Stigma, trust, self-compassion and gratitude

Reflections and lessons learned during the pandemic years

Barbara Gottlieb

Today's journey

- Introduction

- My first virtual patient

- Trust and entrustability

- The new normal
  - Building and sustaining our institutions
  - Sustaining ourselves and each other
    Self-compassion
    Gratitude

How do stigma and shame enter your work with clients/patients?

- CHAT WATERFALL

- Enter a word or phrase into the chat

- WAIT

- When I say now (5-4-3-2-1 NOW!) press send

Case 1

- 50 year old woman with history of sadness, feelings of isolation, hopelessness, decreased interest in family, work, lack of motivation to keep up with 3 jobs

- Refutes/rejects the diagnosis of depression; declines treatment

- Born in Haiti, came to US in early 2000's. bilingual. Completed high school in Haiti and some community college courses in US. Works in several health care settings. Has 2 late adolescent children, close relatives in the town where she lives.

- Expresses belief that mental health problems are signs of weakness and bad character

- Expresses personal shame that she has the feelings described above

- Expressed that she would be better of dead

Case 2

42 year old woman with increased anxiety, including panic attacks, sleep disturbance, impulsive eating, decreased self-confidence, loss of interest in family and work

Agreed to mental health referral; discontinued after 4 sessions; agreed to anti-anxiety medication which reduced panic attacks,"stabilized" mood, improved her ability to function to some extent

White, masters degree in education, special education teacher. Married with 2 children ages 4 and 6. Husband is a first responder. She spent the first 3 months of the pandemic working from home and caring for her 2 children. Husband rarely able to be at home

Prejudice, labeling, exclusion, discrimination directed at an individual or group by the "mainstream" population for possessing or lacking a characteristic that separates them from what is considered normal or desirable

Internalization →

Distortions
Self-devaluation
Self doubt
Self-discrimination
Diminished self-esteem
Diminished self-efficacy

Endorsement →

Overt agreement
Application of negative stereotypes

Public stigma

Personal shame

Self-stigma

Social isolation

Media, highly public normative displays (positive and negative)

Normalized loss of rights and opportunities

Cross-cutting (intersectional) characteristics and experiences that are disempowerment

Gender identity/sexual orientation

Culture, ethnicity

Racism

Class

Ability

Education

Public stigma

Self stigma

Resistance

Social support

Positive group identity

Media, highly public normative displays of counter-messages, healing and justice

Restoration of respect and rights

Enhancement of practices that counter stigma

Self-compassion

Promotion of help-seeking behavior

Coping strategies

Countering stigmatizing beliefs (psycho-education, cognitive restructuring)

Disclosure with a community of peers

Self-compassion practices

En

Self-stigma outcomes

- "why try?" – interferes with motivation, achievement of goals
- Barrier to seeking/accepting help
  - Well-documented barrier to seeking care, engagement and adherence to treatment
- Diminished self-efficacy and self-worth – spiraling effect
- Avoidance of situations in which public/external disrespect is anticipated

Stereotypes and stigma

Depression, mental illness

- Dangerous
- Weak
- Bad character
- Contagious
- Incompetent

Overweight, obesity

- Lazy
- Weak-willed
- Un-intelligent
- Lacking in self-discipline
- Irresponsible

Discrimination against people with mental illness and obesity

- Multiple domains
  - Employment
  - Housing
  - Education
  - Social interactions
  - Medical care
- Range of severity
  - Chronic, day-to-day
  - Crisis (such as firing, eviction)
- Compounded and shaped throughout the life-course
- Compounded by other disadvantages
- Compounded by socialization

Back to our cases
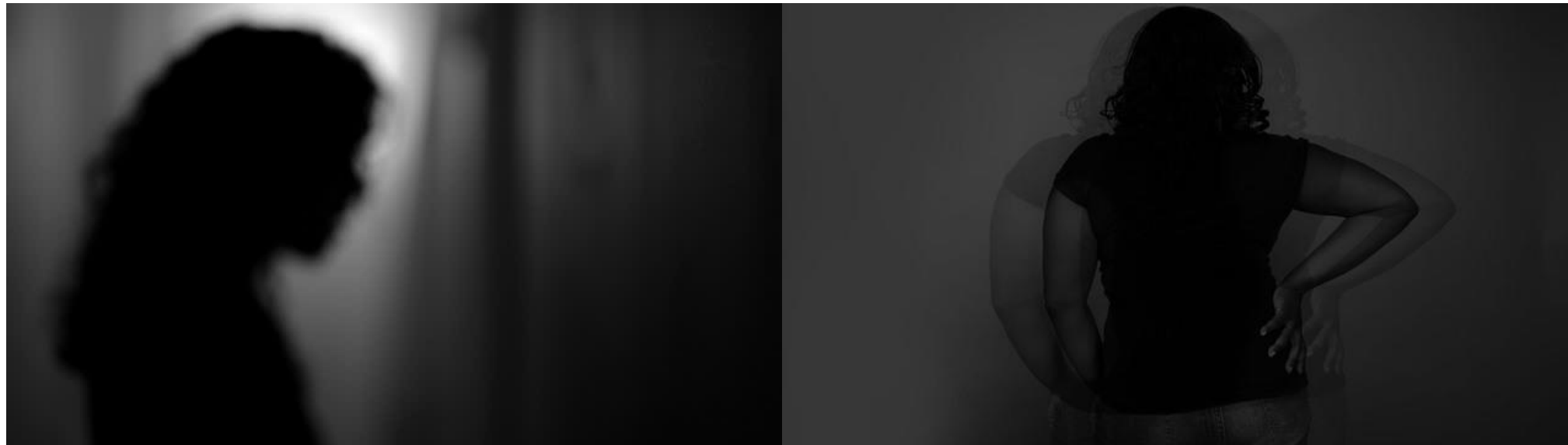
Case 1

Dr Gottlieb – what is the meaning of life?

Case 1

Endorsed cultural stereotypes of mental illness: "fou"

Described personal shame

Took control of the visit

Established the terms of "treatment"

Determined the path forward

Case 2

Ultimately expressed that her greatest concern was that she had regained all of the weight she had worked hard to lose over the past 2 years, plus additional weight

Expressed personal shame related to weight gain, loss of control, loss of self-confidence and self-efficacy

Established the terms of "treatment" she would accept

Established a path forward

OFFICE-BASED CARE

- Components
  - Vital signs, weights, etc
  - Physical exam
  - History/communication
  - Lab
- Who participates?
  - Secretary
  - Medical Assistant
  - Lab personnel
  - Provider
  - Patient
  - ?Family member
- Whose space?
  - Parking lot
  - Waiting room
  - Provider's office
  - Lab

VIRTUAL CARE

- Components
  - Minimal (if any) exam
  - History/communication
  - Technology
- Who participates?
  - Provider
  - Patient
  - ?Family member
- Whose space?
  - Patient's home
  - Provider's home or office

OFFICE-BASED CARE

- Components
  - Vital signs, weights, etc
  - Physical exam
  - Undress
  - History/communication
  - Lab
- Who participates?
  - Secretary
  - Medical Assistant
  - Lab personnel
  - Provider
  - Patient
  - ?Family member
- Whose space?
  - Parking lot
  - Waiting room
  - Provider's office
  - Lab

VIRTUAL CARE

- Components
  - Minimal (if any) exam
  - History/communication
  - Technology
  - Your own clothes
- Who participates?
  - Provider
  - Patient
  - ?Family member
- Whose space?
  - Patient's home
  - Provider's home or office

Freedom from physical exam

Focus on communication

Privacy Anonymity

Intimacy

Leveling of power

Freedom from physical exam

Focus on communication

Privacy Anonymity

Intimacy

Leveling of power

For the patient

- Decreased shame
- Increased self-efficacy
- Safety
- Healing space

What did I learn?

