JOSH GREEN, M.D. GOVERNOR

KEITH T. HAYASHI SUPERINTENDENT

STATE OF HAWAI'I DEPARTMENT OF EDUCATION KA 'OIHANA HO'ONA'AUAO P.O. BOX 2360 HONOLULU, HAWAI'I 96804

> Date: 04/02/2025 Time: 10:30 AM Location: 329 VIA VIDEOCONFERENCE Committee: House Health

**Department:** Education

Person Testifying: Keith T. Hayashi, Superintendent of Education

**Resolution Title:** HCR 0145 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.

#### **Department's Position:**

The Hawai'i State Department of Education (Department) supports HCR 145, which urges the Department, the Department of Health, and other stakeholders to collaborate in developing a strategic plan for Hawai'i's participation in the Centers for Disease Control and Prevention's (CDC) public health surveillance for estimating autism prevalence.

The prevalence of autism has increased drastically over the past decade, underscoring the importance of understanding the scope of autism in Hawai'i. Accurate, data-driven insights are essential for informing policies and programs that support these students and their families. As noted in the resolution, the CDC's Autism and Developmental Disabilities Monitoring Network provides valuable data on autism prevalence, yet Hawai'i has not been included in this national effort. Participation in this initiative would enable the state to better assess the needs of its diverse communities and strengthen support services.

By working collaboratively to establish a surveillance framework, Hawai'i will be better positioned to pursue future federal funding opportunities, particularly through the Autism Collaboration, Accountability, Research, Education, and Support (Autism CARES) Act. Additionally, improving autism data collection and analysis can inform workforce development strategies, addressing the state's critical shortages in special educators, early intervention providers, and allied health professionals.

The Department welcomes the opportunity to contribute to these efforts and remains committed to ensuring students with autism receive the resources and services needed for their success.

Thank you for the opportunity to provide testimony on this resolution.



#### STATE OF HAWAI'I KA MOKU'ĀINA O HAWAI'I STATE COUNCIL ON DEVELOPMENTAL DISABILITIES 'A'UNIKE MOKU'ĀPUNI NO KA NĀ KĀWAI KULA PRINCESS VICTORIA KAMĀMALU BUILDING 1010 RICHARDS STREET, Room 122 HONOLULU, HAWAI'I 96813 TELEPHONE: (808) 586-8100 FAX: (808) 586-7543

April 2, 2025

The Honorable Representative Gregg Takayama, Chair House Committee on Health The Thirty-Third Legislature State Capitol State of Hawai'i Honolulu, Hawai'i 96813

Dear Representative Takayama, 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 Hawai'i 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 Hawai'i'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,

Einty Bartillie

Daintry Bartoldus Executive Administrator

Submitted on: 3/29/2025 8:48:26 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
jessica dias	Free Citizens of Maunalua	Support	Written Testimony Only

Comments:

I SUPPORT this Resolution to finally get more information about the possibility that these injections cause autism in children. In the meantime, there should be NO effort or funding to push for these interventions until they are PROVEN to be NOT risky.



March 30, 2025

**To:** Chair Gregg Takayama, Vice Chair Sue L. Keohokapu-Lee Loy, and Members of the Committee on Health

From: Health Committee

Re: Testimony in Support of HCR 145 / HR 139 - Estimating Autism Prevalence

Date: Wednesday, April 2, 2025, Time: 10:30 AM

**Place**: VIA VIDEOCONFERENCE, Conference Room 329, State Capitol, 415 South Beretania Street

Aloha Chair Takayama, Vice Chair Keohokapu-Lee Loy, and Members of the Committee,

The Health Committee of the Democratic Party of Hawaii is in support of HCR 145 / HR 139, which urges the Department of Education, Department of Health, and other relevant stakeholders to collaborate and develop a strategic plan to prepare Hawaii for pursuing funding and participation in the Centers for Disease Control and Prevention's Public Health Surveillance program for estimating autism prevalence. This resolution is a vital step toward understanding autism prevalence in Hawaii and addressing the needs of individuals and families affected by Autism Spectrum Disorder (ASD).

- Importance of Autism Spectrum Disorder Data:
  - Autism impacts communities across Hawaii, with the CDC reporting that approximately 1 in 36 children in the United States are diagnosed with ASD.
  - Reliable data is critical for shaping effective policies, improving early diagnoses, and developing support systems for individuals with ASD and their families.

### • Benefits of Public Health Surveillance:

• Participation in the CDC's surveillance program will provide Hawaii with access to essential data on autism prevalence.

