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Maternal and Child Health Bureau  
Health Resources and Services Administration  
5600 Fishers Lane, Room 18-05  
Rockville, MD 20857  

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Email: MCHTransformation@hrsa.gov;

Dear Michael,

On behalf of the Lucile Packard Foundation for Children’s Health, we would like to thank you for providing this opportunity to respond to the proposal for transforming the Title V Maternal and Child Health (MCH) block grant program, including the fifteen proposed national performance measures.

The Lucile Packard Foundation for Children’s Health is focused on improving systems of care for children with special health care needs (CSHCN). The Foundation supports efforts that promote development of systems that deliver family-centered, high-quality health care and related services, funded through an efficient and comprehensive payment system. We have a special interest in ensuring care coordination and access to specialty care for CSHCN.

It is our belief that Title V should put greater emphasis on vulnerable children, especially those with special needs. We would like to see the Bureau direct or encourage states to address deficiencies in their systems of care for CSHCN. Activities that we would recommend include:

1. Develop uniform eligibility criteria for Title V CSHCN programs
2. Encourage approaches to financing care of CSHCN that are aligned with achieving their best health outcomes
3. Adopt or promulgate national standards for care systems serving CSHCN
4. Assure that all CSHCN have access to a high quality medical home, and that their care is monitored in standardized ways
5. Require participation of families of CSHCN or special needs youth in all program development and monitoring activities affecting their services
6. Strengthen the focus of school health services on CSHCN
7. Create models of community-based care coordination for CSHCN that links to medical homes
8. Develop community supports to help families who wish to optimally contribute to the management of the care of CSHCN

Thank you for your consideration of our suggestions for the transformation of Title V for children and families.

Sincerely,

Edward L. Schor, MD
Senior Vice President

The California Advocacy Network for Children with Special Health Care Needs, a program of the Foundation, is composed of almost 1,000 parents, caregivers, providers, insurers, disease-specific advocacy organizations, educators, researchers, and public and private agencies that are committed to improving the system of care for CSHCN. We have compiled the comments of members of the California Advocacy Network for Children with Special Health Care Needs in response to Dr. Lu’s presentation on the Transformation of the Title V Maternal and Child Health Block Grant.

Comments on the 15 National Performance Measures:

1. Preconception Care:

   - While I understand the desire to move toward a measure of preconception health, I am not convinced that moving away from a measure of prenatal care or adequate prenatal care is appropriate. A huge amount of resources and energy are still expended on creating appropriate access to prenatal care, and I am concerned that this is will not be captured without a specific measure.
     – Anand Chabra, MD, MPH, San Mateo County California Children’s Services (CCS)

   - I vote for the first straw measure re preconception/interconception and well woman visits: The well woman visits should include questions about the family to identify a need for genetic screening of the woman – and often the partner – to identify or rule out genetic concerns requiring counseling. I also would hope that the well woman visits
would include counseling concerning health issues that should be addressed before conception.

– Marilyn Holle, Disability Rights California

2. Severe Maternal Morbidity:

• This will be a good way to assess efforts addressing overall maternal health, regionalization of perinatal care, and appropriate use of tertiary delivery hospitals.

– Anand Chabra, MD, MPH, San Mateo County CCS

3. Early Elective Delivery:

• A good focus given the work of the March of Dimes, MCHB, state and local health departments, and others on reducing early elective deliveries, and thus prematurity and low/very-low birth weight infants.

– Anand Chabra, MD, MPH, San Mateo County CCS

4. Perinatal Regionalization:

• Important given the massive resources spend on VLBW infants and the outcomes at appropriate level NICUs (California Perinatal Quality Care Collaborative and Vermont-Oxford Network data).

– Anand Chabra, MD, MPH, San Mateo County CCS

5. Safe Sleep:

• Appropriate as an infant health priority and major contributor to infant mortality.

– Anand Chabra, MD, MPH, San Mateo County CCS

6. Developmental Screening:

• Recommend expanding term to developmental / behavioral screening. RE: Parent completed screening tool, recommend adding the word VALIDATED for use of a validated screening tool. RE: early diagnosis and early intervention, need to consider successful models to help parents and providers get connected to the early interventions available in the community, such as Help Me Grow.

