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Statewide Parent Advocacy Network, Inc.

Testimony of Family Voices NJ @ SPAN on the 2009 Maternal & Child Health Block Grant

5/13/08

Family Voices-NJ at the Statewide Parent Advocacy Network is pleased to provide testimony on the 2009 Maternal and Child Health Block Grant. As advocates and parents of children with special needs, we strongly support the programs that have been developed with Maternal and Child Health funds. Areas of continuing concern for Family Voices include diabetes/obesity, autism, asthma, health disparity outcomes and infant mortality, immunizations, lead, newborn screenings, uninsured children, mental health, injury/violence (including bullying), and transition. We were pleased to see the issues of cultural competency, as well as health/safety in childcare addressed, especially in the context of the Early Childhood Comprehensive Systems grant.

The focus on care coordination for specific conditions such as asthma, and diabetes, is an important one. 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 addition, we strongly support the emphasis on the national and state epidemic of childhood obesity and resulting diabetes. We were pleased to see the "Get Moving, Get Healthy!" program in NJ. We are also 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 are concerned that infant mortality for black children in NJ is still triple that of white infants. 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 the Community Collaboratives to improve outreach to diverse communities and families at risk.

Immunizations and lead screenings are essential. We were pleased to see the increase in children up to age 2 who have received immunizations. Lead results are still

an issue, with Newark as the city of the highest concern. We look forward to the forthcoming 2008 Annual Report on Childhood Lead Poisoning in NJ.

We also support the plan's focus on newborn metabolic as well as hearing screenings. The initiative of NJ Statewide Parent to Parent, funded by the NJ Department of Health and Senior Services, continues to focus on families of children with deafness and hearing loss and will contribute to earlier detection, treatment and family support.

We strongly support the continued use and expansion of SPAN Family Resource Specialists in the county case management units including Cape May, Cumberland, Burlington, Salem, and Gloucester. Family Voices receives funding from the Department as part of SPAN's Family WRAP project, and would like to take this opportunity to again thank the Department for its continued support. We have also received additional resources as the Family to Family Health Information & Resource Center for NJ, which allowed us to expand our outreach to families statewide. In addition, we hosted lunchtime teleconferences on health advocacy. Lastly, the Family Voices Coordinator in collaboration with Valerie Powers-Smith (Hinkle & Fingles) has presented free "healthcare across the lifespan" workshops for parents.

We served on the NJ Hospital Association Covering Kids outreach program for Family Care. We are concerned that eligible children are still not enrolled in Family Care and supported the Governor's Initiative to cover more children. 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 will advocate regarding the new proposal on universal healthcare.

We strongly support the "Children's Behavioral Health Services" program initiative on children's mental health. Also, the use of the mobile crisis unit has aided families in need. The NJ Coordinator has taught Visions for Tomorrow courses at NAMI and was the Mercer Co. trainee for new NAMI Basics (NJ is 1 of 6 states), and Educating the Educators, which also cover suicide prevention. The Coordinator is assisting with Spanish translation, parent support groups, speaker planning committee resulting in 1/3 of topics covering children, newsletter, 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 and families, especially children who have both developmental and mental health disabilities. We recently reviewed 2 sets of RFPs for dually diagnosed children and await a third. We were pleased to see that the Federation of Child Evaluation Centers focused on autism. We also strongly supported the development of the Department of Children and Families in NJ. We support the development of the autism registry and agree that referrals will increase requiring

additional screening training. We would suggest the use of the AAP's new developmental screening guidelines.

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 continued to work on the Community Partnership for Healthy Adolescents which included peer developed public service announcements. We are pleased to see the decrease in teen birth rates as well. 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 factsheets with input from healthcare providers.

We are concerned with the proposal of the Regional Early Intervention Collaboratives as the single point of entry into early intervention. According to the NJ state webpage on early intervention, the Regional Early Intervention Collaboratives (REICs) "*provide technical assistance to families, early intervention programs and professionals, and ensure the protection of family rights*". If the collaboratives become the entry point for early intervention, we see this as a conflict of interest. The importance of the existing single point of entry utilizing Special Child Health Services (SCHS) is outlined in various places in the NJ Early Intervention System Part C State Performance Plan (SPP). We are particularly concerned with the process of informal dispute resolution if the REICs become the SPOE as a direct conflict of interest. Again, according to the SPP it states, "Link the REIC data regarding informal complaints by families resolved at the regional level with the state procedural safeguards database." How can families resolve disputes neutrally with the same entity that is the SPOE? It was also mentioned at the 1/25 SICC meeting that the Early Intervention System (EIS) Stakeholder Task Force specifically recommended against the REICs providing services. It is noted in the task force recommendations that besides serving as the SPOE, "service coordination...includes - informing families of the availability of advocacy services" again a conflict of interest if the REICs serve as the SPOE. Of particular concern is the stakeholders task force paper stating "Separate funding contracts shall be written for (1) initial child and family evaluation/initial assessment and (2) service delivery. Contractors' proposals must address *how they would eliminate conflicts of interest* between evaluation, IFSP development and implementation of services.... Each REIC shall develop an evaluation/assessment plan that address standards and *conflict of interest*" – points which remain valid. Still another direct conflict is the concept (task force recommendations) "REICs shall make recommendations regarding allocation of funds based on data from *monitoring and other quality assurance* processes." Besides the obvious financial conflict, how can REICs "monitor" and perform "quality assurance" under the proposed circumstances? It further states "A process shall be developed consistent with existing state grant management procedures to ensure the opportunity for timely conflict resolution between all parties, including appeal by applicants/grantees/REICs."

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.

Overall, we encourage the continued use of culturally competent services. NJ was the first state to require cultural competency for health providers and we belong to the statewide cultural competency listserv. 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 new resource Traducelo Ahora to translate emails and websites for families. In addition, we are collaborating with the NJ Immigration Policy Network on a project to help improve healthcare access for families.

Thank you for the opportunity to comment on the proposed MCH block grant, both as an advocate and as a parent of a child with special healthcare needs who has received, and continues to receive, help from the N.J. Title V program.

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.