



DEVELOPMENTAL DISABILITIES DIVISION

BULLETIN

Winter 2007

<http://www.hawaii.gov/health/disability-services/developmental/current-dddbulletin.pdf>



The mission of the Developmental Disabilities Division is to assure community based supports and services for persons with developmental disabilities through the principles of self-determination and person-centered planning.

Welcome to the Developmental Disabilities Division's (DDD) combined news bulletin with information from Division Administration, Case Management and Information Services Branch, and Disability Supports Branch (Neurotrauma). The DDD news bulletin is a means to communicate Division happenings.

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WINTER 2007
BULLETIN

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“...OF COURSE PEOPLE WITH DEVELOPMENTAL DISABILITIES CAN WORK”

The Developmental Disabilities Division (DDD) knows people with developmental disabilities can work and we believe that our community is enhanced when the diversity of Hawaii is represented in our workforce. Businesses that employ people with developmental disabilities know these workers are capable, effective, and a true asset to their companies. In addition, several individuals served by DDD have shown unique skills and talents through entrepreneurship and self-employment.

As part of our commitment to increase integrated employment options for people with developmental disabilities, DDD has enlisted the help of local and national partners. Locally the Center on Disability Studies



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Monica Perreira showed off her artwork

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Developmental Disabilities

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(CDS) and its Medicaid Infrastructure Grant (MIG) is working on removing employment barriers including how to keep necessary benefits and services.

Nationally DDD and CDS have partnered with the State Employment Leadership Network (SELN). The SELN, headed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute on Community Inclusion (ICI) is a collaboration of 13 states whose role is to develop more effective employment systems and share resources for systems change.

In October, an all day meeting and retreat hosted by MIG brought together major stakeholders in this effort including service providers, Vocational Rehabilitation (VR), individuals with disabilities, and their families. These gatherings were held to assess and review state policies, practices, and strategies impacting integrated employment. As a result, a collaborative plan of action was approved, the Hawaii SELN Work Plan.

In November, another retreat with the Hawaii State Council on Developmental Disabilities further coordinated our joint commitment to employment and their Employment and Education Committee has agreed to act as the advisory body for the SELN Work Plan.

Together we can surely support individuals to engage in their communities through work and

activities they enjoy that result in money in their pockets without a loss of necessary benefits and supports. If you are able to contribute to this effort please

contact Calvin Ebesutani at 733-9191.

Of course people with developmental disabilities can work.



Kimberly Arakaki (left), led a discussion group of case managers, (around the table starting back left) Ray Ho, Les Chinna, Jessie Fernandez and Christy (from Division of Vocational Rehabilitation)

Hi, my name is Isaac Lau and I do Saori weaving and it's based out of Japan. I like weaving because weaving can remind us about life and how we must treat each other. Weavings are long and are very colorful. Every part is different but they complement each other. We are all different but we can learn from each other. If you pull out one of the threads in the weaving, the weaving will fall apart. We all live in this world so we should learn to get along with each other. It's not important of how you look on the outside as what's in your heart. It's not so much a matter of how you look as it is a matter of how you treat people, respect them, learn about them and who knows you might find out that they are not that different after all.



Isaac Lau, Vice President with VSA arts Hawaii, shared experiences about weaving

“HEART OF GOLD”

By Karen K. Lwin, Case Manager, Case Management Unit 1

In the fall of 2007, eight Special Olympics Hawaii athletes featured in the last issue of this newsletter competed as members of Team USA in the 2007 Special Olympics World Summer Games in Shanghai, China from October 2-11. Preparations and training leading up to this event included a four-day training camp at Vanderbilt University Nashville, Tennessee with their two coaches and one staff member.

At the World Games, out of 7,000 athletes from 165 countries, was athlete Leanne Ngai, a 27 year old, power lifter.

For those of us who know her, Leanne can be soft spoken and shy at times, but once she steps on the competition platform, she changes into a powerful and energetic young woman who puts all her effort into each lift. But nothing changes Leanne’s heart which is made out of gold. She is sweet, kind and caring, and has many friends and staff members who love her at Goodwill



Leanne Ngai with her 4 gold medals

Industries, Inc. where she attends Adult Day Health on a daily basis.