– Alyce Mastrianni, Children and Families Commission of Orange County

• This measure seems overly general, since it does not specify that the screening tool should be comprehensive and validated. I am concerned that a high percentage of parents will answer positively, but this may not be an adequate indicator of adequate developmental screen and/or evaluation. I do appreciate, however, that this prioritizes early identification of developmental concerns for CYSHCN.
- Anand Chabra, MD, MPH, San Mateo County CCS

- Developmental screening is a priority but it has to be coupled with developmental intervention to make a difference. I would like to see more specific on-going programs for 0-3 as opposed to ones that come and go with grant money. I would also like to see more work to assure that babies are “wanted” and born to “willing” mothers, e.g., increased preconception counseling.
  – Elizabeth Russel, Public Health, Los Angeles County

- I vote for the sixth straw measure for developmental screens. The sometimes missing element is the pediatrician’s or nurse practitioner’s knowledge about the next step when a question arises. Because autism diagnosis and access to specialized services sometimes turns on signs and signals identified prior to the age of three, we recommend that the questionnaire be kept in the child’s file.
  – Marilyn Holle, Disability Rights California

7. School Readiness:

- While child health and well-being is often a prerequisite for school readiness, I am not convinced that this should be a headline measure for Title V. If we are going to narrow our focus significantly, I think the focus should be on measures more closely related to health.
  – Anand Chabra, MD, MPH, San Mateo County CCS

- Consider rewording to reflect children who are developmentally on track or reaching their developmental potential for school entry.
  – Alyce Mastrianni, Children and Families Commission of Orange County

- I suggest we view this term in more perspective. It tends to lose the concept of EBCD starting before birth and focuses on academic activities rather than early child emotional support, issues of normal early infant and child development and family adjustment, temperament etc. Many aspects of what would be “school readiness” may not be thought to be in the purview of pediatricians, when, in fact, they should consider themselves to be very involved in helping 0-5 year olds get ready for the world.
  – Peter Michael Miller, MD, MPH, FAAP

8. Adolescent Well-Visit:

- Important given the need to for anticipatory guidance, risk assessment, immunization, and health education for adolescents and young adults.
  – Anand Chabra, MD, MPH, San Mateo County CCS
9. Medical Home:

- A significant evaluation of the healthcare system for children/youth, and vital for CYSHCN.
  – Anand Chabra, MD, MPH, San Mateo County CCS

- I strongly suggest grouped process measures for adolescents and young adults (17-25 years) with chronic health conditions to have an identifiable medical home, transfer medical record (if appropriate), and a navigation system to facilitate successful transfer and self management. Thank you for your thoughtful and comprehensive presentation.
  – Roberta G. Williams, MD, Professor and Past Chair of Pediatrics University of Southern California, Children’s Hospital Los Angeles

- Medical Home is a wonderful concept for obvious reasons, but its implementation, I feel, is getting misinterpreted and misdirected and may do more harm than good. In some cases, pediatricians may not be the most appropriate “leader” for service coordination. Coordination among pediatric practices and with community providers and agencies should be facilitated.
  – Peter Michael Miller, MD, MPH, FAAP

10. Insurance Coverage:

- This will help to validate the extensive work on expanding healthcare coverage at the national, state and local levels.
  – Anand Chabra, MD, MPH, San Mateo County CCS

11. Immunization:

- Essential.
  – Anand Chabra, MD, MPH, San Mateo County CCS

12. Nutrition and Physical Activities:

- These are four fairly different measures combined under one heading. Certainly a focus on nutrition, physical activity, gestational weight and breastfeeding are relevant and significant in the MCAH population, but I am not sure that combining measures in this way does them justice.
  – Anand Chabra, MD, MPH, San Mateo County CCS

13. Oral Health:

- An often overlooked component of health; inclusion will prioritize this concern.
  – Anand Chabra, MD, MPH, San Mateo County CCS
14. Open Straw Measures:

