

Navigating Dementia:

Building Capacity of Persons Living with
Dementia and their Care Partners

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Learning Objectives

- ▶ By the end of this presentation, learners will recognize the distinct value occupational therapy has in response to the growing numbers of persons living with cognitive changes due to Alzheimer's disease and other related dementias.
- ▶ By the end of this presentation, learners will understand first hand, priority areas of intervention and care approaches important to persons living with dementia early in the disease process.

Learning Objectives

- ▶ By the end of this presentation, learners will identify evidence-based and evidence-informed occupational therapy interventions to support persons living with dementia and their care partners.
- ▶ By the end of this presentation, learners will discover the significant opportunities to serve persons living in the earlier stages of the disease process.

LiveWell

ALLIANCE, INC.

- ▶ Founded in 1990, LiveWell (formerly Alzheimer's Resource Center) is a pioneer in social change with a mission to positively transform the way people living with dementia (PLWD) are viewed, engaged and supported.
- ▶ Campus in Southington, CT home to 133 people living with dementia (skilled nursing and assisted living communities)
- ▶ Suite of community services including day services, support groups for PLWD and carepartners (CPs), dementia care coaching
- ▶ LiveWell Dementia Specialists - new transdisciplinary outpatient group practice (OT, PT, SLP, Counseling, Geriatrician, Palliative Care MD, APRN)

Prevalence

According to the Alzheimer's Association (2018):

- ▶ Approximately 5.7 million Americans - living with Alzheimer's disease
- ▶ 77,000 reside in Connecticut
- ▶ In 2015, there were 1500 emergency room visits (per 1,000 beneficiaries)
- ▶ 59% of family CG rate emotional stress of caregiving as high or very high
- ▶ 30-40% of CG experience depression, 44% experience anxiety

Review of the Literature

- ▶ 1/3 of the medical expenses for community-dwelling persons living with dementia (PLWD) are for psych meds
- ▶ Evidence demonstrates that neuropsychiatric medications have poor outcomes for PLWD
(Fraker et al., 2014; Kales et al., 2014)

Review of the Literature

- ▶ Evidence indicates that PLWD are at risk for healthcare overutilization during the first year of diagnosis

(Sivananthan & McGrail, 2016)

- ▶ Behavioral symptoms are common for PLWD especially as sensory and cognitive changes progress
- ▶ Mismatches between a CG and the environment in supporting the PLWD may result in neuropsychiatric behaviors

(Fraker et al., 2014)

Review of the Literature

Stress from living with dementia or caregiving in the absence of contextual supports may result in:

- Early placement in institutional settings
- Unnecessary Hospitalization
- Decline in health for the CG and the PLWD
- Inappropriate use of psychiatric medications for behavioral management

(Gitlin et al., 2008; Sivananthan & McGrail, 2016)

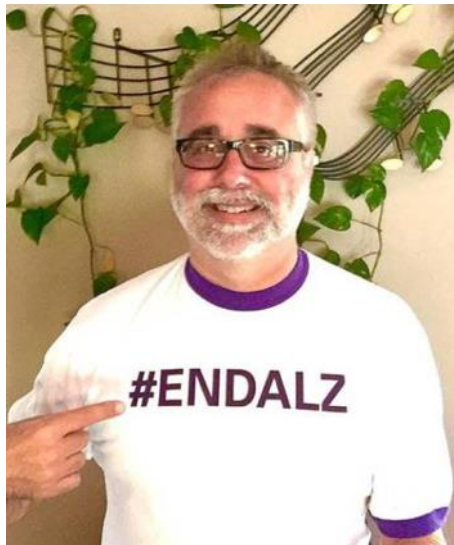
Review of the Literature

- ▶ Evidence indicates community-based OT services are effective in supporting both the CG and PLWD improving QOL, mood and health status
- ▶ Multifactorial interventions of a non-pharmacological nature
 - Functional cognitive assessments
 - Pt/CG education
 - Environmental Adaptation
 - Task Gradation
 - Activity Prescriptions

