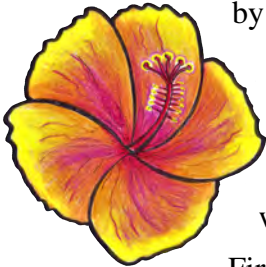




Spring: A Lovely Reminder of How Beautiful Change Can Be

by Mellanie Lee



Spring is happily here. It's a time of planting, new beginnings and growth, and we certainly have a lot of that happening here!! We hope where you live is springing to life with abundance.

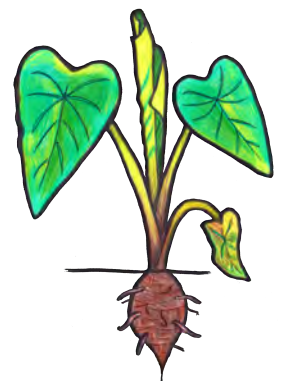
First, we are so excited to announce our new Family Specialist, Ginger Knowles. Please read more about her and her son as well as her awesome advocacy work and Proclamation that made March Trisomy Awareness Month in Hawai'i, signed by the Governor. Go Ginger! We think you will love her just as much as we do.

We experienced virtual growth and goodness with the Collaboration Across the Pacific (CAP) Academy, which brought together about 70 people to learn from each other. This group strategized and exchanged ideas for the benefit of children and teachers in the Marshall Islands and the Federated States of Micronesia. Read more about it!

New beginnings were also experienced by three of our Pacific Liaisons who completed the course Assessment of Students with Cerebral Vision Impairment (CVI): Reliable Scoring of The CVI Range, offered by the Perkins School for the Blind. Mahalo to Connections Beyond Sight and Sound - the Maryland & DC Deaf-Blind Project, for making this possible. CONGRATULATIONS to Diane Artero, Lizelle Ameriz and Olive Iaone for your efforts to learn more to support the children you serve. We look forward to learning from YOU!

As always, our partner, the Comprehensive Service Center (CSC) for Deaf, Hard of Hearing and Deaf-Blind, is rocking and rolling with cool classes and happening events. Check 'em out!

This past year has been challenging for many of us, however, we have been blessed by all the amazing connections with children, families, friends and new partner. We are forging ahead with gratitude and open hearts and minds, and we look forward to hopefully seeing you sooner rather than later. Until then, we share our aloha.... Please read on!!!



MEET @OUR NEWEST TEAM MEMBER

Aloha! Please welcome Ginger Knowles as the Hawaii and Pacific Deaf-Blind Project's Family Support Specialist. Ginger has over 20 years experience working with our youth in early childhood education and special education. She is a graduate from Chaminade University of Honolulu with a degree in Early Childhood Education and a dual licensure degree in Special Education & Elementary Education-Mild to Moderate K-12. Ginger currently resides on the west side of the island of Oahu with her family. When Ginger is not keeping busy as a caregiver to her son who has mild to moderate unilateral hearing loss, autism, and trisomy 12p; you can find her volunteering in the community, shopping, or cooking healthy food.

TRIS@MY PROCLAMATION

Aloha, my name is Ginger Knowles. I am a member of the Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) which is a registered nonprofit charity in Hawai'i. On behalf of The Support Organization for Trisomy (SOFT), this is the second year that I have requested that March be proclaimed as Trisomy Awareness Month in Hawai'i.

A Trisomy is the presence of a single extra chromosome in any one of an individual's 23 pairs of chromosomes. This can be represented in a full trisomy, mosaic trisomy, or partial trisomy. The most common trisomies are Trisomy 21 (Down Syndrome), Trisomy 18 (Edward Syndrome), and Trisomy 13 (Patau Syndrome). Down Syndrome affects 1 out of 800 live births, Trisomy 18 affects 1 out of 5,000 live births, and Trisomy 13 affects 1 out of 16,000 live births.

Only about 10% of our children with Trisomy 18 and 13 live to celebrate their first birthday. To avoid the pain of losing a child most families are given the recommendation to terminate or deliver the child early. This sets a tone of a non-survival rate for the child.

I have a son with an extremely rare chromosomal abnormality called Trisomy 12p. Trisomy 12p is when a portion of the short arm (p) of the 12th chromosome (12p) appears three times (trisomy) instead of twice in cells of the body. It is estimated that 1 out of 50,000 live births is affected by Trisomy 12p. There are only 40 medical documented cases of Trisomy 12p in the world. Most children do not survive after 5 weeks old. In most cases, Trisomy 12p is not inherited but the duplication can be passed on to their children.

