

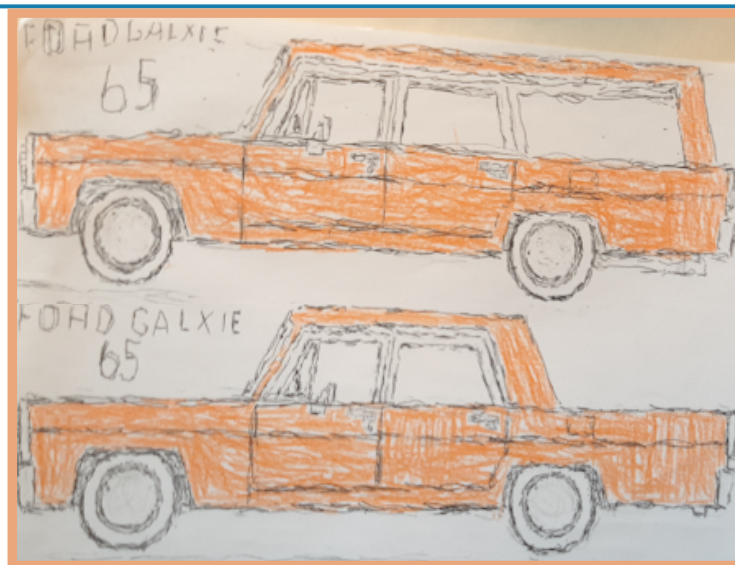
Promoting Diverse Abilities Across the Lifespan



Director's Corner

Welcome to the June 2022 issue of the CDS eNewsletter. Special highlights in this issue include:

- Artist Eben Hooy
- Congratulating Dr. Conway Retirement
- Ready to Work Celebration
- UCEDD Trainees Advocacy in Action
- Opt-Ed: *Addressing the Second Disability Services Cliff*, Oshiro and Kato
- Employment First Bill News with APSE Hawai'i
- Opt-Ed: The Power of the Neurodiverse, Nichols
- Swim Safe ASD Facts and Findings, Dr. Murphy
- Schedule "Worry Time," Mental Wellness Corner, Dr. Matheis
- 44 STEM Fields Inspiring Hōkūlani Scholars, Dr. Park
- SPIN Seminar Announcement: June 9th, 1-2 pm
- Survey Participants: Teens with special health care needs in Hawai'i



Ford Galaxie 65 (2022) Hooy, Kula, Hawai'i

Interested in being included in the next newsletter? Submit a request by the fourth Friday of each month at <http://go.hawaii.edu/JBJ>.



Photo of Kiriko

Dr. Kiriko Takahashi
Center on Disability Studies Director

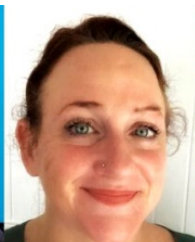
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Mahalo! Dr. Conway Retires after 21 Years



Parent Support | CSC Opt-Eds and Events



WE WANT TO HEAR FROM YOU!