No wonder Leanne not only brought home one gold, but four gold medals to make us proud!

Her favorite lifts included squat, bench, dead lift and combination where she won all categories. For this competition, Leanne trained an average of two hours a day/five days

a week at one of the most popular gyms. She also watched what she ate and lost a total of 30 pounds.

Leanne has been interested in power lifting since she was 16 years old, while attending Kaimuki High School. “It makes me feel powerful and give me strength,” she added. Leanne believes in this year’s Special Olympic motto, “I know I can.” She also shared that highlights of her trip were meeting new friends from all over the world, eating delicious foods and going to Knott’s Berry Farm in Los Angeles before heading home. “China was hot and dusty” she says, “but it was worthwhile.” Her advice to those interested in competing: “Join Special Olympics and get a good coach!” Leanne’s next goal: to compete in more World competitions.

Congratulations Leanne, you have a heart of gold, and we are all so very proud of YOU!

9 GOLD, 19 MEDALS IN ALL

Hawai’i should be proud of its 2007 Special Olympics World Summer Games delegation. Our eight athletes came home with 19 medals — nine of which were gold. Besides Leanne Nagai of Honolulu, who won four gold medals in the bench press, deadlift, squat and powerlift combination events. Kealakekua’s Ray Donager, 40, won three gold medals in the men’s category for bench, squat and combination. He also took third in the deadlift.

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Leanne Ngai, second from right, joins fellow medalists on the stage at the 2007 Special Olympics World Summer Games in Shanghai, China

Olympic Medals

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Other winning athletes included Sean Hively, 28, of Waimanalo; Natalie Miyahira, 25, of Kane'ohe; Nicole Kelley, 32, of 'Ewa Beach; Zachary Mar, 17, of Honolulu; Jennifer Wong, 25, of Kane'ohe; and Solray Duncan, 29, of Pearl City. In golf, Sean Hively won gold in the 9-hole competition and Natalie

Miyahira placed fourth in the women's 9-hole competition.

In swimming, Nicole Kelley placed first in the 200-meter backstroke and third in the 100-meter freestyle. She also placed second in the 200-meter freestyle and second in a 100-meter freestyle relay with three other U.S. team members. In the men's division, Zachary Mar placed second in the 100-meter butterfly, third in

the 200-meter freestyle, and fourth in the 100-meter freestyle.

In track and field, Jennifer Wong placed second in the 800-meter run, third in the 1,500-meter run, and fourth as part of the U.S. women's team in the 400-meter relay. Solray Duncan placed third in the 3,000-meter run, fifth in the 1500-meter run, and his team placed third in the 400-meter relay.

LEGISLATIVE PROCESS SELF-ADVOCATES AND FAMILIES PARTICIPATION

The 2008 Hawaii State Legislature began its annual 60-working day session on Wednesday, January 16, 2008. It will end the first week of May. As part of your citizen responsibilities, you can attend hearings and provide testimony in writing and orally on the bills you want to express your concerns or views. The Legislature has a Public Access Room (PAR) that provides citizens the opportunity to conduct business at the Legislature. The Public Access Room provides:

- Computers for drafting testimony on legislative issues
- Internet access as a resource for legislative and State government information
- Photocopying services for testimony
- Distribution of testimony submitted via fax and email
- Legislative Documents: Hearing notices, bills, resolutions, referral sheets, journals, Orders-of-the-Day, and Governor's messages

- Reference Materials: Hawaii Revised Statutes, auditors reports, Legislative Reference Bureau reports, informational handouts, and books and pamphlets on effective lobbying
- Workshops on legislative process, useful internet sites, writing and presenting testimony and reading and understanding legislative documents, and
- Expert staff to provide answers and information legislative matters and government affairs

The Public Access Room is located at the State Capitol in Room 401. During the session, it is open from

Monday to Friday, 8 a.m. to 6 p.m. and Saturdays, 8 a.m. to 2 p.m. During non-session, it is open from Mondays to Fridays, 9 a.m. to 5 p.m. If you have any questions, please call the office at 808-587-0478, fax at 808-587-0793, or email at par@capitol.hawaii.gov. Testimonies can be emailed to testimony@capitol.hawaii.gov. For neighbor islands, call toll free:

Hawaii: 974-4000 ext. 7-0478

Maui: 984-2400 ext. 7-0478

Kauai: 274-3141 ext. 7-0478

Molokai: 1-800-468-4644,
ext. 7-0478

Lanai: 1-800-468-4644, ext. 7-0478



If you have access to a computer, you can check the Hawaii State Legislature website to find out when bills will be heard at: www.capitol.hawaii.gov. If you have wireless capability on your computer laptops and

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Legislative Process

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notebooks, the Capitol now has **free wireless Internet connectivity** in the PAR office (room 401), as well as House and Senate conference rooms, the auditorium, certain areas of the chamber-level hallway, and the central corridors along railings on the 2nd, 3rd, and 4th floors.

Orientation about the Public Access Room services is conducted by their staff. There is also a series of workshops from January to March of each year. Please contact the office for a workshop schedule or go to their website, www.hawaii.gov/lrb/par and click on the **Workshops** page to learn more about:

- The Legislative Process and Citizen Participation
- Reading and Understanding Legislative Documents, and
- Useful Internet Sites

NEW CMIS BRANCH CHIEF



Kimberly Arakaki (left) with David Fray (right), Developmental Disabilities Division Chief

Kimberly Arakaki is the new CMIS Branch Chief effective December 4, 2007. She previously was the supervisor of the Branch Training Team that provided training and informational sessions to case managers, providers, caregivers, and other state agencies and individuals served within the Developmental Disabilities Division.

She holds a Master of Counseling degree from Chaminade University and has been with the Branch for 14 years. Previously, she was a supervisor at the Waimano Training

School and Hospital and has worked within the private sector. Congratulations to Kim on her promotion.

Mahalo to Kevin Dierks who served as Branch Administrator and Acting Branch Chief for eight months prior to Kimberly's assuming the Branch Chief position. Kevin will continue to be in the Branch working on individualized budgeting, utilization management and employment of individuals with developmental disabilities.

MY ROAD TO SUCCESS

By Dara Fukuhara

The word "independence" can mean different things to different people. Edward Gibbon, the renowned English historian, called it "the first of earthly blessings." Unfortunately, for most people with disabilities, the blessings of independence come with limitations and restrictions. However, there are ways to overcome them. Let me briefly tell you my story.

At age 3, my doctors diagnosed me

with Charcot Marie Tooth disease, a neuromuscular condition that affects the peripheral nerves and is usually characterized by the slow degeneration of the muscles of the feet, lower legs, hands and forearms. While I could walk when I was a child, by age 13, I was wheelchair bound. Today, I rely completely on



others for assistance at home and work. I need help dressing myself, feeding myself and even pushing an elevator button to get to my office – simple, everyday things most people take for granted.

When I was growing up, I had goals – attending and graduating from a university, getting a job and living a fulfilling life. And despite my

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Road to Success

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physical challenges, I DO live a fairly independent life.

As a sophomore in high school, I dreamt of being a journalist. My family and teachers encouraged me to pursue my goals. I spent my high school years writing for the school newspaper, Na Hoku O Moanalua, and became the Editor-In-Chief in my senior year. I graduated magna cum laude from Moanalua High School and enrolled at the University of Hawaii at Manoa.

I brought my passion for writing to UH and joined the staff of the college newspaper, Ka Leo O Hawai'i. While some people may have looked at my wheelchair and doubted my ability to work as a reporter, using a battery-powered wheelchair, I went to my interviews; holding onto a pencil with both hands, I taught myself to type fast; and using a tape recorder, I taped my interviews in lieu of scribbling notes on paper.

These alternative paths to independence enabled me to write my stories and meet my deadlines.

However, not satisfied with just being a writer, I worked hard to prove, if only to myself, that I was capable of doing the job of an editor. I gradually worked my way up from the position of features editor to, eventually, the job of managing editor. And in 2002 I graduated with a bachelor's degree in journalism.

While I was in college, I started receiving assistance from the Division of Vocational Rehabilitation (DVR) Services at the State Department of Human Services. DVR funded my personal

care attendant, Greta Balabagno, who assisted me with my personal care throughout my four years at UH and, with the help of other government programs that DVR led me to, for several years after college. It was the help that Greta provided – and her successors in that work – that made it possible for me to accomplish all that I did.

