



Building Productive Lives

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Feb 3, 2015

To: Senator Suzanne Chun Oakland, HSH Chair
To: Senator Josh Green, HTH Chair

From: FASD Communities
From Gigi Davidson

Subject SB 925, Relating to Health and FASD State Coordinator Position

Aloha Chairs Chun Oakland and Green and members of the Senate Committee on Human Services & Housing and Health,

FASD Communities is a nonprofit organization comprised of 250 people from across the US that are trying to establish communities for young adults with fetal alcohol spectrum disorder to help them become contributing members of society. This is a part of the population that totally fall through the cracks of our system due to lack of understanding of this invisible disability. These young people are the innocent victims of this disability and yet have to suffer lifelong consequences. As for the most part they are underdiagnosed and misunderstood they experience many failures throughout their lives and don't feel they fit in anywhere. The statistics indicate that only 20% of this population are able to live independently and of the 80% that are not able to do so 60% end up incarcerated and the remainder succumb to homelessness, substance abuse and also develop secondary disabilities. FASD Communities is trying to provide a solution whereby these young adults will experience better outcomes.

FASD Communities is respectfully submitting testimony in support of SB 925 which would establish a full-time permanent position to serve as a Fetal Alcohol Spectrum Disorder (FASD) coordinator at the State Department of Health.

I as a parent have been on the FASD State Task force for many years and know how valuable such a person would be to helping our state gain awareness, work on prevention, and provide some sort of help to the families that are living and breathing FASD in their everyday lives. Currently there is no coordinated effort what so ever to bring all of the various entities together to coordinate services in this regards. The statistics in Hawaii are not good concerning drinking during pregnancy and this problem crosses all economic spheres. Furthermore there are huge economic consequences to our society by not dealing more effectively with the preventable problem.

One of the main reasons that I founded this nonprofit is that I knew if I waited for the State to do something it would take years to make progress and those that are living and breathing this cannot afford to wait it out. Our children will outlive us and will need help and supports throughout their entire lives.

Please help us reestablish this critical FASD Coordinator position we cannot afford to wait any longer.. If you need a resource for further information please do not hesitate to contact me.

Respectfully submitted,

Gigi Davidson
President FASD Communities and Parent of Adopted FASD son



February 2, 2015

TESTIMONY: Written Only

To: Senator Suzanne Chun Oakland, HSH Chair
To: Senator Josh Green, HTH Chair
and Members of the Senate Committees on Human Services & Housing and Health

From: Hawaii Public Health Association (HPHA)

Subject: SB 925, Relating to Health

Aloha Chairs Chun Oakland and Green and Members of the Senate Committee on Human Services & Housing and Health,

HPHA is an association of over 600 community members, public health professionals and organizations statewide dedicated to improving public health. HPHA also serves as a voice for public professionals and as a repository for information about public health in the Pacific.

The Hawaii Public Health Association (HPHA) is respectfully submitting testimony in support of SB 925, which would establish one full-time permanent position to serve as a Fetal Alcohol Spectrum Disorder (FASD) coordinator at the Hawaii State Dept. of Health. Fetal Alcohol is an insidious lifelong neurological impairment of the brain that is 100% preventable, if women of childbearing age are aware of the risks of FASD and abstain from drinking at all during pregnancy. Unfortunately, with a 46% unintended pregnancy rate in Hawaii, many women are unaware that they might be pregnant and that if they drink, the risks for FASD are significant for their fetus.

