

2011 UCEDD TA Institute

UCEDD Region 1 & 2 Health Reform Breakout

Facilitator: Charles Drum

Attendees represented the following states:

Massachusetts
Connecticut
Vermont
Maine
New Hampshire
Puerto Rico (PR)
Virgin Islands (VI)
(plus 2 reps from ADD)

How is your Center involved in health reform efforts in your state?

PR – through policy roundtables

VI – through training, legislative initiatives, trying to change Medicaid rules since the current match is too high for our community

MA – Working on autism insurance legislation. Have a program to accept calls with questions related to autism. Massachusetts Health Care “Connector” is a good resource for information

CT – Moving to a fee for service program

NH – the state is not welcoming input from their Center

Other (*many states agreed with this statement*) - There are a lot of unknowns. States are not willing to invest fully without knowing the full cost and benefit.

How is the disability community responding to health reform efforts in your state?

CT – Training for families of children with special needs;
Minimal involvement among DD community;
We need more information dissemination and stronger champions

PR- Our Autism community is involved through work in public policy and Medicaid

VI – We have organized a conference “Voices that Count” bringing politicians running for office together with the DD community. Last year, the focus was on ‘health’ in general.

NH – We are engaged in a major push by legislators to move towards managed care. The consumer impact will be huge.

VT – Green mountain self-advocates have been involved in the health reform efforts; Center for Independent living is also involved – we have a strong voice within the DD community. We are very proud of our medical home!

MA – The DD community is not well represented in our “Health Care for All” program; Need for more advocacy within the DD community

What are some strategies for dealing with the barriers to participation?

CT – Should make sure your staff includes leaders knowledgeable in health care – need knowledgeable champions and mentors.

Need to build capacity among leaders so that they may impact policy

Make policy a core piece of the LEND curriculum

MA – Does have a ‘health care reform’ course within its curriculum

Make health care reform module for LEND available online

MA –Implementation of medical home for ‘other’ issues like diabetes

VT – We are creating a tool kit for physicians. We are also partnering with VCHP trying to extend the program to include other states

NH – We should look at health outcomes by merging databases to track the impact of health reform

PR – We are working with social and behavioral development with our Head Start program to assess autism and early detention. We are also using trainees to help bring health care policy forward

Challenges:

MA – Access to care for people with disabilities is limited. Reimbursement rates are a major hurdle

NH – Communication, physical access and limited numbers of providers make challenges to access.

If you could make a change, what would you do?

CT – start “Partners’ again

VT – Every UCEDD would have a specialist in policy

NH – We would share experts and bring experts to UCEDD on specific topics (ie from CDC)

NH – Hold a conference including all the players (universities, state govt., community- at large, educational programs, etc. Make it mandatory that ALL legislators attend)

ME – Develop an initiative that would involve the entire Region (Regions 1 & 2). Get all the states together to leverage resources. Also, bring the New England Alliance on Children's Health on board.

PR – Offer a Doctorate in PH and Disabilities – we are hoping to build capacity

ME – Get more involved in state PHAs and APHA within their disability sections