- I would really like to see a measure of mental/behavioral health included among the Performance Measures. This could be a measure of anxiety/depression or suicidality from a national survey, could be based on hospitalization data, or could address deaths by suicide. Other mental/behavioral health topics would also be important, such as tobacco, alcohol or other drug use.
  – Anand Chabra, MD, MPH, San Mateo County CCS

- The other measure I would like to see included is one more specifically addressing CYSHCN, such as care coordination for this population (a current area of great focus in the pediatric and public health community, and at children’s hospitals) or transition services for CYSHCN from pediatric to adult care (another area of focus in both the pediatric and public health communities).
  – Anand Chabra, MD, MPH, San Mateo County CCS

- Due to the very high prevalence of autistic spectrum disorders (1 in 88 according to the CDC), The Autism Health Insurance Project would like to see a specific measure within “the children with special health care needs” category which addresses initiation of autism treatment within a certain timeframe. Treatment should involve a multidisciplinary approach, including speech therapy, occupational therapy, social skills, and usually, intensive behavioral intervention therapy. Other treatments may also be included. Given that research shows that nearly half of those who receive early and intensive treatment are less likely to need intensive interventions in the later elementary years, we know that for a large subset, intervention is highly effective. In California, we have insurance mandates for those with state regulated insurance plans which are supposed to cover most of these interventions. For those on Medi-Cal and those with self-insured plans who have classic autism, the state sponsored regional centers are supposed to pick up many of the interventions. There are, however, still many gaps in the system. Those at the high end of the spectrum on Medi-Cal and with self-insured plans frequently do not have access to care. Those in states without autism mandates are also left without critical treatment. When early intervention services end at age three, school districts are frequently not able to simply pick up the treatments, and children lose services (if they ever got them) and regress. We would like to see the MCH Block Grants take a more active role in monitoring progress of those who get treatment, and filling the gaps in treatment so that children don't miss critical opportunities to obtain intervention during the early years when it is so critical. We would also like to see more money and programming in training parents to advocate within the health care system, as more services are shifting from the educational to the health care sector. On a national level, there is an opportunity to partner with other agencies such as EPSDT and the Departments of Disability and Education.
  – Karen Fessel, DrPh, Autism Health Insurance Project
The current set of national performance measures consist of six measures for children with special needs related to families partnering decision making, medical home, early screening and detection, community-based coordination of services, insurance coverage, and transition support. It appears that only two of these performance measures – medical home and insurance coverage – are included in the new draft set of national measures. The proposed screening measure is limited to developmental screening. Further, we do not believe that the draft list of national performance measures represents a balanced set across the maternal and child health lifespan. As many as half of the proposed measures address maternal, infant, and young children’s health. Only one specifically addresses adolescents and young adults, and none explicitly focuses on children and youth with special needs.

– Peggy McManus, MHS, and Patience White, MD, MA, Co-Project Directors, Got Transition/Center for Health Care Transition Improvement

For the 14th or 15th straw measure, I vote for looking at how a state’s Title V program addresses the needs of children with special health care needs – particularly those with low incidence disabilities – who live in rural areas or otherwise at a significant geographical distances from children’s or university based specialty care centers or clinics by ensuring they have access to such state of the art care. That should include integrating the local physician in a particular patient’s care through a specialty clinic. That should include ways through technology to participate in a clinic visit itself, and a way for the local physician to easily consult with the specialty clinic itself so as to reduce the need for in person visits. Ensuring quality care to children with special health care needs redounds to the benefit of all children with special health care needs. For instance, in California, it is CCS that defines the community standard of care for children who have eligible medical conditions even for children who would not financially qualify for CCS services.

– Marilyn Holle, Disability Rights California

Another 14th or 15th straw measure to consider is the extent to which state Title V programs serving children with special health care needs include any children with mental health diagnoses. Although the “physical” limitation was removed decades ago, has any Title V program included any children with a mental or psychiatric diagnosis?