My son does live with several disabilities resulting from Trisomy 12p. However, he is able to learn ASL, express himself, comprehend, and charm others with his personality. We are indeed grateful we did not take the recommendation to terminate our son's life for he is a happy and loving child. My son is a living example of having determination and beating the odds at a very young age. For these reasons, it is important to continue to spread awareness of Trisomy to our community in Hawai'i.



Image Descriptions: Ginger with glasses and pearl earrings smiling at camera; Ginger and her son who is wearing glasses and using a pacifier; Ginger and her family with matching green plaid outfits; Ginger holding the proclamation at the State Capital.

Collaboration Across the Pacific (CAP) Academy

Sharing Technology and Skills for Serving Children with Disabilities and their Families



Spring brought us the very first CAP Academy, when multiple organizations collaborated to form an exciting learning experience that continues to grow. This was an extensive partnership between the following agencies and non-profits: The College of the Marshall Islands, the University of Hawaii/Center on Disability Studies, Navigating Student Success in the Pacific (NSSP program), Hawai`i & Pacific Deaf-Blind Project, Maternal Child and

Health Leadership Education in Neurodevelopmental Disabilities (MCH LEND) Program; and San Francisco State University Department of Speech, Language and Hearing Sciences, Project Building Bridges (PBB), and the NIKA Project (<https://nikaproject.org/>).

CAP was designed to host a series of online sessions with MCH Lend Trainees, NSSP Teachers, and SF State SLP students specializing in AAC (spell out). Everyone collaborated to support specific children with disabilities that NSSP teachers identified from their home island communities. The purpose of these virtual sessions was to share various professional perspectives and make recommendations to NSSP teachers on how to better support their targeted child and family within the context of local cultures, languages and resources.

Faculty members from each of the partner programs helped NSSP teachers create plans tailored to activate local resources on each island community. Three virtual sessions took place this Spring, and more sessions are continuing through the summer with SFSU Project Building Bridges (PBB). Project BB SLP students are specializing in Augmentative and Alternative Communication (AAC). They are sharing their expertise with the NSSP students to help develop communication tools for their target children.

This collaboration has been a win-win for everyone. Perhaps one of the highlights was listening and learning about each other's cultures as everyone had a chance to share and creatively look at ideas and suggestions together.

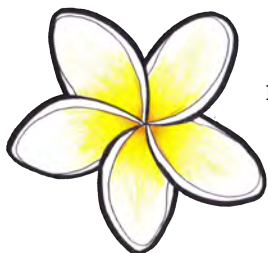
Mahalo to the following CAP Collaborators:

- Hawai`i & Pacific Deaf-Blind Project: A project from UH Manoa whose goal is to support deaf/blind individuals in Hawaii and



- **NSSP Project:** The College of the Marshall Islands with the Center on Disability Studies Navigating Student Success across the Pacific (NSSP), provides training for 14 teachers throughout the Federated States of Micronesia (FSM) and the Republic of the Marshall Islands (RMI). Students are completing a Bachelor’s Degree in Education with Teacher Certification so they can better serve children with severe disabilities and their families on their home islands.

- **University of Hawai‘i MCH LEND:** The UH MCH Leadership Education in Neurodevelopmental Disabilities (LEND) Program prepares professionals for leadership roles to improve supports and services for children with special health needs and their family members.



- **Project Building Bridges at San Francisco State University:** This program provides specialized training in culturally responsive Augmentative and Alternative Communication (AAC) for speech-language pathology (SLP) graduate students at San Francisco State University.

- **NIKA Project:** Team members are volunteer SLPs and Educators who create access to communication and learning for children with disabilities internationally through Augmentative and Alternative

Communication (AAC). NIKA Project Mentors assisted Project BB scholars to create communication and learning tools with CAP teams.



What does NIKA stand for?

This Collaboration Across the Pacific

connected teams of people

to improve the quality of life for students and families. All participants truly learned from each other and developed relationships that will continue. During the closing of our last large group session, representatives from each of the groups shared their appreciation for the process and people involved. Student Herry Wichep from Pohnpei shared the following, which shows how important this learning experience was for these students:

CAP Team members. My respect to Mellanie, Kathy, and Jennifer. I also respect all of you, my NSSP colleagues.

Since today will be our last day with the CAP Team members, we wanted to share that we will always appreciate everything we have done/accomplished together for the past few months.