Win a \$20 gift card!—Teens Survey

FOLLOW US



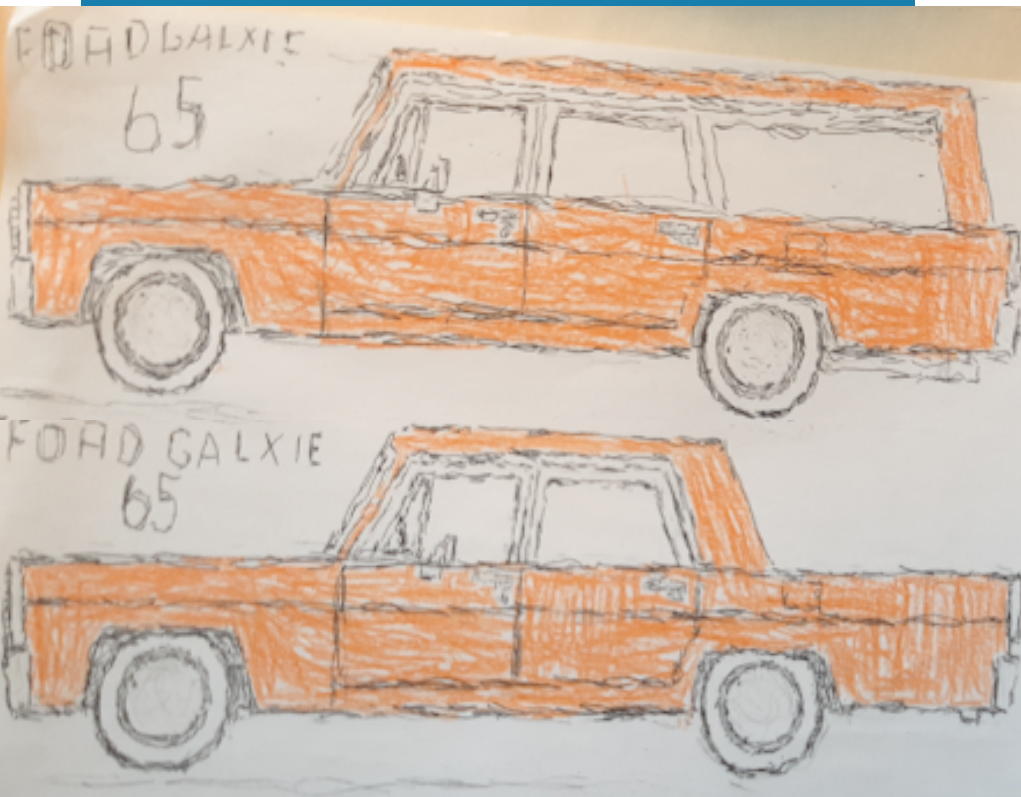
Artist Eben Hooey



Eben Hooey is an Autistic artist who has lived in Maui since 1988. He works on his drawings of vehicles and toy vehicles everyday. He likes to enlarge his works using a photocopy machine and then "puzzle-piecing" the various pieces back together with tape and scissors, creating the finished work. He works in pencil, ballpoint pen, crayon, markers and white-out pens.



*Make Art,
Change Lives!*



Ford Galaxie 65

Ford Galaxie 65 (2022) Hooey, Kula, Hawai'i
Description: A pencil and marker sketch of an orange 1965 Ford Galaxie car and station wagon.



Annie Moriyasu,
Make Art, Change Lives! Founder
amoriyas@hawaii.edu

Follow MACL



"He loves vehicles of all kinds and loves to draw them. He has been known to draw detailed pictures of trucks using the rear vision to view them as he is driven around."

—Maui News, March 2019

Mahalo Nui Loa and Congratulations!

Dr. Thomas Conway

Director of Instruction and Training

Congratulations, Tom, on your retirement from CDS-UHM!!! Believe it or not, Tom Conway was the original MEDIA CENTER Director for the Center on Disability Studies. Back in the day, he was charged with running a staff with responsibility to publish books, journals, curriculums (making print copies hot off the press), as well as producing videos, developing web sites, and about anything else requested. He did the job of keeping many balls in the air at one time – now Tom you can settle in with one job – retirement – well done.

—Dr. Robert Stodden



Description: Photo collage of five photos of CDS activities with Dr. Conway.

We wish to join Bob Stodden on behalf of the many colleagues (at CDS and beyond) and students that Tom Conway has impacted in his 21 years of service, in congratulating Tom on his retirement! —With his commitment integrity and Aloha Tom has contributed to the UHM community in many ways. This has included serving as Accessible Digital Content Trainer, Inclusive Online Instructional Designer, Audio Description Instructor, Director of Instruction and Training at CDS, Virtual Environment Trainer, a founding member of the international journal *Review of Disability Studies*, Conference Co-chair of the 2022 Pacific Rim Conference, service to the Mānoa Senate, and also supporting numerous outreach efforts with strategic partners. He will be missed, and we wish him all the best on his next adventures!