- Role of stigma and self –stigma in vulnerability
- A new understanding of how the medical environment can contribute to vulnerability
- A broader understanding of patient-centeredness
- Trust

Trust and the pandemic

Uncertainty, disruption, emotional consequences

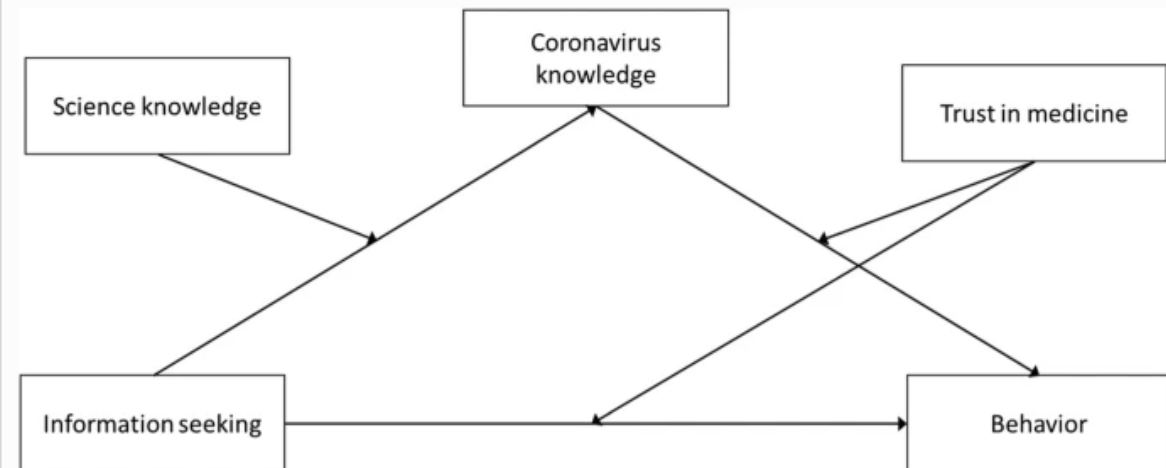Masking and other preventive/protective practices

Vaccines

Treatments

Disproportionate burden

Widening inequities

Fig. 1

Graphical illustration of the moderated mediations. The behavior in the moderated mediation models was either compliance with preventive measures (Model 1) or panic behavior (Model 2)

Sailer M, Stadler M, Bates E et al. Science knowledge and trust in medicine affect individuals' behavior in pandemic crises. European Journal of Psychology of Education. Published on line 14 April, 2021 https://doi.org/10.107/s10212-021-00529-1

Trust in science and medicine

73%

- Declining trust in medical leaders and the health care system

- Different than satisfaction with care

- Historical factors that justify mistrust

- Politically motivated disinformation

- Uncertainties, fear, explosion of knowledge during COVID-19 pandemic

34%

Confidence in Science, 1975 and 2021

Now I am going to read you a list of institutions in American society. Please tell me how much confidence you, yourself, have in each one -- a great deal, quite a lot, some, or very little? How about -- Science?

1975 **2021**

	1975	2021
U.S. adults	70%	64%
Democrats	67%	79%
Independents	73%	65%
Republicans	72%	45%

GALLUP

https://news.gallup.com/poll/352397/democratic-republican-confidence-science-diverges.aspx

WHAT IS TRUST??

https://arbordayblog.org/misctrees/five-trees-need-friend/

asymmetrical vulnerability. When we trust, we allow persons into a position where they can harm us with respect to something we care about deeply. Annette Baier *(philosopher, studied moral psychology)* Baier A. 1986. Trust and antitrust. *Ethics* 96:231–60.

``**whatever matters** to human beings, trust is the atmosphere in which it thrives'' Sissela Bok (philosopher, ethicist) Lying Moral Choice and Public Life, 1978.

trust is the intention to **accept vulnerability** based upon **the positive expectation** of the intentions or behavior of another. Stephen Atkins *(executive coach and mentor)* Trust-based mentoring towards a new knowledge state as a change cycle: Exploring key interpersonal interactions. International Jour Evidence Based Coaching and Mentoring 2019 17(2): pp36-51

How do trust and mistrust enter your role(s)?

CHAT WATERFALL
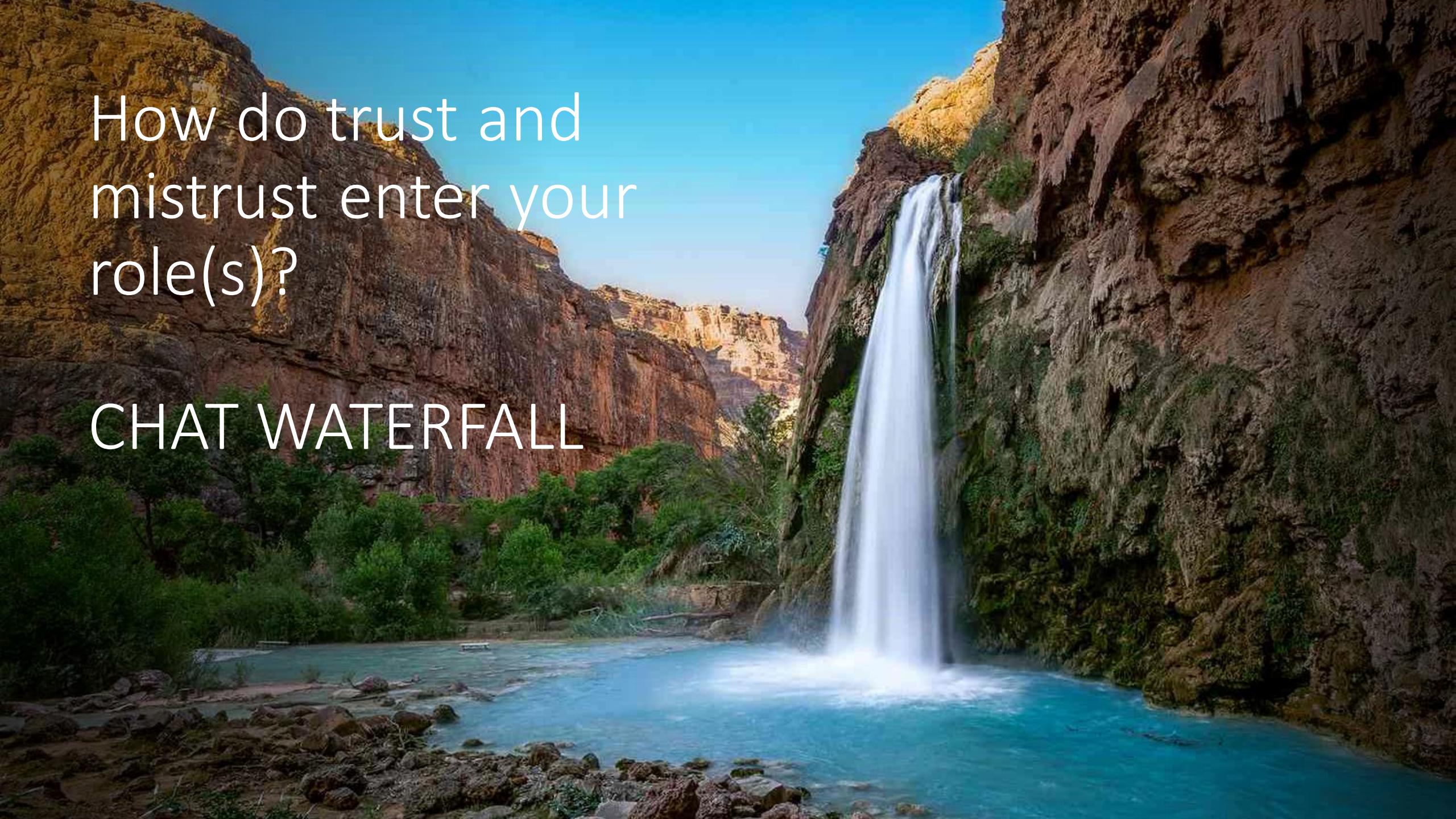
COVID-19 vaccine hesitancy: Race/ethnicity, trust, and fear

