

Beyond Visions Foundation, Inc. (BVF)

on behalf of

**VI Family-to-Family Health Information Center (F2FHIC)
The Virgin Islands Developmental Disabilities Council, Inc. (VIDDC)
The VI Family2Family Network, Inc.
dba Family Voices, U.S. Virgin Islands (FVUSVI)**

Testimony

of

**Yvonne D. Petersen
Executive Director**

before the

**35th Legislature of the U.S. Virgin Islands
Committee on Culture, Youth, Aging, Sports
and Parks**

**3022 Estate Golden Rock,
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1:00 p.m.

Good afternoon, Senator Angel Bolques, Chair of the Youth, Aging, Sports and Parks Committee, other committee members, other members of the 35th Legislature present, fellow testifiers, members of the press, persons in the viewing, on-line viewing and listening audiences, ladies and gentlemen. My name is Yvonne Petersen and I am the Executive Director of Beyond Visions Foundation, Inc. (BVF); the Virgin Islands Developmental Disabilities Council, Inc. (VIDDC) and the VI Family2Family Network, Inc. that is the Family Voices, U.S. Virgin Islands, an affiliate of the Family Voices National organization. Before I begin the key segment of my testimony, it is necessary to provide a brief overview the organizations I represent:

Beyond Visions Foundation, Inc. is an established local not-for-profit incorporated 1997, and currently serves as the Family to Family Health Information Center for the U.S. Virgin Islands, a federally-funded program through the Health Resources and Services Administration. The Virgin Islands Developmental Disabilities Council, Inc. (VIDDC), the previous Family to Family Health Information Center, works in collaboration with Beyond Visions to ensure families of children and youth with developmental disabilities and special healthcare needs remain a key function of this DD Coalition.

Additionally, the VI Family2Family Network, established as an IRS tax-exempt organization in 2022, was approved as the Family Voices National affiliate for the U.S. Virgin Islands this year. The Family Voices, USVI partnered with BVF and the VIDDC to conduct community outreach, provide training for parents to become parent navigators, conduct capacity building for parent/caregiver-led organizations, health professionals and workers that serve or engage families of children and youth with special healthcare needs.

As recent as last week, through contracting a community engagement consultant, Mr. Billy Abraham and I visited medical facilities on all three islands; such as the modular hospital on St. Croix, the Frederiksted Clinic, MCH on St. Thomas and the Morris De Castro Clinic on St. John. These visits included, but are not limited talking with health professional staff, doctors and nurses, and inquiring the needs that impact the population served by F2F Health Information Centers. Areas visited included pediatric, family planning, high risk clinic, OBGYN clinic, and MCH. Such discussions revealed the following needs (not comprehensive):

- Assist in addressing the need of the high rate of diabetes in the territory through community outreach and training to families.
- Assist with capacity building, training and community outreach to support parent-led organizations of families with sickle cell or sickle cell trait.
- Providing support for genetic counseling community outreach upcoming activities.
- Promoting newborn screening for the various populations (both ethnic and those with language barriers) in the VI.

Another key activity conducted was collaborating with Expecting Health from the state of California in reviewing videos to promote and educate new and expecting parents about newborn screening. This included working with VI expecting parents and those with newborns to review the videos, provide feedback so they can be more beneficial to the needs of our population.

At this time, plans are being made for the January 2024 visit of the New York Mid-Atlantic Regional Genetics Network (NYMAC) to meet with health providers and community leaders to discuss their plans regarding the needs for genetic testing, education and training in the VI. This will include a physician trained in genetics who will visit the VI on a quarterly basis. This information was discussed when the community engagement consultant met with Senators Capehart and Fonseca, both members of the Legislature's Health Committee.

One of the key achievements are as follows:

The DD Coalition members opened a Family Resource Center in the public housing community known as Harvey on St. Croix and have recently opened an office on St. Thomas at Nisky Center that also include a training center. They work and assist each other and additionally are in collaboration with organizations such as Christiansen Institute for Community Health and Empowerment and the Disability Rights Center of the Virgin Islands.

With funding from MCH, Beyond Visions will assist with community outreach for newborn screening with plans to include the VI's Spanish, Arabic and Creole population.

Some of the key challenges for the organizations is the following:

- Request local funding support: As the federal funds are not intended to provide the total costs of conducting the programs, and with the territories not having a level access to funding sources as those state side counterparts, assisting with funding to match the federal funds received through HRSA that supports families with children and youth with special healthcare needs will be helpful. This funding will assist in providing community outreach, training, support for parent navigators who provide one-on-one or group training for other parents and caregivers. We will request at least a 50-50 match on a territory wide.
- The U.S. Virgin Islands is the only jurisdiction that does not comply with the Developmental Disabilities and Bill of Rights Act of 2000, in short the DD Act. The DD Act funds, by federal regulations are intended to fund independent State Councils on Developmental Disabilities in each state and territory. However, in VI, the DD Act funds are requested and received by the Department of Human Services through their Consolidated Block Grant. Therefore, the VI DD Council receives no DD Act federal funding to conduct programs and services for the DD population.

I thank you for the opportunity to present to the Committee on Culture, Youth, Aging, Sports and Parks.