Ready to Work End-of-Year Celebration



On May 25, Waipahu High School's signature Ready to Work program celebrated its end of year Celebration. UH-CDS was one of the partners in this unique program that places students with disabilities with companies in their first jobs. The program is the brainchild of Randy and Alison Higa. About a dozen students who are now employed spoke to the throng and shared their feelings about securing their first jobs. Through the program they learned job soft skills and technical skills.

Interim Director Kiriko Takahashi represented UH CDS as one of the partners for the Ready to Work program. More familiar company names were Dunkin Donuts, Little Caesars, Taco Bell, McDonald's, Lyn's Delicatessen and Hawaiian Building Maintenance, as well as the Departments of Labor and Industrial Relations, Department of Education and 'Ōlelo Media. "Gary Chun and Jared Abreu, Academy Principals, have been incredibly supportive and instrumental in creating a space for the program at the high school," according to Randy Higa.

Now that the Higas have made their proof-of-concept program, they hope to replicate this in other high schools and statewide. randyh1818@gmail.com



Photo Description: Zoom group photo of 10 trainers and attendees.

Our Hawai'i UCEDD Emerging Leaders had a wonderful experience with Advocacy in Action training by Tammy Evrard Consulting. Mahalo to Tammy and self-advocates and lead impact trainers, Bathey Fong and Patrick McGoldrick, for walking us through facilitation and inclusion training for person centered planning.

We are now accepting applications for our next cohort of UCEDD Trainees! Contact:

Dr. Holly Manaseri
CDS Outreach Coordinator
hmanaser@hawaii.edu



Addressing the Second Disability Services Cliff

By Sandra Oshiro

Thousands of neurotypical high school and college students graduated this spring and can now look forward toward a future full of promise and possibilities. It's quite another story for young adults on the autism spectrum.

The scaffolding of services that support high schoolers with disabilities collapses when they reach age 18 or 21, a circumstance commonly called the services cliff. Speech therapy, occupational therapy, counseling, transportation, and other supports are typically no longer available when students leave school.

Some students with disabilities, including those on the spectrum, may move on to college. There they can receive such supports as notetaking and extended test times, but these services are nowhere near those they received in high school.

Then, if the students survive college and receive a degree, a second service cliff emerges: they are out in the world with very few programs to transition them into the workforce. What programs exist generally are closed to anyone over age 24. Without employment, those on the spectrum and with other disabilities must depend on government benefits or the financial support of their parents, many of whom are aging.

— “ —

Speech therapy,
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school.

—

I paint this rather gloomy picture as a parent of a 34-year-old on the spectrum. She has three college degrees. Although she is working part-time, her current pay will not sustain her if her benefits are cut or my husband and I pass away.

Our dream for her is that she have a life like any other adult her age -- a passion for her work, close friends, and years of independence full of meaning, accomplishments, and joy. But here is the reality families like us are facing:



Young adults on the spectrum have the lowest rate of employment compared to their peers with other disabilities.

(National Autism Indicators Report, 2015)



Nearly half of 25-year-olds with autism have never held a paying job.

(Autism Speaks, 2021)



Multiple studies report a large share of youth with autism spectrum disorder remain unemployed, underemployed, or in low-wage jobs through adulthood.

(Mathematica, 2021)

As we mark June 18, Autism Pride Day, it's good to reflect on the ways pride can blossom. One of them is through work, which brings with it self-worth, self-identity, friendships with co-workers, and financial independence.

So while transitioning high schoolers and young adults in their early 20s is important and needed, and government funding is certainly flowing in their direction, we should not forget that autism spectrum disorder is a life-long condition. Older neurodiverse adults need our support, too.

Photo of Sandra Oshiro.

