

# Patienthood to Personhood

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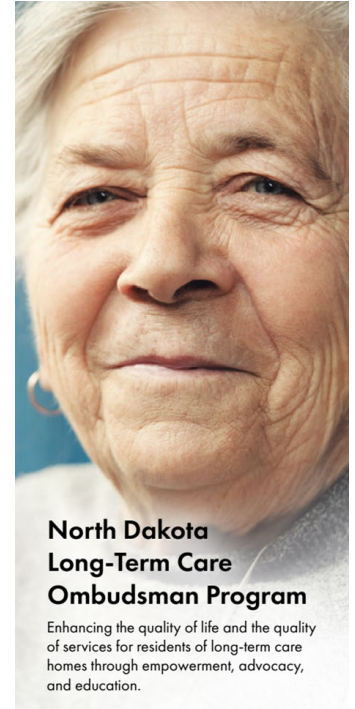
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**North Dakota Long Term Care Ombudsman Program**

**Bismarck, North Dakota**



A map of North Dakota highlighting several Indian Reservations and Service Areas in brown. The map includes major cities like Williston, Minot, Grand Forks, Bismarck, and Fargo, as well as major highways such as I-29, I-94, and I-58. The highlighted areas are: Trenton Indian Service Area (west of Williston), Turtle Mountain Reservation (north of Minot), Fort Berthold Reservation (south of Williston), Spirit Lake Reservation (east of Minot), Standing Rock Reservation (southwest), and Sisseton-Wahpeton Reservation (southeast).

Original keepers of the land  
Tribal nations

*Trenton Indian Service Area*

*Turtle Mountain Reservation*

*Fort Berthold Reservation*

*Spirit Lake Reservation*

*Standing Rock Reservation*

*Sisseton-Wahpeton Reservation*

For being here  
For participating  
For all you do





## Objectives

- Discuss evolution in long term care practice and culture
- Describe ways to support personhood
- Converse effectively about respect, dignity, choice and individuality




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“We did the best with what we knew...  
and when we knew better, we did better.”

*--Maya Angelou*

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A photograph of two women sitting on a tan leather couch. The woman on the left has dark, curly hair and is wearing a light blue polo shirt. She is holding a black pen and writing on a white document. The woman on the right has short, white hair, wears glasses, a light-colored long-sleeved top, and a necklace with a heart-shaped pendant. She is looking at the document and smiling. The background is a simple indoor setting with a window and a wooden table leg visible.

**Years of experience as  
an Ombudsman  
/Family member**

**2020**

**Department of  
Human Services**

**Person-  
Centered  
Initiative**

systemwide culture change  
for person-centered practices  
to

assist individuals to have  
control over the life they desire

engage fully in their  
communities

# Culture & Person -Centered Practices

Community Inclusion

**Focus on the Person**

Availability of Services and  
Support

**Choice and Self-Determination**



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# Person-centered/ Person-directed

## Fad or foundational?

centers on person, not disease

centers on strengths, not losses

**shifts authority to individual**

reduces reliance on professionals

builds natural supports

**gives equal credence to  
psychosocial context**

# Why?

Promotes highest quality of life

Prevents excess disability

Better health outcomes

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# Why?

It's the law!

Autonomy is a human need  
and a human right

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## It's my life

I have a right to:

Be included

Make decisions

Have an individual plan  
based on my hopes,  
dreams and goals



**1987**

Nursing Home Reform Act

OBRA 87

Culture Change

**1970s**

Patient-centered care as a full-fledged medical model...."to provide an antidote for high-tech specialty care that didn't respect patients' values and concerns."

LTCOP demonstration program

Women's Equal Rights





Study symptoms

**Individualize treatment**

**Restore health**

**Promote well-being**

Proper exercise and diet

Treat indiscriminately

Without concern for money



## Long Term Care Continuum

**1999**

Olmstead Decision

Community Based Services



# COVID-19

## The great disrupter



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YOML  
Lohr-Lux GmbH & Co. KG  
Lohr-Lux-Strasse 1  
98520 Lohr am Main  
Tel. +49 3641 9000-11 Fax +49 3641 9000-10

