

Minutes for February 13, 2014

Present: Jean Sherman Mailman Center & FI Alliance for Assistive Services and Technology; Jose Rosa-Olivares, MD, MS/HAS Miami Children's Hospital Pediatric Care Center; Judy Clauser, Epilepsy Foundation of Florida; Mark Rabinowitz, M.D.; Miami Beach Community Health Center; Yana Blaise, Broward Community Health Center; Isabel Garcia, Parent to Parent of Miami; Raquel Linares, CCDH; Nini Hadwen, Epilepsy Foundation of Florida; Alex Blaise, Blaise Podiatry, Sorangelly Menjivar, Miami Beach Community Center; Wilma Steiner, Dade Schools; Jill Brookner, Dade Schools

1. Opening & Overview
 - a. Dr. Lanetta Jordan opened the conversation by explaining what had brought her into the conversation and how a lack of transitional services has led to the death of some patients.
2. Introductions
 - a. Each person introduced him/herself and described something they do to integrate a healthy lifestyle into their everyday life.
3. Objectives & timeline
4. Review of FL Strategic plan for Health Care Transition
 - a. The group reviewed the Florida State Strategic Plan as a road map for creating one for South Florida. The group also agreed that it would like to be called 'South Florida HATS' instead of MiamiHATS
5. To highlight the uniqueness of South FL- review of data
 - a. While reviewing the information presented on the charts in the PowerPoint presentation a question arose regarding people captured in the 'mental' disability category.
 - b. Answer: mental disabilities in this context refers to SSI criteria for children, that is, a cognitive or mental condition that results in "marked and severe functional limitations." and is "disabling, or be expected to be disabling, for at least 12 months; or must be expected to result in death."
6. VISIONING EXERCISE - the group was asked to identify road blocks and opportunities
 - a. Road Blocks
 - i. Inability to find providers (due to provider unwillingness, unmotivated or lack of funding)
 1. This includes OTP speech therapists
 2. Adult Care providers not knowledgeable or comfortable with disabilities
 3. Lack of Medicaid providers
 4. Lack of information on the part of Adult care providers
 5. Inability to find Specialists (Specialists are unreceptive)
 - a. Participants shared stories of families getting an appointment and traveling long distances only to be turned away when they arrive at the appointment
 - ii. Impact of stereotypes on health care providers leads to refusal
 1. An example was given of a school field trip to FIU Medical School. wherein kids were going to receive a blood workup. A young man with Down syndrome was not allowed to participate, although he was on

the field trip, because the Medical Students singled him out and refused his participation

- iii. Need to empowerment of patients
 - 1. Patient outgrows caretakers
 - a. Caretakers age and may have complex medical needs of their own
 - b. Caretakers may die or be unable to continue to care for their child
 - 2. Over protective parents
 - a. Peds is more nurturing
 - b. Adults is more independent
 - 3. Attachment between patient and provider
 - 4. Comfort with Peds provider
 - 5. Patients are not empowered to make decisions / participate in decision making
 - 6. Self-sufficiency and impatience in secondary school settings 'when will you be able to do this for yourself'
 - 7. Use of technology
 - a. Apps and books to help families manage the needs of youth and young adults with complex medical needs
 - i. This suggestion is based on a conversation among participants just after the conversation had wrapped up
- iv. Need for Continuity
 - 1. Lack of policy regarding co-management guidelines
 - 2. Records are not always shared
 - 3. Pressure on Specialty Care provider to act as primary care provider
- v. Need for Resources
 - 1. Need for screening tools to prep and guide care providers
- vi. Lack of continuity
- b. Opportunities
 - i. Models exist to help meet these needs we can adapt what is available
 - 1. Sickle Cell Co-management model includes Specialists, Primary Care and navigators.
 - a. Challenge arises when there is no funding for the navigator
 - 2. Medical Home initiative
 - a. Again challenge arises to funding social worker / navigator position
 - 3. Billing code for navigator or care manager (group believes one exists through Medicaid billing, what about other insurance providers)
 - 4. Managed care continuity
 - 5. Plan for Mental Health patients to provide them with navigation but not for physical or intellectual disabilities
 - ii. Preparing for the transition
 - 1. CMS pairs adult physicians to child caregiver as early as age 12

- iii. Continuity
 - 1. Collaboration
 - 2. Specialization within the field of Nurse Practitioners
 - 3. Hematologists may be a road to continuity
 - iv. Broad and far reaching campaigns to change attitudes
 - 1. Example of Autism Campaign
 - v. Online portals to tap into Specialist Records
7. Vision statement
8. Vision Statement
- a. After reviewing the Vision Statement from the state of Florida, the group decided that this was broad enough to encompass the needs of our region as well. The vision statement was edited some to fit South Florida HATS and now reads:
All youth and young adults in South Florida, including those with Disabilities and special health care needs will successfully transition into adult health care.
9. WRAP UP & NEXT STEPS
- a. The group agreed that more people should be invited to the next meeting.
 - b. Next meeting will take place on March 13th 1pm-3pm

6. Visioning

10 mins – large group

2-3 examples of why we are here – anyone from group, or perhaps, pre-prepared

20 mins – small groups of 5

10 mins – top 10 roadblocks (2 each participant)

10 mins – possible solutions

10-15 Mins – report to group

7. Vision statement should tie back to roadblocks and solutions

- start with low hanging fruit, easier fixes

- highlight more complicated fixes