– Marilyn Holle, Disability Rights California

care coordination - provide and measure care coordination for all persons with a special health care need. Enumeration of whether or not a person has a medical home does not accurately address this and the literature supports that credible care coordination does prevent hospital admissions and ER visits, shortens hospital stays and promotes use of more cost effective and more family satisfying community based services.

– Mary Doyle, MD, Los Angeles County CCS
• **Regionalized care for children with special health care needs** – measure numbers of centers and satellite centers certified to care for specialized and numbers of children with particular conditions who receive care at such centers.
  – *Mary Doyle, MD, Los Angeles County CCS*

• **Transition of children with special health care needs** – measure number of 18 – 21 year old patients transitioned without interruption in care from a pediatric to an adult subspecialist.
  – *Mary Doyle, MD, Los Angeles County CCS*

**Other Recommendations from Advocates:**

*Peter Michael Miller, MD, MPH, FAAP:*

• Change Maternal and Child Health to Family and Child Health
  o The emphasis on women’s health should be continued, but focus really needs to be on Family, to consider:
    ▪ Influences of key adults on children, especially in early childhood
    ▪ “Family” definition in 2014: single parents (including fathers); gay parents (and obstacles to foster care/adoption); absent fathers (e.g., incarcerated men and (black) fathers)); family mobility; foster care.
    ▪ Financial challenges to families, and especially single parent (mother) families (e.g., bankruptcy after divorce) – including negative influences of poverty, especially on young children (living setting/dangers, food insecurity, etc.)

• Change Title V to a focus on Age Group Well-Being

• Preconception – Prenatal – Newborn - 0-5 - School age – Adolescents
  o Health vs. well-being
    ▪ Consider broad needs that emphasize social, nutritional, and other areas that Title V cannot currently address due to structural legislative silos.
  o Health vs. Medical
    ▪ Medical care doesn’t mean receipt of the “health” or “well-being” components which are really needed for a “healthy” society.
    ▪ “Health” is viewed as “medical” by parents and community programs, which decreases the input from pediatricians in developmental and community areas.
    ▪ A wider vision of “well-being” for greater interaction with Social Services programs, including child care, foster care, child abuse & primary prevention.
  http://www.cdc.gov/ViolencePrevention/
• Expand MCH areas of concern
  - A re-focus on key age/developmental periods would allow inclusion of crucial related concerns, such as discipline, community safety, nutrition, child care, living arrangements, injuries, etc. (e.g., food insecurity related to hypoglycemia has grave implications for young children, health care providers, funding processes)

• Remove the “H” in CS(H)CN
  - Many children who need special services may not have medical conditions or become eligible based on medical concerns (e.g., special education; EBCD).

• Expand and Improve Agency Coordination

• How will Title V coordinate their five year plan with:
  - Other federal agencies, including AMCHP and related service programs (e.g., social services, nutrition, housing)
  - Community professional organizations, including the AAP and its programs on EBCD, Poverty, Developmental Screening, Breastfeeding, etc.; APHA; oral health programs
  - Community Programs – both nationally based (e.g., Head Start and Early Head Start) and state and local programs (family support, counseling)

• Focus Support on Health Care, not just Medical Care:
  - The ACA will provide access to medical care for many without adequate coverage. The current silos of care interfere with a seamless health care system that providers and families can use effectively. I encourage Title V to take a more careful look at the problems and potential solutions.

• Make Primary Prevention the Mantra of Title V
  - I think people and program staff tend to get lost in how we can help children with problems, without understanding and acting on what should be the primary goal of preventing the problems in the first place.

• Clarify the Process of Planning and Evaluation
  - I think most of the public and even program people do not really understand the system of planning, use of data and outcome measures as you describe in your talk. I encourage you to think of training in this area as a crucial component of both staff training and public education so that after five years we really have a sense that we’re on the right track to accomplishing our goals, or that we understand what’s lacking and how to adjust appropriately.
Alyce Mastrianni, Children and Families Commission of Orange County:

- Work across federal agencies (MCHB / HRSA / HHS / WHO) to adopt common definitions including:
  - Children with Special Health Care Needs – use federal Maternal and Child Health Bureau definition of children with special health care needs as: “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

- ACA expands access to evidence-based home visiting, well-integrated within comprehensive system of services for children and families. Although there are funding streams such as MIECHV to support home visiting programs, all local communities have not been able to access these funds, and existing funds are limited in terms of the number of families that need to be served. Recommend also expanding the evidence base for other home visitation models that have not yet had the level of study to become evidence based models.

