Statewide Parent Advocacy Network, Inc.

Testimony of Family Voices NJ @ SPAN & the Statewide Parent Advocacy Network on New Jersey’s 2010 Maternal & Child Health Block Grant Application May 19, 2009

Family Voices-NJ and the Statewide Parent Advocacy Network (SPAN) are pleased to provide testimony on New Jersey’s 2010 Maternal and Child Health Block Grant application. SPAN is New Jersey’s federally-funded Parent Training and Information Center, Family to Family Health Information Center, Statewide Parent to Parent, Family Voices and Federation of Families for Children’s Mental Health chapters, and recent recipient of an Integrated Systems (D70) grant from the U.S. Department of Health and Human Services Maternal and Child Health Bureau. Family Voices-NJ is the New Jersey chapter of National Family Voices, which speaks on behalf of children and youth with special healthcare needs and their families. Each year, SPAN and Family Voices-NJ provide information, training, technical assistance, support, and advocacy for over 100,000 families on issues impacting their children, including health, mental health, education, child welfare, family support, juvenile justice, and human services.

As advocates and parents of children and youth with special healthcare needs, SPAN and Family Voices-NJ strongly support the programs and services that have been developed with New Jersey’s Maternal and Child Health block grant funds. Areas of continuing concern and focus include culturally competent care, health disparity outcomes and infant mortality, autism, immunizations, newborn screenings, uninsured children, mental health, and transition to adult systems of care.

We were pleased to see the issues of cultural competency, as well as health/safety in childcare, addressed in the block grant application, especially in the context of the Early Childhood Comprehensive Systems grant. As participants in the ECCS task force, particularly on the family/caregiver committee, we strongly support continuation of the ECCS activities, including development and maintenance of a family-friendly website (which will be linked to SPAN’s website), and leadership development for parents of young children, who will then be connected back to the ECCS team to play leadership roles in planning, implementing, and evaluating ECCS activities.

For families of children and youth with special healthcare needs, the focus on care coordination for specific conditions such as asthma, autism, and obesity/diabetes, is an important one. Overall, SPAN and Family Voices-NJ strongly support continued funding for county Special Child Health Services Case Management Units, which provide a local care management support system for children and youth with special healthcare needs and their families and assist families in accessing critical services.
For *asthma*, we support the initiative on childhood asthma and are pleased to see the continuing decreasing trend in childhood hospitalizations due to asthma. Indeed, if HMO’s have care management for specific conditions, this is one of the primary ones. In the area of *autism*, we congratulated Dr. Eggerding on being named chair of the Governor’s Council for Medical Research and Treatment of Autism. We provided testimony in support of the development of the forthcoming revision of the birth defects registry to include autism. We recently received a copy of “Early Identification of Autism Spectrum Disorders: Guidelines for Healthcare Professionals” and support the Department’s proactive stance in early treatment. SPAN/FV staff were among the interviewers trained by Autism NJ to conduct family interviews and results will be distributed to the Governor’s Task Force on Autism, as well as presented in a forthcoming statewide autism summit. Regarding the *obesity* and resulting diabetes epidemic, we were pleased to see the “Get Moving, Get Healthy!” program in NJ and support the collaboration between the Department of Health and Senior Services and the Department of Education on the grant from the Centers for Disease Control and Prevention on obesity prevention and intervention. We note, however, that mental health issues as well as bullying and harassment are directly related to obesity issues, and that physical and mental health cannot be separated. We are part of the Healthy Child Care NJ advisory council and support the Physical Lifestyles for Active Youngsters task force activities. In addition, we contribute a regular column to the PCORE Early Childhood Health Link newsletter. Family Voices NJ worked on the CDC funded Bright Futures/Family Matters wellness (nutrition/physical activities) goals for children with special needs and was the only state also offering this in Spanish. We continue to receive calls on wellness and provide resources to parents on these topics and note the importance of providing support to families of children with special healthcare needs on health promotion. So often, the healthcare providers for children and youth with special healthcare needs focus so intently on meeting the special healthcare needs of the children and youth that they do not share critical information with families about health promotion.