Don E. Willis, Jennifer A. Andersen, Keneshia Bryant-Moore, James P. Selig, Christopher R. Long, Holly C. Felix, Geoffrey M. Curran, Pearl A. McElfish ✉

1205 on-line survey of Arkansas adults July/Aug 2020 to study relationships of sociodemographics, COVID—19 health literacy, fear of COVID-19 infection, general trust in vaccines and COVID-19 vaccine hesitancy

Major findings:

- 1 in 5 people reported COVID-19 vaccine hesitancy

- 50% of African Americans

- 30% of respondents with income < $25K

- 32% of respondents with some college

- 62% with little to no fear of COVID-19 infection

- 55% of those with low trust in vaccines in general

- OR for vaccine hesitancy 2.42 greater for African Americans compared to whites

Willis DE, Andersen JA, Bryant-Moore K et al. COVID-19 vaccine hesitance: Race/ethnicity, trust and fear. Clin Transl Sci. 2021;14:2200–2207.

How do trust and mistrust affect health?

- Trust correlates with:
  - satisfaction with care/provider
  - adherence to treatment
- Tuskegee disclosure caused ripple effects on health of older Black men:
  - increased medical mistrust
  - decreased outpatient and inpatient interactions with medical care
  - increased mortality: Estimates that the disclosure accounted for 1.5 year decreased life expectancy at age 45 for Black men.

Pearson SD, Raeke LH. Patients' trust in physicians.   *J Gen Intern Med*. 2000;15(7):509-513.

Alsan M, Wanamaker M. Tuskegee and the Health of Black Men. *QJ Econ*. 2018;133(1):407-455. doi:10.1093/qje/qjx029

Perspective

Trustworthiness before Trust — Covid-19 Vaccine Trials and the Black Community

Rueben C. Warren, D.D.S., Dr.P.H., M.Div., Lachlan Forrow, M.D., David Augustin Hodge, Sr., D.Min., Ph.D., and Robert D. Truog, M.D.

"When Covid-19 vaccines are eventually approved by the FDA, their success in Black and other communities will depend on whether members of these communities not only trust that they are safe and effective, but also believe that the organizations offering them are trustworthy...

...Time is running short, and trustworthiness, not trust, must be our first and most urgent priority."

Warren RC, Forrow L, Hodgen DA, Truog RD. Trustworthiness before trust – Covid-19 vaccine trials and the black community. N Engl J Med 2020;383:e121.

A CONCEPTUAL MODEL OF TRUST
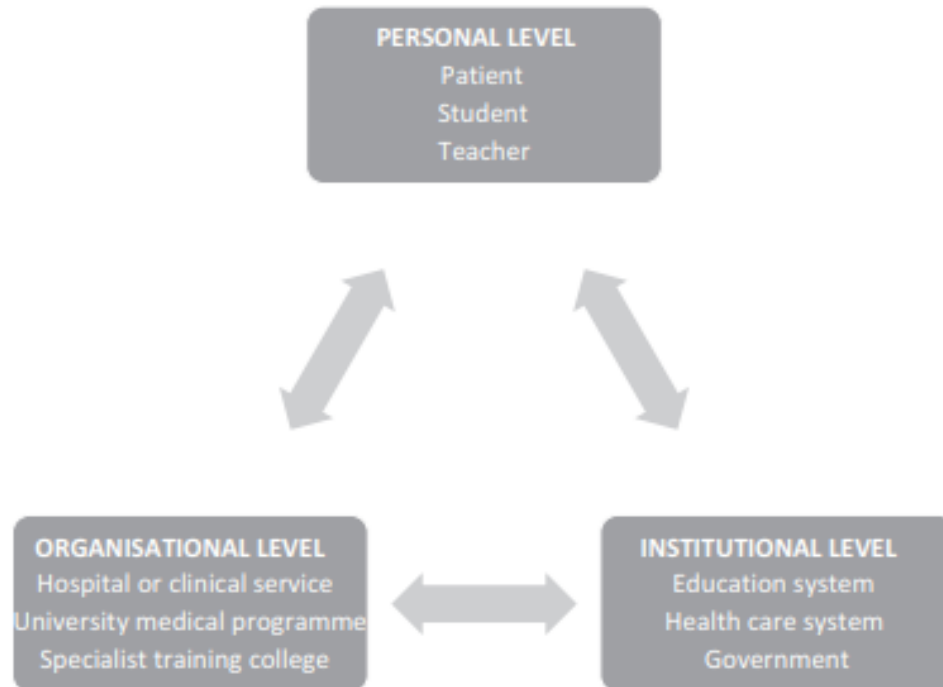
Figure 1 Relationships of trust in medical education. Arrows represent bidirectional relationships

Interpersonal trust – relationship between 2 individuals

General trust – attitudes toward collective entities or social organizations

Foundational elements of trust

- Fidelity, caring, advocating tor the person's welfare

- Competence : good practice; avoiding mistakes

- Honesty

- Confidentiality – proper use of sensitive information

- Global trust – " soul of trust". Multiple dimensions – difficult to characterize

Trust by an individual depends on past experiences with institutions and organizations