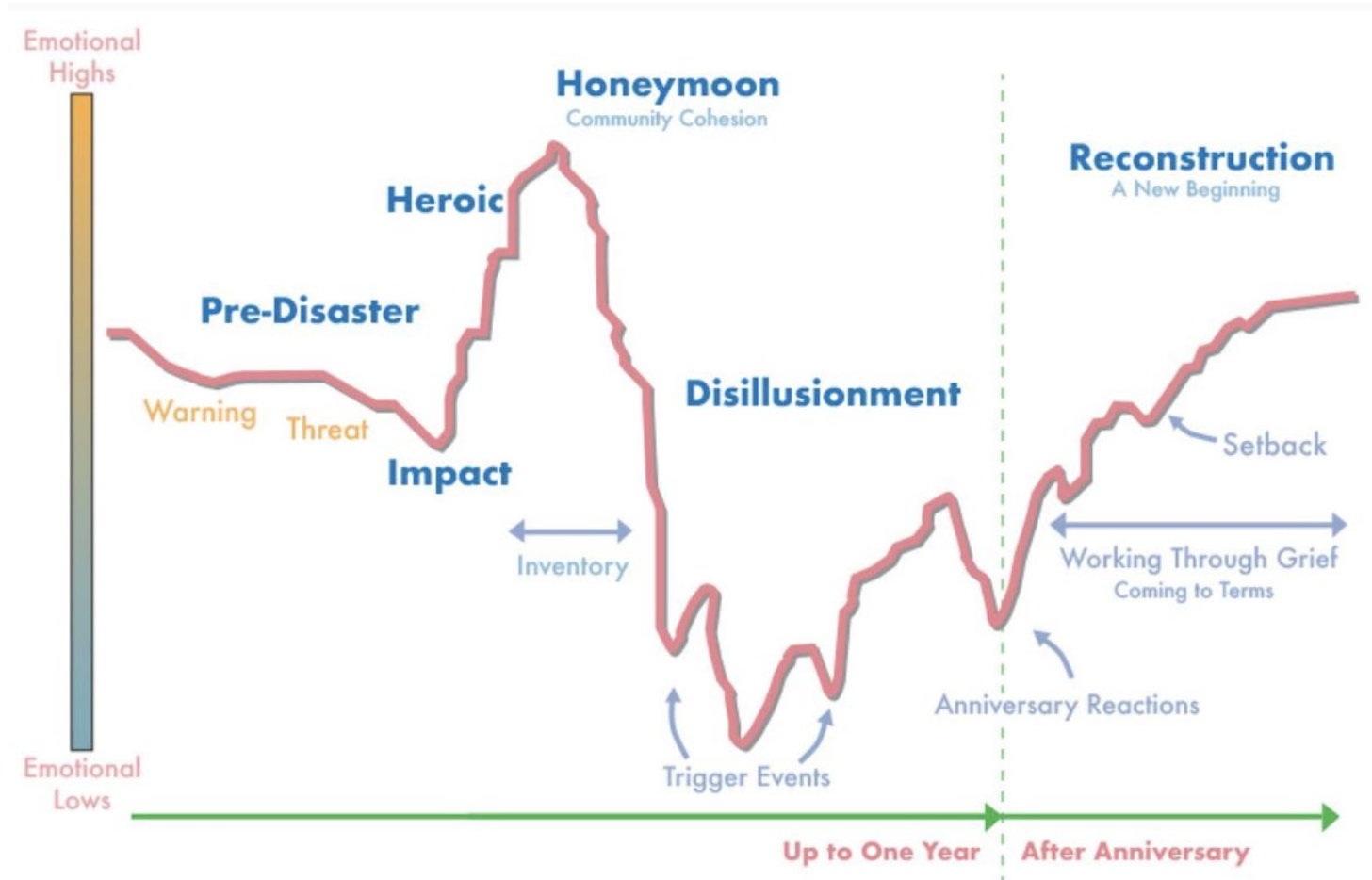


# Relationships are CRITICAL for Person-Centered Care

*Sources of information,  
support, care plans*

*And these were disrupted  
during the pandemic*

# Stages of recovery: Where are you?





# Trauma

No one has been untouched  
Disruption creates opportunity  
Trauma-informed care  
is very person-centered!

Reflections

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# Principles

Safety

**Choice**


**Empowerment**

Understanding

**Trustworthiness**

Collaboration





Physical and  
emotional safety is  
in the relationship

An elderly woman with short, light-colored hair is sitting on a bed in a bedroom. She is wearing a yellow top and is looking out a window to her right. The room is dimly lit, with light coming from the window. There are several framed pictures on the wall behind her, and a lamp is visible on a nightstand. The overall atmosphere is calm and quiet.

Create calm and  
comfortable spaces






Provide options  
in care



Provide options in  
daily living





Remind a person  
they are not  
powerless


A woman with short brown hair and glasses, wearing a white top, is sitting at a desk with a computer monitor and keyboard. She is looking towards the camera. A man with a balding head, wearing a blue and white plaid shirt, is sitting next to her, looking at the computer screen. He has a name tag on his shirt. The background shows a bulletin board with many small photos and a poster on the wall.

Connect residents with  
resources and  
advocate for support



A close-up portrait of an elderly woman with white hair, smiling warmly. Her face is wrinkled, and she is wearing a black and white striped shirt. The background is a soft-focus green and yellow. A semi-transparent white banner is overlaid on the left side of the image.

Listen to their story

A close-up photograph of a hand being washed under a stream of water. The skin is wet, and numerous water droplets are visible on the fingers and palm. The background is dark and out of focus, emphasizing the hand and the water.

