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DATE: April 4, 2019

TO: Senate Committee on Judiciary for Public Hearing – April 5, 2019

Re: IDSP POLICY POSITION for SB579

ISSUER:

W. Kirt Toombs, MMDS, Chief Executive Officer, Eastern Oregon Center for Independent Living's (EOCIL) – Institute for Disability Studies and Policy (IDSP)

ISSUER BACKGROUND:

Eastern Oregon Center for Independent Living (EOCIL) is a global cross-disability resource and advocacy center that promotes independent living and equal access for all persons with disabilities. EOCIL has two primary functions:

1. To operate the Institute for Disability Studies and Policy (IDSP). Through the IDSP's core research and policy officers, the IDSP provides original and scholarly actionable research for disability systems change to enhance independent living, equitable access to services and resources, and universal human rights;

2. To provide peer-based services to people with disabilities living in eastern Oregon. Based in Ontario, Oregon, with additional offices in Pendleton and The Dalles, EOCIL serves consumers in 13 central and eastern Oregon counties: Baker, Gilliam, Grant, Harney, Hood River, Malheur, Morrow, Sherman, Umatilla, Union, Wallowa, Wasco and Wheeler.

The IDSP is the location for disability research, education, and advocacy. The Institute provides actionable research that is disseminated to centers for independent living, other disabled persons' organizations (DPOs), and non-governmental organizations (NGOs).

The IDSP is an integral part of EOCIL and operates as the center's research and policy analysis entity. The IDSP intends to provide recommendations on behalf of Oregonians with disabilities.

IDSP POLICY POSITION FOR SB 579:

SB 579 creates exception under Death with Dignity Act to 15-day waiting period for patient with less than 15 days to live. Creates exception to two-day waiting period for patient with less than two days to live.

EOCIL's IDSP finds there is a lack of Oregon research data to support the proposed policy change.

EOCIL's IDSP finds SB 579 would remove current safeguards and this may be detrimental for persons with disabilities.

Additionally, Oregon's Independent Living Program is not currently included in the Death with Dignity Act design. Persons with disabilities accessing Death with Dignity Act and their families may not be aware of the State Independent Living Council (SILC) or Centers for Independent Living (CILs). Persons with disabilities accessing Death with Dignity Act may not be aware of the role they have in the cross-disability independent living movement including, but not limited to, serving as a member of the SILC, participating in the development of the State Plan for Independent Living (SPIL), and having access to disability advocacy and peer-based support services. This is an extremely important step toward alleviating fear of:

- Losing autonomy;

- Less able to engage in activities making life enjoyable;
- Loss of dignity;
- Losing control of bodily functions;
- Burden on family;
- Inadequate pain control;
- Financial implications of treatment, etc.

The SILC is a governor appointed body, offering people with disabilities control over the design of Oregon's Independent Living program services. The SILC is responsible for the development, implementation, and evaluation of the State Plan for Independent Living (SPIL) for Oregon's cross-disability Independent Living Program¹.

CILs promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.²

SYNOPSIS OF OREGON INDEPENDENT LIVING PROGRAM:

1. Oregon's Statewide Independent Living Council
500 Summer Street NE E-87
Salem, Oregon 97301
2. Oregon has 7 CILs providing five core services in 22 counties:
 - Abilitree (Deschutes, Crook and Jefferson Counties);
 - EOCIL (Baker, Gilliam, Grant, Harney, Malheur, Morrow, Umatilla, Union, Wallowa and Wheeler Counties);
 - HASL (Jackson and Josephine Counties);
 - ILR (Multnomah, Washington and Clackamas Counties);
 - LILA (Lane County);
 - SPOKES (Klamath Falls and Lake Counties)

¹ State Independent Living Council (SILC). https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SILC/Pages/about_us.aspx

² 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.

- UVDN (Douglas County)³.
3. Oregon's CILs provide limited APD – ADRC contract specific services in 14 counties:
- EOCIL (Hood River, Sherman and Wasco Counties);
 - HASL (Curry County);
 - ILR (Clatsop, Columbia, Tillamook Counties);
 - LILA (Benton, Lincoln, Linn, Marion, Yamhill and Polk Counties);
 - UVDN (Coos County)⁴.

³ State Independent Living Council (SILC) (2017). State Plan for Independent Living (SPIL) for Oregon for 2017 – 2019 (pp. 40 – 44).