We support the continued focus on reducing and/or eliminating health disparities in the areas of black infant mortality, lead, asthma, and newborn screening, and note the importance of culturally appropriate outreach and support for New Jersey’s diverse population. We support the concept of the Healthy Start and BIBS programs to address these issues and encourage the Department of Health and Senior Services to work closely with the Department of Human Services' Division of Prevention and Community Partnerships and their Family Success Centers and Differential Response Pilots as well as the member agencies of the Hispanic Directors’ Association and the New Jersey Immigration Policy Network to improve outreach to diverse communities and families at risk. Immunizations and lead screenings are essential.

SPAN and Family Voices-NJ have been involved in efforts to increase rates of adolescent immunization in New Jersey. We conducted focus groups statewide with diverse families and youth; the information from these focus groups demonstrated the continuing need for parent education and outreach regarding the importance of adolescent immunization as well as targeting materials and outreach directly to youth.
SPAN partnered with the Pediatric Council on Research and Education, the non-profit arm of the American Academy of Pediatrics-New Jersey chapter, as well as with youth at Montclair High School and the Academies @ Englewood on development of youth-focused materials on immunization including a website, RUNext.org, and Public Service Announcements for schools. SPAN disseminated information on the website and the availability of the PSAs on a CD to every public school district in New Jersey. Articles for parents on adolescent health and wellness are available on the SPAN website, including articles on the parent’s role in helping their adolescent stay healthy (www.spannj.org/Family2Family/Helping_your_Adolescent_Stay_Healthy.pdf); the new 6th grade immunization requirement (http://www.spannj.org/newvaccine.htm); the value of flu vaccinations for adolescents (http://www.spannj.org/The_Flu_Vaccine.pdf); the HPV vaccine for adolescent girls to help in the prevention of cancer (http://www.spannj.org/HPV_Vaccine.pdf); guidance from the New Jersey Department of Health on religious and health exemptions to immunization requirements (www.spannj.org/newvaccine.htm); and information on health advocacy for their children and adolescents, especially those with special health needs at www.spannj.org/Family2Family/. We worked with the Winning Angels, a support group for immigrant, Spanish speaking families of children and youth with special healthcare needs, on an educational program featuring a bilingual pediatrician and representatives of NJ PCORE/AAP-NJ on the importance of immunization; the forum also debunked myths about the connection between immunizations and autism. Additional forums of this kind should be planned and implemented, particularly targeting parents of children with special healthcare needs who are susceptible to allegations that immunizations cause autism.

We support the plan’s focus on newborn metabolic as well as hearing screenings. NJ Statewide Parent-to-Parent continues to focus on families of children with deafness and hearing loss and will contribute to earlier detection, treatment and family support. We encourage the Department to continue to work with the Division of the Deaf and Hard of Hearing and other partners in bi-annual Family Learning Conferences for families of children with deafness/hearing loss. We were pleased to see the expansion of newborn screening to 54 disorders and encourage the Department to increase outreach to pregnant mothers-to-be regarding the importance of newborn screening. We participate in the NYMAC (NY Mid Atlantic Consortium) on newborn screening and their medical home subcommittee.