Epidemiology studies carried out by Hawaii's BRFSS and PRAMS monitoring systems indicate that women of child-bearing age are drinking alcohol, including binge-drinking, and are therefore at risk of having an infant with FASD. The DOH Hawaii Pregnancy Risk Assessment and Monitoring System (PRAMS) reported that 6.9% (approximately 1,300 per year) of women who gave birth in Hawaii in 2009-2011 reported that they drank alcohol in the last trimester of their most recent pregnancy. PRAMS also indicated that 1.2% (approximately 200 per year) of women who gave birth in Hawaii in 2009-2011 reported binge drinking in the last trimester of their most recent pregnancy. Binge drinking for women is defined as drinking 4 or more alcoholic drinks in one sitting. Hawaii has not had strong data collection on the numbers of newly-diagnosed FASD cases in Hawaii, and lacks a comprehensive data collection, screening, diagnosis's and services system. It is difficult to estimate the number of persons affected by FASD in Hawaii. Because there is no dedicated and centralized location for coordination of FASD, it remains highly problematic for children and adults with FASD to receive diagnosis and appropriate services. As a result, the state is paying more for direct and indirect services that these people require. An FASD coordinator, which was present in the Hawaii DOH from 2008-2013 when the position was abolished, would serve as an organizing and information gathering point, as well as assist with efforts to plan and implement a coordinated system of care for persons with FASD.

The HPHA supports this bill, which seeks to reestablish a point of contact and responsibility for FASD in Hawaii, including prevention efforts. Without a dedicate position, it is unlikely that the state can move forward to adequately address this growing public health concern.

Respectfully submitted,

A handwritten signature in dark ink, appearing to read 'Holly Kessler', is written over a faint, larger version of the same signature.

Holly Kessler, Executive Director
Hawaii Public Health Association

Feb. 1, 2015

As the mother of 2 girls with Fetal Alcohol Spectrum Disorders (FASD) I urge you to pass SB925.

Our family has suffered because the State of Hawaii has not taken responsibility for FASD. With no one to help us navigate the system, I spend hundreds of hours each year trying to find the best mix and fit of services that can help my daughters live productive lives. I say "trying" because what they really need does not exist.

Hawaii lacks expertise in FASD. We lack in the areas of identification of individuals with an FASD, treatment of individuals with an FASD, and general acceptance and support for individuals with an FASD and their families.

Without appropriate supports, people with an FASD often end up homeless, addicted, incarcerated, or dead.

I do not want this to happen to my daughters.

Every aspect of my life has changed since adopting these girls - one of them 15 years ago and the other 12 years ago. I have had to change employment because of their unique needs. Our involvement in the community is restricted because of their needs. Our family life is more isolated because of their needs. I have recently had to step down as the Chair of the Hawaii FASD Task Force after 10 years because my girls' needs have become more complex as they have grown older. The lives of our 3 older children and younger child have changed as they plan their todays and tomorrows with their sisters' needs in mind. Date nights with my husband of 39 years are fewer and farther between because of the girls' needs.

Please support HB925. My girls and our family deserve better.

Ginny Wright
46-316 Kauhaa Place
Kaneohe, HI 96744.

February 2, 2015

RE: SB925

Honorable Senators:

I am submitting testimony in support of SB925 that seeks funding to establish one full-time position in the Department of Health to assist families of people with Fetal Alcohol Spectrum Disorders.

I speak on behalf of friends, adoptive parents of FASD children. Through courage, commitment, love and faith, they have elevated their daughters beyond medical prognosis; however, their challenges and struggles are ever ongoing and never ending. One daughter suffers from a seizure disorder, a result of FASD. She is now at maximum pharmaceutical treatment with minimal results, and her parents are desperate for answers to help her.

FASD are lifelong and create many challenges for individuals affected and their families. FASD can happen anytime a pregnant woman consumes alcohol. No amount of alcohol consumption is safe during pregnancy. Many women in Hawaii drink while pregnant. Individuals with FASD and their families have nowhere to turn for support, information, training, and assistance.

Many individuals with an FASD end up homeless, addicted, incarcerated or worse because there is no support system for them in Hawaii. Many individuals may go through life without diagnosis.

Funding this one position can give hope to individuals and families who have an FASD but also help identify those who are affected and provide intervention and support early so that they can lead productive lives.

Please give your support in vote for the passage of SB925.

Respectfully submitted,

Kennedyne Sampaio