Meeting Minutes
Statewide Health Care Transition Services Task Force
For Youth and Young Adults with Disabilities

Task Force Meeting
September 4, 2009
Tallahassee, CMS Area Office

ATTENDEES:

Joseph Chiaro, MD, FAAP, CMS
Phyllis Sloyer, RN, PhD, PAHM, FAAP, CMS
Janet Hess, MPH, CHES, USF Department of Pediatrics
John Reiss, PhD, Institute for Child Health Policy at UF
David Wood, MD, MPH, UF Department of Pediatrics
Eleanor Cofer, RN, CMS
Martha Kronk, Shriners Hospitals for Children/USF
Teresa Kelly, Health Council of West Central Florida
Mike Hill, Big Bend Health Council
Mark Ryan, RN, Department of Children and Families
Lanetta Jordan, MD, Memorial Regional Hospital, Sickle Cell Services
Debbie Richards, FDDC
Glenda Thomas, RN, CMS, Pensacola
Kirk Hall, Vocational Rehabilitation

Via Teleconference:
Joanne Angel, RN, CMS, Tampa
Julie Perez, RN, CMS, Tampa
Erin DeFries-Bouldin, Florida Office on Disability and Health at UF

CALL TO ORDER:

The meeting was called to order at 10:15 am.

DISCUSSION

Ms. Hess and Dr. Wood provided an overview of meeting goals, agenda, and workshop materials. The group reviewed DOH's Florida MAPP Tour Book (see http://www.doh.state.fl.us/planning_eval/CHAI/Resources/FieldGuide/contentsFguide.htm), and made recommendations to adapt the MAPP process for local coalitions to use in health care transition systems planning. Outlined below are key changes/additions to the MAPP planning guide that were discussed:

Organize for Success/Partnership Development

1. Potential financial resources to help with implementation may include children's hospital, children's services council, large physician's group or association, and "connectors" in the community (influential fundraisers, such as Junior League).
2. Link to existing health-related groups in the community, i.e., piggy-back on other initiatives rather than reinventing the wheel.
3. Consider representation from health care funders (local Medicaid office), community health centers/ FQHCs, military, migrant community, indigent community/"We Care", legislators, locally active condition-specific associations and/or advocacy groups, FDOE/Project 10, and CILs.

4. Important to include Y/YA in process; identify local Y/YA "heroes" through youth leadership/advocacy groups, Family Café, etc.
5. Ideal group size is 12-16 participants, with consistent attendance at planning meetings.
6. Prioritize representation by organization's role in HCT process, i.e., focus initially on health care providers such as pediatricians, adult providers, primary care, specialists, hospitals, and health care funders.

Visioning

1. Present Task Force's state vision as outlined in the Florida strategic plan.
2. Important for local coalition to adapt a version of the state vision or create their own.
3. Consider issuing press release after first coalition meeting to announce the intention of the group and the needs it is addressing.

Community Themes and Strengths Assessment

1. Conduct a pre-planning survey among prospective coalition members that addresses perceived strengths, weaknesses, gaps in the community; compile survey results prior to first meeting to help guide the assessment.
2. Include a matrix in the guide that lists key elements/resources critical for transition to adult health care, including adult primary care, specialists, hospitals, free clinics, access to medications/pharmacies and medical supplies, condition-specific needs, access to transportation, etc. Include a list of questions that coalition members should be thinking about when assessing community assets and relationships necessary to support HCT (What are the dynamics of current relationships? Are there political implications?)
3. Do not be limited in this exercise by geographical boundaries, e.g., state lines.
4. Explore using free PARTNER software from University of Colorado that visually maps relationships within community collaborations.
5. Coalitions should regularly revisit this assessment to update resources and linkages.
6. Consider need for translation services in community; Ms. Kronk to forward information on *Optimal*, the language line service that Shriners Hospital-Tampa uses.

Local Public Health Assessment

1. Collapse into Community Themes and Strengths as a single assessment.
2. Divide the asset mapping activity into 2 sections: core health services and supportive services (includes employment, education, independent living, etc.)

