

Pediatrics Setting

Directors' Retreat

Attendees: Colleen (NJ), Michelle (FL), Susan (NY), Susan (CO), Bruce (TN), David (SC), Rhonda (OR), Wendy (SD), Julie (IA), Ilka (OH), Patricia (NM), Robin (OR), Larry

Susan (Rochester, NY)

- In a division of pediatrics/DD/developmental and behavioral pediatrics
- At a pediatric center in Rochester
- Has a good relationship with legislative affairs
- Tricky to get legislation, lobby, educate
- Tough on UCEDD is across lifespan and pediatrics isn't
- Many layers in this setting
- Separate out advocacy community relationships, and white papers; separate out what Developmental and Behavioral pediatricians don't do
- "advocacy and systems change" is in DD Act
- "Education and information" for UCEDD in DD Act

Ilka (OH)

- Division of the College of Medicine which is a Division of the Children's Hospital
- Lifespan is awkward in peds setting
- Don't work with their government relations/lobbying office
- Challenging relationship with hospital government relations – doesn't like UCEDD doing anything on children's health because they do it; must get official permission to do anything
- But allowed to do their own thing if not children's health
- Education/information isn't the same as lobbying
- Teach CAC members regarding advocacy... can help advocates if they advocate themselves as their own person (as opposed to as part of the UCEDD CAC). Support the team on what they can do.
- Work closely with community members but not use the UCEDD name

Susan (CO)

- In section on Developmental Pediatrics – hired by the university but works at the children's hospital
- Doesn't use the university logo, but collaborate with the Arc, coalitions, or DD Coalition
- Sign on to things → No problems/ "Tiptoe around things"
- Lifespan tricky in department of pediatrics – the children's hospital manages across lifespan for health in some ways (do some adult clinics)

David (SC)

- UCEDD in pediatric division but all of peds is a part of Palmetto Health, except UCEDD -- only division not a part of Palmetto Health
- Very cautious! But, can do some stuff/letterhead and get prior approval (from the dean)
 - Includes Medicaid services, HCBS waver money, number of people served, and if funds

should be reduced/how to reduce services, etc.

- Collaborators are nonprofits (they can say how to vote, where we can't)
- Navigate carefully

Wendy (SD)

- Department of pediatrics (not even a division level)
- Strategy is to find a way to contribute to their needs because UCEDD isn't even a voice at the table at the medical school because they are not a division
 - Rules of the med school are they pick and choose which policies to work and are applicable
- Meets with legislators regularly – in discussions, they can do sway perspectives, get a heads up on where they are going, and they support advocates to go where they want to go
- Disability Coalition – sit there but not sign off on things
- DD network – determine who can lead/go to the bat on a particular issue
- “Amoeba” – all over without name on stuff
- Relationships
- “Plant the seed” for an idea and then they have to come back to you as the resource; make them think it is their idea and they get the credit

Julia (IA)

- Federal strategy but not as active in the state
- Managed care was a risk to the entire system so UCEDD became a resource to clinicians
 - GR affairs/policy people have no capacity to educate, so the UCEDD educated
 - Summarized and sent clinicians current information on what was happening and became their resource.
 - Brown bag lunches for clinicians
 - As a result, good relationship with the University lobbyist now

Patricia (NM)

- Division in department of pediatrics, at the school of medicine
- Last 7 years difficult because Governor and Dean had running battles in the state
- Employ parents/know other parents/parents network
- Never made ask for themselves; instead, always asked on behalf of a state agency; educating on behalf of the Dept. of Health, etc.
- Never on university priority list
- Relationships are everything at the legislative level!

Robin (OR)

- Moved at the division of pediatrics; reorganization, just one year in pediatrics
- Now have to use university services/relationships
- Collaborative with DD network groups
- Write briefs but run through coalition – promote information sharing
- Renew relationship with other disability groups
- Yoked to well-known/face of pediatrics (one doctor), who is the respected voice in the department – “leech” onto him for influence
- Learning how to fold into pediatrics
- Want to activate CAC more

- Use LEND Trainees: policy work, to the capital
- Also use faculty committees and other university committees
- Building FTE for policy position at UCEDD