This is our first time experiencing this type of live collaboration with so many experienced and professional people like you. We are all really proud to have you be part of our learning journey. We know that all of you are very busy with work and studies, yet you all gave up your time to be with us on our zoom meetings, feeding us so many great ideas. We all learned a lot from you and our students and their families will greatly benefit from our new understandings.

If today is our last meeting together it is very sad, but don't worry. We all have your email addresses and we will be bothering each one of you when we need you! We really appreciate your time with us as we learned a lot. We also know whom to reach out to if needed.

It is impossible to thank you. There are no appropriate words to share our appreciation of someone whose words empower students to chase their dreams.

Again, on behalf of the NSSP Team, we thank you: From Yap: Kammagar, Chuuk: Kinisou Chapur, Pohnpei: Kalahngan, Kosrae: Kulo, and RMI: Kommool Tata”





HANDS ACROSS THE PACIFIC, literally!

By Judy Coryell, Project Director, Navigating Student Success in the Pacific, Deaf Education Program

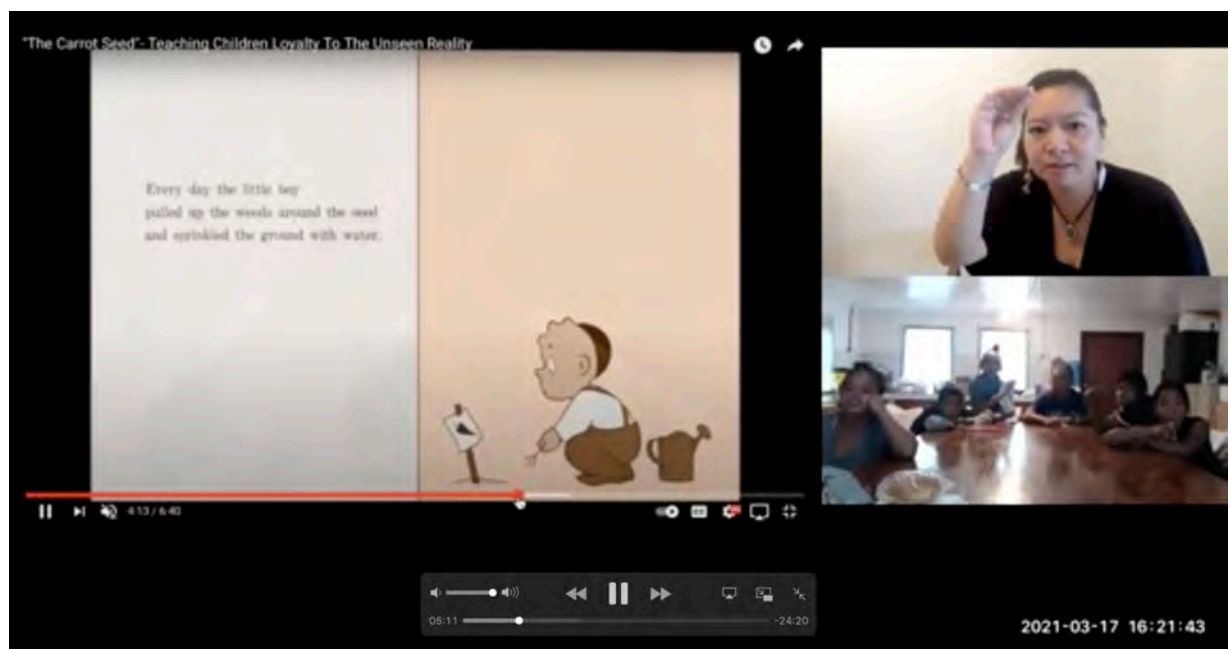
Eleven scholars in the NSSP Deaf Education program have begun their final internship semester/year -- teaching deaf students on 6 Pacific Islands. The Deaf Ed scholars have gotten to know each other really well when they gathered at the College of the Marshall Islands in Majuro for three summers, took NSSP classes together on the CMI campus, and those from islands other than Majuro lived together in the CMI dorms. Many lasting friendships have grown over the years through NSSP. This past year, they connected frequently online via Zoom from their home islands to continue classes and participate in seminars. These experiences have developed strong friendships, much of the time using American Sign Language to communicate with each other and in these ways, creating bridges by joining *Hands Across the Pacific*.

