism. She works for GMSA as Advocacy Director. Nicole has a keen ability and interest in public policy and excels at communicating about the needs of people with developmental disabilities to public officials. Nicole travels around Vermont visiting local self-advocacy groups, supporting her peers to feel comfortable talking to their elected officials about what they need. Nicole completed a 10-week internship at the Administration on Intellectual and

Developmental Disabilities through the Washington Center in Washington, DC. She holds a certificate of professional studies from the University of Vermont. Nicole is a natural leader chosen by her peers due to her unwavering commitment to speaking the truth to power.

Skye Peebles, MPH

Skye Peebles, MPH has worked on media, technology, healthcare, and other self-advocacy projects with GMSA since 2008. Her roles of ally and sibling in the self-advocacy movement make her passionate about building a global community where people with developmental disabilities are truly included and valued. Skye served as a U.S. Peace Corps Volunteer in Botswana working on projects related to HIV/AIDS from 2006-2008. From 2010-2011, Skye was a Health Administration Fellow in the University of Rochester Leadership Education and Neurodevelopmental Disabilities (LEND) program and a Student Fellow in the American Public Health Association's Maternal and Child Health Division. Skye has a Master's Degree in Public Health from the University of Rochester and Bachelor's Degree from Mount Holyoke College.

Karen Topper

Karen Topper is the Administrative Director for GMSA. She manages the office, and trains staff and volunteers with developmental disabilities in techniques of self-advocacy and program development. Topper is the co-author of *Sexuality Education for Adults with Developmental Disabilities*, a curriculum designed for self-advocates and allies to teach sexuality education together as a team. She has been working with people with disabilities for the past 40 years, creating individualized supports for people moving out of institutions in Connecticut, New Jersey, and Pennsylvania. Topper has extensive experience in developing curricula for self-advocates, providers and families on: Independent Living, Abuse Prevention, Supportive Decision-Making, and Sexuality Education.

Vermont Family Network (VFN)

The mission of Vermont Family Network is to empower and support all Vermont families of children with special needs. They provide information on a wide range of topics to families and professionals, including family-centered care, special education, system navigation, transition services, and parent-to-parent matches. They are the early intervention provider for Chittenden County. Their values include being family-centered, respectful, collaborative, accessible, and working to make a difference.

Contact Information: www.vermontfamilynetwork.org or (800) 800-4005

Lisa Maynes

Lisa Maynes is a Family Support Director with Vermont Family Network, working on grants that are health and wellness related. She has been actively involved with work in Vermont that tries to make a better life for individuals with disabilities for 17 years. She has an 18-year-old son with a rare genetic disease and a 23-year-old daughter.

Aline Niyonzima Mukiza

Aline Niyonzima Mukiza recently joined Vermont Family Network (VFN). She serves as a Family Resource Coordinator for Children's Integrated Services-Early Intervention in Chittenden county and as a member of VFN's Family Support Staff where she works on training and special projects. She has three young children. Before joining VFN, Aline spent seven years in the Burlington school district where she was a multilingual liaison supporting students who are English Language Learners and their families. She has been an interpreter for the Vermont Refugee Resettlement Program and can speak Kirundi, Kiswahili, Kinyarwanda and French. Aline was recently featured in this Seven Days article: http://www.sevendaysvt.com/vermont/leading-ladies-new-american-women-in-vermont/Content?oid=3220875.

Janice Sabett

Janice Sabett is a Family Support Consultant/Training Specialist with Vermont Family Network. She has more than 15 years of experience in communications, training, and program development. She is the proud adoptive mother of three young Latino adults. She volunteers with NAMI-VT (The National Alliance on Mental Illness) teaching classes and facilitating a Family Support Group. Her life motto is "no health without mental health!"

Vermont Federation of Families for Children's Mental Health (VFFCMH)

Vermont Federation of Families exists to first support families of children and youth, ages 0-22, who are experiencing or at risk to experience emotional, behavioral or mental health challenges. The Federation also supports youth in transition through Vermont's Youth in Transition program, advocates for appropriate and needed services for all, supports families within the Act 264 process, and values and encourages peer services and supports as a needed part of Vermont's system of care for mental health and addiction recovery.

Contact Information: www.vffcmh.org or (802) 876-7021.

Kathy Holsopple

Kathy Holsopple is the Executive Director of the Vermont Federation of Families for Children's Mental Health. For the past 20 years, Kathy's focus has been assisting families with children and youth experiencing emotional, behavioral, or mental health challenges. She has advocated for system changes through participation on many state and local advisory boards and believes that the family voice must be present at all decision-making tables.

In addition to her leadership and advocacy work, Kathy has facilitated trainings for parents, families, service providers, legislators and community members. She is also a nationally certified Parent Support Provider.

Most importantly, Kathy is a parent of 3 grown children, one of whom has had significant disability and is in need of supports across many service systems. Kathy resides in beautiful Franklin County Vermont, and is active in community partnerships and activities to improve the lives of all residents in Franklin and Grand Isle.

Hannah Rose

Hannah has been working with individuals with addiction, trauma, and mental health conditions both formally and informally for over 30 years.

She is currently the Project Coordinator for a SAMHSA Recovery and Resiliency Grant with the Vermont Federation of Families for Children's Mental Health. In addition, she is the Accreditation Support Services Coordinator for the Council on Accreditation of Peer Recovery Support Services (CAPRSS) and sole proprietor of Impact Coaching and Consulting.

Hannah is a 2016 graduate of the Leadership Institute at the Snelling Center for Government. Her commitment is to inspire, promote, and advocate for system changes in Vermont that will allow for a higher level of service and support best practices in serving vulnerable populations.

Previously, Hannah was the Vice President for Education and Training at Vermont Association for Mental Health and Addiction Recovery. She researched and authored over 45 curricula and facilitated statewide training for 6300 Vermonters from various organizations and agencies. She continues to offer an extensive menu of training topics dedicated to helping individuals and organizations use a strength and resilience based approach with those they serve.

Hannah is a proud mom of two beautiful grown children, one small and sometimes grumpy dog, and two teenage lambs. She and her family reside on a small farm in the Champlain Islands

…and

Matt Wolf

Matt has worked with youth & young adults throughout his professional career. Having been labeled as learning disabled and diagnosed with ADHD early on in his life, Matt continues to understand and empathize with the struggles experienced by "at risk" youth in an adult driven world. Having three children of his own, he is also familiar with the stages of human development and the need to empower our children to cultivate their natural abilities, learn from their daily experiences, and rise to their fullest potential.

With natural abilities as a problem-solver, mediator, and community organizer, Matt has worked with youth and young adults of transition age for over ten years in Vermont – working to inspire & empower their leadership development and advocating for them in the VT system of care and legislature. Matt has been the Program Coordinator of Vermont's Youth in Transition (YIT) Program for the last six years, and in support of these systems level efforts, Matt has a history as a certified trainer in Normative Culture, Trauma 101, and the Transition to Independence Process (TIP) models. Matt was also a member of the People Education Advocacy Recovery (PEAR-VT) training team, delivering trainings and workshops all over the state of Vermont, at conferences, community gatherings and agency staff trainings.

Utilizing his years of experience in direct service work and history as a trainer, Matt is working with a statewide population of young adults and service providers, actively training and promoting young adult leadership & peer support work statewide, as well as, supporting staff in working to develop a strengths driven & empowering system of care for this population the "straddles" the line between the children's and adult service systems.