Sandra Oshiro is a freelance journalist. She coordinates the Hawaii Young Adults in Transition support group for families with adults on the autism spectrum and is a member of the UH Center on Disability Studies Community Advisory Council. Reach her at soshiro8@hawaii.edu.

Follow Sandra



Artist Lauren Kato

Students with disabilities lose support services when they leave high school, an occurrence widely known as the services cliff. But then a second cliff occurs after college and as young adults age out of their 20s.



Photo Description: Students with disabilities leaving high school are shown peering over a cliff, representing the first dropoff in support services. A separate group of students look down a second cliff, representing a further decline in services when they leave college and grow older.

Employment First Bill and Formation of APSE Hawai'i Chapter

Exciting news from the Hawai'i State Legislature for the Employment First Bill. In the most recent session, the Hawaii State Legislature - HB1787 HD2 SD2 CD1, which is Public Service; Persons with Disabilities; Employment First received notice of final reading. This bill establishes "employment first" as a policy of the State and Counties. Defines "employment first" as the competitive employment and full inclusion of persons with a disability in an integrated setting as a first and preferred option for employment services. Requires state and county agencies to implement this policy in hiring practices and all programs and services administered or funded by the state or counties. Beginning June 30, 2023, requires the department of human services to apply employment first principles to Medicaid home and community-based services programs. As of May 5, 2022, this bill received notice of passage on final reading in the House and has been transmitted to the Governor.

Employment First means that employment in the general workforce should be the first and preferred option for individuals with disabilities receiving assistance from publicly-funded systems. Employment First means real jobs for real wages. The Association of People Supporting Employment First (APSE) is the only national membership organization focused exclusively on Employment First to facilitate the full inclusion of people with disabilities in the workplace and community. APSE members recognize that everyone has abilities to contribute and their work should be recognized and rewarded with fair pay, creating inclusive workplaces. The Hawai'i APSE Chapter held our first meeting on May 6, 2022. In this meeting, 4 officers were chosen, with Mr. Patrick Gartside being elected President of the Hawai'i APSE Chapter. CDS staff member Jared Galea'i has been elected to serve as the secretary of the Hawai'i APSE Chapter.

Jared Galea'i
Principal Investigator
galeaij@hawaii.edu



The purpose of the Hawai'i APSE Chapter shall be to pursue the following goals within the area represented by its membership:



To assist in the establishment, expansion and refinement of quality employment for individuals with disabilities.



To advocate for social change consistent with the desire of individuals with disabilities.



To support individuals with disabilities in their efforts and rights in education, employment and community living.

The Hawai'i APSE Chapter will hold quarterly meetings on the first Thursday of February, May, August, and November at 1pm. The National APSE conference will be held in Denver, Colorado on June 13-15 2022. Several members of the Hawaii Chapter will be in attendance. The next Hawai'i APSE Chapter meeting will be on the first Thursday of August 2022. If you are interested in becoming a member of the Hawai'i APSE Chapter, please contact:

Mr. Patrick Gartside
Patrick@WorkNowHawaii.org
Call or Text: (808) 202-2310

Square Pegs in a Round Pegged World: The Power of the Neurodiverse

By Meriah Nichols, <https://www.meriahnichols.com>

We are all taught from an early age to conform and to please others. We're taught that if we conform or please others in different ways to make others happy, we'll be happy ourselves. One of the biggest lessons that we consistently learn while growing up is how to behave in such a way that the fewest people possible will disapprove of us. This is so because if we are disapproved of, we will have a harder time in this world.

One problem with this way of being raised is that we'll never please everyone. As soon as we are perfectly conformed to one group, we will be out of conformity with another. As soon as we learn how to please the Democrats, the Republicans will be displeased! If our happiness is hinging on conformity and pleasing others, we will never, ever be happy.

Another problem with this way of living is that if we are always looking outside of ourselves for what is right and for guidance, we will not be looking inside, and it's only when we look inside ourselves that we are able to connect with our personal power.

