Committee on Energy and Commerce

U.S. House of Representatives
Witness Disclosure Requirement - "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(5)

1.	Your Name:						
	María Isabel Frangenberg						
2.							
3.	The Entity(ies) You are Representing: Family Voices National						
4.	Are you testifying on behalf of the Federal, or a State or local government entity? Yes No X						
5.	5. Please list any Federal grants or contracts, or contracts or payments originating with a foreign government, that you or the entity(ies) you represent have received on or after January 1, 2013. Only grants, contracts, or payments related to the subject matter of the hearing must be listed.						
	See attached						
6.	6. Please attach your curriculum vitae to your completed disclosure form.						

July 7, 2016 hearing on the ACE Kids Act

Attachment to witness disclosure form of Maria Isabel Frangenberg, for Family Voices (3 pp)

FAMILY VOICES FEDERAL GRANTS

Below are the names and amounts of federal grants through which Family Voices has received funding as either the grantee or a sub-grantee.

I. National Center for Family Professional Partnerships (NCFPP)

For the Family Voices fiscal years beginning 6.1.2012 and extending through to the end of this FY (5.31.17), Family Voices has received or will receive the following funding through a cooperative agreement with the Maternal and Child Health Bureau to run the National Center for Family/ Professional Partnerships (NCFPP).

NCFPP grant funding:

- NoA dated 9.10.12 for budget period 6.1.12 5.31.13: **716,830** (included a supplement of 14,870)
- NoA dated 8.28.13 for budget period 6.1.13 5.31.14: **475,000**
- PBA supplemental in FY '14 (11.1.13 8.31.14)— **49,000** (10,809 of budgeted funds targeted for Family Leader meeting in April 2014; included all of 49,000 in total below)
- June 1, 2014- May 31, 2015: **475,000**
- June 1 2015 May 31 2016: Supplemental funding of **118,000**
- June 1, 2015- May 31, 2016: **475,000**
- June 1, 2016 May 31, 2017: **600,000** (Three year grant runs June 2016 through May 2019)*

Total budget for NCFPP funding from 6.1.12 through 5.31.17: \$2,908,830.

*Note: In the 3-year cooperative agreement awarded in June 2016, Family Voices is partnering with the Statewide Parent Advocacy Network of New Jersey (SPAN) to improve health care delivery and quality of life for all children with special health care needs (CSHCN) and their families through promoting effective partnerships between families and professionals. Activities include: assistance and support to Family-to-Family Health Information Centers (F2Fs) and other MCHB investments on family/professional partnerships, family/youth engagement and cultural and linguistic reciprocity, family and youth leadership development and training activities, specifically for racially and ethnically diverse families and youth, to increase knowledge, skills and peer connections; targeted training and support to Title V programs and others geared to authentically engage diverse family and youth leaders. This NCFPP new cycle of three-year funding begins June 1, 2016. (HRSA U40MC00149); 600,000/year for 3 years

II. Other grants

Family Voices is also a grantee or sub-grantee for the following federal grants:

PARTNERSHIP: FRIENDS IN SUPPORT OF THE NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES (NCBDDD)

With funding from Centers for Disease Control (CDC) through the Association of University Centers on Disability, Family Voices supports families to act as liaisons to the Executive Committee of the Friends of NCBDDD and to CDC leadership. Family Voices advises the Friends on strategies to enhance communication between families and key target audiences including policy makers, non-government organizations, and service providers. This project is in its 2nd of 3 year funding @ \$24,000/year.

PARTNERSHIP: CHILD AND ADOLESCENT HEALTH MEASUREMENT INITIATIVE (CAHMI)

Funded by MCHB and other sources, Family Voices assists CAHMI in their overall efforts to ensure that children, youth, and families are at the center of quality measurement and improvement efforts. Family Voices provides family perspective by: serving on the Data Resource Center (DRC) National Advisory Committee; providing input from diverse family leaders on the DRC website; disseminating information on CAHMI products; and contributing to discussions of Adverse Childhood Experiences. Year 2 of 3 began in May 2016. (subcontract to HRSA U59MC27866); \$15,900 year 1; \$17,000 year 2.

ALLIANCE FOR INNOVATION ON MATERNAL AND CHILD HEALTH PROGRAMS (AIM) PROJECTS

Family Voices is advising 5 partners who have funding from MCHB through the AIM initiative, bringing a family perspective to this initiative. The overall purpose of the initiative is to engage teams from 21 states in activities within MCHB focus areas of improving access to health coverage for pregnant women and children, increasing the implementation of Bright Futures and improving services for CYSHCN. This project is $\frac{3}{4}$ through year 2 of 3 years.