- Enhanced data collection empowers policymakers to make informed decisions and allocate resources effectively to address community needs.
- Advocacy for Collaboration:
  - Collaboration among the Department of Education, Department of Health, and other relevant stakeholders is crucial to developing a comprehensive strategic plan.
  - A unified approach maximizes Hawaii's ability to secure funding and resources for this initiative.

#### • Positive Impact on Communities:

- Strengthened public health infrastructure ensures individuals with autism and their families receive the care and resources they need to thrive.
- Inclusive and informed decision-making benefits all residents and fosters a stronger, more supportive community.

Thank you for the opportunity to testify on this important resolution. Passing HCR 145 / HR 139 demonstrates Hawaii's commitment to understanding autism prevalence and enhancing public health services. Together, we can work toward a future where every individual affected by autism is supported and empowered to achieve their fullest potential.

Mahalo nui loa,

Alan Burdick, Chair, Health Committee Melodie Aduja, Vice Chair, Health Committee



WE LOVE WHAT WE DO

Committee on Health Rep. Gregg Takayama, Chair Rep. Sue L. Keohokapu-Lee Loy, Vice Chair

> Wednesday, April 2, 2025 10:30 AM VIA VIDEOCONFERENCE Conference Room 329 State Capitol 415 South Beretania Street

#### SUPPORT HCR145/HR139 ESTIMATING AUTISM PREVELANCE

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 Hawai'i'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 Hawai'i 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



Date: April 2, 2025

To: Committee on Health & Homelessness Representative Della Au Belatti, Chair Representative Jenna Takenouchi, 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.

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 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

Early Childhood Action Strategy is a project under Collaborative Support Services, INC.

Submitted on: 3/31/2025 6:49:23 PM Testimony for HLT on 4/2/2025 10:30:00 AM

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

Comments:

#### Dear Chair, Vice Chair, and Committee Members of the Health Committee,

Understanding the prevalence of autism in Hawai'i is essential for ensuring that children and families receive the services they need. Without accurate data, it becomes challenging to allocate resources effectively, develop evidence-based policies, and plan for future service demands. Public health surveillance efforts, such as the **Centers for Disease Control and Prevention's** (**CDC**) **autism prevalence estimation initiative**, provide vital data that can inform decision-making and improve outcomes for individuals with autism.

I strongly encourage the Department of Education, the Department of Health, and other key stakeholders to collaborate in developing a strategic plan for Hawai'i's participation in this public health initiative. By securing funding and establishing a **comprehensive surveillance system**, Hawai'i can gain a clearer understanding of autism prevalence in the state, advocate for essential supports, and strengthen service delivery for children and families. **Investing in autism prevalence research goes beyond data collection**—it is about ensuring access to high-quality education, healthcare, and community resources that empower individuals with autism to thrive.

Now is the time for Hawai'i to take action and prioritize this effort. Cross-agency collaboration is crucial to securing the necessary resources and infrastructure to support individuals with autism and their families effectively. I urge stakeholders to take the necessary steps to position Hawai'i for CDC funding and participation in this critical public health initiative.

Dr. Marija Čolić, BCBA, LBA Hawaiʻi Association for Behavior Analysis

Submitted on: 3/31/2025 7:39:01 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Crystal Nelson	Pakolea Support Services	Support	Written Testimony Only

Comments:

#### HCR-145

Submitted on: 3/31/2025 8:24:32 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
christina libby	Mau Loa Learning LLC	Support	Written Testimony Only

Comments:

Submitted on: 4/1/2025 9:08:25 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
James Kilgore	Full Life	Support	Written Testimony Only

Comments:

Aloha Chair Takayama, Vice Chair Keohokapu-Lee Loy, and members of the Committee on Health:

My name is Jim Kilgore and I am the Executive Director at Full Life, a non-profit organization serving people with intellectual and developmental disabilities on Hawai'i Island.

We strongly support HCR145, which urges the DOE, DOH, and other stakeholders to collaborate and develop a strategic plan to prepare for Hawai'is pursuit of Funding for and participation in the CDC public health surveillance for estimating autism prevalence.

This opportunity will lead to a better understanding of autism prevalence in Hawai'i and will lead to enhanced autism screening. Accurate data and screening will result in greater advocacy for the necessary services for children with autism and their families.

Mahalo for the opportunity to testify in support of HCR145.

### HCR-145

Submitted on: 4/1/2025 2:38:06 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Crystal Thomas	Balanced ABA	Support	Written Testimony Only

Comments:

#### HCR-145 Submitted on: 3/31/2025 7:02:26 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kaitlin Preciado	Individual	Support	Written Testimony Only

Comments:

Aloha Chair and Committee Members,

I am writing in strong support of H.C.R. 145, urging the Department of Education and Department of Health to develop a strategic plan for Hawai'i's participation in the Centers for Disease Control and Prevention's (CDC) autism prevalence surveillance efforts.