Damodaran A, Shulrut B, Jones P. Trust and risk: A model for medical education. Medical Education 2017; 51:892-902.
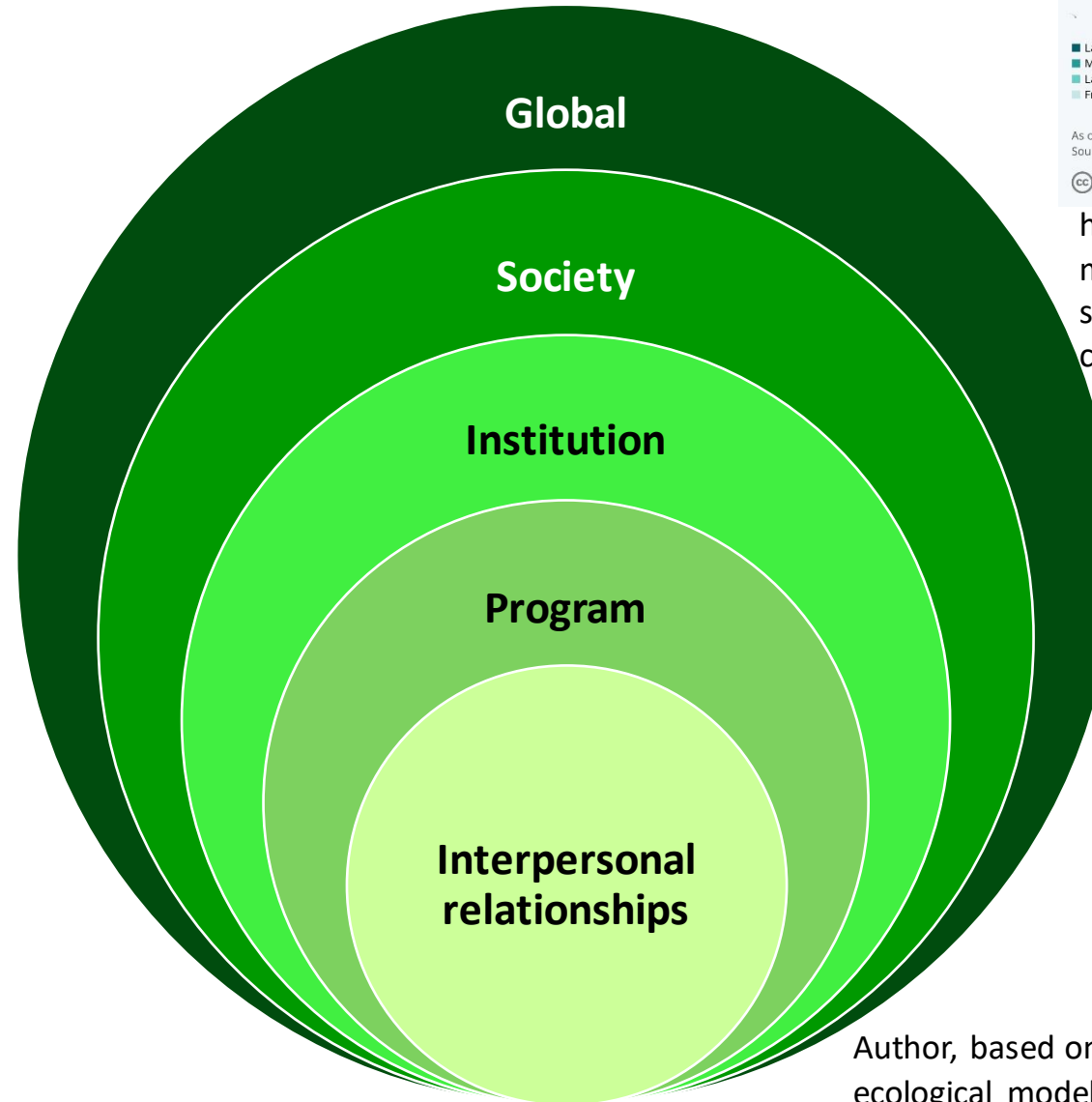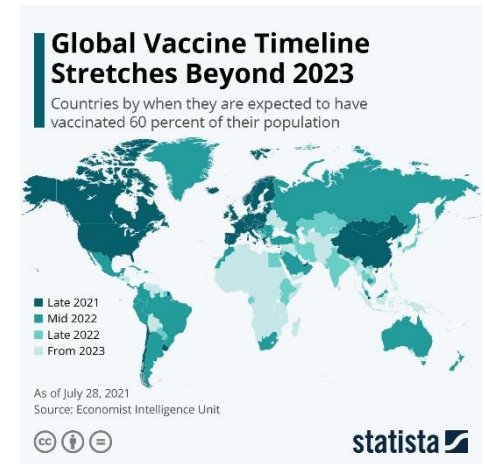
TRUST AND ENTRUSTABILITY IN CONTEXT

Global Vaccine Timeline Stretches Beyond 2023
Countries by when they are expected to have vaccinated 60 percent of their population

Late 2021
Mid 2022
Late 2022
From 2023

As of July 28, 2021
Source: Economist Intelligence Unit

statista

https://thecuencadispatch.com/lenin-moreno-no-country-should-monopolize-access-to-covid-19-vaccines/

https://hms.harvard.edu/news/stand-against-racism

- Global
- Society
- Institution
- Program
- Interpersonal relationships

https://www.wcch.com/services/community-health-center

https://icenetblog.royalcollege.ca/2015/01/20/how-to-improve-your-bedside-teaching-learn-from-the-pros/

Author, based on Bronfenbrenner's social ecological model
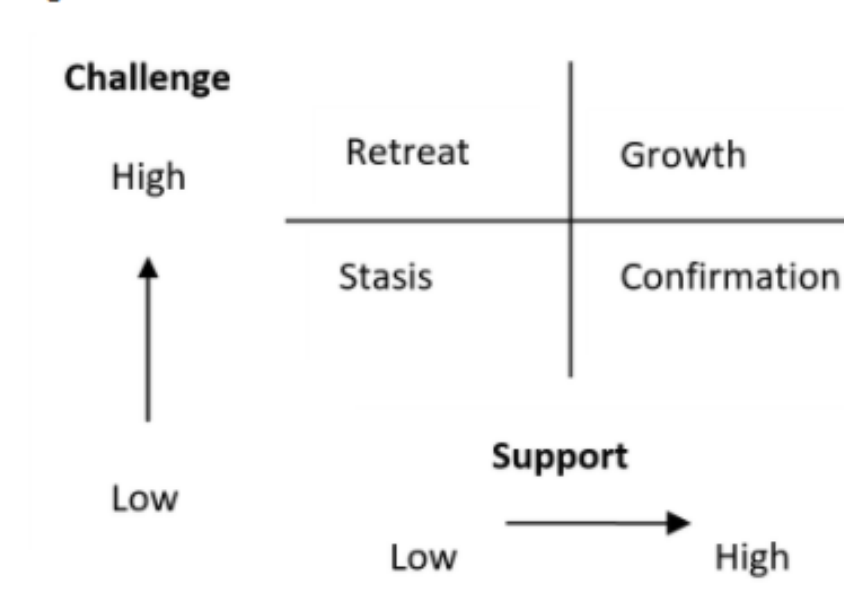
What can we do?

Trust for clinicians, coaches, mentors, peer relationships

Atkins

- Balance challenge and support
- Trust is the foundation

Figure 1: Daloz 2-D Model

Challenge

	Retreat	Growth
High		
	Stasis	Confirmation

Support

Low   Low   →   High

Atkins, S. Trust-based mentoring towards a new knowledge state as a change cycle: Exploring key interpersonal interactions. International Jour Evidence Based Coaching and Mentoring 2019 17(2): pp36-51.

Becoming Trustworthy Clinicians

Figure 3: Guiding Framework for Action
Achieving Cultural Safety

- Build the therapeutic alliance
- Cultivate curiosity, humility, respect
- Trauma –informed care
- Training – bias, health inequities
- Effective communication skills
- Engage in deliberate strategies to build understanding of science and medicine
- Patient navigators
- Interpreters
- Appropriate measurement and data collection
- CQI approach to program

Source: Tripartite Committee on First Nations Health, (2016) Cultural Safety and Humility in Health Services for First Nations and Aboriginal people in British Columbia: A Guiding Framework for Action

Becoming Trustworthy: Educators

- Build the education alliance
- Training – implicit bias, microaggressions
- Effective mentoring
- Monitor outcomes
- Foster curiosity, humility, respect
- CQI approach to education programs

Figure 3: Guiding Framework for Action

Achieving Cultural Safety

Source: Tripartite Committee on First Nations Health, (2016) Cultural Safety and Humility in Health Services for First Nations and Aborigial people in British Columbia: A Guiding Framework for Action

Becoming Trustworthy Institutions

Figure 3: Guiding Framework for Action
Achieving Cultural Safety

Source: Tripartite Committee on First Nations Health, (2016) Cultural Safety and Humility in Health Services for First Nations and Aboriginal people in British Columbia: A Guiding Framework for Action

- Use human-centered design principles to re-design healthcare
- Engage in trust-building activities with communities and key stakeholders
- Appropriate measurement, data collection and transparency
- Promote effective communication within/among teams
- Trainings: bias, health inequities, culture of safety
- Highly functional systems that support all stakeholders