Family Voices encourages family participation at all levels of the project including the connection of AIM state teams to family organizations. Family Voices has participated in two national meetings of state teams, emphasizing the value of family engagement and has disseminated information about the project to Family Voices audiences.

Activities with specific partners are:

Partnership with the American Academy of Pediatrics (AAP) – includes helping AAP to collect information via family survey on problems patients/families identify with access to health care and coverage and collecting more detailed information through phone interviews with selected families. This information collecting is undertaken through SAOs and F2Fs within participating states. (sub contract to HRSA 4 MC28034-01-08); \$25,000/year.

Partnership with National Congress of State Legislators (NCSL) includes advising NCSL on publications and other written work that concern CYSHCN and Bright Futures guidelines for children, including project products that focus on state policies; \$12,500/year.

Partnership with the Association of State and Territorial Health Officers (ASTHO) includes developing an infographic/case study illustrating successful models of care coordination and services for CYSHCN, a checklist that State Health Departments can use to help families, especially those from culturally and linguistically diverse families, in the implementation of Bright Futures Guidelines, and gathering information on the impact of family members on Medicaid or private insurance advisory committees. \$10,000/year.

Partnership with the Association of Maternal and Child Health Programs (AMCHP) includes developing vignettes descriptive of family experiences obtaining coverage under the ACA collected from families in the states.(subcontract to HRSA UC4MC28035); \$10,00 year 1; \$15,000 year 2.

Partnership with the National Association of State Health Policy (NASHP) includes providing guidance on areas for family engagement, participating in an in-person meeting of state D-70 teams to address how to improve access to care for CYSHCN populations, identifying a young adult to present on a webinar about transitions and providing input from the Family Voices network through a structured conference call with NASHP on engaging families to improve polices. \$5,000/year.

PARTNERSHIP WITH AMCHP ON FAMILY LEADERSHIP

Family Voices has assisted AMCHP, through funding from an MCHB cooperative agreement, in areas of family leadership. This includes regular meetings regularly regarding areas to collaborate including developing materials to educate families about Title V and Block Grants; gathering feedback from family Block Grant reviewers; and developing strategies to mentor and support AMCHP Family Scholars. This initiative completed year one at the end of April 2016. We are awaiting word on further activities going forward. (*subcontract to HRSA U01MC00001*). \$12,000 year 1 (July 2015-April 2016).



EDUCATION:

University of North Carolina at	B.A. with	1994	Philosophy and
Chapel Hill	Honors		Political Science
Virginia Commonwealth University	LEND Certification	2010	Virginia Leadership Education in Neurodevelopmental Disabilities (Va- LEND) Family Trainee

SIGNIFICANT WORK EXPERIENCE:

2015- Present: Family Voices – Project Coordinator

- Work with NCFPP Co-Directors, Director of Strategic Planning and other staff to plan, carry out, and track multiple program activities as needed.
- Collect information as needed through interviews, phone calls or other means as background information for fact sheets/issue briefs/infographics
- Participate in planning calls related to development of products, planning and carrying out of initiatives as needed
- Write, edit and revise materials for readability
- Provide input on cultural and linguistic competence as materials are developed
- Develop and implement activities relating to ensuring cultural and linguistic competence in Family Voices activities
- Create materials in Spanish and advise on translation and interpretation services
- Represent Family Voices in meetings and activities as needed.
- Assist with meeting planning and participation as needed.
- Assist with updates and planning for websites and social media as needed.
- Perform tasks as necessary to ensure successful achievement of Family Voices goals and objectives.

2013-2015: Diversity and Inclusion Consultant

2014- 2015: Diversity and Inclusion Fellow, Association of University Centers on Disabilities- AUCD

Conceptualizing a blueprint for diversity and inclusion within the nationwide AUCD network

- Connecting University Centers on Disabilities as well as LENDs across the nation and pairing them for productive mentoring relationships.
- Creating, coordinating and producing a Diversity and Inclusion Webinar Series for the AUCD network
- Identifying and engaging emerging leaders in diversity in disabilities around the US to showcase their work to a nationwide audience
- Coaching nationwide webinar presenters for effective message transmission
- Fostering nationwide partnerships to enhance teamwork among federally funded disability organizations to advance a uniform diversity and inclusion agenda

2011 –2013: Adjunct Faculty, Virginia Commonwealth University, Richmond, VA

- Co-teaching IDDS 600, Interdisciplinary Studies in Developmental Disabilities, Teamwork
- Redesigned syllabus
- Engaging guest lecturers
- Infused the principles of diversity and cultural resonance in the Va-LEND curriculum
- Evaluating assignments and team projects

2011-2014: **Conference Co-creator and Organizer - Building Bridges**: Diagnosis and Treatment of Developmental Disabilities in Racially, Culturally, and Linguistically Diverse Communities Conference

• Developed, planned, engaged nationally known speakers, and designed the agenda of this first of its kind conference in Virginia.

