Administration on Developmental Disabilities Tri-Agency

I Linå' lå-ta
Volume 2, No. 3
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Administration on Developmental Disabilities Tri-Agency

I Linå'lå-ta (Our Life)
A Newsletter For Individuals With Disabilities

Opening Doors...

Guam Resident Fulfills Her Dream

Note: ***I Lina'la-ta Editor, C. P. Cruz, tracked down former Guam resident, Jacqueline "Jackie" Borja Cabrera and conducted the following interview via email and telephone.***

Doors are swung wide open from both sides in the life of Jackie Cabrera. Jackie is a recent graduate of the Western Culinary Institute, Le Cordon Bleu, in Portland, Oregon. Jackie expresses her artistic nature through her love of food, culture, and family. As an individual with disabilities, Jackie takes on life with zeal, passion, and compassion. Her charm and laughter are engaging, and her story inspiring. Come along with me on a tour of this island girl's adventure in the Pacific Northwest!

I Lina'la-ta (IL): *What is the nature of your disability?*
Jackie Cabrera (JC): I am totally blind. I have retinal detachment on both eyes from diabetes. I have been blind for seven years and have been a diabetic since I was 11 years old.

IL: *What made you want to leave Guam?*
JC: After the loss of my father in January 2004, I was diagnosed with heart disease and had to get a triple bypass. I went to the Philippines and had my surgery and returned to Guam. While recovering and healing, I waited to gain some strength back and finally just wanted something more for myself, to learn more about living independently as a blind person.

I wanted to go to a school where I could find more resources to learn about different technology devices, Braille, computers, and more, as well as finding organizations for the blind. I also wanted to learn these things so I could be able to help people in our island of Guam as well as the CNMI (Commonwealth of the Northern Mariana Islands) who are visually challenged. Since I became blind I have learned what I set out to do. When I left Guam in September 2004, I made my way to Spokane, Washington, where I lived with a friend. We did much research for different agencies and organizations that dealt with the blind. Finally, we were able to land the winning ticket and signed up with the Department of Services for the Blind. In this facility, I received information and training with the computer and the voice-recognition program, JAWS (Jobs Access with Speech). With that, I was able to get familiar with the keyboard again and work on my typing skills.

Jackie Cabrera celebrated her graduation from the Western Culinary Institute Le Cordon Bleu in Portland, Oregon on October 25.

> ***Life itself can be a challenge whether you have a disability or not.***

See **Opening Doors.**, page 4

Giving Voice & Presence:

Improving Communication for Individuals with Significant Communication Disabilities on Guam

By Diane Nelson Bryen, Ph.D.
Visiting Professor, University of Guam

Communication is the essence of life. However, more than 2 million Americans (8 -10 per 1000) have significant communication disabilities so that spoken language cannot meet their daily communication needs. That means approximately 1,650 individuals on Guam. There are students and adults who are unable to meet their daily communication needs through more typical modes of communication such as speech, gestures, and writing. Students include those with developmental disabilities, students with physical disabilities such as cerebral palsy, students with mental retardation, students who have significant behavioral disabilities, and students who have severe multiple disabilities (Matas, Mathy-Laikko, Beukelman, & Legresley (1985).

Why is not having an effective means of communicating such a problem? Just ask parents or people with complex communication needs and they will tell you. Listen to one parent:

- Seeing their frustration when others don't understand them.
- Knowing all the interactive play and language learning they are missing out on.
- Seeing the difference in interaction and closeness between our relatives and our kids who can and can't communicate - despite good intentions.
- Watching people's faces in stores when they say "hello, What's your name?' and our kids don't have a way to respond.
- Seeing the substantial difference between education in the average special education segregated class and the average regular education class, and watching the gap widen year after year (despite our children's unused abilities)
- I hear so much about cost of communication devices….less about "lack of a voice and freedom of speech"
- I wonder if the gatekeepers ever think about that common frustration of early parenthood when they consider how long we and our children have had to wait, and how it must feel when they tell us " next year we'll try to do something about augmentative communication."