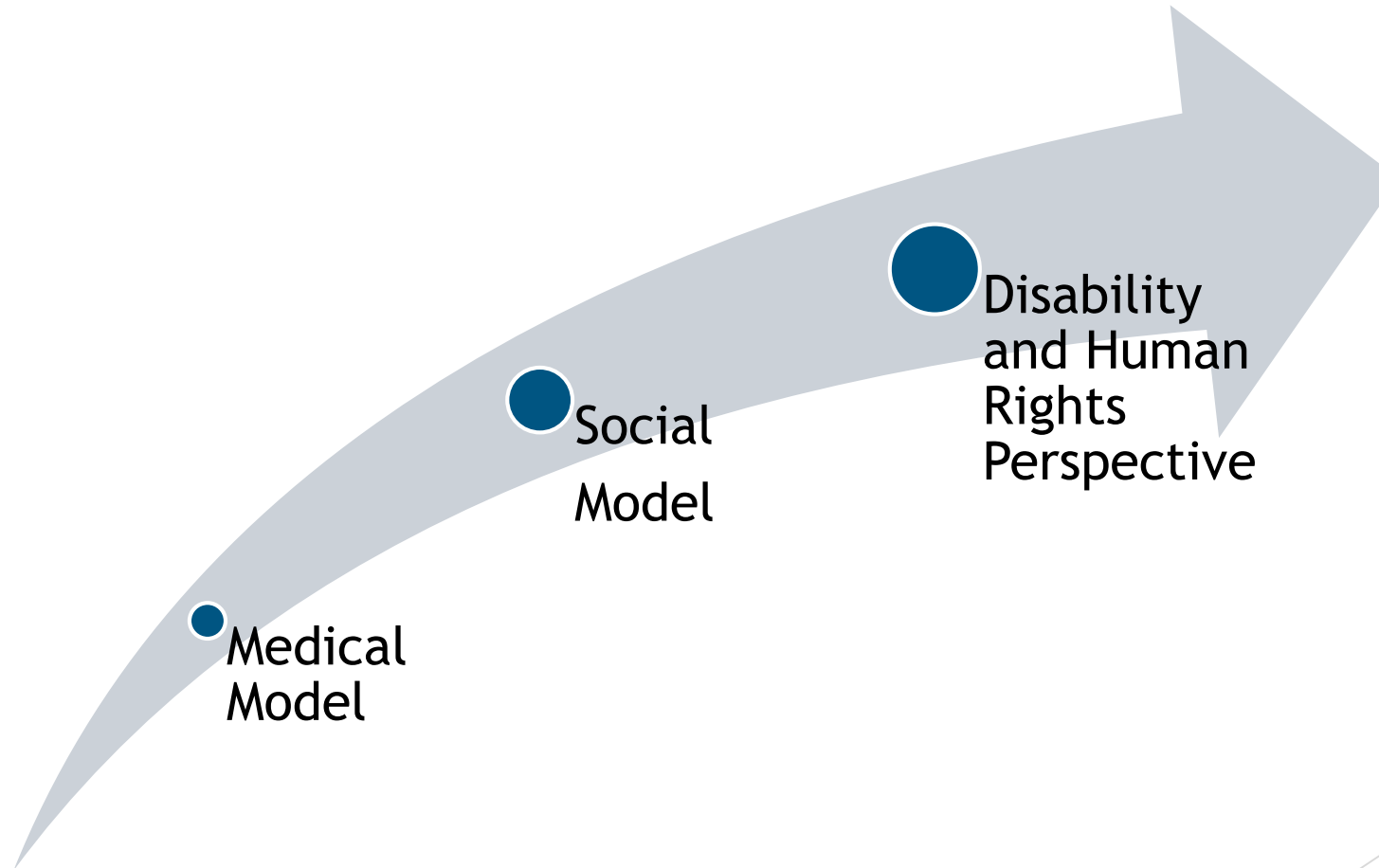
(Brodaty & Arasaratnam, 2012; Graff et al., 2007)

Occupational Therapy - Person Centered

- ▶ Medical Model
- ▶ Social Model of Care
- ▶ Disability and Human Rights Perspective
- ▶ “Nothing About Us Without Us!”



