What is Independent Living (IL)?

From the Oregon State Independent Living Council:
"Independent Living means that people with disabilities have the opportunity to make decisions about their lives and pursue activities of their choosing. Measures of true Independent Living are the opportunity and ability of a person with a disability to direct and personalize services to meet individual situations."

From ILRU:
"It basically is living just like everyone else - having opportunities to make decisions that affect one's life; able to pursue activities of one's own choosing - limited only in the same ways that one's non-disabled neighbors are limited. Independent Living has to do with self-determination. It is having the right and the opportunity to pursue a course of action. And, it is having the freedom to fail and to learn from one's failures, just as non-disabled people do."

How did the IL Movement get started?

- Civil Rights Movement
- Deinstitutionalization
- Demedicalization
- 1960's & 1970's
- University of Berkeley
- Centers for Independent Living
- Culminating in the Rehabilitation Act of 1973

"Let the shameful wall of exclusion finally come tumbling down."
The IL Paradigm

<table>
<thead>
<tr>
<th>Medical Model</th>
<th>Rehabilitation</th>
<th>Community Assistance (service delivery system)</th>
<th>Charity Paradigm</th>
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<tr>
<td>INDIVIDUAL</td>
<td>MEDICAL MODEL</td>
<td>REHABILITATION</td>
<td>COMMUNITY ASSISTANCE (service delivery system)</td>
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<tr>
<td>INDIVIDUAL</td>
<td>INDEPENDENT LIVING</td>
<td>DISABILITY RIGHTS</td>
<td>DISABILITY CULTURAL</td>
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</tbody>
</table>

**Definition of the problem**
- Physical or mental impairment; lack of vocational skill, lack of education, lack of socio-economic status, lack of political and cultural skills.
- Dependence upon professionals, family members and others.
- Hostile attitudes and environments.
- Lack of legal protection.
- Lack of recognition of inherent worth of people with disabilities (stereotypes).

**Focus of the problem**
- In the individual (individual is "broken" or "sick" and needs to be "fixed" or "cured" to "fit" into society).
- In the socio-economic, political, and cultural environment.
- In the physical environment.
- In the medical, rehabilitation, service delivery or charity processes themselves (dependency-creating).

**Solution to the problem**
- Professional interventions; treatment; "case management" or volunteer work based on pity and related attitudes.
- Advocacy; barrier removal; consumer-control over options and services; peer role models and leaders; self-help -- all leading to equitable socio-economic, cultural and political options.

**Social role of person with a disability**
- Individual with a disability is a "patient," "client," or recipient of charity; in many situations, the social role is non-existent.
- Family and community members; "consumers" or "customers," "users" of services and products -- just like anyone else.

**Who controls the professional person with the disability or his/her choice of another individual or group.**

**Desired outcomes**
- Maximum self-care (or "ADL" -- activities of daily living as used in occupational therapeutic sense).
- Gainful employment in the vocational rehabilitation system.
- No "social misfits" or no "manipulative clients".
- Independence through control of options for living in an integrated community of choice.
- Pride in unique talents and attributes of each individual; positive disability identity.

This paradigm was originally developed in 1978 by Gerben DeJong, now with the National Rehabilitation Hospital in Washington, D.C. It has been modified since then by Maggie Shreve, an organization development consultant working in the field of disability rights out of Chicago, and Steve Brown, a disability policy consultant and principle co-owner of the Institute for Disability Culture in Santa Fe, New Mexico.

**Foundation of the IL Philosophy**
- Each individual is different and unique.
- People with disabilities are often the most knowledgeable about their own needs and issues.
- Programs serving people with disabilities should be designed to serve all disability groups.
- "Nothing about us without us."

**Funding Structure Analysis of Area Agencies on Aging (AAAs) and Centers for Independent Living (CILs)**

<table>
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<tr>
<th>Aging Network</th>
<th>Disability Network</th>
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<tbody>
<tr>
<td><strong>Funding</strong></td>
<td><strong>Funding</strong></td>
</tr>
<tr>
<td>Older Americans Act (people 60+)</td>
<td>Rehabilitation Act, Title VII</td>
</tr>
<tr>
<td>Administration on Aging</td>
<td>Rehabilitation Services Administration</td>
</tr>
<tr>
<td>State Units on Aging</td>
<td>SEUs and CID</td>
</tr>
<tr>
<td>AAAs</td>
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</tbody>
</table>

SAUs develop statewide plan for implementing aging programs.