SPAN and Family Voices-NJ acknowledge the support of the Department of Health and Senior Services for our Family WRAP (Wisdom, Resources, Advocacy and Parent to Parent Support) project, a collaboration that includes Project Care (housing SPAN Family Resource Specialists in county Special Child Health Services Case Management Units), Family Voices-NJ, and NJ Statewide Parent to Parent. This base funding has not only provided direct support to thousands of families of children and youth with special healthcare needs each year, but also enhanced SPAN’s capacity to secure additional funding to support families, such as the Champions for Progress grant, which led to development of the Transition Resources CD for youth with special healthcare needs and the Transition Resources for Health Practitioners.
We strongly support the continued use and expansion of SPAN Family Resource Specialists and Family Voices and Parent to Parent staff. In addition to the 10 part-time Family Resource Specialists supported by the Department, SPAN has secured funding through our Parent Training and Information Center grant to house part-time Family Resource Specialists in the five southern SCHS CMUs and have now received confirmation that our application for the Integrated Systems Grant from the US DHHS MCHB has been approved, which will allow us to hire part-time Family Resource Specialists in the remaining counties. The base funding from the Department for our Family Voices coordinator and our Parent to Parent project enhanced our capacity to secure a Family to Family Health Information Center grant from the US DHHS MCHB, which funded a bilingual project director, two part-time TA coordinators, and a part-time bilingual parent to parent coordinator. Through this grant, SPAN conducts county-based health advocacy workshops for families as well as free lunchtime teleconferences on health advocacy that are recorded and archived on our website for free access by families 24 hours/day, 7 days/week at their convenience. In addition, the Family Voices Coordinator in collaboration with Valerie Powers-Smith (Hinkle & Fingles) continues to present free “healthcare across the lifespan” workshops for parents. Thus, the approximately $180,000-200,000 annual base funding for our Family WRAP project has led to an additional $395,700/year ($95,700 for the F2F Health Information Center and now $300,000/year for the Integrated Systems grant) being brought into New Jersey to provide support for families of children and youth with special health care needs.

Our collaboration with the Department led to the successful SCHS nomination of Mercedes Rosa, Director of our Family to Family Health Information Center, for an AMCHP Family Scholarship and participation in this year’s annual AMCHP conference as a family leader.

In terms of the data regarding our project that is contained in the MCH block grant application, we would like to correct the number of contacts for Family Voices for last year to 14,779 contacts with parents and professionals rather than the 7,953 that appears on page 15.

SPAN and Family Voices-NJ are deeply concerned that all eligible children are still not enrolled in Family Care. A recent Star Ledger article has cited that the number of uninsured children in New Jersey has reached an all time high of 360,000 children. This statistic calls for increased efforts on the part of the Department of Health and Senior Services as well as the Department of Human Services to ensure that all eligible children are enrolled. We are also concerned with the freeze on up to 150% FPL on parent enrollment, as research shows when parents have coverage, it increases coverage for children. According to the NJHA conference, a child who is uninsured is diagnosed on average two years later than his insured counterpart. Often illness may reach a more serious stage, sometimes untreatable. Uninsured children suffer healthcare disparities and outcomes, particularly for underserved populations. Not only are there increased costs, but higher morbidity and mortality rates.
Another concern is the proposed Medicaid co-pays as the MI study indicated that even a minimal copay of $2-3 decreased healthcare utilization resulting in increased costs, as conditions worsened without preventive care or treatment, and more importantly again resulted in poorer healthcare outcomes.

We also attend the Medical Assistance Advisory Council. We are also concerned that NJ is third from last nationally on EPSDT (source: NJ Hospital Association). Of note is that only 1/3 of these eligible children receive dental care. As far as traditional Medicaid, we are concerned with dual-eligibles and the Medicare Part D prescription plan as well as the mandatory phase in for the ABD population. We were pleased with the introduction of Family Care Advantage and continue to work on both NJ and national HCAN (Health Care for America Now) coalitions to enhance the availability, quality, and affordability of health care for New Jersey’s children and families.

SPAN and Family Voices-NJ strongly support the “Children’s Behavioral Health Services” program initiative on children’s mental health. In addition to the value of Care management organizations and Family Support Organizations, the use of the mobile crisis unit has aided families in urgent need and helped reduce the number of youth with mental health challenges in out-of-home placements. While we applaud the efforts of the Dual Diagnosis Task Force, we continue to hear of lack of services for children with a dual diagnosis of DD and mental illness. The NJ Coordinator for Family Voices has taught Visions for Tomorrow courses at NAMI and continues to hear of significant concerns from families about barriers to accessing the care their children and youth need. She is the Mercer County trainee for the new NAMI Basics (NJ is 1 of 6 states) and statewide resource person for Basics teachers, and also trained on Educating the Educators, both of which also cover suicide prevention. The Coordinator is assisting with Spanish translation, parent support groups, and speaker planning committee resulting in 1/3 of topics covering children issues, newsletter articles, and NAMI Kids outings in the community. We urge the Department to strengthen its collaboration with Children’s Behavioral Health Services to ensure seamless services for children, especially those who have both developmental and mental health disabilities. We were concerned about the proposal to discontinue the Family Support Organizations and bring them under the Care management organizations, because it would have resulted in the loss of the independent family voice, and were pleased to see that the Department of Children and Families has at least temporarily withdrawn this proposal.

