STATE OF HAWAIʻI
KA MOKUʻĀINA O HAWAIʻI
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
'A'UNIKE MOKU'ĀPUNI NO KA NĀ KĀWAI KULA
1010 RICHARDS STREET, Room 122
HONOLULU, HAWAIʻI 96813
TELEPHONE: (808) 586-8100   FAX: (808) 586-7543

March 20, 2025

The Honorable Representative Justin H. Woodson, Chair
House Committee on Education
The Honorable Representative Andrew Takuya Garrett, Chair
House Committee on Higher Education
The Thirty-Third Legislature
State Capitol
State of Hawaiʻi
Honolulu, Hawaiʻi 96813

Dear Representative Marten and Representative Garrett, and Committee Members:

SUBJECT: HCR145/HR139 URGING THE DEPARTMENT OF EDUCATION, DEPARTMENT OF HEALTH, AND OTHER RELEVANT STAKEHOLDERS TO COLLABORATE AND DEVELOP A STRATEGIC PLAN TO PREPARE FOR HAWAII'S PURSUIT OF FUNDING FOR AND PARTICIPATION IN THE CENTERS FOR DISEASE CONTROL AND PREVENTION'S PUBLIC HEALTH SURVEILLANCE FOR ESTIMATING AUTISM PREVALENCE.

The Hawaiʼi State Council on Developmental Disabilities respectfully submits **in support of HCR145/HR139,** which is urging the Department of Education, Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan to prepare for Hawaiʼi's pursuit of funding for and participation in the centers for disease control and preventions' public health surveillance for estimating autism prevalence.

While the Council acknowledges the importance of tracking autism prevalence, we believe this initiative presents a broader opportunity to update Hawaii's outdated data on the prevalence of all intellectual and developmental disabilities (I/DD). The current prevalence data for I/DD in Hawaii has not been updated in over 20 years, limiting the State's ability to adequately plan services, allocate resources, and support families effectively.

By developing a comprehensive public health surveillance strategy that includes autism and other developmental disabilities, Hawaii can ensure accurate, data-driven decision-making that meets the diverse needs of its residents. Such an approach will improve service delivery and strengthen partnerships across agencies to address the unique challenges individuals with I/DD statewide face.

We appreciate the opportunity to provide testimony in **support of HCR145/HR139**.

Sincerely,

Daintry Bartoldus

Daintry Bartoldus
Executive Administrator

BAYADA®

WE LOVE WHAT WE DO

Committee on Education
Rep. Justin Woodson, Chair
Rep. Trish La Chica, Vice Chair

Committee on Higher Education
Rep. Andrew Takuya Garrett, Chair
Rep. Terez Amato, Vice Chair

Thursday, March 20, 2025
2:00 PM
VIA VIDEOCONFERENCE
Conference Room 309
State Capitol
415 South Beretania Street

SUPPORT HCR145/HR139 RELATING TO THE STATE BUDGET

Honorable Chairs, Vice Chairs, and Members of the Committees:

Mahalo for the opportunity to submit testimony in support of the resolution urging the Department of Education, Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan to prepare for Hawaiʻi's pursuit of funding for and participation in the Centers for Disease Control and Prevention's public health surveillance for estimating the autism prevalence.

BAYADA is a not-for-profit service provider committed to serving our community and children with autism across the state.

As a behavioral health service provider, primarily serving individuals with an autism diagnosis, we strongly support efforts to ensure our population in Hawaiʻi is represented in the Centers for Disease Control's autism prevalence studies. With our diverse population, representing numerous families of Native Hawaiian, Pacific Islander, and/or Asian descent it's imperative we work to participate in these surveillance efforts to ensure adequate representation and advancements in understanding of autism.

Mahalo,

Kristen Koba-Burdt, BCBA, LBA, CDP
BAYADA Behavioral Health

HAWAI`I EARLY INTEVENTION COORDINATING COUNCIL (HEICC)

Date: March 19th, 2025

To: Committee on Education
Representative Justin H. Woodson, Chair
Representative Trish La Chica, Vice Chair
and Committee Members

Committee on Higher Education
Representative Andrew Takuya Garrett, Chair
Representative Terez Amato, Vice Chair
and Committee Members

From: Hawai`i Early Intervention Coordinating Council (HEICC)

Re: **HCR 145/ HR 139 Plan for Surveillance of Autism Prevalence**

The Early Intervention Section (EIS) is a federal and state-mandated program that provides services to support the development of infant and toddlers from birth to three years of age. Information and support are also provided to parents to increase their knowledge about how to support their child's development. The Department of Health (DOH) is the lead agency for the implementation of Part C, Individuals with Disabilities Education Act (IDEA) for the State of Hawaii. Within the DOH, EIS is responsible to ensure that Hawaii meets all the requirements and regulations of Part C of IDEA.