The NSSP Deaf Education interns also encouraged and facilitated "*Hands Across the Pacific*" between their deaf students. Virtual online technology created opportunities for Deaf students from Majuro to connect with a Deaf student from Palau, a Deaf student from American Samoa connecting with their Deaf peers from Majuro, Ebeye and Majuro interacting during Ebeye's week-long Senior trip to Majuro. Another unique *Hands Across the Pacific* experience is a teacher-to-teacher connection. An NSSP student teacher from Guam team taught Deaf students in Pohnpei with two Pohnpeian NSSP Deaf Ed teachers.

These experiences have been enriching and exciting for Deaf students as well as their NSSP teachers. We are hopeful that the Deaf Education *Hands Across the Pacific* connections will continue to thrive long after the NSSP

program is completed.

(Image descriptions: facing page has five photos of large groups smiling at camera. This page photo of a zoom class session with teacher signing boy to a group and the book Carrot Seed on screen.)

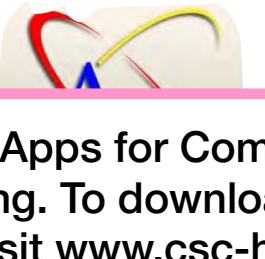


DB Professional Development in American Samoa

Our lovely DB Liaison from American Samoa, Olive Isaako developed and delivered an AMAZING professional development inservice on Deafblindness for our AS SpEd ohana. The half day event, full of learning and laughter, wrapped up with a viewing of the award winning short film, Feeling Through and a live panel discussion. Fa'afetai tele Olive for your hard work in organizing this event, your commitment to improving outcomes for children who are deafblind and you passion for teaching and sharing with others.



(Top: Classroom of adults Right: Olive standing in front of a group of adults holding an O and X.



Free iPad Apps for Communication and Learning. To download the list as a PDF, visit www.csc-hawaii.org.

Dǎngkulu na si Yu'us ma'āse! Fa'afetai!!! (Thank You) to Our Sister Project in DC



In February, three of our Pacific Liaisons worked hard to complete a course titled Assessment of Students with Cerebral Vision Impairment (CVI): Reliable Scoring of The CVI Range with the Perkins School for the Blind. This certification was made possible by the generosity of our sister project, Connections Beyond Sight and Sound, the Maryland & DC Deaf-Blind Project. Here is what the 3 women shared about this experience



(picture of Lizelle holding up her Certificate of Completion)

Lizelle Ameriz – Common Wealth of the Northern Mariana Islands.

Yes! Thank you to Connections Beyond Sight and Sound, the Maryland & DC Deaf-Blind Project, the Perkins School for The Blind, and Sandra Newcomb for this wonderful learning opportunity. Being the only TVI on a small island can be quite difficult as a professional.

Through this course, I was able to not only grow and enhance my skills professionally, I was also able to make connections with others in my field. It was an awesome experience to be able to have in-depth discussions, learn from others, and expand my resource base. I have also gained more confidence in myself and how I assess our students with CVI. It was an amazing experience to explore the different perspectives within the field and offer my own as well. Most of all, it felt really good to know that I am not alone and I that I can easily reach out when I need help. Again, thank you for this wonderful opportunity.

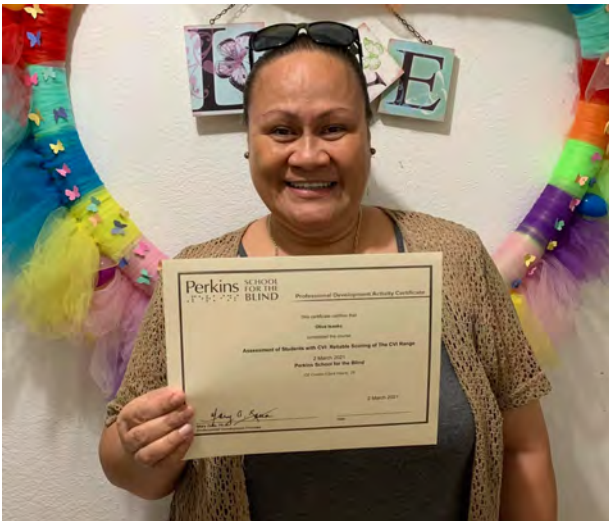
(Picture of Diane outdoors standing in front of greenery holding her certificate)



Diane Artero - Guam.

Hafa Adai! I am very thankful for the opportunities afforded to me through Connections Beyond Sight and Sound, the Maryland & DC Deaf-Blind Project and the Hawai'i & Pacific Deaf-Blind Project. I am proud to be a part of the growing CVI awareness, support and education of my island community. Dǎngkulu na si Yu'us ma'āse! Thank you very much from Guam!

