



# Expanding CIL Public Health Expertise: The Pandemic and Beyond

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Independent Living Resources



# Purpose & Nature of Workshop

## **Purpose**

Let's explore elements of a successful model of public health workforce development at a Center for Independent Living (CIL) in Portland, Oregon

## **Nature**

We'll also examine the value of finding bridges and doorways between the peer-based independent living model and the public health system often steeped a medical service model.

# Five Learning Goals

1. ILR's Public Health Workforce Development Challenges & Successes
2. Accessing Consumer Covid-19 Resources and Personal Choice
3. ILR Public Health Resource and County Public Health Engagement
4. Long Covid-19: Consumer Symptoms, Challenges & Resources
5. CIL-Based Public Health Fund Development: Knight Cancer

# Five Learning Goals

## #1 ILR's Public Health Workforce Development

### **CIL-Based Public Health Specialist: Roles & Opportunities**

- Staff & Consumer Resource: Point of Contact and Information Center
- IL Disability PH Advocate: Municipal & County (3) Advisory Committees
- Networking Opportunities: Public Health Advocacy & Education

# Five Learning Goals

#1 ILR's Public Health Workforce Development

## **CIL-Based Public Health Specialist**

Working with Consumers, IL Staff and Public Health Partners

- Challenges
- Successes

# Five Learning Goals

## #2 Accessing Consumer Covid-19 Resources and Personal Choice

### **Public Health Specialist: Accessing Consumer Pandemic Resources**

- Pandemic Supplies, Vaccine Access, Consumer/Caregiver Testing

### **Public Health Specialist: Honoring Diversity, Personal Choice**

- Consumer Needs Vary, Unable to Wear Masks, Office Visits

# Five Learning Goals

## #3 ILR Public Health Resource and County Public Health Engagement

### **ILR Public Health Resource**

- Weekly Staff Meetings, Monthly Advocacy Team, Consumer Consultations

### **County Public Health Engagement Roles**

- Clackamas
- Multnomah
- Washington

# Five Learning Goals

## #4 Long Covid-19: Consumer Symptoms, Challenges & Resources

### Long Covid-19

The defining disability of a generation (Mild, Moderate, Severe)

330 Million Americans, 85% at least one Covid-19 infection = 280 Million

Mild: 3% of 280 Million People = 8.4 Million (ADLs Mildly Effected)

Moderate: 2.5% of 280 Million = 7.0 Million (ADL Limits, PT Work)

Major: 2.5% of 280 Million = 7.0 Million (Full Disability)

Long Covid-19 Consumers Invisible, Pandemic Amnesia



# Five Learning Goals

## #4 Long Covid-19: Consumer Symptoms, Challenges & Resources

### Consumers

At-Risk of Long Covid-19: Layered Effect of Personal Health History

Severity of Covid-19 Infection: Not Necessarily Predictor of Long Covid-19

Persistent Viral Myalgia is Not New (Long Influenza, Post-Meningitis, etc.)

Triggers: Past Viral Infections, Chronic Pulmonary, Vascular, Autoimmune and Neurological Conditions, Among Others

# Five Learning Goals

## #4 Long Covid-19: Consumer Symptoms, Challenges & Resources

### **Common Consumer Symptoms Similar to Other Conditions**

Dysautonomia, Postural Orthostatic Tachycardia Syndrome (POTS), Orthostatic Hypotension (OH), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Fibro-myalgia and other dysfunctions of the autonomic and immune systems

### **Subjective Descriptors**

Brain Fog, Feels Like ADHD

Weakness Feels Like COPD

Chronic Fatigue Feels Like Limbs Are Heavy (Sandbags)

# Five Learning Goals

## #4 Long Covid-19: Consumer Symptoms, Challenges & Resources

### Long Covid-19 Case Profiles

- Patient “A” History of Multiple Concussions, Severe Neurological Viral Infection
- Patient “B” History of EDS, Asthma, Tick-Borne Infection: Covid-19 = ME/CFS
- Patient “C” No History of Chronic Health Conditions, Benign Tingling

### Patient Therapies

Pacing, Physical Therapy, Occupational/Cogitative Therapy, Support

### Disability of a Generation: National Champion

Sen. Tim Kaine (D-VA): Long Covid-19 Patient, Funding Bills

# Five Learning Goals

## #5 CIL-Based Public Health Fund Development: Knight Cancer

### **Innovative Fund Development**

With expiration of Part C Public Health Workforce Development Funds in 2024, ILR began exploring ways to continue to have an active public health voice.