While spoken language is the main way most people communicate, there are many other ways we can all communicate. We can use sign language, written language, pictures, line drawings, facial expressions, and actions, to name just a few.

Students in a 5-week graduate class offered at the University of Guam and sponsored by Guam CEDDERS learned how the relatively young field of

See **Giving Voice,** page 3

Augmentative & Alternative Communication Key Points

- It is the use of any method, other than speech, to achieve functional communication.
- It may be used instead of speech or in combination with residual speech.
- It may be a temporary or permanent method for communicating.
- It is primarily used to aid expression, but may also be used to aid comprehension.
- It may use unaided, assisted, or aided methods of communication.
- It may be a 'low tech' strategy or a 'high tech' device.
- It should replace only elements that are unintelligible, socially unacceptable, or harmful to the person or to others.
- It should be multimodal (total communication).

Giving Voice & Presence

cont from Page 2

Augmentative and Alternative Communication or AAC can begin to address the frustration of not being able to communicate.

They learned about the importance of promoting the **Communication Bill of Rights** *(see the insert to this newsletter and post it wherever you can).* In addition, they learned that it takes two people to communicate and that successful communication depends on the communication partner just as much as the person with a disability. Learning to be an effective communicator means having opportunities and reasons to communicate. People need to be listened to as well when even the smallest communication attempts are made.

Students learned how to develop a Communication Passport and why it is so important. They also learned how to make a communication board (see samples in Photos), a switch for access, as well as learning about all the different high tech devices that literally can give a person a voice. Finally, students learned some effective assessment and intervention strategies – all aimed at improving the communication of individuals with complex communication needs.

It is our hope that these 24 students will work with hundreds of children and adults who have complex communication needs so that, for them, communication will truly be the essence of life. ■

For more information, visit the Augmentative Communication On-line Users Group at: http://www.temple.edu/instituteondisabilities/programs/assistive/acolug/

Are You Interested in Participating in the Ad Hoc Committee for Emergency Preparedness for Persons with Disabilities?

If so, please contact Ginger Porter at
Guam CEDDERS
735-2478/2369
or email
ginger.porter@guamcedders.org

OPENING DOORS: *Island Girl* *cont from Page 1*

I learned enough about JAWS and its commands to where I was able to understand how this assistive technology was going to help me. With JAWS, I was able to store and access information and important documents; access the internet; and open up communication through e-mail. After about seven months, I was accepted to the Orientation and Training Center in Seattle, where I studied Braille, Computers, Home Economics, Woodshop, Mobility, and Career Education, and attended seminars. What an awesome seven-month experience of adventure, challenges and wonderful memories that was for me. I learned, absorbed, cried, laughed, and most of all, expanded my knowledge and skills on how to live more independently as a blind person and succeed with this training.

I became involved with the Washington Council of the Blind and served as the secretary of our chapter in Port Orchard. The Orientation and Training Center is where I picked up my interest in cooking and techniques for baking. I believe that is where it started for me with the culinary field.

IL: *Where and when did you graduate from high school?*
JC: I am a graduate of the Class of 1990 of George Washington High School, Home of the Mighty Geckos. I was employed at GWHS for 11 years before I became blind. The school never left my heart or sight.

IL: *When things are hard and you feel overwhelmed, what keeps you going?*
JC: Life itself can be a challenge whether you have a disability or not. Sometimes, when I get frustrated, I just take a deep breath, step back, and take a little break. It helps to do that because then I feel refreshed, and I have more focus and concentration.

I believe it is very important to stay positive, have faith in God and yourself, believe in what you want to do and follow through; and most of all, LIVE IT UP!

I have always been a happy and jolly person. I love helping people out and appreciate life and the beauty it has and can have. I look at it as how we have choices, and "Life" is really WHAT you make of it. As much as possible, I try to remain calm and humble myself. I pretty much go with the flow, enjoy each day that God gives me, appreciate the wonderful surroundings, and hold and carry a positive attitude. To top it off, I always think about those who are less fortunate than I, or in a worse condition than I am in. I think about people living with other serious illnesses, especially children, or people that don't have family, friends, or homes to go to. I think about how grateful I am to have a

Food is beautiful!