After graduating from UH, I worked two years as a freelance writer for MidWeek. Freelancing gave me the opportunity to work from home. I decided to put my skills as a journalist to work and also started my own small business as a media consultant. DVR enabled me to start my own business by purchasing a laptop computer so I could produce my stories and manage my finances.

DVR played an integral part in helping me achieve my educational and career goals. After experiencing freelance writing, I reached a point in my career where I wanted a change. Following the advice of a good friend, I decided to go into public relations and got a position at Communications Pacific, the number-one public relations firm in Hawaii.

Working at Communications Pacific was the best career move I could ever make. I have found my true calling in PR. I love helping clients achieve their goals, and I have met many influential business and community leaders. And it was CommPac's CEO, Kitty Lagareta, who nominated me to serve on the gubernatorially appointed Statewide Independent Living Council, which I currently vice-chair.

I am very fortunate to have been able to take advantage of these excellent opportunities. But my road to success has had its bumps

and bruises. I found that if I worked full time, I could jeopardize my government benefits, most importantly the vital funding for my personal care attendant, who makes it possible for me to work in the first place.

Federal Supplemental Security Income benefits and state-funded nursing services are sometimes jeopardized due to employment. Additional income adds to a person's assets and benefits could be eliminated or drastically reduced. This is one of the main concerns I face if I were to get a raise or find a job with higher pay.

I decided to accept this risk because I could not continue living with the fear of the government controlling what I do with my life. Why should anybody have to live like this? But many people with disabilities do.

For a variety of reasons, people with disabilities are often discouraged from working. Many go to college and graduate with a degree. But once they discover that their benefits may be lost by getting a job, they stay home and collect welfare.

It is also unhealthy for society at large, which not only loses the economic and social benefit of this "human capital," but must actually pay for their maintenance when they might otherwise be earning their keep, contributing to society and paying taxes.

A new survey released by the National Organization on Disability showed that employment of people with disabilities has not improved despite the Americans with Disabilities Act (ADA).

The ADA prohibits discrimination

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Road to Success

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against people with disabilities, yet the employment rate for those with disabilities has been nearly flat for almost 20 years. In 1986, only 34 percent of working-age people with disabilities had full-time or part-time jobs. In 2004, the figure was only 35 percent. In 18 years, that is an increase of just ONE percent.

People with disabilities should not be penalized for seeking to live independently. They should not be consigned to a life of welfare or institutionalization.

On the contrary, they should be encouraged to work and contribute. But enabling people with disabilities to work requires a new way of thinking about dependency and independence, that “first of earthly blessings.”

It requires a fresh look at how providing the assistance needed to put people in the workforce is a solid economic as well as social investment. It requires, before any of this can happen, much broader public awareness than exists at present. That’s why, as a first step, it requires your awareness and your help in getting the word out.

WE CAN HELP !

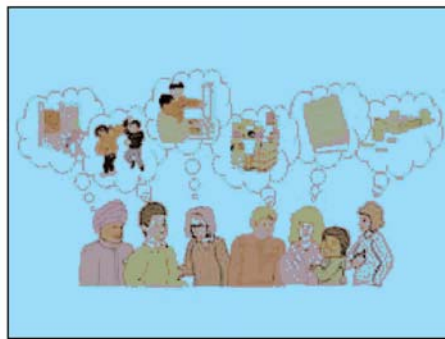
By Laura Kinkley, Case Manager, Case Management Unit 1

Vernon is a 50-year-old, part Hawaiian man who lives by himself at Palolo Housing. Vernon found happiness living independently because he can be free to do whatever he wants, he can wear what he likes, and the people there are friendly with him. He needs a lot of help to be able to remain independent. He said many times that he would rather die than be institutionalized.

Vernon was admitted to the Developmental Disabilities Division (DDD) in 2001 after a long hospitalization at Queen’s for cellulites of the left leg. He almost lost his leg, according to Queen’s, because the infection was neglected for so long. Vernon does not have anybody to look after him.

Vernon has a long history of not taking good care of himself. Many, many years ago (he did not remember when) he had a mosquito bite on his left foot. It got infected after much scratching, it worsened over time, and it became severe chronic cellulites.

According to his friend Renee, back in 2001, the leg with cellulites got severely infected and was not treated



until the smell became unbearable. Renee called the police to escort him to the hospital. Luckily, the hospital was able to save his leg.

At Vernon’s first meeting with a DDD case manager upon release from the hospital, he was very reluctant to receive any services. He said, “I don’t want somebody to come here and tell me what to do or how I should live my life.”

After long periods of consistent, frequent visits and a lot of patience, the case manager was able to gain Vernon’s trust. He was willing to accept services and listen to advice. Over the years, his cellulites got infected several times and each time the case manager was able to convince him to see his physician. With the help of the Case Management Branch’s nurse, he got treatment before it became worse.

A few years ago, Vernon finally agreed to receive Medicaid Waiver services to help him care for his foot and help with medication on a daily basis. The nurse constantly monitors his health, helps him communicate with his physician, and explains the treatment he receives. Now that Vernon understands the value of caring for his health, his compliance to treatment is excellent. Vernon is now seeing his primary care physician once every two weeks on a regular basis.

The Partnerships in Community Living (PICL) program assisted Vernon to access other support that he needed that could not be covered by Medicaid Waiver services. Accessing these support has helped him to remain independent and to be able to live more comfortably in his home.

The services he receives from the DDD help him to continue living independently in the community of his choice. Vernon said he is very happy and likes the way everything is now. Without the DDD Vernon would not have the life he wants.

RECREATION ACTIVITIES AT PARKS ISLAND-WIDE

Like to do line dancing? Exercise? What about learning to cook simple dishes or snacks? Or are you looking for other kinds of recreation activities? The City and County of Honolulu Department of Parks and Recreation (DPR) is the place to go. With over seventy parks on the island of Oahu with hundreds of different classes, activities and events, you will surely find something to fulfill your interests. There are activities for children, teens, adults and senior citizens. Many are free or available for a small fee.

Programs are held in the spring, summer and fall. Information on programs, a list of parks, telephone numbers, types of activities, and the areas offering them appear in the MidWeek newspaper approximately one week prior to registration for each term. For additional information on fall and other activities, visit the internet site <http://www.co.honolulu.hi.us/parks/programs/index.htm>.

Individuals with a disability can bring someone with them to provide assistance. Or they can register on their own and request assistance from the park. In an effort to promote full inclusion, the DPR has

hired Inclusion Aides to plan and implement reasonable modifications of programs and services, as needed, to include people with disabilities into the community recreation programs. The intention is for people with various disabilities to be able to actively participate in the programs.

The Aides will foster independence



and encourage participants to do as much as they can without assistance. They will communicate and contribute ideas to the leaders of the program activities, as well as modify the activities for individuals with disabilities. They will also communicate with parents, guardians, caregivers, teachers, and/or supervisors, and participants, to obtain consents and information on how to assist the participants so there is consistency between home, school and/or work, and the park.

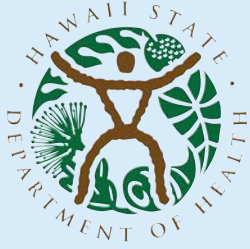
If an accommodation



such as an Inclusion Aide, (who can develop and provide reasonable modifications for individuals with disabilities), modification to the program, adaptive equipment, etc., is needed, remember to make the request when registering. Some examples of support that can be made upon request are:

- Sign Language interpreters
- Material in alternate formats such as Braille, large print, cassette tape, computer disk
- Assistance with registration
- Adapted equipment, modified rules or procedures
- Positive Behavior Supports
- Support staff (they do not provide personal care)
- Accommodations for Non-DPR Support personnel to accompany you. (No registration fees will be charged for the companion, however the participant is responsible for any additional fees for excursions, etc.)

Programs at all parks encourage full access and are tremendous opportunities for community inclusion. For additional information and questions on accommodations, contact the program director at your nearest playground or the Therapeutic Recreation Unit of the DPR at 692-5750.



NEUROTRAUMA SUPPORTS

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If you have Microsoft Windows media player, check our website: www.hawaii.gov/health/disability-services/neurotrauma/index.html for videos on-line. Videos that are relevant to survivors of brain, spinal cord injury and stroke will be shown periodically.

For information and resources, or to suggest topics of interest for this newsletter, call the Neurotrauma Helpline at 808-453-6151.

TREATING MINI-STROKES QUICKLY IS KEY

The Associated Press has reported two studies that could change standard treatment and potentially save millions of people from stroke's damaging effects. British and French doctors found that patients treated within 24 hours of having a mini-stroke cut their chances by eighty percent of having a more serious stroke in the next three months. Mini-strokes, or TIAs (transient ischemic attacks) have the same symptoms as a large stroke including facial numbness, slurred speech, weakness or paralysis on one side of the body, blurry vision or a sudden headache. Formerly, the British standard of care was to refer a patient to an outpatient clinic, wait about three weeks, then prescribe aspirin (typically) or other drugs to lower blood pressure and cholesterol and prevent clotting.

With the new treatment, patients are given those same medications within 24 hours of a suspected mini-stroke.

Results found that those treated immediately had only about a two percent chance of having a major stroke within the next three months, compared to about ten percent for those who were not treated as quickly. In the French study, a 24 hour clinic was set up to treat patients with suspected mini-strokes. The chance that these patients would have another stroke within 90 days was slightly more than one percent, compared to a predicted stroke rate of nearly six percent. "The main message from these studies is that treatment delays can be dangerous."

NASHIA CONFERENCE 2007

Elzy Kaina, RN/CM from the Rehabilitation Hospital of the Pacific and the Chair of the STBIAB, and Ken Fukuhara,

Neurotrauma Supports staff, attended the National Association of State Head Injury Administrators 18th Annual State of the State in



Elzy Kaina and Ken Currier, NASHIA Executive Director

Head Injury Meeting held in St. Louis, Missouri in September. This year's meeting attracted more than 160 agency administrators, professionals, state Brain Injury Association leaders, and advocates from 45 states and

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NASHIA Conference

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territories. The theme, "Gateway to Solutions: Doing What Works," gave direction to the informative and stimulating training that was delivered in keynotes as well as workshop sessions.

In a general session, Jean Langlois, senior epidemiologist with the Center for Disease Control and

Prevention, described the impact of TBI in the U.S. and planning for improved identification of TBI among military personnel after bomb blasts. Participants were educated on new state-based TBI data resources and materials for educating TBI professionals and the public.

Elzy attended a workshop on "What Works in Florida: Injury Prevention for Children, Youth and Older Adults." It highlighted initiatives

that demonstrated collaboration and education of health educators, law enforcement, emergency services personnel, and other safety advocates to address bicycle safety, concussion in sports, drunk driving, and falls. She was also able to meet the speaker, Sandra Dreker, from the BIA of Florida, who agreed to send her a copy of the initiative targeting law enforcement.

ADVISORY BOARDS

The State Traumatic Brain Injury Advisory Board (STBIAB) held its annual meeting in July with members developing their goal and objective for the 2007-2008 year. This year's goal is to increase the knowledge of law enforcement agencies about Traumatic Brain Injury (TBI). The objective is to assess the current knowledge of the Honolulu Police Department on TBI. A guest speaker at the meeting was Dr. Kent Yamamoto, psychiatrist from REHAB Hospital who spoke on Mild TBI. Neurotrauma staff provided a brief overview of the 1115 Waiver Application and members were able to review and give input on the

neurotrauma waiver menu of services.

At the Neurotrauma Advisory Board meeting in August, members were informed that the menu of services recommended for the waiver amendment was submitted to DHS and is now awaiting its response. Staff presented a power-point overview of the 'Club House' model whose members usually have some mental health involvement. A proposal was made to utilize the basic concepts and adapt them to develop a similar program for persons with neurotrauma. Further research will be done to investigate existing 'Club Houses' that serve

persons with brain injury.

The STBIAB meets on the third Friday of odd months at the Capitol Center, 1177 Alakea St., Rm. 302; and Neurotrauma on the fourth Friday, even months at the Kalanimoku Bldg., 1151 Punchbowl St., Basement, and the State Bldg. in Kapolei on Oahu.

Both meetings can be accessed via the State video conference centers (VCCs) on Maui, Hawaii and Kauai. Meetings are from 1:30 to 4:00 pm and open to the public. Call 453-6295 for the specific dates, times or more information.



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Director of Health