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Statewide Parent Advocacy Network, Inc.

Testimony of Family Voices NJ @ SPAN & the Statewide Parent Advocacy Network on NJ's 2011 Maternal & Child Health Block Grant Application & State Needs Assessment Submitted June 22, 2010

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 and Needs Assessment. SPAN is New Jersey's federally-funded Parent Training and Information Center, Family to Family Health Information Center, Statewide Parent to Parent, and Federation of Families for Children's Mental Health chapter, and recipient of an Integrated Systems grant. Family Voices-NJ is the New Jersey chapter of National Family Voices, which advocates to "*keep families at the center of children's healthcare*," with a special focus on children and youth with special healthcare needs (CYSHCN). 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, in part with funding from the NHDHSS.

In the past several years we have conducted numerous focus groups with diverse families of the full range of children and youth with special healthcare needs, including families of children with autism spectrum disorders (ASD) and other developmental disabilities, deafness/hearing loss, deaf-blindness, chronic and acute health conditions, and other needs and have shared that information with the NJ Department of Health and Senior Services (NJDHSS) to assist in their MCH needs assessment. This past year our Community of Care Consortium for CYSHCN Statewide Summit brought together 100 key stakeholders (1/3 parents of CYSHCN) to develop an action plan based on identified needs as part of our State Implementation Grant for Community Systems of Care for CYSHCN and their families, and this information has also been shared with the NJDHSS for development of the MCH Block Grant Application.

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

We were pleased to see the issue of 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, we strongly support continuation of the ECCS activities, including launching the new Early Childhood Health website (which will be linked to SPAN's website). However, we are disappointed that the funding used this past year to facilitate parent leadership development for parents of young children will not be followed up with funding to support the participation of those parents in leadership opportunities, including the ECCS Advisory Committee.

As an original and continuing member of the Map to Inclusive Childcare Team and home of the NJ Inclusive Child Care Project, we support the Block Grant application's commitment for the NJ Department of Health and Senior Services (NJDHSS) to continue its collaboration with the Map to Inclusive Childcare Team and the NJ Inclusive Child Care Project.

For families of children 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 with special healthcare needs and their 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. The needs assessment identified asthma as the "most common chronic disease in children". Indeed, if HMO's have care management for specific conditions, this is one of the primary ones. In the area of *autism spectrum disorders (ASD)*, we provided testimony supporting the inclusion of autism in the birth defects registry, but feel more training is needed for providers despite the finding of the needs assessment that "85-90% of the children with birth defects are appropriately reported." We support the development of the second module of the BDARS (Birth Defects and Autism Reporting System) to track and monitor family services as well as an electronic version of an IFSP (Individual Family Service Plan). 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. We are deeply concerned that the average age of diagnosis reported to the Autism Registry was 4.5 years and support the Department's efforts for sooner identification due to the importance of early intervention. We strongly supported the Governor's Council for Medical Research and Treatment of Autism and the 6 grantees. In addition, we testified on the importance of an Autism Center of Excellence for NJ. Although we support insurance coverage for ASD and other developmental disabilities (and were vocal advocates to expand the proposed ASD-only legislation to include other developmental disabilities), the current legislation only covers 25% of NJ's plans, leaving most families without this critical protection.

Regarding the *obesity* and resulting diabetes epidemic, we are pleased to see the CDC (Center for Disease Control) grant for a state NPAO (nutrition, physical activity, and obesity) initiative. We understand that the needs assessment identified NJ as having "one of the highest rates of obesity among low-income children 2 to 5 years of age at nearly 18%...NJ Student Health Survey of high school students, 14% of males and 7% of females as obese, and 15% of males and 14% of females...overweight." We continue on the Healthy Child Care NJ advisory council and supported their Physical Lifestyles for Active Youngsters task force activities. In addition, we contribute to the PCORE (Pediatric Council on Research and Education) 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. Too often, the healthcare providers focus so much on the special needs of the children that they do not share critical information about wellness and overall health promotion.