See **Island Girl,** page 5

Jackie Cabrera stirs up a feast during her culinary classes at the prestigious Western Culinary Institute, Le Cordon Bleu in Portland, Oregon.

Island Girl cont from Page 4

roof over my head, clothes on my back, food on my table, as well as family and special friends.

Another thing that keeps me going is cooking and baking. My kitchen is my castle, and that is where I spend most of my time working on tweaking or experimenting with recipes. Food is beautiful! I also look at it as my therapy. It helps me to keep my mind off my blindness. I love it when I can share my productions and when people can appreciate what I give from my heart.

I love it when I can share my productions and when people can appreciate what I give from my heart.

IL: *What is the name of your culinary school?*
JC: The school I attended is the Western Culinary Institute, Le Cordon Bleu in Portland, Oregon. I graduated with a degree certificate in culinary arts on October 25. I completed my internship in the kitchen of the Guide Dog School for the Blind in a town called Boring, Oregon, which is located one hour away from where I live in Beaverton, Oregon. What a wonderful experience!

IL: *What is your signature dish? Can you describe it?*
JC: I don't actually have a signature dish. I think it is because I am always open to all kinds of food. I love to learn, explore, experiment, taste, share and eat different types of cuisine. Asian cuisine is my favorite. Stir-fry is a winner for me. In the Culinary field, there are so many kinds of food to venture into and feast on. So, with all that I have been taught by my parents, grandparents, other family and friends, and in the Culinary School, I am open to a variety of food and tie them all in together.

IL: *Can you describe how you traveled between school and home?*
JC: My transportation resource to school was on the TriMet Lift which is a door-to-door service for individuals with disabilities and senior citizens. My friend, Dee, is also one of my sources of transportation. She picks me up after school, or one of my classmates will escort me to and on the train and make sure I get off at the correct "park and ride" station. From there, Dee meets me and takes me home.

While I was in the Western Culinary Institute I had notetakers who acted as my eyes only.

IL: *Is there any Assistive Technology (AT) device that has helped you in this latest endeavor of cooking professionally?*
JC: While I was in the Western Culinary Institute, I had notetakers that acted as my eyes only. The devices that I used to help me are: my computer, where I store recipes and important documents; a mini-cassette recorder; digital recorder; a DAISY (Digitized Accessible Information System) Reader, with which I was able to access my books; and a scanner that reads books and handouts.

I also have AT devices such as a talking scale, timer, a liquider which gives an audio cue that tells you when a cup is full of liquid, a talking thermometer, and a talking watch. I use my Braille skills to label spice bottles, containers or anything that needs to be identified. Other than the devices, I use my hands and all my other senses to act as my eyes.

My words of advice are to always try to remain positive and live your life to the fullest.

IL: *What words of advice do you have for others here at home who are challenged with a disability?*
JC: My words of advice are to always try to remain positive and live your life to the fullest. Take things step-by-step and one day at a time. If there are dreams, goals, and adventures you want to explore and fulfill, go for it because the sky is the limit and anything is possible. Many things in life are done by the choices we make. For every first step we take, it always seems scary, but as you walk through it, you learn to adapt, accept, adjust, move on, and LIVE IT UP! It helps to keep your prayers locked in, appreciate life, educate yourself and others, seek alternatives and opportunities, and challenge yourself with new horizons. Remember, "LIFE" is really how and WHAT you make of it. ■

Jackie currently resides in Olympia, Washington. She is a former resident of Barrigada and the daughter of I Mandifuntu (the late) Jose Sablan Cabrera and Julia Borja Cabrera.

