I'm IN webinar
Community Inclusion

May 26, 2020 | 2:00-3:30pm

Welcome to the 2nd part of this series, which focuses on ways to build and maintain meaningful connections with people with mental illness (and the rest of us) during this period of isolation.

Our panelists are both people with lived experience with mental health challenges who also work in the field in North Carolina.

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MOVING FROM THE MARGINS
creating community

Webinar focus

- Understanding exclusion and self-exclusion
- Reversing self-exclusion through self-determination
- Supporting validating relationships

Why this matters

People living with mental illness experience exclusion from the community. They even exclude themselves sometimes.

For Community Inclusion to work, that exclusion must be understood and addressed. No matter what our role, we have a part to play in creating inclusive community.

With thanks to our sponsors.

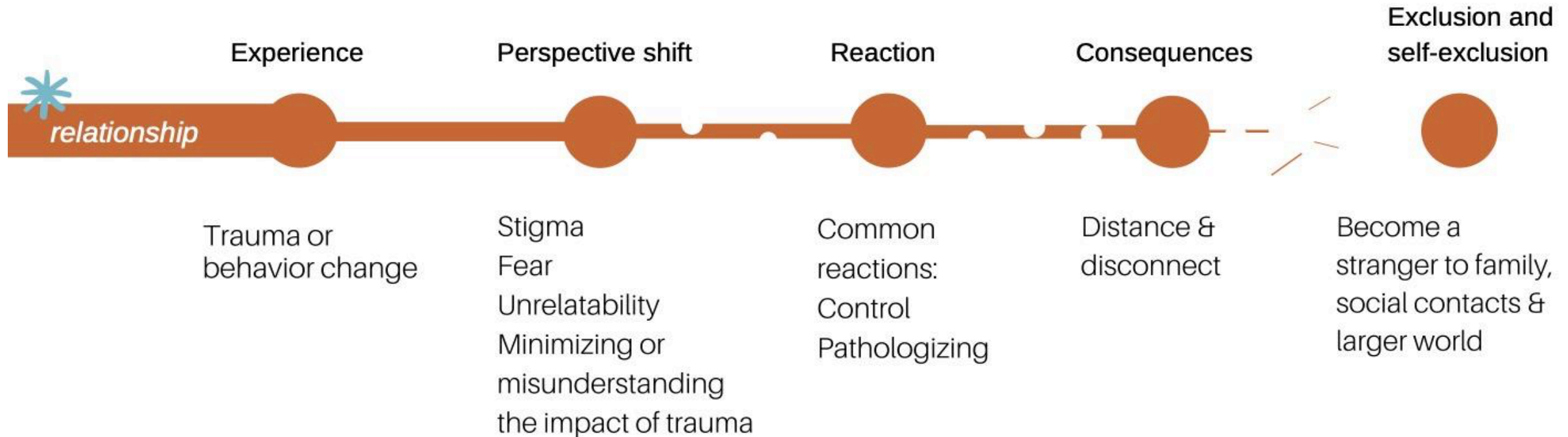NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES

i2i CENTER for INTEGRATIVE HEALTH
insight to innovation

i'm IN
COMMUNITY INCLUSION

*A passion
for inclusion
and
self-
inclusion . . .*

Laurie Coker

GreenTree Peer Center

How do exclusion & self-exclusion start?

Experience	Perspective shift	Reaction	Consequences	Exclusion and self-exclusion
Trauma or behavior change	Stigma Fear Unrelatability Minimizing or misunderstanding the impact of trauma	Common reactions: Control Pathologizing	Distance & disconnect	Become a stranger to family, social contacts & larger world

relationship

* This can be any kind of relationship, but this presentation will focus on just a few.

Poll #2   Joining in opportunities

Stigma in families

Mental health challenges and the impacts of trauma can strain families, inserting stigma between loved ones who need each other more than ever.

