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DATE: March 18, 2019

TO: Senate Committee on Human Services

Re: IDSP POLICY POSITION (SB 1 With One Amendment Recommendation)

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 1:

SB 1 establishes Statewide System of Care Task Force. Directs task force to make series of reports and recommend legislation to Legislative Assembly and Governor. Directs task force to make recommendations to Director of Oregon Health Authority, Director of Oregon Youth Authority and Director of Human Services regarding systems of care. Directs task force to create data dashboard regarding youths being served by Oregon Youth Authority, Oregon Health Authority and Department of Human Services. Appropriates moneys from General Fund to Oregon Health Authority for biennial expenses related to task force. Directs Oregon Health Authority, in consultation with Department of Human Services and Oregon Youth Authority, to prepare and publish requests for proposals for regional evaluation and care teams. Appropriates moneys from General Fund to Department of Human Services for biennial expenses related to regional evaluation and care teams.

EOCIL's IDSP finds SB 1 will benefit persons with disabilities and their families with one vital amendment recommendation.

1. EOCIL’s IDSP recommends the Statewide System of Care Task Force include designated representation from Oregon’s Statewide Independent Living Program, specifically, the cross-disability State Independent Living Council (SILC) and Centers for Independent Living Program (CILs). Oregon’s Independent Living Program is disability culturally responsive. The cross-disability representation from the SILC and CILs should not be overlooked or excluded from the Statewide System of Care Task Force.

Furthermore, Oregon’s State Plan for Independent Living (SPIL) requires coordination with Oregon’s Independent Living Program¹.

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 Program².

CILs are federally required to:

- Provide the following services to Oregonians with disabilities statewide:
 - a. Information and referrals,
 - b. peer-counseling,
 - c. independent living skills training,
 - d. individual advocacy and systems advocacy
 - e. 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;
- Centers also may provide, among other services: psychological counseling, assistance in securing housing or shelter, personal assistance services, transportation referral and assistance, physical

¹ State Independent Living Council (SILC) (2017). State Plan for Independent Living (SPIL) for Oregon for 2017 – 2019 (1.5 Cooperation, Coordination, and Working Relationships Among Various Entities).

² State Independent Living Council (SILC). https://www.oregon.gov/DHS/SENIORS-DISABILITIES/SILC/Pages/about_us.aspx

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 employment³.

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.⁴

EOCIL's IDSP emphasizes OREGON DISABILITY STATISTICAL SNAPSHOT to support the urgency of why the Statewide System of Care Task Force should have designated representation from Oregon's Independent Living Program.

1. EDUCATION (OREGON):

- 5% of students with disabilities dropped out in 2016; compared to just 3% of their nondisabled peers
 - 4.7% Hispanic with disabilities dropout rate
- 88% of girls and 75% of boys within the OYA have a diagnosed mental health disability
- Adults living with a disability are less likely to have graduated from college; 15% of individuals with disabilities graduate college; compared to 32% of their nondisabled peers

2. Positive youth development (PYD) is a significant protective factor for emotional well-being among youth. Youth without a disability are more likely to meet the benchmark for PYD; Positive youth development benchmark achievement by 35% among 11th graders with disabilities; compared to 68% of their nondisabled peers

³ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.

⁴ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.

3. Youth with disabilities are more likely to attempt suicide. 16% of youth with disabilities experienced suicide attempts among 11th grade youth; compared to 3% of their nondisabled peers.

4. SUICIDE (OREGON):
 - 762 total suicides in 2017
 - Cost \$740 million – work loss and lifetime medical costs
 - 13th highest in nation
 - 8th leading cause of death (statewide)
 - 2nd leading cause of death for ages 15-34 (statewide)
 - 3rd leading cause of death for ages 10-14 (statewide)
 - 3rd leading cause of death for ages 35-44 (statewide)
 - The highest suicide rates occurred among males aged 75 years and older, while among females the highest rate occurred among 45-54
 - Narrative: Major concern is youth with disabilities/mental health issues; Boys are 4x more likely to commit suicide than girls; CILs are being innovative in reaching YwDs – i.e. leadership conferences, educational trainings, etc.
 - 71,805 YwDs (statewide); 13.8% of youth population
 - 97 youth suicides – 2014
 - 90 youth suicides – 2015
 - 98 youth suicides – 2016 (3 were in Malheur Co.; 11&10 in Multno./Washington Cos.; 11 in Lane)
 - 3-4% higher than the national average

5. ADVERSE CHILDHOOD EXPERIENCES (ACEs)⁵
 - Early childhood experiences influence the developing brain, and adversity/trauma during sensitive periods of development can create toxic stress and interrupt normal brain development. Adverse childhood experiences (ACEs) are a root cause of many social, emotional, physical, and cognitive impairments that lead to increased incidence of developmental delays and other problems in childhood⁶, as well as adult health risk behaviors (e.g.

⁵ Oregon Health Authority

⁶ <http://46y5eh11fhgw3ve3ytpwxt9r.wpengine.netdna-cdn.com/wp-content/uploads/2015/05/inbrief-adversity-1.pdf>

smoking, alcoholism), mental illness (e.g. depression and suicide), diseases (e.g. heart disease, cancer, diabetes), disability, and premature mortality.⁷ Understanding the prevalence and impact of ACEs can inform efforts to prevent trauma and promote individual, family and community resilience; as well as to create trauma informed systems and services.

- 12% of individuals with disabilities were sexually abused during childhood; compared to 4% of their nondisabled peers
- 36% of individuals with disabilities were physically abused during childhood; compared to 17% of their nondisabled peers

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)
 - UVDN (Douglas County)⁸.
3. Oregon's CILs provide limited APD – ADRC contract specific services in 14 counties:
 - EOCIL (Hood River, Sherman and Wasco Counties);
 - HASL (Curry County);

⁷ Felitti, Anda, Nordenberg et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study AM J of Prev Med, 1998

⁸ State Independent Living Council (SILC) (2017). State Plan for Independent Living (SPIL) for Oregon for 2017 – 2019 (pp. 40 – 44).

- ILR (Clatsop, Columbia, Tillamook Counties);
- LILA (Benton, Lincoln, Linn, Marion, Yamhill and Polk Counties);
- UVDN (Coos County)⁹.

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

⁹ The Oregon Department of Human Services Aging and People with Disabilities (2016). Oregon CILs Service Area IR/IA Numbers 2016.

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 center¹⁰.

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:

1. Provide the following services to Oregonians with disabilities statewide:
 - a. Information and referrals,
 - b. peer-counseling,
 - c. independent living skills training,
 - d. individual advocacy and systems advocacy
 - e. 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**;
2. 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

¹⁰ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.

significant disabilities to function independently in their family or community and/or to continue employment¹¹.

¹¹ 113th Congress of the United States of America (2013 – 2014). Workforce Innovation and Opportunity Act.