

Minutes for South FloridaHATS strategic Planning Meeting March 13, 2014

In attendance: Present: Jean Sherman Mailman Center & FL Alliance for Assistive Services and Technology; Jose Rosa-Olivares, MD, MS/HAS Miami Children's Hospital Pediatric Care Center; Carmen Caricedo.; Miami Beach Community Health Center; Wilma Steiner, Dade Schools; Jill Brookner, Dade Schools; Paul Monte, MD Optum Healthcare

1. Welcome Dr. Jose Rosa-Olivares

Dr. Rosa-Olivares provided an overview of why a conversation about health care transition and introduced participants to tools and models to assist with health care transition. Dr. Rosa-Olivares's presentation is attached.

2. Review minutes from last meeting

- a. Overarching barriers and opportunities identified in the February meeting were reviewed in preparation for the following conversation.

3. Community Strengths and Themes were discussed. Participants identified the following:

- a. Most important to youth and young adults with complex medical needs regarding health care transition?
 - a. Getting to know / Feeling comfortable with adult providers
 - b. Knowing when & how to ask for help
 - c. Knowing what documents to track
 - d. Reducing anxiety about going to the Dr.
 - e. Finding providers who will be patient
 - f. Not looking / feeling different
 - g. Adults provider who will respect and explain prescriptions to them
 - h. Better understanding of their own unique conditions
 - i. Ability to make decisions re: care when in conflict with parents
 - j. Will I have a normal life? (Job, Family, Kids)
 - k. Am I comfortable with my doctor- does the Dr. understand me?
 - l. What tools / helps / assistance can I get to learn about my disease and advocate for myself?
 - m. My Drs schedule availability
- b. Most important for families of youth and young adults with complex medical needs regarding health care transition?
 - a. Helping youth/young adults understand the importance of managing their health care
 - b. Finding providers who will accept Medicaid
 - c. Teaching youth/young adults how to advocate for themselves
 - d. Financial commitments
 - e. Educating parents to help them understand the need for transition and the need for youth/young adult independence
 - f. Encouraging one to one visits between physician and youth/young adult
 - g. Understanding the spectrum of dependence to independence- and assessing the extent to which someone can be independent.

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- h. Who will care for child when caregiver is no longer available
 - i. Locating knowledgeable adult specialists
 - j. Not enough adult medical homes
 - k. Enable parents to have necessary information regarding the diagnosis
 - l. Understanding the impact that other physical or mental health diagnoses may have and ensuring access to treatment for those needs as well
- c. Most important to Providers of Care to youth and young adults with complex medical needs regarding health care transition
- a. Patient compliance
 - b. Ability to speak to / empower patient
 - c. More time for patients with complex needs
 - d. Will I get paid??
 - e. Billing codes
 - f. Additional training to deal with 'pediatric' conditions
 - g. Information Flow (between providers)
 - h. Collaboration with specialists
 - i. Managing after hour care needs
 - j. Knowledge of disabilities
 - k. Education for adult care providers (re: that their catchment area may include Y/YA with complex medical needs)
 - l. Access to patient's history / collated information
- d. Themes were identified and items discussed above were categorized. Many items fit into several categories.
- a. Ethics
 - 1. Regarding conflict between Y/YA and Family decisions for treatment
 - 2. Who will care for my child when I'm no longer available
 - 3. Legal issues
 - b. Finances
 - 1. Medicaid providers
 - 2. Insurance gap
 - 3. Locating specialists who will take Medicaid
 - 4. Not enough adult medical homes
 - 5. Treatment for additional diagnoses (physical or mental health related)
 - 6. Who will care for my child when I'm no longer available
 - 7. More time for patients with complex needs
 - 8. Will I get paid??
 - 9. Billing codes
 - c. Education
 - 1. To provider regarding how to communicate to patients with complex medical needs

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2. To public
3. Within taskforce about what other groups (working on similar issues) are doing
4. To Parents: RE: Future caregiver planning
5. To Parents: letting go and helping the Y/YA to be as independent as possible
6. About the role of the provider & the family in Child's medical decisions
7. To Provider: About the ability of the child
8. Who will care for my child when I'm no longer available
9. Locating specialists who will take medicaid
10. Not enough adult medical homes
11. Enable parents to have necessary information regarding the diagnosis
12. Encouraging one to one visits between physician and youth/young adult
13. Will I get paid??
14. Billing codes
15. Additional training to deal with 'pediatric' conditions
16. Education for adult care providers (re: that their catchment area may include Y/YA with complex medical needs)

d. Advocacy

1. Empower families & individuals & Providers
2. 'Traditional' Advocacy to communities and local, state and federal governments
3. To managed Care providers
4. To professional associations such as: AAP, AMA
5. Not enough adult medical homes
6. Treatment for additional diagnoses (physical or mental health related)
7. Spectrum of dependence to independence according to each person's ability
8. Will I have a normal life? (Job, Family, Kids)

e. Communication

1. Continuity
2. Electronic medical records
3. Between patient, parent, adult provider and peds provider (along with specialists, etc)
4. Clear and consistent communication
5. Communication that works for the patient
6. Enable parents to have necessary information regarding the diagnosis
7. Treatment for additional diagnoses (physical or mental health related)
8. Patient compliance
9. Ability to speak to / empower patient
10. Information Flow (between providers)
11. Collaboration with specialists

- f. Collaboration
 - 1. Between physicians and community agencies (to support patient in obtaining most 'normal' life possible)
 - 2. Treatment for additional diagnoses (physical or mental health related)
 - 3. Information Flow (between providers)
 - 4. Collaboration with specialists
 - 5. Access to patient's history / collated information
 - g. Outreach
 - 1. Re transition planning to adult care providers
 - 2. Locating specialists who will take medicaid
 - 3. Not enough adult medical homes
 - h. Empowerment
 - 1. Spectrum of dependence to independence according to each person's ability
 - i. Electronic Medical Records
 - 1. Access to patient's history / collated information
 - j. Medical Office Environment
 - 1. Accessibility
 - 2. How comfortable / welcoming they feel
 - 3. More time for patients with complex needs
 - 4. Better use of resources (i.e. Nurse Practitioner may be able to spend more time with patient with complex medical needs)
 - 5. Managing after hour care needs
 - 6. My drs schedule availability
 - 7.
 - k. Networking
 - e. Each participant to vote on top 2-3 themes (5 minutes)
 - f.
 - g.
4. Vote revealed the following results. Each item listed below had at least one vote. Items with more than one vote are indicated by the number of votes at the side of the theme.
- a. Advocacy(6)
 - b. Education(5)
 - c. Communication (4)
 - d. Finances (3)
 - e. Collaboration (2)
 - f. Electronic Medical Records

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- g. “Comprehensive multidisciplinary care model” (this vote was placed under ‘collaboration’)
 - h. It was agreed upon that all themes would be addressed in action plan from three perspectives (Y/YA, Family & Provider)
5. Wrap up
- a. Next meeting is April 3rd- 11-1
 - a. Opportunity to vote for people who were not present this meeting /GAP assessment / Forces of Change Assessment
 - b. A survey will be sent out two weeks prior to the meeting
 - c. A reminder will be emailed out 1 week prior to the meeting