Brookside Community Health Center and the Pandemic

Challenges

- Our patients are invisible
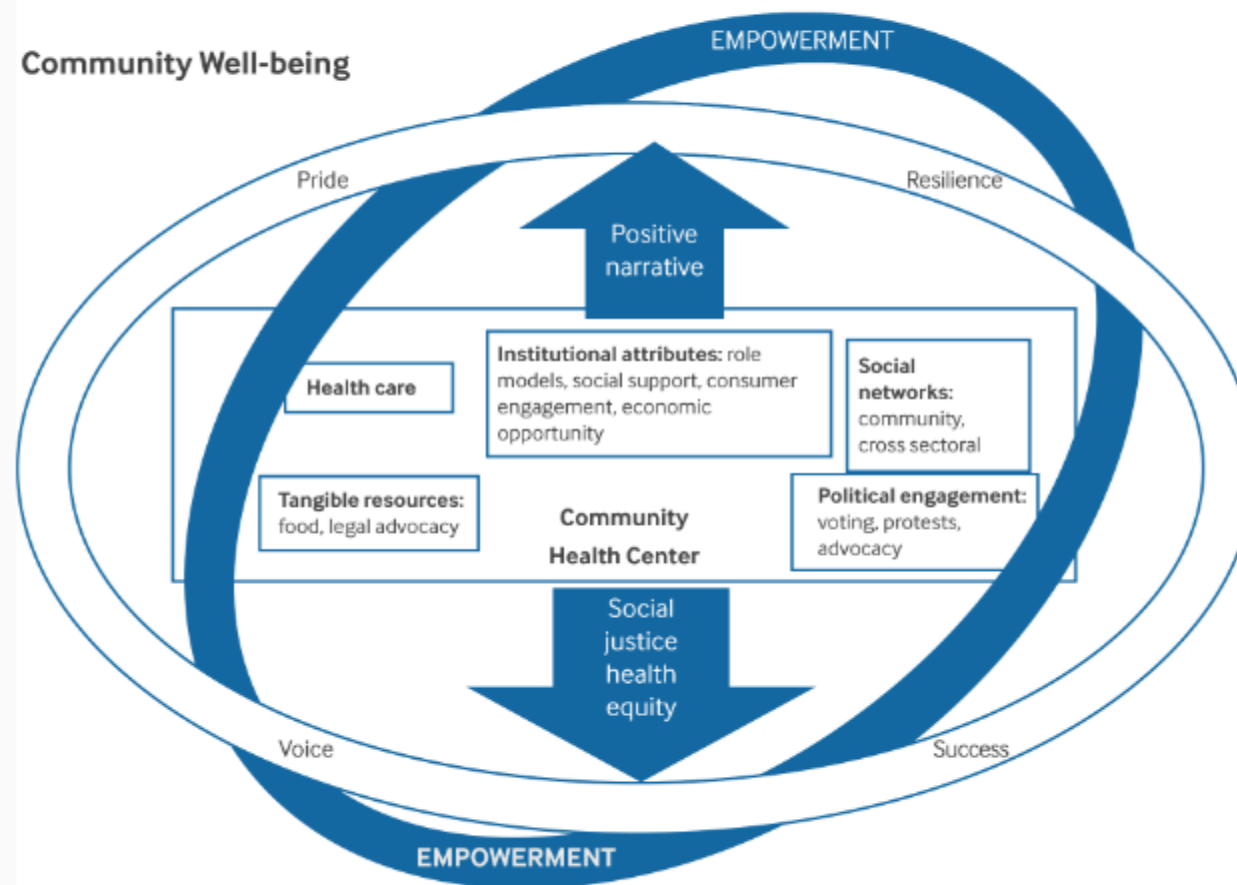
- Stigma

- Mistrust

Opportunities

- Trust and stature in the community

- Tangible assets

- Value- and mission- driven

- Health care embedded in public health model
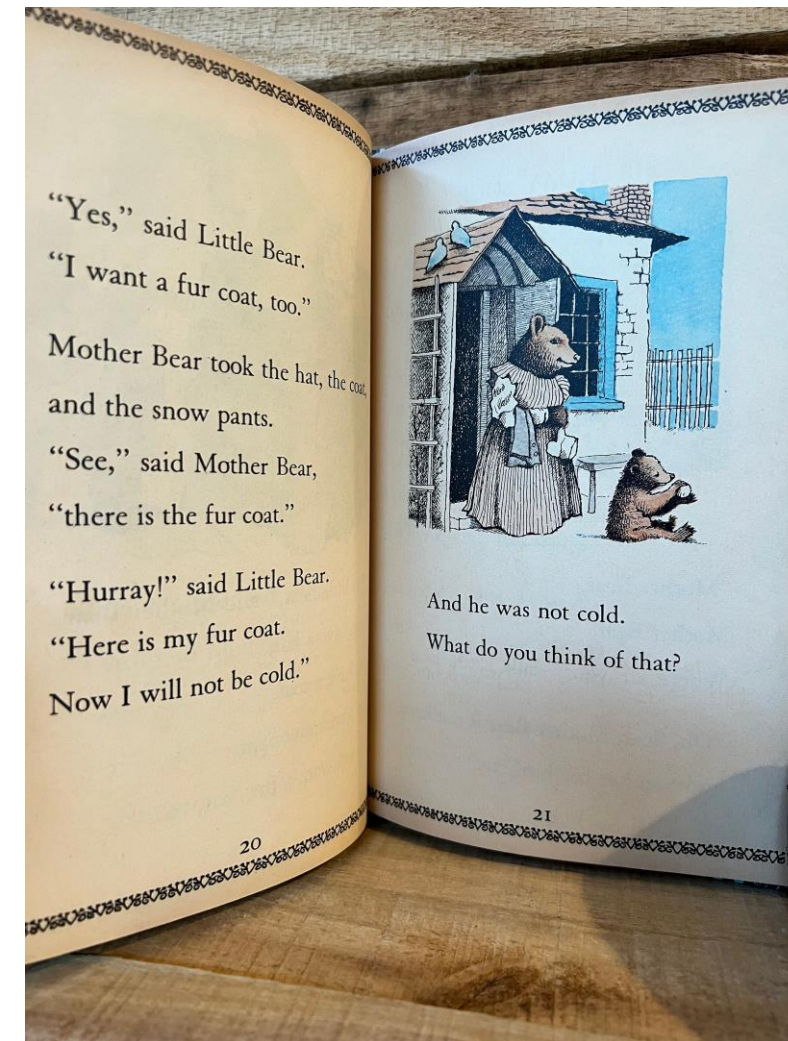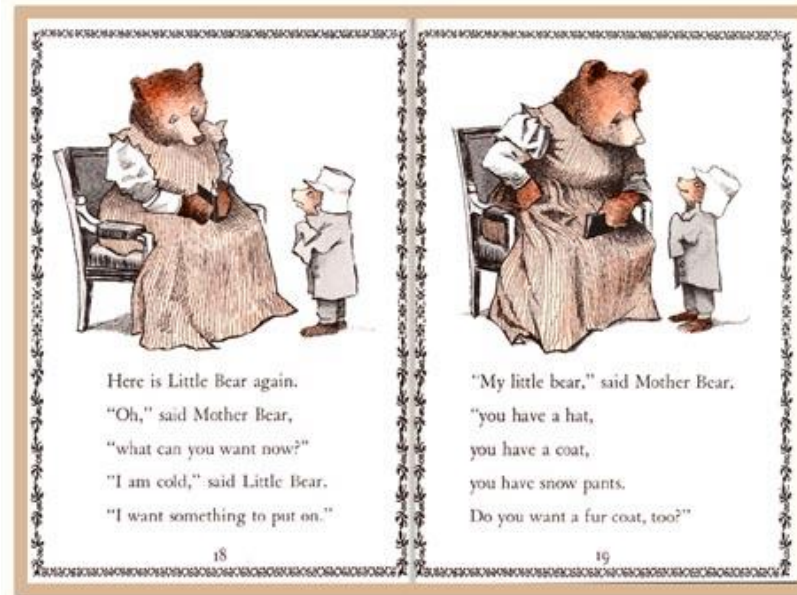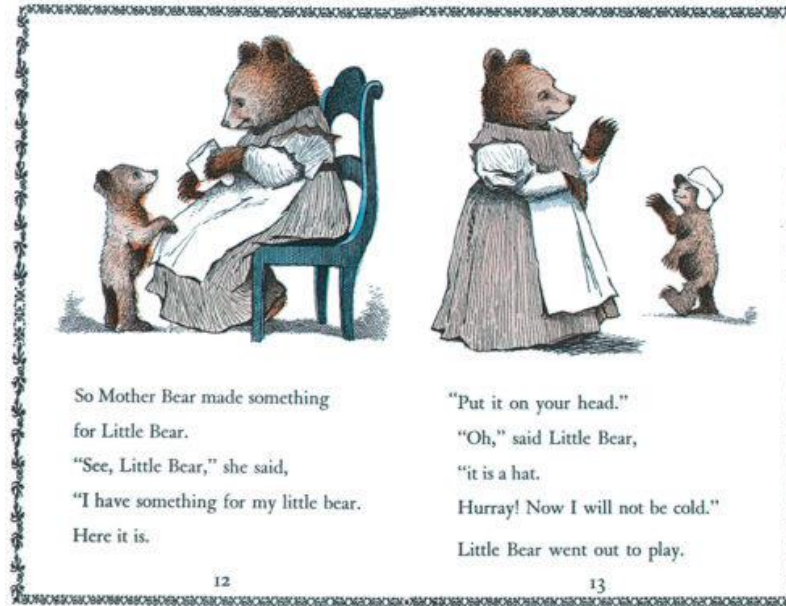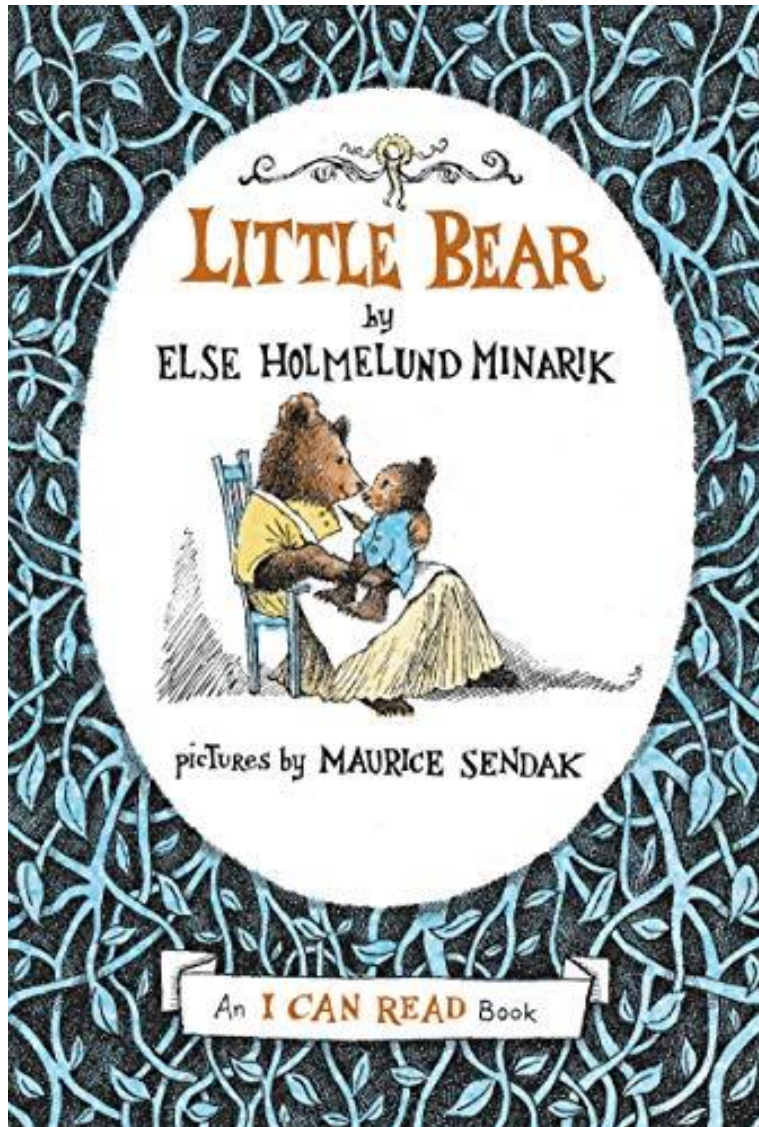
- Tradition of problem-solving

A Conceptual Diagram of Community Health Centers

This conceptual diagram reveals how community health centers are designed to promote the well-being and empowerment of the communities they serve. At the center are concrete activities and processes that promote the community's strengths and address the drivers of health and well-being. Through those activities, the health center promotes social justice and expresses a positive narrative of the community, activating the community's voice and resilience. Ultimately, the community is able to express its power.

Community Well-being

EMPOWERMENT

Pride

Resilience

Positive narrative

Health care

Institutional attributes: role models, social support, consumer engagement, economic opportunity

Social networks: community, cross sectoral

Tangible resources: food, legal advocacy

Community Health Center

Political engagement: voting, protests, advocacy

Social justice health equity

Voice

Success

EMPOWERMENT

LITTLE BEAR

by

ELSE HOLMELUND MINARIK

pictures by MAURICE SENDAK

An **I CAN READ** Book

So Mother Bear made something
for Little Bear.
"See, Little Bear," she said,
"I have something for my little bear.
Here it is.

12

"Put it on your head."
"Oh," said Little Bear,
"it is a hat.
Hurray! Now I will not be cold."
Little Bear went out to play.

13

Here is Little Bear again.
"Oh," said Mother Bear,
"what can you want now?"
"I am cold," said Little Bear.
"I want something to put on."

18

"My little bear," said Mother Bear,
"you have a hat,
you have a coat,
you have snow pants.
Do you want a fur coat, too?"

19

"Yes," said Little Bear.
"I want a fur coat, too."

Mother Bear took the hat, the coat,
and the snow pants.
"See," said Mother Bear,
"there is the fur coat."

"Hurray!" said Little Bear.
"Here is my fur coat.
Now I will not be cold."

20

And he was not cold.
What do you think of that?