The Hawai`i Early Intervention Coordinating Council (HEICC) **strongly supports HCR 145/ HR 139 which requires the** Department of Education, Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan to prepare for Hawaii's pursuit of funding for and participation in the Centers for Disease Control and Prevention's public health surveillance for estimating autism prevalence.

Autism prevalence has increased dramatically, with the Centers for Disease Control and Prevention (CDC) now estimating that one in thirty-six children in the United States is affected, up from one in one hundred forty-nine in 2000. Research suggests that Asians, Native Hawaiians, and other Pacific Islanders have a higher prevalence of autism, with an estimated one in thirty affected, making it crucial for Hawai`i to gather accurate data to address the needs of its communities to inform program designs, workforce requirements, costs and policy changes.

CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network has been the primary source of autism prevalence data in the United States, but Hawai`i has never been included in this national surveillance effort. Creating a state plan for assessing autism prevalence will allow Hawai`i to become part of CDC's network and to be eligible for federal monies to support autism screening, referral and treatment supports. The younger we can diagnose autism, the greater chance our keiki have at developing to their full potential and living independent, happy and successful lives.

Mahalo, on behalf of the Hawai`i Early Intervention Coordinating council (HEICC) for your continued support to improve  the health, safety and well-being of our youngest keiki with significant support needs and their `ohana. We appreciate you supporting **HCR145/ HR139.**

Aloha nui,

Kerrie Urosevich

Kerrie Urosevich, PhD

Chair, Hawai`i Early Intervention Coordinating Council

earlychildhood
ACTION STRATEGY
TAKING ACTION FOR HAWAII'S CHILDREN

Date: March 19th, 2025

To: Committee on Education
Representative Justin H. Woodson, Chair
Representative Trish La Chica, Vice Chair
and Committee Members

Committee on Higher Education
Representative Andrew Takuya Garrett, Chair
Representative Terez Amato, Vice Chair
and Committee Members

From: Early Childhood Action Strategy (ECAS)

Re: **HCR 145/ HR 139 Plan for Surveillance of Autism Prevalence**

Early Childhood Action Strategy (ECAS) is a statewide cross-sector collaborative designed to improve the system of care for Hawai‘i’s youngest children and their families. ECAS partners work to align priorities for children prenatal to age eight, streamline services, maximize resources, and improve programs to support our youngest keiki.

Early Childhood Action Strategy (ECAS) **strongly supports HCR 145/ HR 139 which requires the** Department of Education, Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan to prepare for Hawaii’s pursuit of funding for and participation in the Centers for Disease Control and Prevention’s public health surveillance for estimating autism prevalence.

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Mahalo for your continued support to improve the health, safety and well-being of our youngest keiki with significant support needs and their `ohana. We appreciate you supporting **HCR145/ HR139.**

Mahalo Nui Loa,

Jonathan R. Alexander, MSW

Hawaii Comprehensive System of Personnel Development Coordinator (CSPD), ECAS

HR-139
Submitted on: 3/19/2025 12:40:04 PM
Testimony for EDN on 3/20/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Dr. Marija Colic	Hawai'i Association for Behavior Analysis	Support	Written Testimony Only

Comments:

Dear chair, vice chair, and committee members,

Understanding the prevalence of autism in Hawaiʻi is critical to ensuring that children and families receive the services they need. Without accurate data, it is difficult to allocate resources effectively, develop evidence-based policies, and plan for future service demands. Public health surveillance, such as the Centers for Disease Control and Prevention’s (CDC) autism prevalence estimation efforts, provides essential data that can guide decision-making and improve outcomes for individuals with autism.

