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**Statewide Parent Advocacy Network, Inc.**  
***Empowered Families: Educated, Engaged, Effective!***

Family Voices-NJ Comments on URAC Patient Survey and Performance Measures for the Medical Home toolkits 10/1/10

Thank you for the opportunity to comment on URAC (Utilization Review Accreditation Commission) Patient Survey and Performance Measures toolkits for the medical home. Family Voices is a national network that advocates on behalf of children with special healthcare needs and works to “keep families at the center of children’s healthcare”. Our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), NJ’s federally designated Parent Training and Information Center, and Family-to-Family Health Information Center. SPAN also houses the State Implementation Grant for Integrated Community-Based Systems of Care for Children and Youth with Special Healthcare Needs (CYSHCN) and their Families in collaboration with the New Jersey Department of Health and Senior Services and the New Jersey Pediatric Council on Research and Education (NJ-PCORE), the nonprofit arm of the American Academy of Pediatrics. A major component of this project is medical home implementation.

Our comments are based on our work with thousands of NJ families of children with special healthcare needs as well as the experiences of our own staff, most of whom are parents of special children.

**Comment Area #1 Draft PCHCH Survey Toolkit**

Although we support the use of the CAHPS (Consumer Assessment of Healthcare Providers and Systems) particularly with the inclusion of additional questions, we would strongly recommend instead the incorporation of the other measures. For children with special needs, we would recommend the use of the Family Centered Care survey found at [www.familyvoices.org/pub/projects/fcca\\_FamilyTool.pdf](http://www.familyvoices.org/pub/projects/fcca_FamilyTool.pdf) . We would also recommend the medical home measurement tools for adults [www.medicalhomeimprovement.org/pdf/CMHI-MHI-Adult-Primary-Care\\_Short-Version.pdf](http://www.medicalhomeimprovement.org/pdf/CMHI-MHI-Adult-Primary-Care_Short-Version.pdf) and general pediatric populations [www.medicalhomeimprovement.org/pdf/CMHI-MHI-Pediatric\\_Short-Version.pdf](http://www.medicalhomeimprovement.org/pdf/CMHI-MHI-Pediatric_Short-Version.pdf) from the Center on Medical Home Improvement. In addition, we look forward to the forthcoming Agency for Healthcare Research and Quality (AHRQ) CAHPS survey on the medical home and agree that URAC would also need to reassess its recommendations based on this.

We understand that the draft has not yet been piloted or validated, but rather URAC is seeking comments on the concepts, rather than the survey questions which are acknowledged as possibly “not consumer friendly”. We further understand that the questions are from the patient’s perspective with regard to the 6 domains of communication, shared decision-making, care coordination, practice culture, behavioral health, and transparency. We would recommend including measurement of all the core values of a medical home: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. We also would hope that health literacy, which is the single largest barrier to healthcare access, is considered in the survey development.

#### *Domain 1 Mode of Communication/Interaction with Practice*

##### Questions #1-3

We think there needs to be more clarification or combination of the categories in the response regarding “Personal Health Record, Secure interactive web portal, Web-cam visit, Electronic monitoring, and E-Visit”. Too many response categories or confusion of participants will lead to less survey completion or invalid data.

##### Question #6

The question is extremely vague regarding the “opportunity to discuss the top concern in your life?” Does this mean related to healthcare? If so, this should be made more specific/explicit.

#### *Domain 2 Care Plan/Shared Decision Making*

##### Questions #11-13

Although it is good to ask about health decision support aids, an example will clarify this and distinguish it from “educational materials” asked in questions #9 and 10.

#### *Domain 3 Care Coordination*

This is the core of the medical home. There need to be questions regarding access to healthcare, after hours care, communications with specialists, test/lab results, connection to easily accessible community resources, etc.

#### *Domain 4 Practice Care Team/Practice Culture*

It was good to mention “lifestyle changes” but this would fit better in domain #2 on shared decision making. This would be a good place for a question on respectfulness of diversity and cultural competency. We would also like to see performance measurement on eliminating health disparities to underserved populations.

### *Domain 5 Behavioral Health*

We strongly support the inclusion of this domain as often the focus is only on physical health despite the recognition that mental illness is biologically based.

### *Domain 6 Transparency*

#### Question #27

Clarification is needed for consumers on performance measures. The majority of consumers would not be aware if the “practice received any special recognition awards” or reporting on practice performance.

#### **Comment Area #2 Performance Measures Toolkit**

We understand that commenters are to “measure concepts” and that comments are to reflect “meaningfulness...suggestions for operationalizing...additional measures they are aware of...and prioritize the measures”. We strongly agree that evidence-based measures are preferable. We will be commenting on all the measure domains regarding access, communication, patient engagement, shared decision making, care coordination, prevention, and outcomes but only those in the document that pertain to the pediatric population.

### *Domain #1 Access to Services*

#### Proposed Access Measure Concept 1: Third Next Available Appointment

Although we understand the “next available appointment” could reflect cancellations etc., it may be better to say second rather than third available appointment to avoid confusion.

#### Proposed Access Measure Concept 2: Participation in Alternative Visits

We strongly agree with the rationale in measurement of “alternative modes of communication/visits” such as telehealth. This will become even more important as access to health information technology increases. Indeed a recent report indicates the health information technology is essential for the success of the medical home (see [www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/US\\_CHS\\_MedicalHome2\\_092210.pdf](http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/US_CHS_MedicalHome2_092210.pdf) )

### *Domain #2 Communication*

#### Proposed Communication Measure Concept 1: Percentage of Patients who had a Clinical Encounter During the Measurement Period that Received an After-visit Summary

We agree that core information for the AVS should include: patient and provider names, date/location, medication list, reason for visit, vitals, and patient instructions. We agree that additional information could include: problem list/history, medication history/summary of medications, immunizations or medications administered, topics covered, test results, etc. We would however add immunizations and test results to the core information.