We support the Child/Adolescent Health Program initiatives, particularly in relation to injury and violence prevention. We sit on the advisory councils of some of the HMO’s, which indicated adolescents as the most underserved age with regards to children, and are pleased to see targeted efforts in this area. SPAN continues to work on the Community Partnership for Healthy Adolescents which included peer developed public service announcements. Under Preventive and Primary Care for children with Special Health Care Needs, we were pleased to see the focus on transition to adult life and have collaborated with the department on the Champions for Progress grant, including an expansion from the Council on Developmental Disabilities. Besides the transition CD, SPAN developed and disseminates factsheets with input from healthcare providers.
We were pleased to see the NJ Core Curriculum Content Standards revised to include Health Literacy. We also attended the statewide summit on health literacy and belong to the national health literacy listserv. We encourage the Department to work with health literacy advocates to focus efforts on the most underserved populations including families with limited literacy and/or families with limited English proficiency, particularly immigrants.

In terms of early intervention for infants and toddlers with developmental delays and disabilities, we remain concerned with the expansion of the role of the Regional Early Intervention Collaboratives as some of the prior issues raised by SPAN, Family Voices-NJ, and other advocates, haven't been addressed. We provided comments on the Application for Federal Funds under Part C. Although we strongly support the activities of the REICs and requested that their role and functions be included in the NJ regulations, there are some concerns with the expansion of their role and the shift of funding from the lead agency to the REICs in the budget. In some counties where the REICs were already operating in lieu of the SCHS CMUs, there were concerns of eligible children in residential services or with DNR orders being denied services. In addition, there were also concerns about delays in referrals from early intervention to school districts during transition. Also, if the REICs are required to do informal complaint resolution, their new role as service provider is clearly a conflict of interest. These concerns must be addressed prior to the expansion of REIC responsibilities.

In general, we support the use of the “medical home” model developed by the American Academy of Pediatrics (AAP). We’ve distributed medical home literature at conferences and serve on the AAP-NJ Chapter Council for Children with Disabilities, to collaborate on how children with special needs access health care to maximize their development. We are pleased that healthcare and childcare issues are being considered together, rather than separately. We now serve on the PCORE Medical Home pilot leadership council. Our new Integrated Systems grant will provide significant support to the Department’s efforts to achieve the MCHB six core outcomes, including access to a medical home for all children and youth with special healthcare needs. The Integrated Systems grant includes funds to expand medical home pilots and train parents to participate in medical home pediatric visits to train primary care practices including private practices, Federally Qualified Health Centers, and hospitals.

Overall, we encourage the continued focus on culturally competent services. New Jersey was the first state to require cultural competency for health providers, and we belong to the statewide cultural competency listserv to advocate on improving cultural competence among providers. However, Hispanic and Asian children remain underserved in early intervention, and Hispanic and African American children remain uninsured, which also results in health disparity outcomes. We make our materials and technical assistance for families available in Spanish. We’ve also added a resource, Traducelo Ahora, to translate emails and websites for families, which we have offered to make available to each SCHS CMU at no charge. This resource not only allows families to access English-language websites in Spanish but also translates emails sent to and from families and service providers including doctors, teachers, and state, county, local government, and non-profit agencies.
Thank you for the opportunity to comment on the proposed MCH block grant, both as advocacy organizations and as parents of children and youth with special healthcare needs who have received, and continue to receive, help from New Jersey's Title V program and other programs funded through New Jersey's MCH Block grant.

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.