21

Taking care of ourselves and each other

SELF-DETERMINATION THEORY

Autonomy

Competence

Relatedness

Self-determination theory
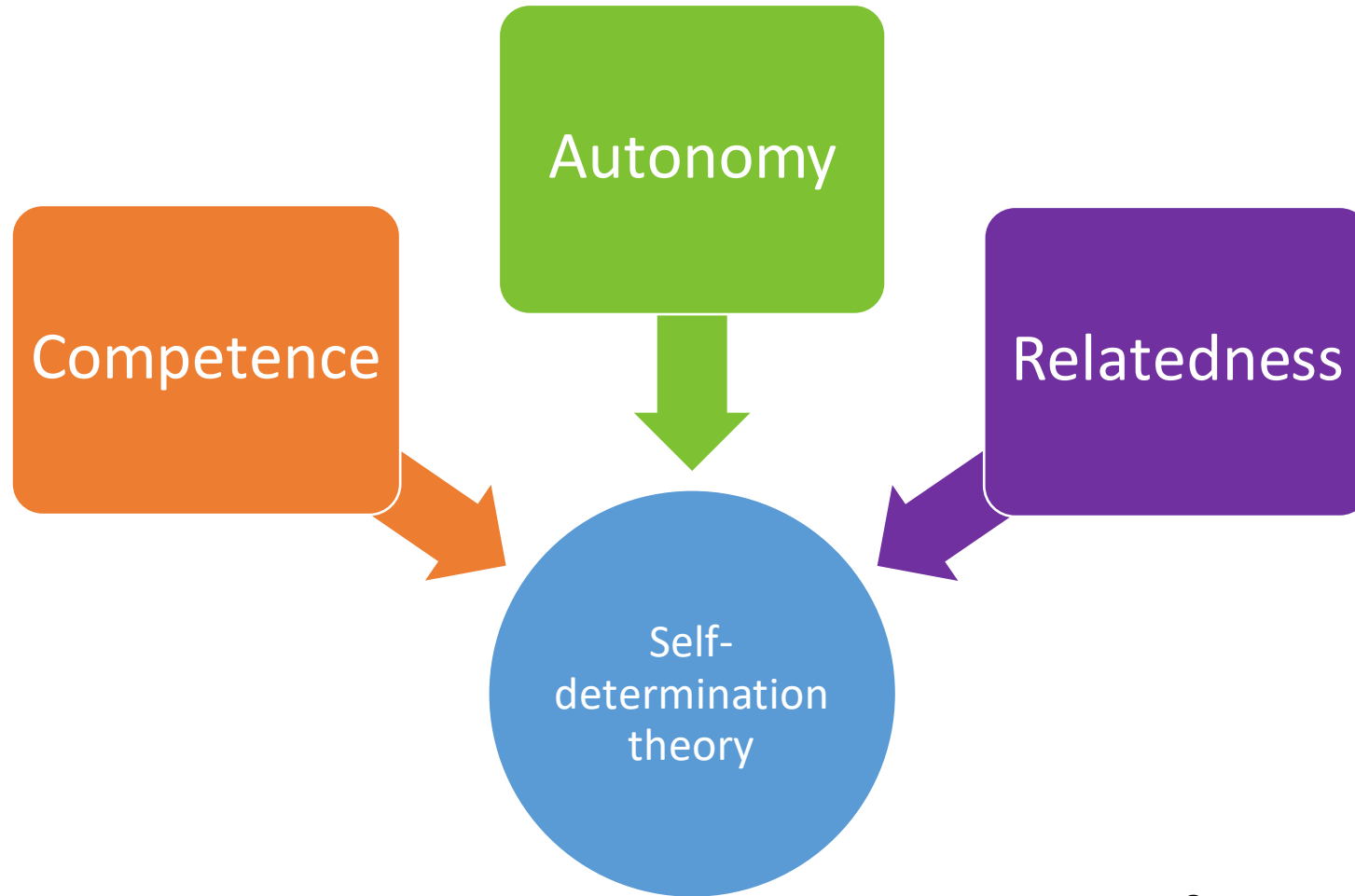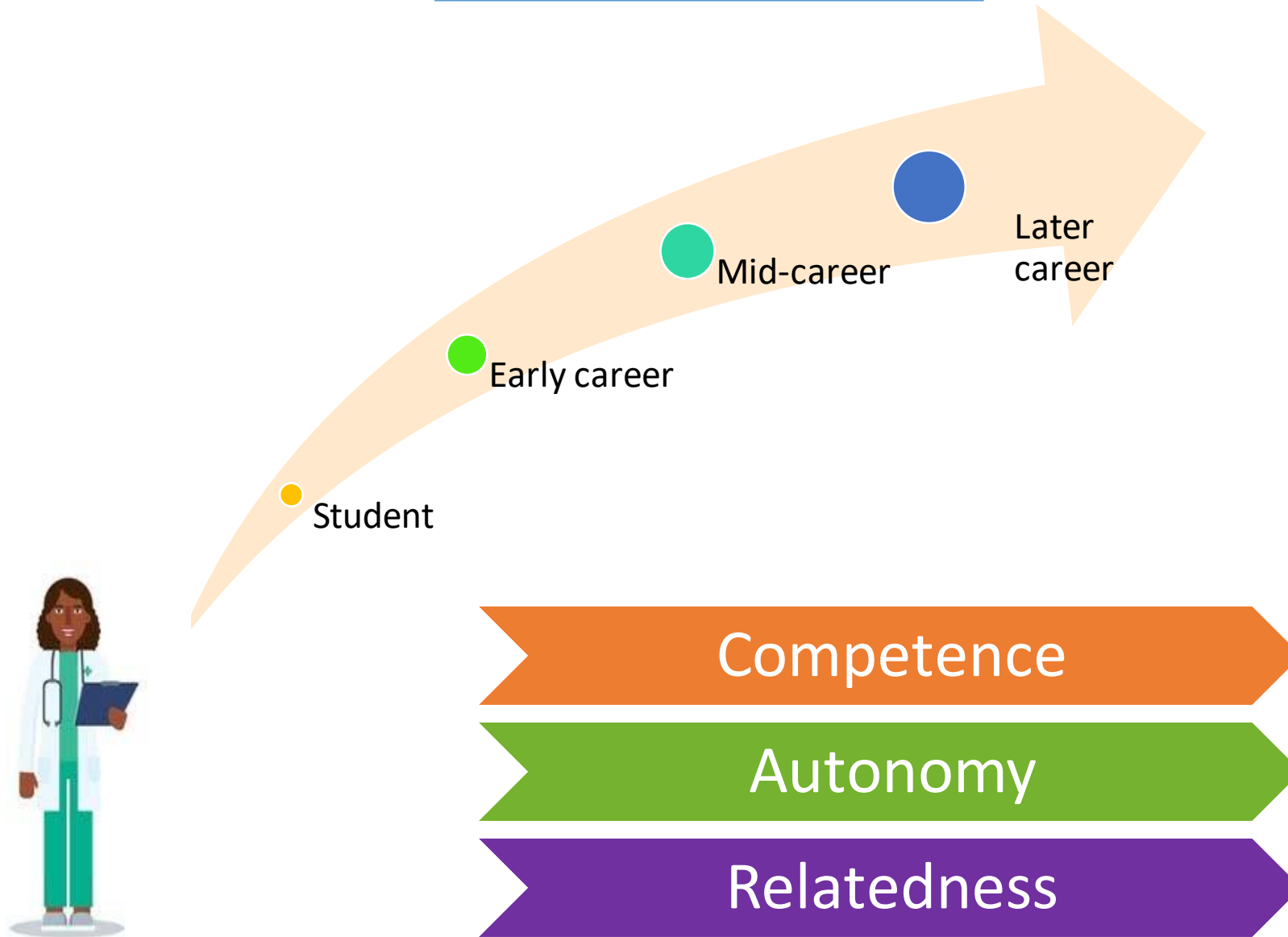
Deci, E. L., & Ryan, R. M. (1985). Intrinsic motivation and self-determination in human behavior.