My Mother's Voice

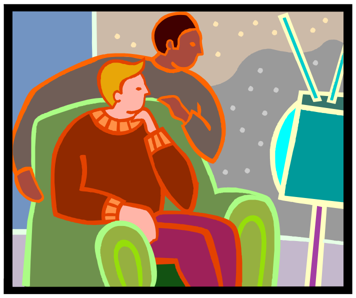
By C.P. Cruz, M.A.
Guam CEDDERS and GSAT Advisory Council Member

I am one of the 24 students of Dr. Diane Bryen. I am not a teacher, a speech language therapist, social worker, or any other category of service provider to people who may have complex communication needs. How I am connected to this story, other than being a student, is that I am my mother's daughter.

Twenty-two years ago, I left graduate school to come home to Guam to care for my mother, who had suffered a stroke as a result of cancer. After her stroke, this woman who had devoted a lifetime teaching high school students and raising three children, found herself without the power of effective speech.

She could understand what was being said, but when she would try to respond the words, she had in mind to say did not come out that way. For example, her word for coffee was "Veenah." After some time, I developed an understanding of this language we shared. For hot and cold, I would show her a mug or a glass. By touching or indicating either of the two, she could communicate hot or cold. Her twin sister figured this system out. My mother's three sisters, a sister-in-law, my brother, and I were my mother's main caregivers.

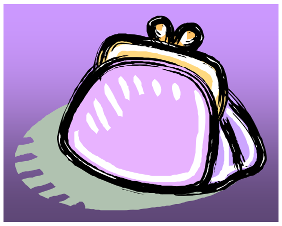
We developed the skill of translating what my mother was saying. She would express herself through one or two syllable words of her own making, gestures, eye movement, pauses and head movements. We would "speak" for her and look to her to see if we had translated accurately. I once translated for my mother as she was being interviewed by a newspaper reporter.



My mother died a year after that stroke. She had many hours of visits with her family. She loved to do 500-piece picture puzzles with all of us; enjoying merienda with her sisters and sister-in-law; sitting and watching the goings-on in the neighborhood; and watching reruns with my brother and me of "The Donna Reed Show" and "Leave It To Beaver."

In her life before her stroke, my mother was an avid reader. She loved novels; cookbooks; and books on psychology, geography, and many other topics. After her stroke, she was no longer able to make sense of the printed words.

To this day, I am grief-stricken when I think of the time my mother had to ask me for currency to keep in her purse. I didn't understand her need for money, since we did everything for her. As I painstakingly learned, all she had wanted was pocket change to be able to stop the ice cream truck that passed by in the afternoons and buy a "pahskul (popsicle)" for herself. It was important to her to have her purse with her and have a wallet with money available to her.



As a working single parent, my mother was highly independent, and here we had taken it away from her in our efforts to "help" her. I learned that day the significance of that purse to her. I have that purse to this day.

I would be lying if I did not admit that allowing her this independence scared me. I was afraid that she would get hurt or that someone would take advantage of her. It wasn't my decision to make. All that had been affected was her speech and her ability to understand the written word. She was still my mother, and I was her daughter. Our roles had not been reversed, just modified to accommodate the circumstances.

> ***"...it is not too late for you or someone you love to have the opportunity to enrich their lives through the use of AAC devices, strategies and services."***

How many people's lives are affected in similar ways by similar circumstances? Is it rare or more commonplace than most people think?

If you still think that Augmentative and Alternate Communication (AAC) has nothing or little to do with you, read on.

About 20 years later, my mother's twin had a near-death experience. She was in an intensive care unit. She was having trouble breathing and so had a breathing tube placed in her air passage. This affected her speech. There were complications and her heart failed. As she heard someone say, "She's gone," my aunt told them in no uncertain terms, "No, I'm not." In a direct gesture, she grabbed the clothes of someone within hand's reach. They got the message.

My mother's twin is alive today and still getting the message across in any way she can. She still has a breathing tube and has only a whisper of speech that comes and goes. She mainly relies on written language on pieces of paper, gestures and looks. I hear that the looks are quite effective and articulate her intent well. Imagine how much more effectively she could

See **My Mother's,** page 8

Transit Talk

Planned Improvements.

