

**2011 UCEDD TA Institute
Health Reform Breakout: Report Back & Reflections**

Regions 1 & 2

- hire a full time healthcare policy expert for UCEDD and LENDs
- invite healthcare agencies to
- 6 states are close together and maybe should provide a common thread to help and take from the red states the money they are returning... joking
- but seriously be consistent across the 6 states in direction

Regions 3 & 4

- Politics in states are causing difficulties in healthcare but in every aspect and partnerships are essential (big D and dd)
- information how we present it to make it issues that effect all of us (social aspects, medical, pediatrics, approach of adopting MCH's view of life course)
- we have not found ways to frame what the ACA is... only what it takes away or destroys
 - needs to be in an uplifting, accessible way, distill it positively
- need to access data to understand and model not doing the ACA reforms (what broad impacts does this have)
- there is hope amongst young self-advocates and young professionals, but we must reach out and it is an issue of social commitment

Regions 5 & 6

- they talked about healthcare reform, but it blended into everything else going on
- since the governor is suing against ACA it has been hard to get UCEDD involved at the moment
- it has seemed to be helpful to be a part of the disability collections and consortiums to understand and disseminate healthcare info
- David (AR)'s UCEDD has been tasked with going around the state to 15 different sessions to determine what is happening to inform ACA in state
- In Wisconsin they hired with DD Council and P&A hired a policy coordinator for 3 years
- There is money in training healthcare professionals and we should be looking into this training at the UCEDDs
- NM is doing home visting in state which is a programmatic connection that we should look for similar connections
- David Mank "when people are EMPLOYED it is a huge benefit to their health" so please look beyond just "medical"

Regions 7 & 8

- rigorous discussion
- they were all red states and the attorney generals all signed onto the ACA which has framed the collective approaches on healthcare reform
- UCEDD medical campus are seen as service providers too
- one of the concerns that folks have is the lack of rules and regs
 - people see ACA as solving all the problems (especially the autism community which then upsets other DD communities)
- is cost effectiveness affecting our own values ("I don't want my kids living with me later in life"). Living out of home should not be discouraged but can be encouraged

- strategy in some states seems to be to not discuss ACA... maybe it will go away
attitude

Regions 9 & 10

- in a zero sum minus game that we need to adjust to.... Find the things we need not just
the things we like

- group did not have commonalities politically (red v. blue states)
- - health care reform is not on agenda due to acute care issues
- anything that needs adapting to is currently not out there and there is massive ambiguity
- there will be a great deal of time and energy to find commonality of language in the ACA
- LEND programs definitely have a way to help contribute positively
- Might be good to work with local P&As to clarify legal/lawsuit issues
- We should be helping define optional and optimal services
- Timeslines are well defined but not well disseminated... ucedds could help this
- UCEDDs would fight repeal and help with home visiting portion
- Maybe as an opportunity for NIRS to help network