LIFELONG LEARNING AND PROFESSIONAL DEVELOPMENT
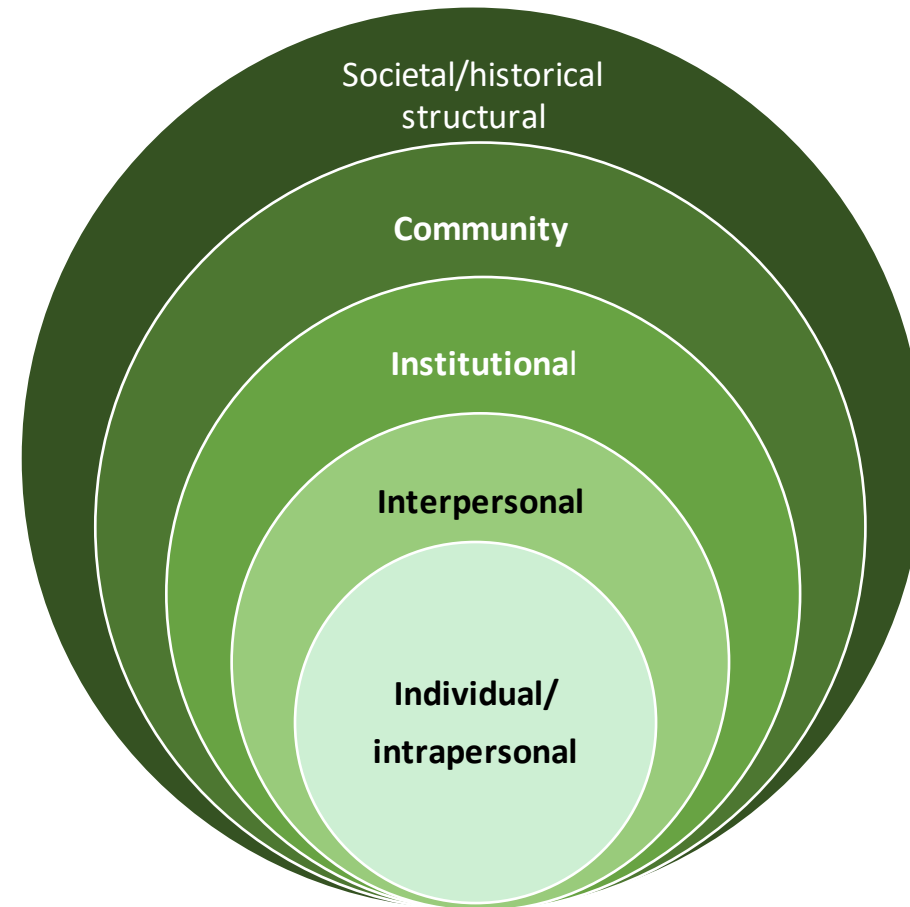
Student

Early career

Mid-career

Later career

Competence

Autonomy

Relatedness
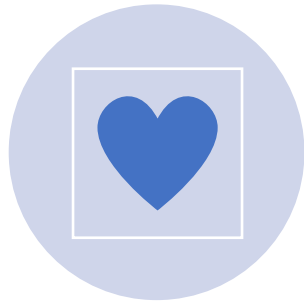
SOCIAL ECOLOGICAL MODEL PROFESSIONAL DEVELOPMENT

SELF-COMPASSION

Self-compassion: for ourselves and for each other

SELF-KINDNESS

COMMON
HUMANITY

MINDFULNESS

Promoting self-compassion amongst ourselves

- ❑ Dialogue about self-compassion
- ❑ Serve as a sounding board
  - Recognize the self-critical voice
  - Re-frame self-critical thoughts
- ❑ Promote practice of self-compassion through role modeling
  - When discussing fears, mistakes
- ❑ Promote self-awareness, self-appreciation and self-gratitude
- ❑ Un-pack imposter syndrome
- ❑ Support pursuit of opportunities and challenges
- ❑ Promote skills of reflection
  - To learn and improve
- ❑ Promote self-care

Outcomes of self-compassion

Emotional regulation

Decreased anxiety, rumination and fear

Greater happiness and optimism

Cognitive effects

Enhanced working memory and cognitive flexibility

Curiosity, creativity and problem-solving skills

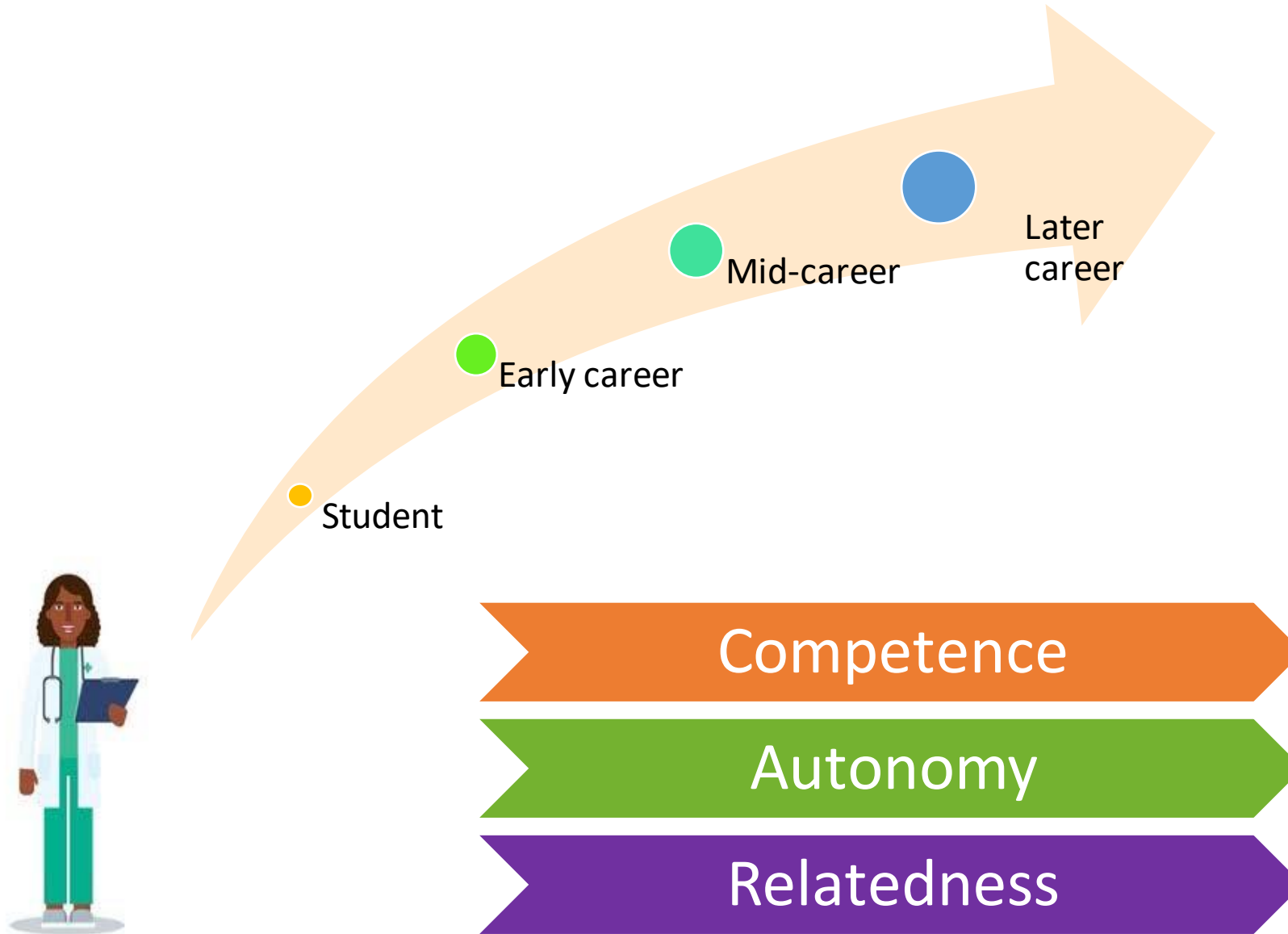**Behavioral changes**

Productive self-reflections

Greater capacity to admit and learn from mistakes

Greater capacity to demonstrate initiative and take on new challenges

Enhanced Self-confidence
Greater intrinsic motivation
Growth mindset

LIFELONG LEARNING AND PROFESSIONAL DEVELOPMENT

Later career

Mid-career

Early career

Student

Competence

Autonomy

Relatedness

NUTRTURING GRATITUDE