I strongly urge the Department of Education, the Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan for Hawaiʻi’s participation in this public health initiative. By securing funding and implementing a robust surveillance system, Hawaiʻi can better understand the scope of autism within the state, advocate for necessary supports, and enhance service delivery for children and families. Investing in autism prevalence research is not just about numbers—it is about ensuring access to high-quality education, healthcare, and community resources that allow individuals with autism to thrive.

Now is the time for Hawaiʻi to take action and prioritize this effort. Collaboration among agencies is essential to securing the resources needed to support individuals with autism and their families effectively. I urge stakeholders to move forward in preparing for Hawaiʻi’s pursuit of CDC funding and participation in this critical public health initiative.

Dr. Marija Čolić, BCBA

Hawai'i Association for Behavior Analysis

HR-139
Submitted on: 3/18/2025 11:23:02 PM
Testimony for EDN on 3/20/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
M. Leilani DeMello	Individual	Support	Written Testimony Only

Comments:

Aloha,

I SUPPORT this bill.

Mahalo,

M. Leilani DeMello

‘Ōla‘a, Puna, Hawai‘i

HR-139
Submitted on: 3/19/2025 10:15:31 AM
Testimony for EDN on 3/20/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Kaitlin Preciado	Individual	Support	Written Testimony Only

Comments:

I am writing in strong support of HCR145 because accurate autism data in Hawaiʻi is long overdue. Right now, we rely on national estimates that don’t reflect the unique needs of our communities, making it harder to advocate for the right funding, services, and policies. Families already face challenges accessing timely evaluations and support, and without real data, we’re left guessing where resources are needed most. By participating in the CDC’s Autism Surveillance Program, Hawaiʻi can better identify children earlier, secure more funding, and ensure schools and providers have what they need to serve our keiki. This resolution is a chance to take a proactive, informed approach to autism care in our state. I urge you to support HCR145 and help build a future where every child gets the support they deserve.

HR-139
Submitted on: 3/19/2025 1:44:08 PM
Testimony for EDN on 3/20/2025 2:00:00 PM

Submitted By	Organization	Testifier Position	Testify
Jessica McCullum	Individual	Support	Remotely Via Zoom

Comments:

Mahalo all for your time today. I'd like to share personal testimony that when my daughter, Ava, was first diagnosed around the age of 4 with Profound Autism, the prevalence rate per the CDC was 1 in 54 children (2017). It took my family 8 years of my daughter's life to eventually establish services outside of the DOE for Ava. Today the prevalence rate for autism is 1 in 36 children and this is per the CDC data of the 2020 surveillance year - so pre-COVID numbers. Furthermore, 1 in 6 children have been diagnosed with a developmental disability per the CDC.

It is necessary that the children that represent the populations of Asian, Native Hawaiian, and other Pacific Islander, adequately reflect the people of Hawai'i and the variety of those very people that are most prominent in our state. If it has been determined that these populations have been the most prevalent and profoundly impacted despite having adequate representation and data within our State, then the future of research in autism must exist in our home especially given the extreme adversities and economic disparities that exist within our remote location.

Our 501(c)(3) nonprofit the Ava Sofia Foundation DBA Autism Moms of Kona started as a small grassroots organization that was born out of an extreme need for support as a caregiver that lacked adequate support in the community and that experienced endless waitlists when it came to service provision. Our motto is WE are Special Needs, and we believed that the entire family needed specialized support so that families raising a child with developmental delays or disabilities could thrive in the home with the proper education, establishment of services, support and resources. By doing so, this thereby encouraged families to gain the courage to integrate into a community that was also educated on autism acceptance. We work together with community partners and parents to teach people what autism is, and then we curate immersive and engaging experiences that are accommodating to people with any ability. Our efforts have been therapeutic not only for the individuals with disabilities, but also for those who participate whether family member or volunteer. We believe very strongly in supporting all involved in raising a child with autism, not only the family but also the educators and service providers that work with these individuals on a daily basis. I've attached a visual year in review and here is our instagram to give you a better idea of our work in action: https://www.instagram.com/autismmomsofkona/

I believe our organizational culture founded on Hawaiian cultural values - Kuleana, Hoʻokipa, and Aloha - has brought much healing and hope to many who would have otherwise struggled with this silent disability in shame and isolation (shared in the news). I believe our efforts have sparked momentum and an eagerness to participate in progress for our autism community, which has been augmented & expounded through our recent partnership with Vanderbilt. Because of the increased education and awareness brought by Vanderbilt University in 2023, my ‘ohana was able to obtain official diagnoses and gold standard assessments and recommendations for all 3 of my children. I learned the diversity of the autism spectrum and how to support each individual profile, compared to my limited knowledge of the autism spectrum through my lived experience of raising Ava who is a non-verbal 11 year old with a profound disability. Most importantly, I felt informed and supported which empowered me to to fiercely advocate for my children‘s needs, while also reaffirming my dedication as a mother and enhancing my parent engagement & involvement with confidence.