We give some lip service these days to following our own inner guidance, urging ourselves and others to "be yourself!" and "stay true to you!" All of this is, of course, still conforming, because when we say, "be yourself!" we're really just saying,

"be yourself in a way that makes me feel good and makes others comfortable!"

We're really saying, "be yourself while staying on the path, now!" Because when someone is really themselves and really stays absolutely in tune with themselves (and thus with their inner connection with Source), then watch the freak out happen!

Nowhere better is this exemplified, I think, than with people who are neurodiverse, including people on the Autism spectrum and with Down syndrome.

I am using those two with this because my son is on the spectrum and my daughter has Down syndrome.

Square Pegs in a Round Peg World

I see this all time with them, people loving them until they get “weird,” loving how smart my son is but distancing themselves from him because of how uncomfortable his stimming or subject obsessions makes them feel. I see people loving my super adorable daughter but wanting her to change the way she expresses her abundance of joy when she shrieks loudly in delight.



Photo of two Nichols children.

I see it daily with both:
“just change this, this and that and we’ll be happy.”

*But this is the thing: they can’t.
They are hardwired to be who they are.*

As I get to know my children better, I can’t help but think that they were born missing the factor of needing to please others. If I - or anyone else - tries to get them to be like some social expectation of who they should be, we only succeed in making all of us intensely miserable.

This bothered me for a while. I was worried that they would be unhappy or have a harder time in this world because they were not conforming, and thus, facing disapproval. But over time, I see their inability to conform to be a real gift that they bring to the world and to themselves. They find their own happiness in their lives and depend on no-one to approve of them to be happy.

This is huge and has taken me a long time basically to even understand. But my neurodiverse children operate on a different wavelength. They are square pegs in a world full of round ones.

In their being a square peg, I believe that we all benefit, because there is value in diversity and difference. In embracing their diversity and difference, there is joy. It’s like being on a river ride and enjoying the ride instead of fighting it, even though my ride might be different from someone else’s ride.

I think this is where a lot of parents of neurodiverse people get it wrong: trying to make their kids more like neurotypical mainstream culture. But they were not born to be like that; they were born to be like themselves, and there is so much value in that!

The Value and Power of Neurodiversity

As a society, we need to pivot. So many children are coming into our world now that society cannot conform, no matter what. We need to see the value in their non-conformity.

We need to recognize the value of diversity - and that includes more than racial diversity, it's diversity in thought, expression, thinking, moving, feeling, sensing, hearing, seeing and being.

That means valuing the entire spectrum of disability, and all the intense, amazing, differences that exist in the disability community.

Valuing all of this helps us as human beings to push beyond our round peg worlds, see things in new ways, explore new ways of experiencing the world and understand that no person comes into their full power and ability by striving to be like their neighbor. Valuing all of this helps us as human beings to push beyond our round peg worlds and see things in new ways, explore different ways of experiencing the world and understand that no person comes into their full power and ability by striving to be like their neighbor.

We don't get new ideas and expand the kernel of human consciousness by being like the Kardashians. No. We get new ideas and expand the kernel of human consciousness by turning our gaze inward and allowing ourselves the space and grace to connect with who we really are.

We expand by allowing ourselves and our children to grow into our personal power, skills, and talents, and by valuing diversity, even (and maybe especially) aspects of diversity that we do not yet fully understand.

Meriah Nichols is the mother to 3 young children, one on the Autism spectrum and one with Down syndrome. She is a member of the UH Center on Disability Studies Community Advisory Council, a plant nerd, film buff and runs the award-winning blog, [Unpacking Disability with Meriah Nichols](https://www.meriahnichols.com) (<https://www.meriahnichols.com>) in her spare time.

Follow Meriah



Photo of Meriah Nichols.