Our Trajectory of Service



Human & Disability Rights Agenda



The Human Rights of People Living with Dementia: from Rhetoric to Reality



A Dementia Alliance International publication
to coincide with the adoption by Alzheimer's Disease International
of a Human Rights based approach,
and to coincide with Dementia Awareness Week UK 2016

16 May 2016 (first edition)



Our Dementia, Our Rights



A brief guide co-produced by The Dementia Policy Think Tank
(member group of DEEP) & Innovations in Dementia CIC
Authored by Philly Hare (Winter 2016)

deep The UK Network
of Dementia Voices

id Innovations
in Dementia



CONVENTION on the RIGHTS of PERSONS with DISABILITIES

Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia

Neil Crowther, 1 March 2016

Executive Summary

It is proposed that ADI in partnership with DAI should make active use of the Convention on the Rights of Persons with Disabilities (CRPD) as part of a suite of advocacy strategies to ensure people with dementia are able to enjoy their human rights and access services on an equal basis of dementia friendly, accessible and enabling national dementia strategies in every country dementia in the UN 2016-2030 Sustainable



Mental Health
Foundation

The use of the CPRD as a tool for social change in countries where the stigma associated with dementia can achieve practical outcomes in access to health care, use of restraints and anti-psychotic medication, social care and support.



Dementia, rights, and the social model of disability

A new direction for policy and practice?

USING CRPD TO PROMOTE THE RIGHTS OF PEOPLE WITH DEMENTIA

GENERAL PRINCIPLES

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination e.g. age, gender, race, disability
- Full participation and inclusion in civil society
- Respect for difference; acceptance of disability as part of human diversity
- Equal opportunity
- Accessibility
- Equality between women and men

*Living Well with Dementia,
Professor Peter Mittler, CBE,
AAIC July 2016*

Gaps in Translation - An Opportunity to Serve

- ▶ Current gaps in services within the state of CT

LiveWell's Administration on Community Living - Alzheimer's Disease Program Initiative

Navigating Dementia: LiveWell's dementia capability project to build the abilities of people living with dementia, their caregivers and communities

Project Goal: to improve quality of life, preparedness, knowledge and abilities to live well with dementia through proactive and evidence based approaches with people living with dementia, caregivers, health professionals, and Connecticut communities.

ACL & ADPI Projects

- ▶ ACL was initially established in April 2012, bringing together federal advocacy for older adults and people with disabilities
- ▶ The ACL's ADPI is dedicated to filling services gaps, through the provision of HCBS to both targeted special populations and through targeted training at both the State and Community levels.
- ▶ ADPI projects are designed to pilot much needed HCBS programs, to evaluate program outcomes, and use program outcome data to garner support to sustain successful initiatives beyond the federal program period.
- ▶ 3 year cooperative agreements, up to \$1M



Project Partners

- ▶ James Pearson: Director of Policy and Research, Alzheimer Scotland
- ▶ Elaine Hunter, MSc, BSc (Hons) Dip COT: National Allied Health Professional Consultant, Alzheimer Scotland and Scottish Government
- ▶ Michelle Miller, MBA: Portfolio Lead - Focus on Dementia, Healthcare Improvement Scotland
- ▶ Catherine Verrier Piersol, PhD, OTR/L, FAOTA: Professor and Interim Chair, Department of Occupational Therapy, Thomas Jefferson University
- ▶ Maureen C McIntyre, MA: Chief Executive Officer, North Central Area Agency on Aging
- ▶ Julie Robison, PhD: Professor, UCONN Center for Aging
- ▶ Rick Fortinsky, PhD: Professor and Health Net, Inc. Endowed Chair in Geriatrics and Gerontology



Other Supporters

Evidence Based OT Interventions

- ▶ Jill Cigliana, MSOT, OTR/L: Program Director, Memory Care Home Solutions
- ▶ Connecticut OT Association

Physician Liasons

- ▶ Karina M. Berg, MD, MS: Associate Professor of Medicine, UCONN Health Center on Aging
- ▶ Gerard J. Kerins, MD, FACP: Associate Chief of Geriatrics for Education, Yale University School of Medicine

Government

- ▶ Dawn Lambert: Program Director, Connecticut Department of Social Services
- ▶ Siobhan C. Morgan, MA: Director of Medicaid Operations, Connecticut Department of Developmental Services

Dementia Friendly Communities

- ▶ Meredith Hanley, Director, Dementia Friendly America
- ▶ Penelope Young: President, Connecticut Area Agencies on Aging
- ▶ Mag Morelli: President, Leading Age Connecticut

Professional Development and IDD Training

- ▶ Judith O. Sheehan, OTR/L CFo: President, ConnOTA
- ▶ Mary Beth Bruder, PhD: Director, University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service
- ▶ Kathryn G. Pears, MPPM, Co-Chair, NTG Training and Education Committee



