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

Family Voices-NJ Comments on the Patient Centered Medical Home 4/7/09

Thank you for the opportunity to comment on the Patient Centered Medical Home model. Family Voices is a national network that advocates on behalf of children with special healthcare needs; our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), New Jersey's federally funded Parent Training and Information Center and Family-to-Family Health Information Center. The Family Voices Coordinator also serves as the NJ Caregiver Community Action Network representative for National Family Caregivers Association, representing caregivers across the lifespan, in a volunteer capacity. Our comments are based on our work with thousands of New Jersey families of children and youth with special healthcare needs as well as the experiences of our own staff, most of whom are parents.

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. In addition, the use of HIPAA compliant Health Information Technology, including telemedicine, will improve access for families. Lastly, the focus must be outreach to traditionally underserved families due to cultural diversity, language barriers, uninsured, etc.

Incentives will increase patient participation in their healthcare. For example, our organization facilitated statewide focus groups on adolescent immunization as well as oral health for children with special needs offering \$25 per family, resulting in positive responses from families, including underserved families such as low-income families, families speaking languages other than English, immigrant families, and families of color. Incentives can be as simple as a coupon for a free child's meal or even a tea bag stapled to a survey as a small sign of appreciation for participating. Many organizations will also donate small, low-cost incentives like free coffee or promotional items.

Sometimes the incentive doesn't have to cost anything. Patients need to know their concerns are heard and their input is valuable. Often the incentive is a patient feeling they actually have a voice. For those with chronic diseases (68% of those over age 44), Stanford has a proven effective patient education program which should be funded nationally. According to the National Council on Aging survey of this age group, 57% say their doctor doesn't ask if they can manage their condition at home. Post-outcomes include reduced doctor visits, emergency use, and hospitalization. Estimated cost savings per patient range from \$390-\$750 per participant. For more information, see <http://patienteducation.stanford.edu/programs/cdsmp.html>.

A significant barrier is lack of cultural and linguistic competency; lack of language access is one of the most challenging barriers to overcome. New Jersey was the first state to pass a statewide mandate for cultural competency training for healthcare providers, which should be mandated nationally. Some religious beliefs, for example, don't allow for blood to be drawn for a lead screening. Some cultures have shame and blame regarding mental health issues. Others have stigma associated with disability. Still others are fearful of any system, including healthcare, due to recent immigration raids. An excellent resource for medical professional pre-service and in-service training in *The Spirit Catches You and You Fall Down*, a true story that demonstrates the tragic consequences of U.S. health systems refusing to acknowledge and address the impact of religious/spiritual and cultural beliefs on health outcomes. Besides onsite translators, AT&T language lines and IBM computer translation programs can assist in communicating with patients in other languages by phone and email.

Health literacy is the largest barrier for all groups, including underserved populations. Latest estimates indicate that 1 in 7 adults, or 32 million Americans, can't read the instructions on a medication bottle. The costs of healthcare literacy are high, besides the human factor of poor health outcomes. The University of Connecticut study showed that \$106-238 billion is lost every year on healthcare costs due to poor communication between patients and providers. NJ just held the first statewide summit on health literacy and used the models developed in Missouri (see [www.mffh.org/pag2.html](http://www.mffh.org/pag2.html)) and Wisconsin (see [www.wisconsinliteracy.org](http://www.wisconsinliteracy.org)). The New Jersey Department of Education recently revised the Core Curriculum Content Standards for all students statewide to include health literacy, which is a model for other states. The American Medical Association has also developed a free video addressing the issue of health literacy at [www.ama-assn.org/ama/no-index/about-ama/8035.shtml](http://www.ama-assn.org/ama/no-index/about-ama/8035.shtml).

Other barriers include patients who are uninsured or underinsured. Patients need to know what their rights are as well as the responsibilities of their healthcare provider and insurance carrier. The Children's Health Insurance Program has helped cover many children, and in some states also adults, nationally. In our state there is a recent mandate for coverage under age 18 which should eliminate the barrier of children being uninsured. We also have a buy-in program if children are ineligible for Medicaid/SCHIP due to family income. In the future, healthcare reform should lead to universal coverage for adults and children. Lastly, patients need to know what benefits are covered and how to appeal denied claims.

The Medical Home model works and has been utilized by the American Academy of Pediatrics (see [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)) and should also be expanded to include adults. 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 engaging consumers, including barriers and incentives, in the Patient Centered Medical Home model.

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.**