We support the continued focus on reducing and/or eliminating health disparities in the areas of uninsured/underinsured, lead, asthma, obesity, newborn screening, transition, and the importance of culturally appropriate care. We support these focus areas in collaboration with the Division of Prevention and Community Partnerships, Family Success Centers, Foster and Adoptive Family Services, and the New Jersey Immigration Policy Network to improve outreach to diverse families. In collaboration with the NJ Alliance of Family Support Organizations, Parents Anonymous of NJ, and Family Intervention Services of NJ, SPAN provides information,

training, and technical assistance to the Family Success Centers through the Partnership for Family Success Training and TA Center. As part of this project, SPAN shares information with the Family Success Centers regarding resources for families of children with special healthcare needs and collaborates with them on connecting families to those resources.

SPAN and Family Voices-NJ have been involved in efforts to increase rates of adolescent immunization in New Jersey and continue to support efforts to ensure that all children, including children with special healthcare needs, receive the immunizations they need to maximize their health. We conducted focus groups statewide and continue to collaborate with PCORE on their vaccine congress and Immunization Action Group.

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 hearing loss and will contribute to earlier detection, treatment and family support. Our collaboration with the NJDHSS has resulted in a grant from the US Centers for Disease Control and Prevention to support a statewide conference for families of children and youth with deafness and hearing loss in the coming year. We were pleased to see the expansion of newborn screening to 54 disorders with NJ now "among the top 5-10 states in offering the most screenings for newborns". We continue to participate in the NYMAC (NY Mid Atlantic Consortium) on newborn screening and their medical home and other consumer subcommittees.

SPAN and Family Voices-NJ acknowledge the support of the Department for our Family WRAP (Wisdom, Resources, Advocacy and Parent to Parent Support) project that includes Project Care (Family Resource Specialists), Family Voices-NJ, and NJ Parent to Parent. Due to this collaboration, we were also able to obtain the Champions for Progress grant, which led to development of the Transition Resources CD for youth, Transition Resources for Health Practitioners, and development of a Youth Advisory Council. This support also enhanced our capacity to secure a Family to Family Health Information Center grant as well as the D70 (State Implementation Grant for Integrated Community Systems for CYSHSN) and the Military Family Support 360 grant. SPAN acknowledges and appreciates the collaborative approach of the NJDHSS, which has contributed to our receipt of the first-ever Genetic Alliance "Novel Art of Partnership Award" for our Community Consortium of Care for CYSHCN.

In addition, our staff in collaboration with Valerie Powers-Smith Esq., and Hinkle & Fingles, continues to present free "healthcare across the lifespan" workshops for parents and distribute our free booklet to parents and professionals who work with CYSHCN.

SPAN and Family Voices-NJ remain deeply concerned that all eligible children are still not enrolled in Family Care. The most recent data from Rutgers's showed almost 450,000 children, and ACNJ's report showed over half a million uninsured children. This is despite the state mandate for coverage for all children. We do think that the Express Lane application will facilitate enrollment and we will continue outreach through our CHIPRA grant, a partnership with the NJ Hospital Association. We are also concerned with the freeze on parental enrollment, and dropping immigrant families with documentation, as research shows when parents have coverage, it increases coverage for children. Research also shows that a child who is uninsured is diagnosed on average two years later than his insured counterpart and then the illness is more serious, more costly, and sometimes results in increased mortality. Although the FQHCs received additional funding, we are concerned that they will now have up to 13,000 more individuals to serve. Further, FQHCs provide primary care, not specialty care, placing the needs of families facing acute or chronic health conditions needing primary care in a situation without access to that needed care, especially given the cuts in funding to NJ hospitals for

emergency care for uninsured patients. Even for those families with health coverage, due to the merging of HMOs there will be 100,000 Medicaid enrollees switching plans. We strongly support continued collaboration with the MAAC (Medical Assistance Advisory Committee) and ARC's Mainstreaming Medical Care. We were pleased with the introduction of Family Care Advantage but remain concerned that families must be aware of its availability; very few families who could benefit from this program are actually accessing it. Once again the needs assessment showed the underserved as an area of concern "6.2% of Latino CYSHCN and 6.1% in families with incomes below 200% FPL lacked insurance at the time of the survey... 18.1% of Latino CYSHCN and 20.5% in families below 200% FPL went without insurance at some point during the year... 51.9% of Spanish-speaking families and 43% of 'other' families reported inadequate insurance."