As a behavior analyst who has worked closely with individuals on the autism spectrum across the state, and as the current CEO of an organization that provides daily support services, I can speak firsthand to the urgent need for accurate, state-specific data. Hawai'i's exclusion from the CDC's monitoring network has created a longstanding gap in our understanding of autism prevalence within our own diverse and unique communities.

Reliable data drives funding, shapes programming, and ensures that critical services are both accessible and appropriately tailored to those we serve. Without this foundation, we risk falling behind in meeting the needs of our keiki and their families. With new opportunities through the Autism CARES Act, now is the time for Hawai'i to take deliberate and meaningful action.

Participation in this initiative is not simply about statistics—it's about ensuring that every child has the opportunity to thrive, and that our systems are informed, proactive, and inclusive.

Mahalo for your consideration and commitment to children and families across Hawai'i.

Submitted on: 3/31/2025 7:10:06 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kendra Bean	Individual	Support	Written Testimony Only

Comments:

Submitted on: 3/31/2025 7:19:44 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Melissa Kramer	Individual	Support	Written Testimony Only

Comments:

#### Aloha,

I am a BCBA, mother of a child with Autism, and former Special Education Teacher. So many years were missed before iautism was covered under insurance where my child could have had more intensive treatment in addition to my support during his developmental years. At that time, treatment was costly to my posketbook as well as to my other children.

I strongly support H.C.R. 145 as it is crucial for Hawai'i to participate in the CDC's autism prevalence monitoring to better understand the needs of our diverse communities and ensure appropriate services and resources are allocated for children with autism.

Mahalo,

Melissa H Kramer

Submitted on: 3/31/2025 7:25:44 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Shaianne Kealoha	Individual	Support	Written Testimony Only

Comments:

Submitted on: 3/31/2025 7:37:09 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Siyuan Wang	Individual	Support	Written Testimony Only

Comments:

Submitted on: 3/31/2025 7:59:16 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Amanda Martin	Individual	Support	Written Testimony Only

Comments:

# HCR-145

Submitted on: 3/31/2025 8:40:51 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Jessie Mitchell	Individual	Support	Written Testimony Only

Comments:

I strongly support H.C.R. 145 as it is crucial for Hawai'i to participate in the CDC's autism prevalence monitoring to better understand the needs of our diverse communities and ensure appropriate services and resources are allocated for children with autism.

Jessie Mitchell, MA, LBA, LMHC

Submitted on: 3/31/2025 9:16:00 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Stanley Bloom	Individual	Support	Written Testimony Only

Comments:

Submitted on: 3/31/2025 9:25:50 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kimberlynne Galapon	Individual	Support	Written Testimony Only

Comments:

#### HCR-145 Submitted on: 3/31/2025 9:25:55 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Naomi Tachera	Individual	Support	Written Testimony Only

Comments:

Aloha Chair, Vice Chair, and Members of the Committee,

My name is Naomi Tachera, and I am submitting testimony in strong support of House Concurrent Resolution 145.

As both a parent of children with autism and a special education teacher, I know firsthand the importance of understanding autism prevalence in our state. Hawai'i's participation in the CDC's autism prevalence monitoring is not just data collection—it's about visibility, equity, and informed action for our keiki and their 'ohana.

Our communities are diverse, and our needs are equally unique. Without accurate, up-to-date information on autism rates in Hawai'i, we risk falling short in providing appropriate services, supports, and resources to those who need them most.

Mahalo for your time and consideration,

Naomi Tachera

# HCR-145

Submitted on: 3/31/2025 9:29:04 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Dodi Pritchett	Individual	Support	Written Testimony Only

Comments:

Without data, we cannot know how to support our families. It's important that our unique needs be recognized and prioritized.

Submitted on: 3/31/2025 9:59:56 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Jessica Noochan	Individual	Support	Written Testimony Only

Comments:

Submitted on: 3/31/2025 10:17:41 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Valerie Clack	Individual	Support	Written Testimony Only

Comments:

#### HCR-145

Submitted on: 3/31/2025 11:21:37 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Shanda Strickland	Individual	Support	Written Testimony Only

Comments:

Aloha,

I am in support of H.C.R. 145. I belive it to be necessary to ensure a thorough understanding of the needs pertinent to those who need services and aid in the allocation of resources for children with autism.