Community Health Status Assessment

1. Clarify how data will be used by coalitions:
    a. Coalitions will need to start collecting data to use as performance measures, though it is not the primary purpose of this MAPP activity. The Task Force will form a sub-committee to develop indicators to use at both local and state levels; indicators will be added to the guide when they're finalized. Coalitions should start data collection early in the systems development process to use as baseline measures. It will likely include both primary (via surveys) and secondary data collection (e.g., hospital admissions, ER visit data, etc.)
    b. A report on health status of Y/YA, quality of life/services, and service utilization will be provided to coalitions as part of the planning guide. These data are from a variety of secondary sources, and will provide a profile of Y/YA and the community for coalitions to use in the MAPP process. These data are outlined below.
2. Report data from each source by county (where possible), CMS region, and state.
3. Include existing community health profiles and/or more comprehensive needs assessments (developed by health councils), where available.

4. U.S. Census:
    a. Coalitions may want to consider drilling down to zip code-level data during the MAPP process.
    b. Explore reporting projected prevalence of specific diseases in planning guide using census data and accepted prevalence rates (e.g., estimated number of residents with diabetes in the county).
5. BRFSS:
    a. Due to small sample sizes for ages 18-29 w/disabilities, data is reported for combined CMS regions (3) and for the state.
    b. Report on ages 30-64 and 65+ (65+ represents universal insurance coverage) rather than 30+.
    c. Explore potential to oversample by age (18-29) and/or geography in 2010 survey; Ms. Bouldin will contact the DOH BRFSS representative.
    d. FODH will provide results from all survey questions relevant for ages18-29, to include in the planning guide.
    e. These data demonstrate disparities in access to care - between younger and older adults, and between those with and without disabilities – and could be very useful for legislative education and advocacy.
6. Investigate utilizing CAHPS data from both consumer and provider surveys, as well as PedsQL to capture regional differences in quality of life indicators.
7. SSI:
    a. *Note:* SSI determination and enrollment process is so cumbersome that many families give up (i.e., strict eligibility criteria are not the only barrier).
    b. Investigate whether we can differentiate between enrollees with cognitive disability vs physical disability (likely to have more intensive health care needs).
8. CMS data provided through ICHP.
9. FDOE/ESE:
    a. Include those on 504 Plans.
    b. *Note:* Many students with manageable chronic health conditions will not be represented in this data set (e.g., asthma).
10. DCF child welfare county-level data may be available through Laurie Blades; Ms. Hess will request the data and cc: Mark Ryan.
11. Juvenile Justice data will skew heavily towards young people with mental health or behavioral disabilities versus physical disabilities.
12. APD MedWaiver: Explore results from FDDC/FODH's APD wait list survey,
13. Medicare/SSDI
    a. Mr. Hill checking with Dr. Richards to get that data.
    b. We have a contact at FL AHCA to help with analysis (Quantara Williams).
14. Mental Health Services: Ms. Hess will contact Christine Small for information.
15. Vocational Rehabilitation:
    a. Mr. Hall will provide data on ages 14-17 and 18-26 by county and CMS region.
    b. VocRehab reports include insurance coverage information.
16. Health Care Resources:
    a. In the planning guide, include licensed professionals (rate per 1,000) and low cost/no cost clinics such as FQHCs (re: Bob Hester) and free clinics (Ms. Kronk).
    b. Suggest that coalitions consider looking at hospital capacity and utilization figures, and compile list of disability-related service providers.

<u>Forces of Change Assessment</u>

No suggested change to the process; utilize SWOT analysis.

Identify Strategic Issues

1. Use Health Council's PEACH process to set priorities for goals, objectives, and action steps (it sounds fun!)
2. Need to include some general information about PEACH and other priority setting approaches in the planning guide; could list some web sites as references.

Other/Miscellaneous

1. Explore whether there are other studies or reports in the state specific to young adults (with or without disabilities); Ms. Kelly will ask other health councils, and Dr. Reiss will follow up on CF studies.
2. Projected timeline for Hillsborough and Panhandle pilots: Oct-Dec '09 for preparation (complete initial version of planning guide, compile participant list, conduct survey, identify meeting location, etc.), and Jan-May '10 for planning meetings (1x/month for 3-4 hours each). Once agreements regarding MAPP facilitation in pilots are finalized, steering committees for each site should be identified and begin pre-planning activities.
3. Health councils participating in the pilot will hopefully encourage other health councils to facilitate this planning activity in their respective areas. Dr. Reiss suggested that, when the pilot is completed, they record an audiotape describing lessons learned that could potentially be posted on the web site.
4. The planning guide should be as concise as possible, with check lists, how-to guides, etc. – not a large, comprehensive guide.

Next step is for Ms. Hess to forward a draft of the guide (or draft sections) to the group for review and edits over the next 6 weeks.

Adjournment

Meeting was adjourned at 2:45 pm.