The article, 'Square Pegs in a Round Pegged World: The Power of the Neurodiverse' was originally published in *Unpacking Disability*. Read this and other disability-focused articles at www.meriahnichols.com/power-of-the-neurodiverse.

Swim Safe: ASD

Aquatic Skills Development Program



Kroc Center swimming pool.

Drowning is the leading cause of death for individuals with Autism Spectrum Disorder (ASD). 91% of ALL accidental drownings in the U.S. involve children with ASD!



Participant swimming.

Autism Spectrum Disorder (ASD) in the United States (2019)

- 1 in 59 children are diagnosed with ASD
- 1 in 42 boys and 1 in 189 girls are diagnosed
- ASD is 4 times more prevalent in boys
- ASD diagnoses are increasing at a rate of 10 – 17% annually
- 48% of individuals with ASD are reported to wander

ASD in Hawai'i

- Children with ASD ages of 3-12 receiving special education services rose from 1.52% to 8.39%
- 1 in 67 military dependents have ASD
- An estimated 20,000 military dependents have some form of autism
- 4,568 residents in Hawai'i will likely to be diagnosed with ASD

Swim Safe: ASD Program

- Program has been running since 2017
- Over 133 families have participated
- Parent-centered approach (parents serve as instructor)
- Program is at various locations: Kroc Center and Duke Kahanamoku Aquatics Center-University of Hawai'i at Mānoa

Research Results of Past Programs

We have collected data on our past programs and have found:

- Improved swimming skills of all participants
- Decrease in occurrence of repetitive behaviors
- Increase in comfort level in aquatic environment
- Increase in communication skills
- High parental satisfaction of program



Participant and instructor.



Special thanks to the Hawai'i Autism Foundation (HAF) who funded the very first Swim Safe: ASD program and got it started. In addition, thank you to all of the other community partners who support Swim Safe: ASD program and promote it to their communities.

For program information and enrollment, contact:

Follow Swim Safe ASD



Dr. Kelle L. Murphy
Program Director
kellem@hawaii.edu



MENTAL WELLNESS CORNER

Schedule “Worry Time”



Graphic art of worrying.

Do you find yourself worrying or having anxious thoughts throughout the day? Scheduling “worry time” in your calendar may help! “Worry time,” or “stimulus control training” as it is known in the behavioral literature, is a research-backed technique from cognitive-behavioral therapy (CBT). By actively carving out time in your weekly schedule to devote to your worries, you can develop control over the frequency and timing of your anxious thoughts. With practice, you will find that anxious thoughts come up less often during the day and when you are trying to fall asleep. This will not happen right away, as chronic worrying is a habit, and all habits take time to change. Use the “worry time” strategy routinely, even if it feels silly at first, and give it time to take effect.

STEPS FOR “WORRY TIME”

1. Schedule “worry time” each day for one week. This will be a period of about 15 minutes. Morning or afternoon usually works the best for most people. Try not to schedule your worry time right before you go to bed.
2. During your worry time, write down all of the worries that you can think of. This is not the time to problem solve, so don’t put pressure on yourself and just let your thoughts flow. This writing process is therapeutic in itself.
3. If you start to worry between worry times, tell yourself to let go of those thoughts until your next scheduled worry period. This will be difficult at first and you may need to use repeated self-talk to tell yourself to let go of the worries until it is the appropriate time. Try not to judge your thoughts or yourself for worrying.
4. At the end of the week, reserve a few moments to look at what you wrote down during your worry times. Are there any patterns? Any repeat worries? Any changes? It is very common to have a “Top 10” most played worries.
5. After a week, consider trying for another. With more practice, you will notice increased control over the timing and frequency of your anxious thoughts.

For further reading on “Worry Time”:

Borkovec, T. D., Wilkinson, L., Folensbee, R., & Lerman, C. (1983). Stimulus control applications to the treatment of worry. *Behaviour Research and Therapy*, 21(3), 247-251. [https://doi.org/10.1016/0005-7967\(83\)90206-1](https://doi.org/10.1016/0005-7967(83)90206-1).