Wouldn't it be great to have the number of transit buses tripled and more fixed routes to ride? Wouldn't it be great to have a bus arrive every 15 or 20 minutes and to count on 18 hours of daily bus service? Wouldn't it be great to know that every single bus on route was accessible and there would be fewer break downs and delays? Wouldn't it be great to have more stops with shelters, seating and signs, and sidewalks to access the stops? And wouldn't it be great to see that in our lifetime? According to Larry Perez, Department of Public Works (DPW) Director, ***great things are about to happen***!

At the October Transportation Commission meeting, DPW provided a sneak preview of transit planning timelines under the 2030 Transportation Plan, which projects that within 2 to 3 years, we should begin to see new federal dollars turn those "great ideas" into reality. Just think of the places you could go on the regular bus system; exciting, isn't it? If you aren't already riding the fixed route system, you may want to think about learning to ride the system, which could make some of your future rides easier than scheduling paratransit.

In the meantime, we still need bus service operations. Based on the Department of Administration (DOA), DPW, and the Attorney General's Office agreed timelines, a contract to stabilize operations should be on target for January 2009. Finally!

Speak up to improve the system.

Transit problems aren't always caused by riders, as you well know. In order to help fix some of the bus and service problems, you have to be willing to identify yourself, speak up, and be the extra set of eyes and ears for DOA. **Be educated** on your rights and responsibilities and be a **good** advocate. You can file a complaint by calling 475-4616 or by submitting the complaint on an official form, available at the transit office in Hagåtña or on accessible computers at GSAT. Written complaints are not forgotten and provide good documentation of problems that need to be fixed. Any written complaint can be filed via email to epereira@mail.gov.gu, saving you time and the expense of travel. Don't be afraid to speak up in a positive way, make your voice count.

Advocate for your rights!

As Helen Keller stated, "When one comes to think of it, there are no such things as divine, immutable or inalienable rights. Rights are things we get when we are strong enough to make good our claim on them." One voice representing you on the Transportation Commission brought attention to the problems arising from agency inaction in regards to a long term operations contract. Agency directors listened and committed additional dollars to the operation of transit from the Federal Highway Fund and moved forward. This is proof in the pudding that positive, factual, and respectful but assertive input can only help the system become better. There is ***no better advocacy voice than yours***; you who use and ride the system. ■

Travel Passport Can Take You Where You Need To Be!

Just flip, point, and go.

Ever heard of a point-point joint? It's an eaterie where you go in and point to what you want, y'know, one choice, two choice. Well, a travel passport is kinda like that.

You carry a small album with photos of places you frequent, at the entrance you desire. The idea is that you won't have to exhaust yourself trying to find common vocabulary between you and the transit driver to explain where you need to be dropped off. Just take out your travel passport album, flip to the page you need, point it out to the driver, and you're on your way.

Not a problem for riders who can simply point to where they want to go or give the driver visual cues, but for those of us who struggle conveying accurate directions and being understood, this travel passport album may be the solution to being dropped off at the wrong place.

Customize the passport to your needs and personality. You can use a wallet with a photo foldout, or a hand-size photo album ala Nana's brag book of her grandchildren's photos.

For more ideas on how to put a travel passport together and how it can make your travel easier you can contact the staff at the Guam System for Assistive Technology (GSAT) at 735-2490. ■

My Mother's Voice *cont from Page 6*

communicate through some of the methods and strategies that were taught in the five-week class on AAC.

Although my mother was able to communicate her needs and thoughts to some degree of effectiveness, I cannot help but wonder how the last days of her life might have been enriched if she had had other options in the area of communication aids, such as the ones we learned about in the five-week class on augmentative and alternative communication.

It is too late for my mother, but it is not too late for you or someone you love to have the opportunity to enrich their lives through the use of AAC devices, strategies, and services. ■

Are You A Person with A Disability Interested In Setting Up a Home-Based Business?

The Get Guam Teleworking (GGT) Program

Provides affordable loans to help persons with disabilities purchase equipment for a home-based business.