Remain sensitive to  
issues of isolation





Provide consistent,  
clear information

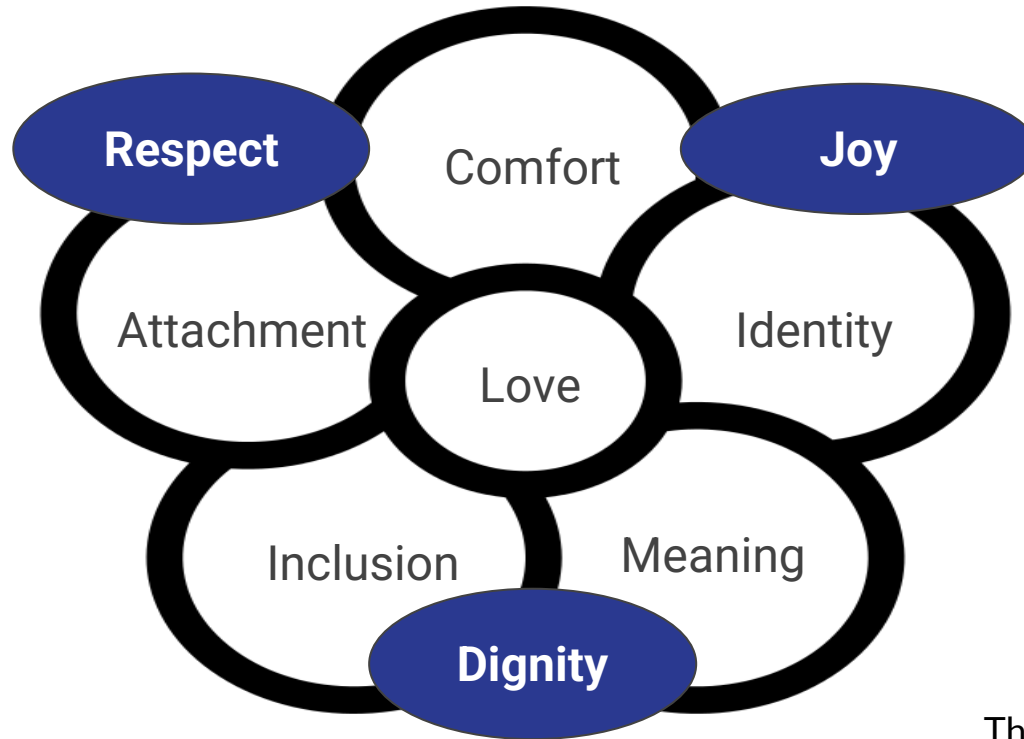


Support decisions  
AND decision-  
making



What about  
people living with dementia?

# Maintain Personhood



Thomas Kitwood, 1996,  
Dementia Reconsidered



A person with **DEMENTIA**

A **PERSON** with dementia

A **PERSON**



**WHO a person is**  
**What a person CAN STILL DO**

What's in "the who?"

Who are *YOU*?



**“We desperately need others to see our abilities and not simply focus on our inabilities. Please enable us, don’t further disable us.”**

~ Myriam Marquez, living with early onset Alzheimer’s dementia



# What a person can do

## Early Stage

Carries on conversations

Can plan common tasks like dinner

Navigates familiar surroundings

Recognizes familiar people and places

## Middle Stage

Remembers things that happened long ago

Recognizes people from early in life

Reads and understands singular words

Mimics simple actions

Carries out over-learned processes like "Hello, how are you."

Makes simple decisions

## Late Stage

Interprets and uses basic body language

Enjoys sounds, tastes, smells, sights and touch

# What a person can't do

## Early Stage

May need help doing familiar tasks

May need assistance recalling familiar places or people

May need assistance with planning or organizing

May need help remembering words or names

May get frustrated easily

## Middle Stage

May need hands-on care

May get lost easily

More repetition of questions or statements

Anger, suspicion

Changes in personality

## Late Stage

Needs hands on personal care

Significant confusion

Loss of ability to communicate

May not recognize self or family

May lose ability to smile

# Valuing staff

If staff feel abandoned and abused, residents will be too. Staff who feel supported and encouraged simply give better care

Creating the right environment

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## Model

Respect and caring

Curiosity

Start with hello

Fact-finding, not fault  
finding


Person-first language



# Palliative care

Preserves values and identity of the individual, even in the advanced stages

Comfort Care



**We are in  
this together.**



## Palliative Care for People with Dementia:

Why Comfort Matters in Long-Term Care

**caringkind**

*The Heart of Alzheimer's Caregiving*

# Resources

[Dementia Action Alliance](#)

[The Gerontologist Care Practice Recommendations](#)

[Palliative Care for People with Dementia:](#)

[Raising The Bar: Practice Guide for Nursing Home Communities](#)


[NCAPPS Shorts](#)

**For being here  
For your interest  
For all you do**

**Please stay in touch  
swehry@une.edu  
@beingwithaging**



INNOVATION FOR A HEALTHIER PLANET

A close-up photograph of a blue marker writing the words 'Thank you' in cursive on a piece of white paper. The marker is positioned at the end of the word 'you', and the paper is tilted diagonally.

*Thank  
you*