McGowan, S. K., & Behar, E. (2013). A preliminary investigation of stimulus control training for worry: Effects on anxiety and insomnia. *Behavior Modification*, 37(1), 90-112. <https://doi.org/10.1177/0145445512455661>.

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Follow Maya



Author

Hōkūlani STEM Fields

From *mauka* (mountains) to *makai* (sea), Project Hōkūlani mentors and internship partners play vital roles in the next generation of Hawai'i STEM professionals. Similar to a traditional ahapua'a system, our internship worksites share the latest findings and practices to their fields, as well as contribute to the interrelationships needed among each other to build a thriving community in Hawai'i.

Representing a 21st century ahapua'a community, we are proud to introduce a data image representing the 44 STEM fields inspiring our student scholars.

Dr. Hye-Jin Park
Principal Investigator
parkhye@hawaii.edu



Follow Project Hōkūlani



Figure Description: Data infographic with 44 STEM fields sized by the number of occurrences. For further info visit cde.hawaii.edu/hokulani/internship_sites.

Explore Parent Resources in Hawai'i



Photo of Susan Rocco.

CDS proudly presents our next Partner Seminar event on

**Thursday,
June 9th
1-2 pm**

FEATURING

Susan Rocco, coordinator of the Special Parent Information Network (SPIN) of Hawai'i.



Register Now to attend at
<https://go.hawaii.edu/FWx>

Susan will highlight some of the recent work of SPIN as well as their upcoming annual conference. This organization is an important connector to our Hawai'i families so please attend to find out more about how you can connect and partner with them to better serve children with disabilities.

The Special Parent Information Network (SPIN) is a **parent-to-parent organization** in Hawai'i that provides information, support and referral to parents of children and young adults with disabilities and the professionals who serve them.

SPIN tries to make the journey of parenting a child with disabilities a little less puzzling by keeping families linked to important information through a variety of media and events including:

- a free electronic quarterly newsletter with current events and trends
- a "warm" line of parent-to-parent support and understanding
- information about services, educational programs, and support and advocacy agencies
- an annual conference with opportunities for information gathering & networking

Follow SPIN



The Special Parent Information Network represents a unique partnership between the Disability and Communication Access Board and the Department of Education.



Images: UH Mānoa, CDS and DOH logos.

Presented by the Center on
Disability Studies at UH Mānoa:

SPIN: A WORLD OF SUPPORT FOR PARENTS OF KIDS WITH DISABILITIES

A FREE WEBINAR



With Susan Rocco
SPIN Coordinator

More Information

The Special Parent Information Network (SPIN) is a project of the Disability and Communication Access Board and the Department of Education. Its purpose is to enhance the participation of parents with children with disabilities in the decision making process involving their child's education. SPIN promotes parent involvement in the education of their child with special needs through information about the special education process, due process options, and parent-professional partnerships. Susan found her calling as a systems advocate for children with disabilities and their families after her son Jason experienced significant disabilities resulting from surgery as an infant. She became a parent volunteer in early 1985 on the new pilot offering information, referrals and parent-to-parent support to families whose children were eligible for early intervention and special education services and has continued to serve as SPIN's coordinator ever since.

Thursday, June 9th
1:00-2:00 PM HST

Register Now!

<https://go.hawaii.edu/FWx>



Registration QR Code.



Hawai'i State Department of Health &
University of Hawai'i's Center on Disability Studies

WE WANT TO HEAR FROM YOU!



Survey for teens with
special health care needs in Hawai'i:
TELL US WHAT YOU NEED



SCAN ME

**250 participants will
win a \$20 gift card!**

Survey Link:
go.hawaii.edu/xRD

For more information:
Visit our project website: <http://go.hawaii.edu/xhV>

Contact us:
Maya Matheis, mmatheis@hawaii.edu
(808) 956-4457