- National Performance Measures / Accountability:
  - A challenge faced by many large diverse communities is that countywide data portray the county as doing very well across most indicators, but overlook the significant pockets of need in many of the communities. Unfortunately, data are not always available at a sub-community level (e.g., city, census track) to represent the significant needs and inequities across the many communities that contribute to the countywide picture. Improvement could be made in the availability of data in this area.

- Additionally, there are needed data related to early childhood development that are unavailable in a standardized manner either countywide or sub-county. One such example is the seemingly straightforward question of how many of the County’s children have received some sort of developmental screening using a validated instrument (e.g., Ages & Stages Questionnaire (ASQ), Parents Evaluation of Developmental Status (PEDS, etc.). The same holds true for screening data on children’s oral health, vision, and obesity.

- Well-Integrated Comprehensive systems of services for children and families (ACA / Home Visitation):
  - Endorse population-level data sharing through information technology. Many service sectors (and funding streams) provide health care, early intervention and medical services to young children including Medicaid, Child Health Disability Prevention / EPSDT, Regional Center, School Districts and pediatric providers. Improved data technology would assist in ensuing coordination of care and integration of services across these diverse sectors.
We commend MCHB for including young adult health along with adolescent health in its MCH life stages. As you well know, this is a particularly vulnerable age period when transitions in all aspects of life occur. We encourage MCHB to retain its emphasis on children and youth and now young adults with special health care needs. No other federal or state agency has the authority to lead the development of family-centered systems of health care for youth and young adults with physical, developmental, behavioral, or emotional conditions.

Transition to Adulthood:

- We strongly recommend that MCHB add transition from pediatric to adulthood as one of the 15 national performance measures. New and groundbreaking efforts are being accomplished on transition, which have been made possible primarily because of MCHB leadership and funding. The new Got Transition/Center for Health Care Transition Improvement – like the Collaborative Improvement & Innovation Network to Reduce Infant Mortality – has developed a collaborative strategy to implement and evaluate transition performance. We focus on both innovation and improvement. We have designed and tested a quality improvement model for use in pediatric, family medicine, and internal medicine practices. We are now finalizing the updating of this model, “Six Core Elements of Health Care Transition” (Version 2.0), which will be made available at the upcoming AMCHP meeting. We also have developed a set of metrics to track transition progress, elicit consumer feedback, and measure return on investment. We are happy to share these metrics with you, which will be completed in time for the AMCHP meeting.

- Starting shortly, Got Transition will begin to partner with four large integrated care systems – Kaiser Northern California, Health Partners, Henry Ford Health System, and the Uniformed Health Services – to dramatically expand transition innovation. We are also training State Title V leaders (CSHCN directors and adolescent coordinators) in 6 states to become leaders in transition quality improvement, working in partnership within their own states and across other states. This will sharpen the role of Title V as it pertains to transition quality improvement. We are at the beginning of a very exciting and innovative initiative for which MCHB and Title V can take full ownership.

- To further articulate the importance of transition as a national performance priority, we would like to emphasize its significance related to access and equity, quality, integration, and Title V accountability.
  - **Access and Equity:**

    - The vast majority of US youth with special health care needs (and presumably the same pattern exists for youth without special needs)
are NOT receiving recommended transition support, according to the National Survey of CSHCN.

- Transition disparities are significant, particularly for males, non-Whites, those in Spanish-language households, those with low incomes, those with emotional, behavioral, and developmental conditions, those with limitations of activities, and those without a medical home. Most youth are ill-prepared for transition and transfer to adult-centered care. The literature highlights the adverse impacts of diminished health associated with inadequate transition support. Gaps in continuity of care result not only in compromised health, but also in preventable costs associated with lack of a usual source of care, duplicative tests, medication errors, increased use of ER, and unnecessary hospitalizations.