Although EPSDT remains a concern, we were pleased to see that all Medicaid/SCHIP enrolled infants received at least one screening. We were also pleased to see the improvement in dental sealant rates. In addition, we were pleased to see the improvement in lead screening; indeed SPAN was invited to the county lead coalition meetings this year. However, the needs assessment showed that EPSDT is particularly of concern to underserved families as "only 63.1% Latino, 60.9% of African-American, 32.5% of Spanish speaking Latino, 52% of families below 200% FPL, and 57.9% of uninsured CYSHCN met this outcome."

SPAN and Family Voices-NJ strongly support the "Children's Behavioral Health Services" program initiative on children's mental health, including funding for county Family Support and Care management organizations and mobile response, and strongly support maintaining the FSOs as independent, family-run non-profit organizations as opposed to pulling them under the umbrella of the CMOs. We were pleased to provide comments on the dual diagnosis (MI/DD) task force, and appreciate the fact that children and youth with dual diagnoses of MH and DD now have some access to care, although barriers still remain. We were pleased to provide comments on the Family Crisis Handbook and on the on-line training on DD for first responders and appreciate the fact that NJ requires first responders to participate in such training. The NJ Coordinator for Family Voices is involved with the NAMI (National Alliance for Mental Illness) on a local/state/national level and continues to hear significant concerns from families about barriers to accessing mental health care. We support the Department's efforts in suicide prevention, which the needs assessment identified as the "third leading cause of death among youth 10-24 years." We urge the Department to strengthen its collaboration with Children's Behavioral Health Services, Parents Anonymous, and also NAMI which presented at SEAC (Special Education Advisory Council) "Educating the Educators" (CEUs for professional development) and "Every Mind Matters" (aligned with the Core Curriculum Content Standards).

We support the Child/Adolescent Health Program initiatives, particularly in relation to injury and violence prevention. As participants on HMO advisory councils, which indicated adolescents as the most underserved age with regards to children, we are pleased to see targeted efforts in this area. 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 as well as a focus on transition in the current D70 SIG project. We also support the "Building a Coordinated School Health System" grant. Most recently, the Family Voices Coordinator developed a healthcare transition one-pager for families which also had advisory support from the Department. However, underserved families were again indicated in the needs assessment as the area of most concern with only "17.2% of Latino and 25% of African-American...reported they received services necessary..." for transition.

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 as this is a significant barrier for access to care.

In terms of early intervention for infants and toddlers with developmental delays, we are extremely concerned with the budget cuts which will result in increased family cost share. The last time this was increased, families dropped out of the system and children didn't get the services they needed, despite the research that early intervention is cost effective and results in better health outcomes. In addition, there remain concerns about delays in referrals from early intervention to school districts during transition. We are also concerned with cuts to medical daycare, a critical service for children with significant healthcare needs.

We are deeply concerned that there were also budget cuts to the Catastrophic Illness Relief Fund. Families USA research indicates that the majority of bankruptcies are due to medical debt. Further, due to the economic downturn, more NJ families are applying for the Catastrophic Fund and the NJ needs assessment indicated a 20% increase in 2009. NJ's Family Voices Coordinator personally applied for the first time (even though both she and her husband work) and one example is a \$12,000 lab bill of which \$700 was out of pocket and that was only one of three costs that *day*; this family is now going to Children's Hospital biweekly.

We support the SSA referral system transition from paper to electronic transmission which facilitated referrals to SCHS.

In general, we support the use of the "medical home" model developed by the American Academy of Pediatrics (AAP). We continue to serve on the AAP-NJ Chapter Council for Children with Disabilities. We now serve on the PCORE statewide Medical Home pilot leadership council, medical home initiative in Monmouth, and assisted with the development of their ASD curriculum for health providers. Our continued collaboration with the Department on the 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. We strongly support the forthcoming wellness initiatives under health reform to utilize Bright Futures which will further enhance the medical home.

We were pleased to see the development of the NJ Special Needs Registry for Disasters. However, we feel that more work needs to be done on emergency preparedness for families of children with special needs. We would suggest collaboration with the Centers for Independent Living, who have already developed a curriculum on this, as well as collaboration with the Office of Emergency Management. Family Voices NJ would also like to be involved in this initiative.

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. We also attended the NJ Statewide Network on Cultural Competency meeting. 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.

Thank you for the opportunity to comment on the proposed MCH block grant and needs assessment, both as advocacy organizations and as parents of children with special needs who have received, and continue to receive, help from NJ'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.