In closing, too much time, exertion of energy and financial resources are forfeited through inadequate measures of early identification of autism, and we need to do better. By improving outcomes for our children, we are improving outcomes for thriving families and systems that are under immense economic pressure, and in turn alleviating the overall liability that people with disabilities present to the government in the long term. As a mother, I learned that an autism diagnosis is not a catastrophic one though it can be devastating with a fear of the unknown. To me, the increased prevalence not only gives us a better understanding of the breadth and the scope of the challenges that our keiki face in the current landscape, but it also gives us an opportunity to identify adequate, efficient and impactful supports and to increase the resources and strategic reinforcements of systems necessary for all of our shared outcomes - our future generation and our beloved keiki.

Ava has struggled for years with her disability and she has not been able to access the full extent of her potential until recently. Even we as her loving parents took a while to presume competence because she is non-speaking and had other challenges that presented barriers for her interactions.

Ava used to be a child that was subject to the waiting game of:

- Age 18 months - early intervention (8 months until her pediatrician agreed to refer her to early intervention, and another 6 months for assessments & processing)
- Age 4 years - an official diagnosis (an additional 2 years to complete with no proper assessments, only a 30 minute doctor‘s appointment with a neurologist)
- Age 8 years - therapeutic interventions in home (another 4 years to wait for ABA therapists and Occupational Therapists to become available, especially due to a relocation),
- Age 10 years - approval for DDD waiver services after a year-long application process
- Age 11 years - securing a Direct Support Worker through DDD (despite approval) due to worker shortage ($17/hr)

We struggled in isolation for years. The hardest for me were ages 4-5 when she was poop smearing on a daily basis, grabbing her sensory defecation due to her sensory-seeking behaviors, and smearing it across walls, carpets and sheets. I felt like I was drowning in poop and despair. At age 6-7, her elopement (darting off) increased and she would escape our home in

Kona, trying to run to the ocean as often as she could - crossing busy streets and entering strangers homes at odd hours of the day.

ABA intervention and Occupational Therapy has changed our lives. ABA assisted us with these detrimental behaviors and OT helped us to alleviate Ava‘s basic "fight or flight" instincts due to her unmet sensory needs. We still do not have a Speech & Language Pathologist to guide us with functional communication for a non-speaking individual with an AAC device, but Ava‘s support team in the school and in home work really hard to troubleshoot different modes of communication to assist Ava with communicating her basic needs. If we had had this sooner, which has been demonstrated with my younger 2 children also on the autism spectrum, she could have had her needs met a lot sooner and her struggle (and ours) would have delivered us a different story. Sometimes I despair, witnessing the trajectory of other parents‘ stories and their shared achievements in celebrating career success and advancement in life. But I am reminded that this is our kuleana and I am forever grateful for our journey - we get to share our story to better the lives of others with disabilities. Our simple struggle to access our basic needs and acknowledgement in life - it has enriched our being and a life of service is an ultimate blessing.

Furthermore, the hard work and dedication not only from Ava‘s home support workers, but her IEP team in the schools, has resulted in a successful inclusionary model where she has been moved to an SFA classroom where she can access grade level content with grade level peers and accommodation through Teach Town. She went from meltdowns after 2 minutes, to a level of dignity and intrigue where she now attends with her peers from 20-30 minutes and is exposed to curriculum and content despite being able to speak and maintain eye contact and other socially acceptable behaviors.

Today was a great one for us, but for a girl who at the very core of her being was unable to exist with ease, to now be at a place where she can complete an alt assessment for 3 hours and be *excited* about it? That‘s success if I ever heard of it, and we will continue to commit to increasing education and resources to achieve these outcomes for other families struggling in our community.