### *Domain #3 Patient Engagement*

#### Proposed Patient Engagement Measure Concept 1: Percentage of Patients with Chronic Conditions that have Documented Self-management Goals

We strongly support the use of personal health care action plans. We would also include the use of health information technology with regards to clinical health summaries and reporting of lab results which would affect self-management and health care action plans. See also our comments under domain #5, concept 1, for medication reconciliation.

### *Domain #4 Shared Decision Making*

#### Proposed Shared Decision Making Measure Concept 1: Use of Decision Aids

We strongly support the use of decision aids and would highly recommend those in such as Health Dialog [www.healthdialog.com/Main/PersonalHealthCoaching/SharedDecisionMaking](http://www.healthdialog.com/Main/PersonalHealthCoaching/SharedDecisionMaking). We would also recommend the national "Take Charge of Your Health Program" from Stanford found at <http://patienteducation.stanford.edu/programs/cdsmp.html>.

### *Domain #5 Care Coordination*

We feel that measures of care coordination should be the priority in reporting practice performance measures, as it is the cornerstone of the medical home concept. See also our comments in Domain 3 under care coordination in the PCHCH patient survey.

#### Proposed Care Coordination Measure Concept 1: Medication Reconciliation

We strongly agree that medication monitoring is crucial to the medical home concept. Indeed recent research on health information technology indicates that this is the area in which HIT is currently most useful. We would suggest measuring HIT in the area of monitoring medication errors as well as e-prescribing.

#### Proposed Care Coordination Measure Concept 2: Follow-up after Hospital Discharge – All Discharges from Acute Care Facility to Home

We strongly agree with performance measures on discharge follow-up which will be cost effective and more importantly result in better health outcomes by avoiding preventable re-hospitalization.

#### *Domain #6 Preventive Care*

#### Proposed Preventive Care Measure Concept 1: Health Risk Assessment Completion Rate

We support this concept as it dovetails with prevention as well as shared decision making.

#### Proposed Preventive Care Measure Concept 2: Reminders and Follow-up for Preventive Care

We strongly support this concept as prevention/wellness initiatives in the medical home again reduce costs and improve outcomes. For children, we would highly recommend the use of the Bright Futures initiatives endorsed by the AAP found at <http://brightfutures.aap.org>.

#### Proposed Preventive Care Measure Concept 3: Preventive Care

Again, we strongly support the preventive care concept. See our comments above under concept #2.

#### Concept 3 Subcategory 3: Metabolic, Nutritional, and Endocrine Conditions

Although we support screening for type 2 diabetes in adults, we would add screening for children as well. Due to the obesity epidemic, unfortunately children are also now getting diabetes. We do note that there are obesity screening requirements for both adults and children in the performance measures.

#### Concept 3 Subcategory 3: Child-age Measures: Vision and Hearing Disorders

We strongly support the concept of universal hearing screening in newborns and vision screening for children under 5. SPAN has been part of the NJ Early Hearing Detection and Intervention Program as well as a participant in the NY Mid Atlantic Consortium for genetics and newborn screening.

#### Concept 3 Subcategory 3: Child-age Measures: Perinatal Care and Dental Care

We strongly support the concept of including dental care in performance measures as poor oral care can lead to serious health consequences.

#### General Comment on Preventive Care Measure Concept 3

We would strongly urge you to include developmental screening for prevention in pediatric care. We would strongly recommend the use of the tools developed by the AAP in their national medical home webinar “Developmental Surveillance, Screening, and Diagnosis” at [www.medicalhomeinfo.org/downloads/ppts/DPIPteleconference.ppt](http://www.medicalhomeinfo.org/downloads/ppts/DPIPteleconference.ppt) as well as their information on identification and management at [www.medicalhomeinfo.org/downloads/ppts/ASDWebinar.ppt](http://www.medicalhomeinfo.org/downloads/ppts/ASDWebinar.ppt) .

#### *Domain #7 Outcome Evaluation*

#### Proposed Outcome Measure Concept 1: Hospitalization Rates for Ambulatory Care-Sensitive Conditions

We understand that the pediatric quality indicators (PQI) regarding preventable hospitalizations are asthma, diabetes (again which is why we suggested adding under prevention), gastroenteritis, appendix, and urinary tract infections. Asthma is unfortunately common and if Medicaid managed care plans have disease management, asthma is part of their care management for pediatrics. We appreciate that low birth rate, while not a PQI, was included and would suggest adding a question on referrals to early intervention. **Programs for children with special needs ages birth to three can be found at the National Early Childhood Technical Assistance Center at [www.nectac.org](http://www.nectac.org) .** Low birth rate infants are at risk and research on early intervention demonstrates improved health outcomes.

#### **Comment Area #3 General Comments**

We agree with most of the survey assessment areas and practice performance measures. Research has proven that the medical home concept is cost effective and results in better health outcomes. Patient centered care will not only focus on the individual, but increase patient compliance and responsibility for their own care. Patient/professional collaboration on healthcare increases accountability on both sides. Patient centered care will lead to decreased morbidity and mortality, cost savings, and most importantly improved health outcomes for families.

Thank you for the opportunity to comment on the URAC Patient Survey and Performance Measures toolkits.

Sincerely,

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**Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.**