⁴ The Oregon Department of Human Services Aging and People with Disabilities (2016). Oregon CILs Service Area IR/IA Numbers 2016.





CENTERS FOR INDEPENDENT LIVING MAKE COMMUNITY LIVING POSSIBLE

WHAT IS COMMUNITY LIVING?

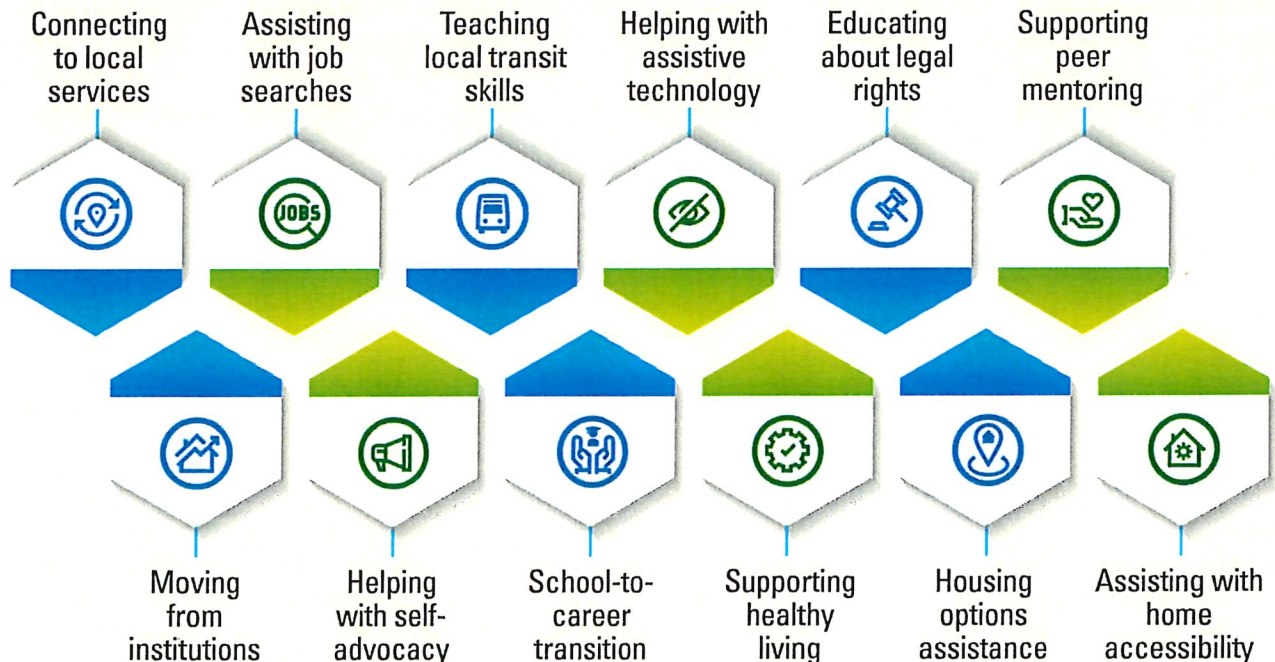
People with disabilities and older adults have the same opportunities as everyone else to:

- Choose for themselves where to live
- Earn a living
- Lead the lives they want
- Make decisions about their lives

WHY COMMUNITY LIVING?

-  People prefer it
-  It usually costs less
-  It's a legal right
-  Everyone benefits when everyone can contribute

HOW DO INDEPENDENT LIVING PROGRAMS HELP?



ADMINISTRATION OF COMMUNITY LIVING (ACL) INFORMATION ON INDEPENDENT LIVING PROGRAM:

Independent living can be considered a movement, a philosophy, or specific programs. In the context of ACL, independent living programs are supported through funding authorized by the Rehabilitation Act of 1973, as amended (The Act). Title VII, chapter 1 of the Act states the current purpose of the program is to “promote a philosophy of independent living including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society.”

In July 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law, transferring the Independent Living programs, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), and the Assistive Technology programs to ACL. WIOA also included statutory changes that affect independent living programs, including the addition of new core services (transition), shifts in the process of developing and adopting state plans and changes in the functions of the SILC.

ROLES:

The Statewide Independent Living Council is an independent entity responsible to monitor, review, and evaluate the implementation of the State Plan for Independent Living.