2009-2013: Latino Community Liaison at the VA Family 2 Family (VA F2F) Center,

Partnership for People with Disabilities, Virginia Commonwealth University, Richmond, VA

- Administered and analyzed the Cultural Competence Assessment for Disability Organizations at the VA UCEDD, The Partnership for People with Disabilities
- Assisted Latino/Hispanic families by providing direct information and referral services
- Designed cultural awareness trainings and presentations for provider associations and state school districts
- Analyzed data on the families and providers served statewide for program improvement purposes
- Provided community-based trainings to Latino/Hispanic families on topics of interest to families with children with disabilities
- Identified, recruited, trained and mentored cultural brokers to serve within Latino/Hispanic communities
- Assisted with recruitment of Hispanic families to participate in focus groups
- Facilitated focus groups statewide, among Latino parents of children with Disabilities

2010- 2013: Commonwealth Autism Services Latino and African American Clinic Pilot Program

- Initiated, conceptualized and implemented the structure of culturally appropriate autism clinics to provide autism evaluations to underserved minority populations.
- Serve as a family navigator and cultural broker for the Spanish-speaking parents of the

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children being evaluated.

September 2009- October 2010: **Research Assistant, Best In Class Development Grant, School of Education, Virginia Commonwealth University, Richmond, VA** - Provide consultation to preschool teachers related to an evidence-based intervention that has been designed to reduce challenging behaviors in young children at risk for emotional and behavioral disorders.

- Performed literature reviews pertinent to the development of the grant.
- Assisted in writing and conceptualizing the intervention's consultation manual.
- Assisted in developing training for the teachers who participate in the intervention.

PUBLIC SPEAKING:

Provided cultural trainings and designed learning activities for:

- Virginia Department of Health- October 2010
- Colaborando Juntos- November 2010
- Catholic Diocese health care ministries February 2011
- Partnership for People with Disabilities February 2011
- Commonwealth Autism Services June, 2011
- Virginia Department of Health: Virginia Systems Improvement Project
- Medical Home Learning Collaborative October 2011
- Virginia Association of School Nurses 27th Annual Fall Conference November 2011

Provided diversity trainings regarding the use of interpreters, cultural brokers, and appropriate interactions with both, for:

- Colaborando Juntos Annual Conference: the Importance of Cultural Brokers in providing Access to Underserved Communities
- Richmond Behavioral Health Authority- November 2011
- Virginia State Special Education Advisory Committee December 2011
- Fundación Nueva Vida: A Cancer Group for Latina Women March 2012
- Virginia Department of Education LEAD SLP Group March 2013
- STAR Lecture Series Guest Presenter at Kennedy-Krieger Institute's Center for Autism and Related Disorders (CARD) March 2013 Provided training to staff on how to optimize autism diagnostic services for low-income families who are speakers of other languages.
- Georgetown Reflective Engagement Conference October 2013 Interactive conference
- NYMAC Summit Keynote Panel Speaker 2014

OFFICES/MEMBERSHIP IN PROFESSIONAL ORGANIZATIONS, ADVISORY COUNCILS, BOARDS:

- NYMAC Consumer Collaborative (2014-Present)
- Family Voices Cultural Competency Committee

- Member of the Diversity Advisory Committee at Kennedy Krieger's Center for Autism and Related Disorders (2013)
- Planning Team for the Consortium for Children and Youth with Special Needs (2011)
- Virginia team for the "Act Early" Summit Center for Disease Control and Prevention campaign (2010-2013)

MAJOR RESEARCH/PROFESSIONAL INTERESTS:

- Children and families of children with special needs, as they evolve in a multi-cultural arena.
- Exploration of the experiences within the healthcare and educational system of families of children with special needs.
- Creation of Guidance documents that inform and encourage uniform state and federal practices regarding language access services within the parameters of Executive Order 13166.
- Continuous evolution in the concepts of cultural humility, resonance, and diversity and inclusion.

LANGUAGES:

- English
- Native Fluency in speaking and writing Spanish
- Elementary French

OTHER WORK EXPERIENCE:

1999-2002	Verizon Yellow Pages - Norfolk, Virginia Advertising Account Executive
1998 – 1999	The Virginian-Pilot - Norfolk, VA Advertising and Marketing Representative
1998	IBM Global Services - Raleigh, NC Business Assistant to the Director of South Help Desk
1996- 1998	Preston Optometry Center Practice Manager – Cary, NC
1994 - 1996 1990 - 1992	Office Manager, Southern Optometry Group Optical Sales Associate, LensCrafters