For more information contact the Guam System for Assistive Technology (GSAT) office at 735-2490 or email at gsat@guamcedders.org.

Need To Purchase an Assistive Technology Device?

Guam Options for Alternative Loans for Assistive Technology (GOAL-AT)

Provides affordable loans to persons with disabilities for the purchase of assistive technology devices and services.

For more information contact the Guam System for Assistive Technology (GSAT) office at **735-2490** or email at **gsat@guamcedders.org**.

Guam Developmental Disabilities Council

Upcoming Events

Guam Developmental Disabilities Council

General Membership Meeting

January 14, 2009	**March 11, 2009**
11:00 a.m. to 2:00 p.m.	11:00 a.m. to 2:00 p.m.
Hilton Resort & Spa	Hilton Resort & Spa

Guma' Mami's
Consumer Christmas Party
Saturday, January 3, 2009
12:00 Noon
Sinajana Mayor's Office

For more information call
Kristina Perez at **735-9127**

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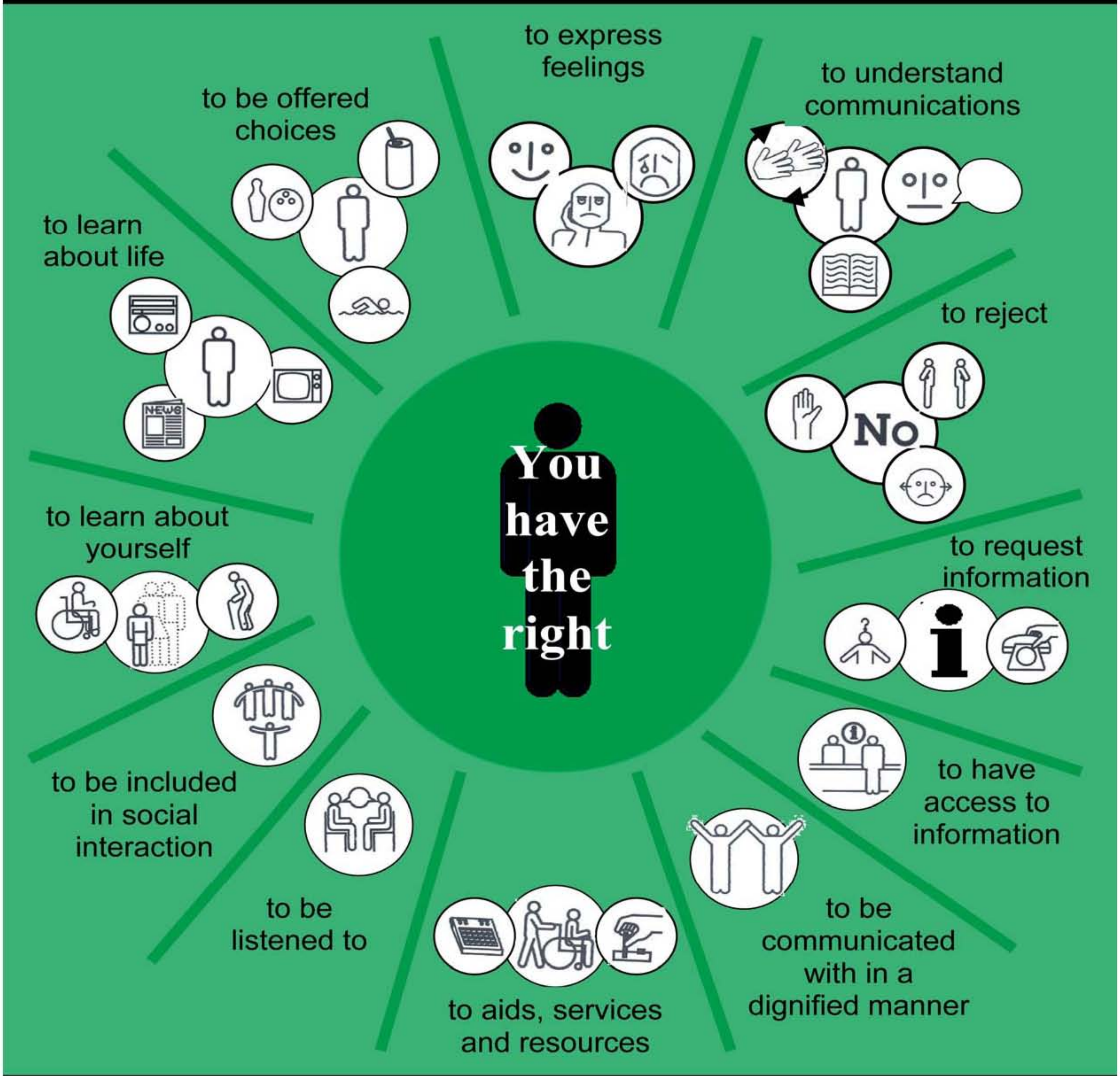
Alternative formats (e.g. Braille, large print, or audio tapes) of ***I Linå'lå-ta*** will be made available upon request. Please contact Margaret Johnson at 735-2477 (v), 734-6531 (TTY), or 734-5709 (fax) or margie.johnson@guamcedders.org for more information.