CILs:

Federal: Rehabilitation Act of 1973 as amended by WIOA, TITLE VII— INDEPENDENT LIVING SERVICES AND CENTERS FOR INDEPENDENT LIVING CHAPTER 1—INDIVIDUALS WITH SIGNIFICANT DISABILITIES: PART A—GENERAL PROVISIONS SEC. 701. PURPOSE. The purpose of this chapter is to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society...;

Centers for Independent Living are consumer-controlled, community-based, cross-disability, nonresidential private non-profit agency that is designed and operated within a local community by individuals with disabilities, and provides an array of independent living services.

The State Plan for Independent Living must designate the DSE. Under WIOA, the SPIL is jointly developed by the chairperson of the Statewide Independent Living Council, and the directors of the Centers for Independent Living in the state, after receiving public input from individuals with disabilities and other stakeholders throughout the state. The SPIL is signed by the chair of the Statewide Independent Living Council (SILC or Council), acting on behalf of and at the direction of the Council and at least 51 percent of the directors of the centers for independent living in the state. The SPIL is also signed by the director of the DSE. By signing the SPIL, the director of the DSE agrees to execute the responsibilities of the DSE identified in the law. The responsibilities are:

- Receive, account for, and disburse funds received by the state based on the SPIL;
- Provide administrative support services for a program under part B, and a program under part C in a case in which the program is administered by the state under section 723;
- Keep such records and afford such access to such records as the Administrator (of ACL) finds to be necessary with respect to the programs;
- Submit such additional information or provide such assurances as the Administrator may require with respect to the programs; and
- Retain not more than 5% of the funds received by the State for any fiscal year under Part B for the performance of the services outlined in paragraphs (1) through (4). See Section 704 (c) of the Rehabilitation Act, as amended, 29 U.S.C. 796c(c).

SPIL:

Sec. 704(a) of The Rehabilitation Act, as amended requires the review and revision of the State Plan for Independent Living, not less than once every three years, to ensure the existence of appropriate planning, financial support and

coordination, and other assistance to appropriately address, on a statewide and comprehensive basis, needs in the state for—

(A) the provision of independent living services in the state;

(B) the development and support of a statewide network of centers for independent living; and

(C) working relationships and collaboration between—

(i) centers for independent living; and

(ii)(I) entities carrying out programs that provide independent living services, including those serving older individuals;

(II) other community-based organizations that provide or coordinate the provision of housing, transportation, employment, information and referral assistance, services, and supports for individuals with significant disabilities; and

(III) entities carrying out other programs providing services for individuals with disabilities.

CILs:

Federal: Rehabilitation Act of 1973 as amended by WIOA, TITLE VII— INDEPENDENT LIVING SERVICES AND CENTERS FOR INDEPENDENT LIVING CHAPTER 1—INDIVIDUALS WITH SIGNIFICANT DISABILITIES: PART A—GENERAL PROVISIONS SEC. 701. PURPOSE. The purpose of this chapter is to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society...;

(2) CENTER FOR INDEPENDENT LIVING.—The term “center for independent living” means a consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency for individuals with significant disabilities (regardless of age or income) that— (A) is designed and operated within a local community by individuals with disabilities; and (B) provides an array of

independent living services, including, at a minimum, independent living core services as defined in section 7(17);

(3) 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, in terms of the management, staffing, decision making, operation, and provisions of services, of the center⁵.

STATE AND FEDERAL MANDATES OF OREGON CILs:

CILs are federally mandated to jointly develop, implement, and evaluate Oregon’s 3-year State Plan for Independent Living (SPIL) with the State Independent Living Council (SILC) and Oregon Vocational Rehabilitation Services (OVRS). The 3-year plan is submitted to, and approved by, the Administration of Community Living (ACL).

Additionally, CILs are required to:

4. Provide the following services to Oregonians with disabilities statewide:
 - Information and referrals,
 - peer-counseling,
 - independent living skills training,
 - individual advocacy and systems advocacy
 - transitioning services (services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life;
5. Centers also may provide, among other services: psychological counseling, assistance in securing housing or shelter, personal assistance services, transportation referral and assistance, physical therapy, mobility training, rehabilitation technology, recreation, and other services necessary to improve the ability of individuals with significant disabilities to function independently in their family or community and/or to continue employment⁶.

⁵ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.

⁶ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.