SRA collaborates with State Units on Vocational Rehabilitation to develop plans to ensure planning and coordination of services.
Questions?

What is a Center for Independent Living (CIL)?

From the Rehabilitation Act, Title VII: Section 702. Definitions
The term “center for independent living” means a consumer-controlled, community-based, cross disability, nonresidential private nonprofit agency that –
(A) is designed and operated within a local community by individuals with disabilities; and
(B) provides an array of independent living services.

From the ILRU brochure:
These organizations, called Independent Living Centers, are extraordinary: they are run by people with disabilities who themselves have been successful in establishing independent lives. These people have both the training and the personal experience to know exactly what is needed to live independently. And, they have deep commitment to assisting other people with disabilities in becoming more independent.

KEY is CONSUMER CONTROL-
The term “consumer control” means, with respect to a center for independent living, that the center vests power and authority in individuals with disabilities. A majority of both the Governing Board and staff are persons with disabilities.

Who Do CILs Serve?

CILs serve people with all types of disabilities including, but not limited to people with hearing impairments, sight impairments, mobility impairments, mental illness, learning disabilities, developmental disabilities, Traumatic Brain Injuries and more.

CILs serve individuals of all ages, their families and also offer a great many services to members of the general public like other non-profit agencies, businesses, local, state and federal agencies, school districts and the community.
**Peer Role in IL**

- In IL terms, a peer is someone with a disability who is a role model and/or support person for another person with a disability.
- Peer support and personal choice are key elements of Centers for Independent Living.
- In IL, the peer is the “professional.”

**CILs focus on a set of CORE Independent Living services**

Each Center for Independent Living must provide the following services:

- Information & Referral
- Independent Living Skills Training
- Peer Counseling
- Individual and Systems Advocacy (You will find that every effort is made to train individuals to be their own best advocate.)

Individual Centers for Independent Living also may provide various other services, based on the needs in their community. Examples include support groups, recreation activities, work incentive counseling, mental health drop-in centers, etc.

**Information and Referral Examples**

- Provide information on:
  - Housing assistance
  - Transportation options
  - Personal Care Assistants - PCAs
  - Social Security
  - Employed Persons with Disabilities Program
  - Employment and Education Opportunities
  - Aids to daily living/adaptive equipment
  - Sign Language Interpreters, Readers (Communication Access)
  - Disability Law: Rights, Responsibilities & Enforcement
  - Physical and/or Mental Health services
  - Oregon Health Plan
  - Work site modifications
  - Recreation

- Make referrals to entities where aids to daily living/adaptive equipment can be accessed, which will increase the consumer’s ability to function as independently as possible.
**Skills Training Example(s)**

SKILLS TRAINING IN IL always attempts to "teach to fish" versus "giving a fish."

- Help develop transportation options: Bus training, learner's permit or driver's license
- Use Assistive Technology
- Improve personal care skills (e.g., dress, grooming)
- Help learn to form or better relationships/communications with neighbors, coworkers, etc.
- Assist with learning time management skills
- Learn to write resumes, cover letters as well as prepare for job interviews
- Learn daily living skills such as cooking, cleaning, laundry, etc.
- Learn to interview and select personal care assistants, job developers and job coaches
- Learn or improve money management
- Learn to use tools, such as a memory book, cue cards, etc.
- **BE GOOD SELF-ADVOCATES!!**

**Peer Counseling Example(s)**

Assist a consumer to:
- Understand his/her disability and the impact on their lives
- Adjust to a newly acquired disability
- Identify his/her strengths, interests, and skills; develop a plan to achieve their IL goals
- Define what personal supports they need to be independent
- Learn problem solving skills, decision-making, conflict management, negotiation, and/or communication skills
- Learn when and how to ask for accommodations
- Explore/adapt to changes in living arrangements (e.g., NH Transition)
- Learn to use community services more effectively

CILs Also:
- Work with a consumer's family to increase their understanding of why independence and often employment, are important to their family member with a disability; help them work through changing family dynamics, increased independence, etc.
- Facilitate Person Centered Planning

**Advocacy Example(s)**

SYSTEMS ADVOCACY: Making changes in the community which enable individuals with disabilities to live and work more independently. These changes may affect legislation, policy, housing, business, transportation, healthcare, employment, accessibility, etc.