The Communication Bill of Rights



You have the right

- to express feelings
- to understand communications
- to reject
- to request information
- to have access to information
- to be communicated with in a dignified manner
- to aids, services and resources
- to be listened to
- to be included in social interaction
- to learn about yourself
- to learn about life
- to be offered choices

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PH. (03) 9843 2000, FAX. (03) 9843 2033, Email. crc@scopevic.org.au

Resources for Identifying, Borrowing, and Purchasing AAC devices on Guam


Hip Talk Plus Communicator

1. **GSAT (Guam System for Assistive Technology) can:**
   - ★ Help you identify which AAC device is right for you,
   - ★ GSAT has the following devices:
     - Cheap Talk 8 Direct & Scan w/Jacks
     - Cheap Talk 4 In-Line Direct, Scan, & Jacks
     - Communicator 4-Compartment w/ Speech & Lights
     - Hip Talk Plus
     - Super Sized Communicator
     - Symbol Communicator
     - Compact 4 Message Communicator
     - On-the-Go 7-Level Communication Builder
     - Partner/Two—Double Message Communication Device
     - Partner/Four—4 Message AAC Device
     - Super Talker
   - ★ Demonstrate any of the several AAC devices or communication boards they have in their inventory,
   - ★ Lend you a device of communication board through their 30-day loan library,
   - ★ Help you find where you can obtain the desired AAC device, and
   - ★ Provide funding options to purchase AAC or other assistive technology (AT) devices through their GOAL AT (Guam Option for Alternate Loans for Assistive Technology) and their Get Guam Teleworking program. You can reach them by calling 735-2490 (voice) or 735-2491 (TTY).
2. Guam DVR (Division of Vocational Rehabilitation) can:
   - * Fund purchase of necessary AAC and AT devices and services for postsecondary education, employment, or your own small business.
3. DISID (Division of Integrated Services for Individuals with Disabilities) has:
   - * A grant program which allows funds to be used for purchasing AAC devices
4. Medicare – if medically necessary (fund AAC devices and services that are medically necessary)
5. Tri-Care – military insurance that can fund AAC devices and services if it is medically necessary
6. Medicaid – if you are Medicaid eligible, it MAY be covered again if it is medically necessary
7. Special Education – if written into the IEP and it is necessary for access to a Free and Appropriate Public Education.
8. Non-Profit Financial support may be available through:
   - ★ Churches
   - ★ Civic Organizations, such as the Rotary Club,
   - ★ Young Men's League of Guam, Chinese Association of Guam,
   - ★ Disability-specific organizations such as, Parkinson's, Down Syndrome, Autism

Remember when looking for funding, you need funds for the AAC device as well as the services to learn how to use the device.


Direct 8 Scan & Jacks


Symbol Communicator