CONNOTA
CONNECTICUT OCCUPATIONAL THERAPY ASSOCIATION

DDS



UConn HEALTH

UConn Center for Excellence in Developmental Disabilities

Three gap areas:

- ▶ Supportive services to persons living alone with ADRD in the community
- ▶ Delivery of behavioral symptom management training and expert consultations for family caregivers
- ▶ Services dedicated to individuals aging with intellectual and developmental disabilities with ADRD or those at high risk of developing ADRD

ACL - ADPI Project Scope

- ▶ Navigation services for post-diagnostic support
- ▶ Evidence-based/Evidence-Informed OT services
- ▶ Education to build capacity of community and AHPs throughout CT

Role of Occupational Therapy in Prevention

- ▶ Primary Level
- ▶ Secondary Level
- ▶ Tertiary Level

Objective 1: Create and implement a navigated post-diagnostic support process (PDS) and person centered plan for dementia (PCPD) with PLWD/CG based on the Alzheimer Scotland Models

- ▶ All PLWD/CGs in the project will be offered PDS services. A Navigator will meet with PLWD/CP to focus on 5 key pillars for resilient living. Over the course of 12 months (8-10 visits), families will map goals, develop adaptive strategies and create a personalized plan to guide their future.

Community Education Offerings

PDS will be supplemented by a robust education curriculum

- ▶ *Resilient Living with Dementia - First Steps* is a 5-6 week workshop that will focus on dementia symptoms/strategies, communication, legal/financial planning, planning for future care needs, peer support, community engagement, living well with dementia.
- ▶ *Resilient Living - Next Steps* will be topical sessions to take a deeper dive into issues such as driving, palliative approaches, end of life, technology solutions, restlessness, and others.

LiveWell Pillars for Resilient Living

1. Peer and Emotional Support
2. Understanding Dementia & Managing Symptoms
3. Social & Meaningful Engagement
4. Planning
5. Physical Health

Objective 2: Implement proactive services and evidence-based interventions designed to increase the self-efficacy, and quality of life of PLWD alone.

- ▶ Deliver evidence based Home Based Memory Rehabilitation and a LiveWell Technology Consultation by Occupational Therapists

Bob Savage



Pat Murphy



Objective 4a: Deliver evidence-based training to CGs to build skill and confidence in behavioral symptom management

- ▶ Deliver personalized OT intervention using Skills2Care® (S2C) or Care of Persons with dementia in their Environment (COPE).

Patricia Little - COPE Caregiver

Objective 5: Build knowledge and skills of first responders and other workers/volunteers who have contact with individuals living alone who may be experiencing symptoms of dementia through Dementia Friendly trainings

- ▶ Develop/deliver sector based training in partnership with the Connecticut Area Agencies on Aging (C4A) and LeadingAge housing providers using best practice resources from the Dementia Friendly America network. First responder/community contact training will occur with Meals on Wheels workers, local police/fire, emergency responders, housing community staff, etc.

Objective 3: Implement proactive and evidence-based/informed education and interventions designed to increase the knowledge, abilities, and quality of life of PLWD with ID and their CG.

- ▶ Host *Dementia Capable Care of Adults with ID & Dementia* 3 day training (including train the trainer)
- ▶ Deliver OT intervention Skills2Care®-ID adaptation with family and group home caregivers

DDS



UConn HEALTH

UConn Center for Excellence in
Developmental Disabilities

Objective 4b: Build skill and confidence in behavioral symptom management of the professional workforce to increase knowledge of EB/EI interventions

- ▶ Host professional development summit to build knowledge and skill of professional workforce in dementia specific evidence-based/informed interventions for PLWD with and without ID.



Dementia Summit - Fall 2019!

- ▶ SAVE the DATE
- ▶ Watch for email from LiveWell and CONNOTA
- ▶ Sign up if you have interest in becoming Skills2Care or COPE-CT certified

Summary

OT interventions designed to instill knowledge, skills, and preparedness

- preserve function of the PLWD
- improve behavioral symptom management
- prevent unnecessary psychotropic medications
- Prevent early placement
- Improve self-efficacy
- Improve QOL, health and well-being for both the CG and PLWD

Contact Us

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Thank you!

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