



Medicaid Recipients Fighting To Keep PCA & Chore Services

Did something funny happen during your Annual Medicaid PCA or Chore Service Review this year? If so, then you're not alone. SAIL has been hearing numerous complaints from individuals around Southeast who have lost services after an assessment occurred in their homes.

It seems that these visits often occur on very short notice (as in, "We'll be there in the morning") or on weekends, which often eliminates the opportunity for a care coordinator or independent living advocate to be present. Some Medicaid recipients said they weren't even sure for what they were being evaluated.

INSIDE THIS ISSUE:

Medicaid News	1
SILC Legislative Priorities	1
Deaf Community News	2
Haines Office News	2
Juneau Office News	3, 4
Juneau ORCA	5
Ketchikan Office News	6
Sitka Office News	7
Pick, Click, Give Campaign	8

Many people with disabilities are proud of what they can do, and with good reason, but this kind of pride can hurt an individual's chances during an assessment. If a person can do a task such as dressing or toileting on most days, but not on a few days, and the Assessor hears this from you directly, then they must mark that you can do that task.

So, if the assessment sounds like a game of hide and seek, then it is time to make a plan for when you get a knock on the door or a phone call asking if you are available in the morning for an Assessment. Here are some tips:
 * Prepare your answers about what you can and can't do in advance. Write them down. Do a mock assessment with a friend. * Do not meet with the assessor alone no matter what. You still have rights in America. Use them. Immediately contact SAIL or your care coordinator and your family and friends. Have an advocate and friends/family **(Story continues on page 4)**

STATEWIDE INDEPENDENT LIVING COUNCIL LEGISLATIVE PRIORITIES

The State Independent Living Council (SILC) is comprised of a majority of Alaskans with disabilities who are appointed by the Governor to provide guidance and direction to the State's Independent Living Program through the Division of Vocational Rehabilitation, Department of Labor. Below are the SILC's and the Centers for Independent Living (CIL's) advocacy priorities for the 2009 Legislative session.

Increased funding for Independent Living, DOLWD

We encourage the Legislature to consider increasing funding for Independent Living services to the \$300,000 that was requested by the Centers. The total average cost of independent living service in Alaska is \$2467/ person with the State's contribution being \$320 per person. The FY 09 State General Fund contribution to IL Rehabilitation in the Department of Labor budget is \$888,300.

Increased funding for Home Modification and Home Barrier Free Access (DHHS)

Alaskans with disabilities who live in rural, as well as urban communities prefer to remain in the home of their choice until the end of their lives. Unfortunately, individual residence & community architectural accessibility, especially in rural Alaska, is extremely limited. **In addition, the SILC and CIL's supports the following:**
Increased funding for the expansion of the Aging and Disability Resource Centers—Now that the State of Alaska Division of Senior and Disability Services has assumed leadership of the ADRC program, increased funding will be needed to sustain the expansion of this valuable program. **Home and Community-Based Services Rate Reviews**—Establish regular and periodic rate reviews and adjustments for all home and community-based service providers serving beneficiaries. **Adult Dental Services**—Reauthorize the adult dental Medicaid services to avoid costly and potentially catastrophic dental emergencies later in life. **Alaska Housing Trust**—Enact legislation creating the Alaska Housing Trust with appropriate sufficient funds to support meaningful services through the housing trust. **Public Transportation Fund**—Establish an Alaska Public Transportation Fund for coordinating a public transportation system. **Name change for Governor's Committee on Employment and Rehabilitation of People with Disabilities, and update to regulations.**

Need an interpreter?
Call us!

Deaf Community & Interpreter Referral Line News

By Pam Mueller-Guy

How to Reach Pam Mueller-Guy, SAIL's Deaf Services & Interpreter Referral Line Coordinator:

TTY users can call direct 907-523-5285, my VRS, auto-answer & message machine. Hearing callers can use Video Relay Service (VRS) number 1-866-563-9886, will automatically go to an e-mail message to Pam if she is not available. If you can't reach Pam and need immediate services during regular business hours (Monday through Friday, 9am-5pm), you can also call the Juneau SAIL office 907-586-4920 Voice/TTY, toll free in AK 1-800-478-7245, and/or Fax 907-586-4980. You can email Pam at psmguy@sailinc.org. For interpreter requests after work hours, on holidays or weekends, please use the IRL pager: 907-463-7490.



Deaf and Hard of Hearing, Late Deafened and Older Alaskans with Hearing Loss Support Group meets on the following dates. Please join us! Interpreters, ASL students, family and friends are welcome too!

IMPORTANT CHANGE!! THE DEAF SOCIAL LAB (previously held on the 4th Wednesday of the month) HAS BEEN POSTPONED UNTIL FURTHER NOTICE DUE TO LACK OF PEOPLE

Silent Dinner ~ 1st Saturday of the month: Downtown Bullwinkles: January 3, and February 7; 5-6PM Silent Dinner at Downtown Bullwinkles, located at 318 Willoughby, Remember: No Voices! It will cost a penny to talk with voice. Brown bag or order from the menu.

Deaf Coffee ~ 3rd Friday of the month 7-8PM Tres Hermanos Restaurant at Mendenhall Mall: Come eat and chat with us.

Closed-captioned movies have not been set up yet at Gross-Cinema Theater. Remember: Please ask the staff of Gross-AK Cinema Theaters to have closed-captioned movies every month!

Sorenson Videophone or D-link Videophone applications are available through Internet to sign up. Nick or Aaron will come down to help set up for Sorenson Videophone --he needs more customers first—so please sign up! [Requires 5 & up applicants!] or Please contact Pam Mueller-Guy at SAIL Office 907 523- 5285 TTY or by email address: psmguy@sailinc.org or check website www.sorensonvrs.com for the online application to sign up. Also prices for our area check online: <http://gci.com/business/internet/livewire.htm> or <http://acsalaska.com/consumer/c-internet/c-i-services/dsl/area1a.stm>

This Turkey Ice Sculpture was featured in the Juneau Empire on Thanksgiving Day. The sculpture was created by SAIL's long time friend, Brian Johnson! With all the new snow this Holiday Season—we wonder what Brian has in store for us next!! Stay tuned to this newsletter for more pictures of his great work. Thank you Brian for sharing your fun with us!

...HAINES SAIL...

Sam Jackson of Haines looks forward to traveling to Juneau once a year. He saves for it all year long, but it isn't always financially feasible for him to save enough money to pay for his travel expenses for himself and a support/care provider. This year Sam will be making the annual trip thanks to a small stipend from the CARE (Culturally Aware Recreation and Employment) grant, a joint project between Tlingit and Haida Central Council's Tribal Vocational Rehabilitation (TVR) program and SAIL. "I can't wait" he said of his upcoming trip, "I'm going to eat Chinese food, go to McDonalds, go to the Lions Club's annual basketball tournament and see my sister too!"



SAIL Kicks Off Annual Drive

SAIL's annual fundraising campaign will be running through the end of February to raise the necessary funds to support both our Independent Living (IL) and Outdoor Recreation & Community Access (ORCA) programs. If you receive this newsletter, it is likely that you, a family member or your neighbor has benefited from SAIL's services in the past. The IL Program provides peer support, skills training, & adaptive technology to help individuals' live full lives independently in their own homes. Our ORCA program has challenging activities designed to increase self confidence and physical strength, while also building on those critical IL skills. As a non-profit, we depend on annual fundraising, particularly in these times of economical uncertainty and shrinking grant funds. We realize that it might seem like an illogical time to ask for a financial contribution, but it is times like this when the need is the greatest. Your contribution will not only help seniors and people with disabilities live with dignity, but they will also speak volumes to our other funders about the value of these services, and will allow us to continue offering the services upon which you and your neighbors depend. If you are able to donate to SAIL this year, an envelope is inside this newsletter. You will also be receiving a letter in the mail in mid January. Thank you in advance!

...JUNEAU SAIL...

ANNUAL GALA SELLS OUT

SAIL's annual auction was a huge success this year! Over 250 people attended the event, many there to hear our guest speaker, Ryan Knighton, speak about his many journeys he has taken, including his most challenging journey of his life, his slow descent into blindness. With the help of Western Auto Marine, and Alaska Glacier Seafoods Company, Ryan came to Juneau to speak to SAIL consumers, donors, and to the others who attended our auction this year. SAIL raised over \$30,000 to continue our mission to promote equality and opportunity for all seniors and people with disabilities in Southeast Alaska. More information on Ryan Knighton can be found on his website at: www.ryanknighton.com. Special thanks goes out to all who attended, as well as our businesses and individuals who generously donated auction items, the dessert makers, our tireless volunteers and to our table sponsors. Next year the event is slated for October 2, 2009. Watch our website www.sailinc.org for more details this summer following the conclusion of our popular summer event *Only Fools Run At Midnight-6/27/09*.



Ryan Knighton speaks during SAIL's Annual Dinner in Juneau.



WHAT IS AN ADRC?

Howdy! I'm Doug Fanyak and I'm pleased to join SAIL as the Aging and Disability Resource Center Coordinator for Southeast Alaskan communities! Now most folks are asking, "What is an ADRC?" Developed by the Administration on Aging and the Centers for Medicare and Medicaid Services, the Aging and Disability Resource Center (ADRC) is a one stop information and referral center designed to assist individuals and family members in making choices for long term care needs. The intent of the center is to minimize confusion, reduce the number of hoops that must be jumped through by a consumer to receive services, enhance individual choice, and support informed decision-making. Whether it's a question of Medicaid eligibility or transitioning from a hospital back to your home, ADRC can assist you and your family to access public and private services within your community! How does ADRC do it? The answer is within our intake process. By assisting with identifying what your needs are and any values or preferences you have, ADRC can then assist you in choosing the appropriate service(s) within our extensive database of private and public pay agencies and providers to meet your needs. Of course the trick to acquiring those services (such as public assistance, housing, adaptive devices ext.) is the paperwork. Ask us to help you find the right forms. Our standardize intake form can be used by other agencies and providers as well! ADRC will always follow-up with any referrals we give to ensure consumer satisfaction! "Does ADRC just help elders?" ADRC is where people of all incomes, ages and disabilities can turn for information! Professionals, family members, concerned neighbors and friends of people with disabilities and seniors are welcome to call on SAIL and our ADRC coordinator! **(ADRC Story continues on page 8...)**

(Site Reviews... continued from page 1) with you to observe and help you clarify your answers. * Ask to video or audio record the assessment for documentation. If not, have someone take good notes.* Be fair to yourself when answering the questions. Let them know what you can't do and can do and how it can vary from week to week.

If you've already been assessed and denied services or had your assistance hours cut, it isn't too late. Contact Alaska Legal Services, your care coordinator, and SAIL for help in filing an appeal. Alaska Legal Services is already representing some individuals in the above situations. While waiting for the appeal, you can still receive services, but if you lose the appeal, then you must pay the State back. Finally, be an advocate for better Medicaid services!

Alaska disability advocates have been expecting the negative backlash against Medicaid personal assistance funding for a while now, as Alaska has consistently been at the top of national lists rating state programs for people with disabilities. But we did not expect services to be cut so quickly to people with significant disabilities!

Kevin Gadsey, Ketchikan Program Director, Independent Living Advocate, and Statewide Independent Living Councilmember (SILC), is starting up the SAIL advocacy machine in hopes that we will be able to stop the cuts in services before this becomes a disaster.

"I'm having flashbacks to what happened in my home state of Tennessee in 2005," Gadsey said. "The governor illegally cut off all in-home services for more than a year to supposedly save the state money. People had to go back to nursing homes. A few people chose to stay in their homes and die rather than go back to the nursing homes....now I know for sure why I am here in Alaska - to make sure that Alaskans who receive in-home services are able to stay in their homes."

We don't expect this to be easy or quick. It may take a campaign to the Legislature in early 2009 to stop these cuts, and that is why we need desperately to hear from you about your experiences. Testimonies from consumers like you can reach the hearts of your legislators in a way that we at SAIL cannot. Contact your SAIL office or e-mail your story to kevin@sailinc.org and be ready to make a difference. Remember that SAIL is consumer-led organization and it is time for YOU to lead!

Press Time Story Update: SAIL has just heard from an Assessment Supervisor with the State of Alaska that beginning in January, assessments will be scheduled by newly hired state clerks at least a week in advance. Changes are occurring, but still send your stories in—it will take all of us to make a permanent change!



RECWORKS PROJECT TAKES OFF!

RecWorks! is a grant-funded pilot project, designed to demonstrate that participation in recreation can build pre-employment and ultimately long-term employability skills. The motto of the program is "From Enjoyment to Employment." The RecWorks! program is focused on transition-aged individuals. It is a strengths-based exploration of talents, interests, and skills. Strengths of participants are identified through a process called "Discovery". Through participation in ORCA, and in concert with focused pre-employment training geared to build on positive employment outcomes, participants are supported and encouraged in their personal development. The RecWorks! philosophy is that positive recreational opportunities build confidence and myriad skills, thereby enhancing an individual's prospects for employment matches. Linni Esther, an experienced job developer for people with disabilities, joined the SAIL team in late October of this year to become the "dedicated" person in the Juneau area for this project. Linni has been actively networking throughout the community to locate participants for the program. She is enjoying connecting with other service providers in the Juneau disability support community and is excitedly working with her first client.

JUNEAU LOW VISION SUPPORT GROUP

The Low Vision support group has moved to the Fourth Tuesday of each month at 1:00pm at the Downtown Senior Center.



JUNEAU ORCA

ORCA enjoyed another wonderfully rainy fall in Juneau, welcoming both new and old participants to a variety of after-school and evening activities. ORCA's many adventures over the past few months have ranged from rock climbing, to cooking, to caroling; all bringing a unique combination of fun, friends, and lots of learning!



ORCA's Young Adventure Club (**YAC**) has come alive again with several new participants joining to discover the wide world of ORCA fun! Middle Adventure Club (**MAC**) and Adventure Club (**AC**) have also enjoyed strong participation, not to mention a wonderful enthusiasm for new exploring new people and places including: career day at Juneau Fire Department, the Juneau Job Center, hot cocoa and s'mores at Skater's cabin and spreading holiday cheer at The Bridge Adult Day program. The Healthy Choices (**HC**) activities continue to be a night of diverse activity and excitement. Continuing on bi-weekly schedule, the Thursday evening HC activities have included: music at the canvas, a play at the Perseverance Theater, a beautiful tram ride, climbing at The Rock Dump, and most recently caroling at Wildflower Court! Finally, ORCA/JAMHI activities have continued to set a relaxing tone for the weekend. Bowling, bonfires, art at The Canvas, and yoga have been but a few of the laid back recreation outings this autumn. Watch your calendars for upcoming activities for all the age groups.

SKIING IS BACK FOR JUNEAU ORCA PARTICIPANTS

Eaglecrest is open!! ORCA is getting ready! Several staff went to Challenge Alaska in Anchorage for ski training and we have begun to train ski volunteers. The ORCA ski program will start skiing Saturdays and Sundays beginning January 3rd. Both full day and Half day lessons are available. Full days are 10am-3pm and half days are 10:30-12:30 or 1pm-3pm. The cost is \$38 for either. Door to door accessible transportation is available for the full day time frame for \$6rt/ \$3ow. Call ORCA for more details or questions.

Aloha ORCA!

For the first time in quite some time, ORCA took a BIG trip this fall! Fourteen folks headed to Oahu for fun in the sun. While we got off to a rough start with some flight delays, from there on out the trip was smooth sailing. Highlights



included swimming at the beach, heading to the zoo, a fun catamaran ride and



visiting the Polynesian Cultural Center. ORCA friends from Juneau, Sitka, and Ketchikan attended the trip. After such a successful trip, there is already talk about another Hawaii visit for 2009! Stay tuned to ORCA flyers and the Full SAIL Ahead Newsletter for announcements.

...KETCHIKAN SAIL...

A BUSY FALL IN KETCHIKAN

SAIL Ketchikan kept a torrid pace during autumn and Disability Awareness Month in October. We partnered with the University of Alaska to bring eight films about people with disabilities to Ketchikan, including Emmanuel's Gift, which was shown at our Community Appreciation Dinner on November 1. More than 50 people attended the Free Dinner and Movie, \$800 was raised for the Ketchikan program via the Silent Auction, and First Bank was honored as the Ketchikan Corporate Donor of the Year.

SUCCESSFUL MENTORING DAY

Ketchikan's 2008 Disability Mentoring Day was a huge success thanks to the support of local businesses and consumer participation. SAIL partnered with Community Connections and DVR to place some 25 consumers at more than 15 businesses. The program was a great learning experience for the consumers as they sampled a wide variety of work. Some even found that their placement was a perfect match for them. All the participating businesses reported positive feedback.

KETCHIKAN ORCALAND

ORCA has been very busy with activities this fall. Each month, we have been cooking deserts for the Monthly Grind then going to the shows to enjoy the entertainment. Other outings have included playing at the rec center, splashing around in the pool, geo-caching, making crafts, a Halloween party, and a fun tailgating event at the Kayhi Homecoming game. The ORCA group has also been exploring the island by hiking each month. These hikes are getting the group ready to go on a Backpacking trip to Denali National Park in the summer of 2009. Each month we go hiking and work on being able to walk further as well as handle rougher terrain. Eventually we will add packs so that we will be ready for a wilderness experience



at Denali. Our hikes happen rain or shine, but everyone has enjoyed the trips and learning a little more about themselves and being prepared for all types of weather. These activities encourage the consumers to be active and live a healthy lifestyle. The group is looking forward to exploring Denali National Park and more of Alaska. Remember that ORCA always welcomes new consumers and volunteers so please spread the word!

...SITKA SAIL...

SITKA ORCA GOING STRONG



Sitka has had several successful ORCA activities this fall since ORCA has been back up and running. However, we recently had an activity that seemed to stand out from the rest. The activity was on November 25th and the plan was to get together and enjoy a Thanksgiving meal. After discussing with my other team members, we decided an even better idea would be to let the consumers each make something to take and share with their own family and friends on



Thanksgiving. Consumers were able to make sweet potatoes and a cranberry raspberry sauce. They loaded up their two dishes and were given the instructions on how to bake the sweet potatoes in the oven. Everyone was



involved and excited about making something to bring and share with their own family and friends on Thanksgiving. This activity went from being fun to identifying and allowing each consumer to show and develop their independence. We even ended by enjoying some home-made pumpkin pie! ORCA continues to promote and engage in safe recreational opportunities for people with disabilities.

We've gone on several hikes and recently visited the Artesian well. Looking forward to 2009 we plan to kick-off with snowshoeing, a trip to the Coast Guard station, and the Sitka High School basketball game. These activities will continue to provide recreation and inclusion opportunities for people with disabilities in Sitka area.

SITKA STAFF GROWS

Barbara Morse joins the SAIL Sitka team as a part time Independent Living Specialist. Barbara was born in Fairbanks but has lived in Sitka since 1990. She has a Masters degree in Recreation Management and has worked extensively in the schools and with other youth programs.

E-mail vs. Snail Mail



Want to get our newsletter in PDF format and stop the paper copies? Just email Danielle Lindoff at dbuster@sailinc.org with your name and email address and your mailing address where you normally get your newsletter, and we'll get you added to the email list!



Shown above: Sitka ORCA participants Marilyn Ungudruk and Barb Kitka walk the Juneau Wetlands trail with ORCA Program Director Kate Walters. Several Sitka consumers visited Juneau this summer for Celebration 2008!

THIS NEWSLETTER IS AVAILABLE IN ACCESSIBLE FORMATS UPON REQUEST. PLEASE CONTACT ANY SAIL OFFICE TO REQUEST AN ALTERNATIVE FORMAT SUCH AS BRAILLE OR LARGE PRINT, OR YOU CAN DOWNLOAD IT FROM OUR WEBSITE AT: WWW.SAILINC.ORG



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CHANGE SERVICE REQUESTED

(ADRC story continued from page 3...) But don't worry too much, the ADRC really is SAIL, and SAIL is an ADRC, we've just added some enhanced features, such as more comprehensive counseling on long-term options to help seniors and people with disabilities best plan for all the twists and turns that life can take! We're still the same teamwork-oriented and collaborative agency you've known over the years, only better. So if you have any questions about how to make your life better as a person with a disability or a senior, call us, we're here to help! Please contact us at 1-800-478-7245 or (907) 586-4920. You can also email Doug at: dfanyak@sailinc.org. For more information about ADRC's go to: <http://www.hss.state.ak.us/dsds/grantservices/adrc.htm> which is the state website or you can check the national web page at: <http://www.adrc-tae.org/tiki-index.php?page=PublicHomePage>

A NEW WAY TO GIVE IN 2009

SAIL is proud to be a part of the new Pick, Click, Give campaign! As of January 2009 Alaskans can now choose SAIL to be the recipient of their tax deductible donation through their PFD. All you have to do is apply for your dividend online and you can choose SAIL (or other non-profits) to receive a donation by you when the dividends are distributed in the fall. For more detailed information on this exciting new opportunity to give to local non-profits, simply go online to: www.PickClickGive.org

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Public Participation is encouraged at the monthly board meetings! They are held every 4th Tuesday of the month at 5:45pm at the Juneau SAIL office. For more information:

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