(Picture of Olive holding her certificate in front of rainbow feathered circle.)



Olive Ioane – American Samoa

Fa'afetai!!! Thank you so much for this opportunity. I am so grateful to all the people that made it happen. Because CVI is not diagnosed in American Samoa, I will promote and increase awareness about CVI, making sure parents and teaching professionals are well informed!

Announcement from HKNC: Free Online Courses EXTENDED



HKNC Announces: Free Online Courses for Professionals who are working with Individuals who are Deaf-Blind EXTENDED until further notice

We at HKNC hope that you are well and staying safe. The COVID-19 virus has had an impact on how we live, provide services to consumers and continue to develop our skills as professionals. As our partners, we would like to say thank you for all you have been doing and extend the opportunity to access our online courses free of charge until further notice.

Continuing Education Credits (CEUs) are offered with many of our courses.

You can access our class catalogue by going to:
<https://www.helenkeller.org/hknc/available-classes>.



Hi Auntie,

I need your kokua. Is it ok for my 14 year old son, who is Deaf-Blind and has Cerebral Palsy, to get the COVID vaccine? I think it will make him sick so we are worried. Please let us know.

Mahalo,
Concerned Mama



Aloha Concerned Mama,

Good question... Auntie believes in science, so I like what the Center for Disease Control tells us.

They say it's safe for people over 12 years with disabilities to get the vaccine. Also, good to check with your Doctor.

(<https://www.cdc.gov/coronavirus/2019-ncov/vaccines/recommendations/disabilities.html>)

In my ohana we all got our vaccines, so I feel good. The more we all do this, the safer our community.

Malama... take good care.
Auntie

Dear Auntie,

My friend's daughter is going to be 5 years in a few months. We were invited to her birthday party and have no idea what to get her. She has some vision (bright colors), and she likes very loud music and soft material. She likes to put most things in her mouth. Got ideas? I have no clue. Looking forward to hearing from you.

Yours,
Jezebelle

Aloha Jezebelle,

I know... getting something for our keiki can be hard to figure out. We lucky now, though, as we get plenty ideas by asking our good friend "Google".

On your computer, type in the words "sensory toys, bright colors, music" and choke ideas show up. You can also check out YouTube and Pinterest at this site: (<https://www.pinterest.com/>).

Have fun looking. You can even make some cool gifts!

Have good fun!
Auntie





HAWAI'I & PACIFIC DEAF-BLIND PR@JECT

Project Staff

Mellanie Lee

Project Director/Education Specialist
(808) 753-0981
mellanie@hawaii.edu

Jennifer Tarnay

Project Coordinator/Speech-
Language Pathologist
(808) 753-2351
jtarnay@hawaii.edu

Rosalind Kia

Resource Specialist
(808) 284-3551
rkia@hawaii.edu

Ginger Knowles

Family Specialist
gingermk@hawaii.edu

Shayleen Siquig

Mentor
shayleen.siquig@gmail.com

Contact Information

Center on Disability Studies

University of Hawai'i at Manoa
1410 Lower Campus Road, 171F
Honolulu, HI 96822
Ph. (808) 956-5861
Fax (808) 956-7878
www.pdb.Hawaii.edu

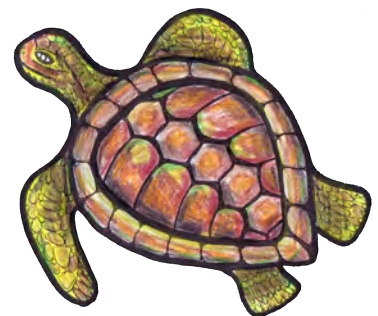
Special Mahalo to Rande Golden for editing.

As always, we want to hear from you, so please feel free to email us (mellanie@Hawaii.edu) or reach out on Facebook (Hawai'i & Pacific Deaf-Blind Project) and we will make sure to respond.

We are migrating to a new listserv host, if you have not been receiving emails from us or would like to be included on our listserv please let us know, write [to:jtarnay@hawaii.edu](mailto:jtarnay@hawaii.edu) and we will happily add you.

Be safe and well and remember, we are here to provide information, connections, and support. Much love and strength to you and your loved ones! While times are changing, we remain committed to supporting you however we are able.

Mellanie, Jennifer, Roz, Ginger, & Shayleen



The contents of this newsletter were developed under a grant from the U.S. Department of Education #H326T180027. However, these contents do not necessarily represent the policy of The Center on Disability Studies at University of Hawai'i, Manoa, nor the US