- **Quality:**
  - Quality of care is compromised when pediatric, family medicine, and internal medicine fail to deliver recommended transition supports, consistent with the AAP/AAFP/ACP Clinical Report on Transition (which was funded by MCHB). Health providers often fail to anticipate the importance and complexity of teaching youth and young adults health care management skills. Consequently, youth, young adults, and parents/caregivers typically express dissatisfaction about their lack of engagement around transition preparation, the absence of information about adult-centered care and vetted adult providers, inadequate communication between pediatric and adult providers, and inconsistency in sharing updated medical information to adult providers. “Falling off a cliff” has been used by many to characterize transition from pediatric to adult health care.

- **Integration:**
  - To the extent that transition is incorporated into the medical home, there is a much greater chance that recommended transition support will be offered to youth and families. However, there are few examples of transition as part of ongoing clinical processes in primary or specialty care. Moreover, organized linkages between pediatric and adult systems of care seldom exist, resulting in discontinuity of care for youth and young adults. Another gap that persists is the linkage of transition interventions across health, education, employment, and independent living.

- **Accountability:**
  - CMS has taken on a prominent role in advancing transition improvements from hospital to home. This emphasis has resulted in major improvements in delivery system changes, payment, and
accountability. No one, except MCHB, has assumed responsibility for addressing transition quality improvements for a broad population of youth with and without special needs.

- **We strongly urge MCHB to retain transition as a national performance measure.** We also urge you to keep the previous six core national performance measures for children with special needs. Certainly these measures could be extended to include those without chronic conditions. We welcome the opportunity to work with you to strengthen Title V’s role in achieving and measuring transition results by 2020.

*T. Allen Merritt, MD MHA, Professor of Pediatrics, Loma Linda University School of Medicine:*

“Everyone likes progress, but no one wants to change” is a topic of discussion about reviewing maternal and neonatal mortality and morbidities. Through the CPQCC and CCS it has always astounded me that the best and worse NICUs in California get the same funding on a per case basis. Given that CPQCC and CCS and other groups such as the California Maternity Quality Collaborative Program, there is firm data regarding outcomes of various NICUs throughout California on important and measurable outcomes. Is there some methodology that Title V can reward those performing at the top and reward less those who continue to lag in the bottom 25th percentile on several important outcomes?

While several quality collaboratives permit those who join to learn from the best performers, some languish in the lower rungs on several outcomes. Some NICUs (although only a few) in California are CCS approved and rely on MediCal payments.

What can be done to reward the higher achievers who have invested time, talent, and treasure in improving their outcomes while others have not?

One other comment is that many of the CCS rules and regulations derived from numbered letters are helpful, but on occasion woefully dated. What can be done to establish more current, evidence based guidelines, regulations, technologically sound, and contemporary care patterns to guide what will and will not be considered eligible for state/federal funding under Title V?
Nancy Keleher, FIMR/CDRT Coordinator, Maternal, Child & Adolescent Health:

The Maternal, Child and Adolescent Health Division of the Humboldt County (California) Department of Health and Human Services would like to add a comment regarding the Title V request. In our area we are addressing perinatal depression, and feel this topic should rank highly in our work. While quantitative data is slim, qualitative information for our county shows perinatal depression to be as high as 50%. Humboldt County formed a task force in 2008, and we feel that as we are going forward, increased support and awareness on the part of our Federal partners, is crucial. We are sure Dr. Lu will understand!

Mary Doyle, MD, Los Angeles County, CCS:

While most are about prevention of preterm delivery and amelioration of morbidity associated with preterm delivery and infant mortality and offering preventative care to children and adolescents, few directly address the needs of those already afflicted with a condition or special health care need. In addition, it does not recognize that the fundamental barrier to cost-effective, quality care for this population is the existence of fragmented systems of care. Though difficult to quantify and even more difficult to affect change in a 5-year period or with limited funds, there are measures that would ameliorate this issue while global solutions progress.

cc: Renato Littaua, DVM, MPVM
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