In early 2024, Dr. Michelle Williams, ND, working with one of our graduate field-work students in Social Work from Arizona State University, began designing a funding request to the OHSU Knight Cancer Institute.

ILR welcomed a 12-month award in August 2024 expanding health education at ILR with a \$30,000 Tier 2 Grant. The award ensures an ongoing public health presence at ILR well into 2025 (perhaps beyond).



### Background

Within disability communities there is an increased incidence of cancer and worse outcomes when compared to non-disabled individuals. Risk increases in communities of color who also experience disability. Lifestyle factors that increase the incidence of cancer such as smoking, obesity, and diabetes are 10-30% higher in disabled individuals when compared to individuals without disabilities. In the tri-county area (Multnomah, Clackamas, and Washington counties) the incidence of cancer is 433.4 per 100,000 individuals. 21.9% of individuals residing in the tri-county area experience

### Goals & Objectives

some form of disability. These numbers exceed the national averages and therefore pose a This project aims to address disparities in

#### cancer screening and prevention for

individuals who experience disability in Multnomah, Clackamas, and Washington counties.

The short-term goals of this project are to identify individuals in the disability community in the tri-county area who will benefit from education surrounding cancer prevention and screening to attend our educational events.

The long-term goals of our project are to offer individuals sense of empowerment in advocating for

### Key Partners



#### Disability Awareness Resource Team (DART)

Project DART is a group of advocates and volunteers joining together to provide direct services to people with disabilities in the Portland Tri-county area.



### Project Design & Methods

#### Target Audience

- Adults aged 18-85+ living in the tri-county who self-identify as living with a disability.
- Individuals who experience homelessness, veterans or are domestic violence survivors who experience disability and are residing in the tri-county area.

#### Overview of the design of the project

- Address disparities by providing accessible educational opportunities where individuals will learn about cancer risk, screening recommendations, and preventative measures including but not limited to nutritional and lifestyle modifications.
- The approach will be based upon recommendations set forth by the American Cancer Society on screening, vaccinations, and preventative measures and evidence-based nutritional and lifestyle modifications.

#### Activities/efforts/initiatives

- 3 educational events offered over the course of 12 months.
- Events will address risk factors, screening and preventative measures, and lifestyle and nutritional applications to reduce risk of cancer.
- Participants will be expected to attend one of the three events. Resource guides outlining screening recommendations and preventative/lifestyle measures will be created and disseminated to each individual participant.

#### Time frame of the project

- Planning and development of materials month 2-6
- Recruitment beginning month 5-7

### Evaluation Plan

- Participants will be given an intake survey to assess their baseline knowledge that will be administered at the beginning of each educational event.
- Participants will be given a post-event survey to assess their gains in knowledge and readiness to seek screening measures after attending the event.
- Intake and post survey results will be added to a tracking sheet to identify the level of knowledge gained through attending the event.
- For each tracking sheet: attendance, pre and post intake/survey data, location of participant, how they found us, and educational materials distributed will be collected and stored on the secure ILR server.
- Success of our project will be defined by a minimum of 50% increase in knowledge gained following the three educational events.
- The information collected will be used to assess success of the project and feasibility of a second tier 2 project or a tier 3 project focused on implementation of screenings and referrals.



### References & Acknowledgements



Funding for this project was provided in part by the OHSU Knight Cancer Institute Community Partnership Program, a grant program that supports communities across Oregon in addressing local cancer-related needs.

# Workshop Review

## **Purpose**

So we've explored elements of a successful model of public health workforce development at a Center for Independent Living (CIL) in Oregon

## **Nature**

We've also examined the value of finding bridges and doorways between the peer-based independent living model and the public health system often steeped in a medical service model.

## **Shared Experiences & Insights**

We'd like to hear about your experiences and comments!

# Workshop Resources

## Presenters

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