

Medical Setting

Speaker: Karen Bonuck, Rose F. Kennedy University Center for Excellence in Developmental Disabilities, Albert Einstein College of Medicine, New York

Intros: Karen, Chris Smith from MD at Kennedy Krieger, Oliva from UCLA, Tawara at Georgetown, Joanne from Rose Kennedy, John from AUCD, Melanie at Oregon Health and Science, Kara from Cincinnati, Lesley from West Virginia, Marcia from New Mexico, Derrick from University of Iowa

Strengths?

Notes: Lots of medical school are associated with pediatrics. They intersect in many ways. What are the strengths with being associated with a medical center?

Kara- it was a strength to Cincinnati and the CHIP program and they had Senator Brown visit them.

Tawara- taking on health disparities in a big way. It helps people think about racial and ethnic disparities and people with disabilities.

Lesley- WV is trying to get CMS funding and revisiting the state model. The initial group who determines that is from a medical school which is advantageous because they are associated with a medical center.

Tawara- trying to increase awareness for disabilities to first year medical students. From early intervention to older age. A number of the students come back because they are interested in pursuing this study.

Karen- disabilities is not often on the radar

Joanne- Einstein buddies- connecting students with clinical aspects of their UCEDDS and self-advocates. Its working with a club for medical students.

Weaknesses?

Karen- challenges with people who don't want to be identified with receiving services due to documentation.

Joanne- No one showed up to a clinic in a Latino community due to people being fearful of being identified as undocumented.

Chris- NIRS is a weakness and they created a system where they input their data and are able to connect with other UCEDDS

Tawara- faculty evaluations are slanted towards physicians.

Marcia- community and state wide efforts impacted by policy. Trying to create exceptions for policy.

Kara- analyzed the president's budget. Preference for direct service. In the current climate it is shown as a weakness

Derrick- housed in a clinic environment. It is hard to view and see how they work with the community. The clinic is being threatened and therefore they take precedence. Who's needs trump?

Chris- lots of blind spots in our job. There are bureaucracy issues. Issues that happens in everyone's lives: Staff, Faculty, self-advocates. 18 month waiting list to get in.

Joanne- erosion of the ability to pay for the services that are provided for children's and adults. There is tension between the department and the medical center. It can put programs in jeopardy.

Tawara- MedStar had implemented all these changes at Georgetown. Had to choose between a university employee or MedStar employee. Couldn't have all these clinics because MedStar couldn't serve too many clinics. Most of their clinical services have gone away.

Opportunities?

Karen- social workers found that patients were not coming in because of immigration issues. They have turned it into a research project. Patients feel that their safety is threatened. The opportunity for the families is to identify the impact and how the parents can parent and their child's wellbeing. It can become a mental health issue.

Chris- They have staff who fight Baltimore City Schools- schools are not seen as a positive investments. Staff have been able to fight for their families. Which has shown an increased in donations to help fight for families.

Derrick- they did community conversations. They offered a voice of the community to the clinic. Advance diversity issues, social deterrents of health.

Kara- parents with disabilities. They look at keeping families intact and keep government out of families.

Joanne- more people with disabilities are slowing being able to look at opportunities for employment. More inclusion. There is a recognition by corporations.

Marcia- soft money goes away and there is no mechanism to bring it back. Circling back how to diversify their work and not just be a clinical machine.

Melanie-They sit on the medical student conduct committee. Looking at why a student is flunking out. Spending a lot of energy from pediatrics to adult services and created a transition clinic.

Olivia- navigating that different systems that touch healthcare and helping families with transitions. They do presentations on how policy affects healthcare.

Chris- they negotiated with the 8% down to 5% and they take 20% from the cost centers to help cover the other 3% that wasn't covered.

Marcia- looking for opportunities to share the wealth. They do training and TA with these statewide projects. They were asked to support their NICU families. 2 year process to forge a relationship.

Karen- developed a relationship with the family advocacy center to help families with legal issues.

Tawara- they have a relationship with their law center. Part of the law center focuses on the underserved populations in the city. The law center has been looking at the legal rights for the children. GEMS- Georgetown Experimental Studies. Used to disadvantaged people across the community and national to bring them in to the medical school and some students have an interest in disabilities.