**Examples:**
- Work with the city and county to increase the number of curb cuts in the area.
- Talk with legislators about funding for state programs.

INDIVIDUAL ADVOCACY: CIL Staff and/or volunteers act with, or on behalf of when necessary, an individual with a disability to secure benefits, services, accessibility, etc. The practice of good Independent Living is ALWAYS to teach a consumer to learn the skills necessary to be effective self-advocates.

**Examples:**
- Role play with a consumer how to request a workplace accommodation
- Accompany a consumer to a meeting with a vocational rehabilitation counselor who they are having trouble communicating with, concerning problems with a job coach. This would include helping consumer prepare for meeting and assisting them during such only if asked.
- Make a call to a consumer's dentist with the consumer sitting beside you, to explain the law regarding providing the accommodation of them remaining in their wheelchair due to accessibility needs.
There are now more than 600 Centers for Independent Living in existence within the US and many countries.

There are 7 CILs in Oregon.

Oregon’s CIL Network

Questions?
ADRC is:
- a collaborative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS)
- designed to streamline access to long-term supports and services
- part of a nationwide effort to restructure services and supports for older adults, all persons with disabilities, family members and care providers
- complements long term care system change activities designed to enhance access by older adults and people with disabilities of all ages to community living, personal choice and independence.

Aging and Disability Resource Center – ADRC
(Aging and Disability Resource Connection in Oregon)

WHAT MAKES ADRCs DIFFERENT?

WHAT IS DIFFERENT ABOUT AN ADRC?
- Integrates or coordinates aging and disability service systems.
- Establishes formal partnerships between aging, disability & Medicaid agencies and stakeholder groups.
- Serves individuals of all ages and income levels.
- Makes effective use of technology - invests in management information systems that facilitates service delivery, supports integration of data, streamlines access to information and options.

Why ADRC?
- Moving from experts working in isolation to partnership, coordination, cross-training, routine communication
- Moving from focus on eligibility to offering a set of options in a consumer-driven approach
- ADRC is NOT about replacing existing organizations and networks. It’s about building a better, more coordinated network
Partnerships/Collaborations

WHAT ARE SOME COMMON PROGRAM SIMILARITIES BETWEEN AAAs and CILs?

- Housing Referral and Assistance
- Transportation
- Personal Assistance & Care Provider Programs
- Accessibility
- Counseling Services
- Advocacy Services
- Legal Services
- Deinstitutionalization/HCBS
- Employment and Education Opportunities
- Community Education and Awareness
- Services for Multiple Disabilities
- Emergency Preparedness
- Home Repair, Renovation, Modification
- Assistive Technology

Comparative Analysis of Services/Programs Offered by Area Agencies on Aging (AAAs) and Centers for Independent Living (CILs)

<table>
<thead>
<tr>
<th>Components</th>
<th>AAAs</th>
<th>CILs</th>
<th>ADRCs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible Participants/Consumer</td>
<td>Elder persons age 60+ who are frail, live alone and have low economic status</td>
<td>Anyone with a disability (physical, mental or cognitive) of any age</td>
<td>Elder adults, all persons with disabilities, family members and care providers</td>
</tr>
</tbody>
</table>
| Core Services Provided                          | 1. Information & Access  
  2. Nutritional Services  
  3. In-Home Services  
  4. Preventive Health Services | 1. Information & Referral  
  2. Individual/Systems Advocacy  
  3. Independent Living Skills Training  
  4. Peer Counseling/Support  
  5. Nursing Home Transition (soon to be 5th CORE Service) | 1. Information & Assistance  
  2. Options/Benefits Counseling  
  3. Health Promotion  
  4. Care/Transition Support (Person-Centered)  
  5. Quality Assurance and Continuous Improvement |

How and Where do we START?

Strategies Worth Considering???

- Establish common language / Cross-train staff
- Sharing Resource Databases / I & A
- Utilize Common/Similar I Intake Processes to Improve Referrals and Maximize Resources

Next Steps????