Mahalo,

Submitted on: 4/1/2025 2:23:24 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Carla T Schmidt	Individual	Support	Written Testimony Only

Comments:

Submitted on: 4/1/2025 7:06:43 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Amanda Lipinski	Individual	Support	Written Testimony Only

Comments:

I strongly support H.C.R. 145 as it is crucial for Hawai'i to participate in the CDC's autism prevalence monitoring to better understand the needs of our diverse communities and ensure appropriate services and resources are allocated for children with autism. I believe having this monitoring system available would allow for a better understanding of who and how we can support autistic individuals.

Submitted on: 4/1/2025 7:19:54 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Sara Dinkelo	Individual	Support	Written Testimony Only

Comments:

Aloha Legislatures and committee chairs;

My name is Sara Dinkelo and I have been a practicing BCBA for almost 10 years and working actively in the field supporting people affected by autism for close to 20 years. I am writing to you in strong support of HCR145 to participate in the CDC's prevalance study.

I see individuals impacted by funding by insurance providers as well as in the school. We need to be included in this important study as funding streams are monitoring the results of these studies closely. In order to continue to move towards building sustianable services for individuals affected by autism in the state of Hawai'i, having this information will be critical for not only knowing how the people of Hawai'i are impacted by autism, but to also secure funding for needed services.

Representation matters here; it is important for Hawai'i to be represented in this study to ensure future funding. Additionally, peer reviewed journals will cite the report presented by CDC and could be helpful in ensuring that Hawai'i is included in future research studies in developing vital evidenced based strategies for people affected by autism.

I implore the committee to puruse participation in the CDC's study on the prevalance of autism in Hawai'i. My testimony is in strong support of HCR145.

Sincerely,

Sara Dinkelo, M.S., BCBA, LBA

#### HCR-145 Submitted on: 4/1/2025 8:15:12 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Felicia Linton	Individual	Support	Written Testimony Only

Comments:

I support this bill as long as it does not place additional requirements for the DOE for monitoring. DOE already has systems to provide data needed.

Our state has a lack of facitilies to educate our more intensive support needs youth and could benefit from more facilites.

As a member of the DOE and in my current role I have become increasing more aware of the lack of facilities for our moderate to intensive needs ASD individuals to live more independently. There are few homes or facilities for this population to live outside of their family homes. We need an increase in homes for this group.

In order to determine the growing needs we need a way to better monitor and track this population and this bill is a step in that direction. This bill will better help our state determine current needs and plan ahead for future needs.

Submitted on: 4/1/2025 8:38:32 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Emily Lethlean	Individual	Support	Written Testimony Only

Comments:

I strongly support H.C.R. 145 as it is crucial for Hawai'i to participate in the CDC's autism prevalence monitoring to better understand the needs of our diverse communities and ensure appropriate services and resources are allocated for children with autism. The ratio of kids being diagnosed is growing and currently at 1 in 36 children.

In Service,

Emily Lethlean

Autism Consultant Teacher

HIDOE HKKK

# HCR-145

Submitted on: 4/1/2025 8:44:28 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Melissa Dixon- Pennington	Individual	Support	Written Testimony Only

Comments:

Submitted on: 4/1/2025 9:40:32 AM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Gesine Dommer	DOE	Support	Written Testimony Only

Comments:

I support HCR145 because it represents a vital step toward understanding and addressing autism in Hawaii. By participating in the CDC's surveillance program, we can gather much-needed data on autism trends, disparities, and service gaps across our diverse communities. This information is essential for creating targeted interventions, improving access to resources, and ensuring families across the state receive the support they need.

#### HCR-145 Submitted on: 3/19/2025 1:44:08 PM Testimony for EDN on 3/20/2025 2:00:00 PM

Submitted By	Organization	<b>Testifier Position</b>	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 <u>1 in 54 children (2017)</u>. 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, <u>1 in 6 children</u> have been diagnosed with a developmental disability per the CDC.

It is necessary that the children that represent the populations of <u>Asian, Native Hawaiian, and</u> <u>other Pacific Islander</u>, 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 - <u>Kuleana, Ho'okipa,</u> <u>and Aloha</u> - has brought much healing and hope to many who would have otherwise struggled with this silent disability in shame and isolation <u>(shared in the news)</u>. 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.

#### HCR-145

Submitted on: 4/1/2025 2:16:10 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Natasha Bailey	Individual	Support	Written Testimony Only

Comments:

As an autism provider in the DOE, we have very many students with autism or who have similar topographies of symptoms perhaps due to COVID restrictions, poverty, etc.

Submitted on: 4/1/2025 2:24:35 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Kristin Le	Individual	Support	Written Testimony Only

Comments:

Submitted on: 4/1/2025 6:43:19 PM Testimony for HLT on 4/2/2025 10:30:00 AM

Submitted By	Organization	<b>Testifier Position</b>	Testify
Sho Araiba	Individual	Support	Written Testimony Only

Comments: