



**Oregon
Independent
Living**



*News from the Oregon State Independent Living Council (SILC)
Issue # 30 ~ February 2007*

What is the SILC? What is Independent Living Philosophy?

The State Independent Living Council (SILC) is a disability advocacy council that promotes Independent Living (IL) services and IL philosophy ~ the life philosophy that all people have the right and opportunity to make decisions about their lives and pursue activities of their choosing, with the associated responsibilities and consequences. The SILC works to ensure that people with disabilities are not denied these basic human rights.

IL philosophy promotes informed choice, equal access, and full inclusion ~ all contributing to increasing the independence of people with disabilities, and ensuring that people with disabilities can actively participate in families, communities, careers, and recreation... as peers.

The SILC partners with Centers for Independent Living (CILs) ~ non-profit organizations, run by people with disabilities, for people with disabilities. Every CIL provides four core Independent Living Services: 1) individual and systems advocacy, 2) information and referral, 3) independent living skills training, and 4) peer counseling. Oregon has nine Centers for Independent Living.

Executive Director Update ~ Tina Treasure

This quarter seems to have been one of the most difficult and unusual in recent memory. It included challenges, setbacks, delays, disillusionment, and yes, deep sadness. It was so in work and in life, for myself and for many others I know. Implementing special projects was unexpectedly rocky; IL funding and advocacy issues needed extensive attention at a time when staff is already stretched too thin; and Bill Linden ~ one of the CIL's lobbyists in the 2001

successful attempt to get state IL funding, passed away. He was one of what we called "IL's 3 Angels" and we, along with hundreds of others, will miss him terribly. This loss and great sadness led me to look back at Oregon's IL story, Bill's role in that story, and to think about where we've been, where we are, where we want to be, and how to get there.

I think...no I'm sure, it circles back to us ~ to individual efforts that seem too small to matter. But... add one voice, one story, a letter, phone call, email, another voice, another story, and individual efforts form a grass roots movement that builds, grows, and results in positive changes.

And with a new State Plan for Independent Living in development, this seems like a timely realization. CILs and other agencies are understaffed and over-worked, and struggling to provide needed services; it's hard to find time to write letters, make calls, and share views, or we think "someone else will do it."

Yet, the SILC and each CIL started as grass roots groups, and although we are now bigger, stronger, and much busier, grass roots advocacy is where we came from, and it's the core of what we still are, or should be. In order to preserve and increase the opportunities, choice, independence, and inclusion of people with disabilities, it's important that we make time to share our views, voices, and our stories. We ARE the "someone else". And so, the theme of this newsletter is grass roots advocacy ~ re-focusing on planting seeds of change to make a difference ~ voice by voice. From one "someone else" to another... Tina.

Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it is the only thing that ever does. ~ Margaret Mead

The Mission of the SILC is to promote choice, equal access, and full inclusion of people with disabilities, throughout the State of Oregon.

Oregon IL Loses an Advocate and Gains an Angel ~ Tina Treasure

Bill Linden, of Public Affairs Counsel (PAC) passed away last month, at age 55.

Bill, Mark Nelson, and Kaen Mainzer of PAC were the CIL lobbyists who played a MAJOR role in the huge accomplishment of obtaining the first state IL funds in Oregon ever ~ \$1.3 Million for the 2001-2003 biennium.

At the news of Bill's death, I remembered how the CILs and SILC came to know Bill and his colleagues.

He's someone I'll never forget for his kindness and his special gift for making you feel so comfortable in his presence. I still remember so clearly the day Trish Holescher (former Executive Director of UVDN) and I walked into the PAC offices ~ without money or for sure political savvy, to ask this top lobbying firm to represent IL. ~ "IL who?!"

They made time for us, listened with an open mind and caring heart to naive "political outsiders" tell a story about Oregonians with disabilities and their need for greater independence... and how IL could deliver that hope and opportunity to them.

They patiently listened to me tell my story of how IL had given me back my life. Without pity nor condescension, they proceeded to tell us about their services and other clients ~ most with tons of bucks, high profiles, and political clout, who pay PAC more money a year for representation than our largest funded CIL's yearly budget. After we shared our stories, they kindly told us they usually don't take on issues pro bono and then said..."we need to talk this over, call us tomorrow."

Little did we know until many, many months later that the minute we walked out the door, they had looked at each other and said, well I guess we all agree...there's no way we aren't going to do this!!!!

Expect victory and you make victory. ~ unknown

That was the beginning of an unbelievable partnership where the legislature started hearing about IL every day from one of them in many of the hundreds of meetings they hold with legislators on both sides of the aisle, as well as the Governor's office. They were a team. Karen ~ with her persistent, tell it from the heart with an iron fist style; BILL with his subtle, calm professional style of laying out the facts, figures, need, and just why it "has to be"; and Mark, the long-standing, well respected power broker and owner of the firm. What a combination ~ it's no wonder IL not only got name recognition that year, but bucks that were very scarce!

And all the time, and to this very day, PAC says that it was the consumers, CIL staff/ boards and local supporters of IL that made the difference ~ that it was us, not them, that were the heroes. In truth it was IL that was the story, the services that save money in the long run, and the many hundreds of consumers that wrote letters about how IL changed their lives that made the difference, and it always will be. But it was BILL and his colleagues that got people to listen!!!!

That's the way I think we can pay tribute to BILL ~ through keeping IL's dream alive, we keep his work and dreams alive as well. It may well be much harder work this year, but it's up to CILs, their boards, and consumers, the SILC, and all people who believe in IL, to give it our best shot. I know we are all busy delivering services, but we can also recommitment to sharing our views and stories ~ to keep the IL movement alive and moving forward ~ by stepping up ...like BILL, Mark, and Karen did.... and take on this challenge.

After the 2001 legislature approved \$1.3M state IL funding for the first time ever, the CILs gave a plaque to PAC. Among other things, it said: "to our IL angels..." now that's truer than ever for Bill. Sending thank you's and smiles to that angel, as we carry on his work and pursue our IL dreams.

SILC Members

<u>Name</u>	<u>Location/Representing</u>
1. Jack Benson	St. Helens
2. Charlotte Buxton	Ontario
3. Jan Campbell ~ Chair	Portland
4. Brad Collins	Eugene
5. Chuck Davis	Portland
6. Sharon Ely	White City
7. Kristi Laney	Baker City
8. Angel Hale	Salem
9. Wendy Howard	CIL-Klamath Falls
10. Martha Simpson	Florence
11. Frank Synoground	Ex-officio ~ OCB
12. Stephaine Parrish-Taylor	Ex-officio ~ OVRs
13. Glenn Van Cise	CIL-Bend
14. Dean Westwood	Portland
15. Ulee Yanok	Huntington

National IL News

- **NCIL 704 Measurable Outcomes** ~ This national committee is working to develop and implement measurable outcomes that prove the benefits, success, and cost savings of IL services. The draft outcome tools have been shared for input, and training is underway via conferences and training sessions so CILs and SILCs can become familiar with, and provide input ~ it's an opportunity to "drive the bus" instead of riding someone else's... right into the future.
- **Money Follows the Person** ~ Federal funds are available for states to use to help people move from nursing homes/institutions to community based living. DHS/SPD submitted a proposal and they're currently in the process of preparing additional information to respond to questions about their proposal. The SILC submitted a support letter and agreed to serve on a project planning committee if the proposal is approved for funding. We look forward to hearing those funding decisions soon and working in partnership to make what is a good system into an even better one!

Share Your Story!!

Announcing an exciting opportunity for promoting Independent Living (IL)! We want to hear your unique and compelling story. By relating your experience of how you have retained/developed/regained your ability to live independently, you may be able to assist others in obtaining more independence and improving their quality of life. Are you ready to make a difference? If so, please share your personal experiences so that others will also be inspired and compelled to live and advocate as IL champions. Together we can make a difference. Contact SILC staff for a list of questions, or for more info, or to schedule an interview: 503-370-8157; email: lynellex@comcast.net.

An IL Story

NG ~ I am 20 years old. I have short-term memory loss, ADD, and a speech impediment. The disabilities made school and dealing with people very difficult cause I got made fun on a daily basis. I did have some control over my disabilities, but still needed more help than the other kids when it came to explaining things or just help on an assignment. My self-esteem was and still is a little shaky at times. A big accomplishment for me was when I graduated High School and proved a lot of people wrong. I learned many skills but the two that have helped with my job is Adobe Photoshop and computer skills. For the last 2 years, I have been more organized, being a self-starter, working more independently, trying not to get so stressed about things, and just do one thing at a time. SCILS has been helping with work skills and confidence... I am a lot more independent now and think for myself and try not to let my disabilities get to me. My goals in life seem hard but so far seem reachable. My self-esteem has gotten better over the years so I'm ready for bigger things now.

Hear Ye, Hear Ye... Get Involved!

The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy. ~ Martin Luther King, Jr.

State IL News ~ 2008-2010 State Plan for Independent Living (SPIL)

SPIL Planning ~ All SILCs are required to develop and implement a three year State Plan for Independent Living (SPIL). Among other things, the SPIL includes IL statistics, outreach plans, goals and objectives, CIL funding priorities, and an evaluation plan. The following is a brief summary of key aspects of the draft 2008-2010 SPIL, based on initial input from two SPIL planning sessions.

Public input ~ The full SPIL draft will be available upon request in mid March, and it will be shared via public hearing(s), disseminated to our email list, and discussed in detail at the March and June 2007 SILC meetings, with public input actively sought.

Purpose ~ The SPIL goals and objectives drive the IL activities for a three year period, and further the SILC's vision and mission ~ to promote choice, equal access, and full inclusion of people with disabilities, throughout the state of Oregon.

SPIL Goals ~ 2008-2010

1) **Advocate** ~ Expand awareness and implementation of IL philosophy

Advocacy targets:

- **ADA** ~ Increase inclusion of people with disabilities by advocating for increased implementation of the ADA

- **Deinstitutionalization**

- **Oregon Conference on Disabilities** ~ advocate for funding, planning, and coordinating an Oregon Conference on Disabilities.

2) **Develop IL leaders**

3) **Educate/Outreach** ~ Educate Oregonians about IL services and philosophy. Targets: health care providers and youth

4) **IL funding** ~ Support the expansion of Oregon's provision of IL services

5) **IL support** ~ Improve and expand implementation of IL philosophy in CILs, grass root IL groups, partner and other agencies, and in the personal lives of Oregonians

6) **Standards and Assurances Goal** ~ Attain

and maintain full compliance with SILC Standards and Assurances.

SPIL Network of CILs funding priorities ~ AFTER the SILC basic budget and carryover is allocated, remaining funds will be allocated to eligible CILs, based on the priority funding order, as listed below. Eligibility is based on CILs achieving and maintaining compliance with the Rehab Act's Section 725 Standards and Assurances.

1. Maintain \$200,000 funding goal for CORIL, SPOKES, HASL, and UVDN ~ *These 4 CILs receive some level of federal Title VII, C funding less than \$200,000. These CILs are the first priority based on their established long-term history of meeting CIL requirements and eligibility for federal funds.*
2. Fund EOCIL to \$63,000 ~ *This priority is based on EOCIL's history of accomplishments, the very large area that they serve, the fact that eastern Oregon is a large and otherwise unserved population, and based on non-SILC grants that EOCIL has been awarded throughout their development.*
3. Balance of funds, up to \$48,000, divided equally between other eligible CILs (currently LILA, POCIL, SCILS)
4. Fund EOCIL to \$100,000
5. Bring other eligible CILs to \$100,000 each
6. Fund EOCIL to \$200,000
7. Outreach to underserved/unserved areas ~ up to \$50,000 for this activity
8. Bring other eligible CILs to \$200,000 each

SPIL Development Calendar

- March/April 2007 ~ Disseminate draft SPIL; solicit input via email, public forums, etc.
- May 10, 2007 ~ Deadline for public input
- June 1 ~ Share revised draft SPIL for final review and input.
- June 2007 ~ SILC and DSUs approve and sign final SPIL
- June 30, 2007 ~ Submit signed SPIL to RSA

- September 2007 ~ SILC Retreat to solidify plans for implementation of new SPIL.
- October 1, 2007 ~ New 2008-2010 SPIL goes into effect

IL Resources, Information, and Websites

- **Free NFB Newslines** ~ Oregonian and the Statesman-Journal are accessible via phone to eligible individuals, including seniors who are experiencing decreases in eyesight and physical dexterity. For info or to sign up, contact the State Library's Talking Book and Braille Services: 800-452-0292, or visit www.tbabs.org. Free demo: 1-888-882-1629 ~ access code 000 999 ~ security code 9999
- **Audio Described performance mailing list** ~ Audio described plays, operas and movies. To subscribe, send e-mail to: AD_performances-request@listsmart.osl.state.or.us with the word "subscribe" in the subject line.
- **Youth with disabilities** ~ resources and info for/about youth with disabilities and youth transition ~ <http://www.fvkasa.org/nylnkasa/index.php>
- **Talking Checkbook** ~ The only PC-based talking bank account management software ~ makes account management and check writing truly accessible. www.emediawire.com/releases/2003/11/emw89577.php
- **Oregon Parent Training Information Center** ~ Educates and supports parents, families, and professionals to meet the needs of children and youth with disabilities, by offering programs, services, and trainings throughout the state. <http://www.orpti.org/>
- **National Clearinghouse for Long-Term Care Information** ~ www.longtermcare.gov
- **Hands on Banking** ~ innovative, banking curriculum ~ self-paced, individual learning for kids, teens and adults. Lessons are narrated, animated, colorful, and fun! <http://www.handsonbanking.org> or <http://www.elfuturoentusmanos.org>

Always use the word impossible with the greatest caution. ~ Werner Von Braun

Advocacy Success

A few months ago, the SILC wrote letters in opposition to proposed CMS rules on DME ~ specifically, a proposed rule that severely restricted the purchase of some of the more costly wheelchairs. We feared this would result in people who need more options (recliners, special seating, etc.) due to their type of disability, not being able to get such.

The current status is that the Power Mobility Device (PMD) policy was implemented on November 15, 2006. However, prior to implementation, and in response to consumer/advocacy input, CMS issued a clarification on the PMD policy. In particular, CMS clarified that any decision on the type of wheelchair to be used should be determined by a patient's physician and based on patient needs, and is not automatically limited to the least costly device. Sharing views and opinions CAN make a difference!

I am only one, but I am still one. I cannot do everything, but I can do something. ~ Helen Keller

Upcoming Conference

Building Futures ~ A conference on High School Transition to College and Employment ~ May 15 – 16, 2007 ~ Embassy Suites Hotel ~ Tigard Oregon. For anyone who has an interest in supporting individuals with disabilities in transition from school to adult life ~ secondary educators, post secondary educators, VR counselors, special educators, therapists, school counselors, service providers, job developers, other rehabilitation specialists, and especially secondary students with disabilities and their

families. Throughout the three-day event there will be presentations by regional and national experts on issues surrounding secondary

transition and assistive technology.
<http://www.orpti.org/>

SILC Meetings ~ General Information

GUESTS ~ Guests are welcome to attend SILC meetings. You may speak or share materials during the Public Input part of the meeting; materials must be available in alternate formats.

ACCOMMODATIONS ~ Accommodations, including provision of interpreters, assistive listening devices and materials in alternate formats, are available upon request. Although efforts will be made to arrange accommodations with 48 hours notice, the SILC requests 2 weeks notice to ensure accommodations.

INCLUSION ~ In support of the SILC mission of inclusion, we request that people refrain from wearing perfumes or other scents at the meetings so that people with chemical sensitivities may attend and participate comfortably. All service and companion animals must be in control throughout the meetings. Thank you in advance for your cooperation.

1st QUARTER SILC MEETINGS

Red Lion Hotel ~ 3301 Market Street, NE ~ Salem, OR ~ 503-370-7888

Thursday, March 1, 2007

1:30 p.m. ~ Membership, Development, and Training Committee meeting

4:00-7:00 ~ Executive Committee meeting

Friday March 2, 2007

8:30 a.m.-4:00 p.m. ~ Quarterly SILC meeting

SILC Standing Committee Meetings

Individuals interested in attending committee meetings must contact staff in advance to confirm meeting time and to coordinate logistics, if applicable. SILC committee meetings are via conference call unless indicated otherwise, and are all subject to change based on the availability of committee members.

- **CIL Support/Mentoring Committee** (CSMC) ~ January 25, April 26, July 26, and October 25, 2007 2:00 p.m ~ 2:00 p.m.
- **Advocacy Committee** (AC) ~ 3rd Tuesday of each non-SILC meeting month ~ 10:00 a.m.
- **Education, Outreach, Leadership Development Committee** (EOLDC) ~ 4th Monday each month ~ 1:00 to 2:00 p.m.
- **Executive Committee** (EC) ~ 4th Friday each month ~ 1:30 p.m. 1st Thursday each quarter, 4:00 p.m. (in-person meeting)
- **Membership, Development and Training Committee** (MDTC) ~ 3rd Friday of non-SILC meeting months at 10:00 a.m. 1st Thursday each quarter 1:30 ~ 3:30 p.m. (in-person meeting)

It only takes a single idea, a single action to move the world. ~ unknown

***Nothing is more powerful than an individual acting out their conscience,
thus helping bring the collective conscience to life. ~ Norman Cousins***

SILC QUARTERLY MEETING AGENDA ~ Friday, March 2, 2007

<p>8:30 WELCOME/INTRODUCTIONS</p> <p>8:45 AGENDA REVIEW</p> <p>8:50 HOUSEKEEPING</p> <p>9:00 DHS UPDATE</p> <p>9:15 SILC APPLICANT INTRODUCTIONS</p> <p>9:30 CIL PRESENTATION ~ HASL</p> <p>9:45 SILC ACTION ITEMS</p> <p>10:00 BREAK</p> <p>10:20 UPDATE ITEMS</p> <p>11:00 PUBLIC COMMENT</p> <p>11:15 PRESENTATION ~ UNITED WE RIDE</p>	<p>11:45 STAFF AND AGENCY REPORTS</p> <p>12:00 WORKING LUNCH/NETWORKING</p> <p>1:00 SPIL PROGRESS REPORTS</p> <p>1:15 CONFERENCE REPORT</p> <p>1:30 DRAFT SPIL REVIEW/APPROVAL</p> <p>2:15 BREAK</p> <p>2:35 SPIL PLANNING</p> <p>3:45 NEXT MEETING ~ June 1, 2007</p> <p>3:50 WRAP UP/NEXT STEPS</p> <p>4:00 ADJOURN</p>
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Oregon Centers for Independent Living

Centers for Independent Living are non-profit organizations, run by people with disabilities, for people with disabilities. CILs serve all ages and all disability groups. Every CIL provides four core Independent Living Services: 1) individual and systems advocacy, 2) information and referral, 3) independent living skills training, and 4) peer counseling. Oregon has nine Centers for Independent Living.

CORIL (Central Oregon Resources for Independent Living) ~ Bend ~ 541-388-8103 ~ www.coril.org
Service Area: Deschutes, Crook & Jefferson Counties

EOCIL (Eastern Oregon Center for Independent Living) ~ Ontario ~ 541-889-3119 (voice/TTY) ~ www.eocil.org
Service Area: Baker, Gilliam, Grant, Harney, Malheur, Morrow, Umatilla, Union, Wallowa and Wheeler Counties

EOCIL Pendleton Satellite Office
541-276-0883

HASL (Independent Abilities Center) ~ Grants Pass ~ 541-479-4275 (voice) ~ hasl1@qwest.net ~ <http://haslonline.org/index.php>
Service Area: Josephine and Jackson Counties

ILR (Independent Living Resources) ~ Portland 503-232-7411 ~ 503-232-8408 ~ ilrpx@qwest.net ~ www.ilr.org
Service Area: Multnomah, Washington & Clackamas Counties

LILA (Lane Independent Living Alliance) ~ Eugene ~ 541-607-7020 ~ 541-284-9474 (Message) ~ lila@lilaoregon.org ~ www.lilaoregon.org
Service Area: Lane County

Progressive Options ~ Newport ~ 541-574-0384 ~ progop541@yahoo.com ~ www.progressive-options.org
Service Area: Lincoln County

SCILS (South Coast Independent Living Services) ~ Brookings ~ 541-469-5306 x303 or 800-481-5777 ~ scils06@yahoo.com
Service Area: Coos & Curry Counties

SPOKES Unlimited ~ Klamath Falls 541-883-7547
Service Area: Klamath & Lake Counties

UVDN (Umpqua Valley disAbilities Network) ~ Roseburg ~ 541-672-6336 ~ 541-440-2882 (TTY)
Service Area: Douglas County

Success is often achieved by those who don't know that failure is inevitable. ~ Coco Chanel

You must be the change you wish to see in the world. ~ Gandhi

Newsletter Subscription Info ~ OIL News is a quarterly publication of the Oregon SILC. For a free on-line subscription send a request with your email address to: oregon.silc@state.or.us.

If you receive this newsletter in print format and would like to receive it via e-mail or alternate format, please let us know. We encourage people to consider the on-line option ~ it reduces printing/mailing costs.

SILC Contact Information

500 Summer Street NE E-87

Salem, OR 97301-1120

Phone: 503-945-6204 FAX: 503-945-8991

TTY: 1-866-813-3526

Email ~ oregon.silc@state.or.us

Website:

www.oregon.gov/DHS/vr/silc/index.shtml