Why stigma can manifest in families

- Information inadequate, narrowly focused

- Few available resources that support family staying connected

- Fatigue from daily concern and effort

Stigmatizing attitudes in relatives of people with schizophrenia: A study using the Attribution Questionnaire AQ-27. Trends in Psychiatry and Psychotherapy, Vol. 34, No. 4

. . . and what it can look like

- Exclusion from gatherings, conversations, and decisions
  - 25.8% of respondents in Australian national survey experienced this

- Marginalizing or disregarding important aspects of the full person

- Doubt or dismissal of the potential for recovery

Family members can also feel stigma, decreasing own self-esteem and connection to others in community.

Stigma in services

Stigma also impacts services. Research shows that this can put individuals at greater risk of exclusion and other negative impacts.

It is counterintuitive

but research shows…

"Although it seems intuitive that individuals with more contact with mental illness should hold less stigmatizing beliefs, research has not supported this proposition."

Understanding the social norms, attitudes, beliefs, and behaviors towards mental illness in the United States. Manago, Bianco: Indiana University researcher.

• In present treatment/service paradigm, service recipients often feel invisible, voiceless. Impact: dictates of providers can invalidate social role and personhood. Results in re-traumatization. *(See On Being Invisible in the Mental Health System)*

• In spite of a biologically based treatment model, stigma results in misdirected focus by providers on individual's will as a major factor for behavior.

Fear

Discomfort caused by extraordinary experiences and how they are conveyed through actions (behavior.)

"We fear what we do not understand . . . "

Control is a common way that humans address fear.

The promises of control...

- Desire to contain risks related to the behavior of another person who appears out of control
- **Pathologizing** *is a narrow approach, but prevalent in our country.*
  - *Labels provide a sense of reassurance*
  - *Assumed concrete steps to treatment, deference to a clinical system and professionals*
  - *Relative convenience of a medical treatment model, deflecting need for other efforts*

the pitfalls of pathology

- Not aligned with more current bio-psycho-social-(spiritual) approach important to other advanced countries.
- Imperfect diagnostic processes, imperfect medications, unstable science.
- Imperfect service systems
- Coercive treatment approaches

Fear

As the promise of pathology and control fade, we realize the inherent wedge that results in exclusion and self-exclusion.

Control can look like this…

- Energy and focus in the relationship is now devoted to maintaining instead of growing closer

- Restrictions and expectations on the person with mental health challenges

- Treatment compliance focus vs. holistic focus

- System navigation frustrations, fatigue

Contributing to exclusion & self-exclusion

Power dynamics inherent in control

- Decrease in personal agency & self-determination
- Human to human aspects of relationship fade to background

The actual experience of the person with mental health challenges can be lost in the shuffle

- E.g. Impacts of trauma are not addressed, hindering actual recovery
- Deeper ways of understanding a person's experiences and the array of impacts are lost.

Trauma

Trauma is a factor in the suffering of a majority of individuals who suffer with mental ill being. Understanding the impact of trauma is critical to inclusion and recovery.

Because trauma is complex, recovery requires more than clinical treatment.

Trauma is often minimized or misunderstood within families or other support relationships, furthering the breech between an individual and others.

"Individual trauma results from an event, series, of events, or set of circumstances experienced by an individual as physically or emotionally harmful or life-threatening with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being."

Relationships that are supportive and validating are necessary to healing and living *beside*, not *inside* or overshadowed by the trauma.

SAMHSA's 6 key principles of a trauma-informed approach <u>focus on inclusion & social connection.</u>

- Safety (includes *sense of safety!*)

- Trust and transparency

- Peer-to-peer support

- Collaboration and mutuality

- Empowerment and choice

- Cultural, historical, and gender issues

https://www.integration.samhsa.gov/clinical-practice/trauma

Self-exclusion stems from internalized discrimination arising from experience and society's messages.

"Self-discrimination or internalized discrimination is the process in which people with mental health problems turn the stereotypes about mental illness adopted by the public toward themselves. They assume they will be rejected socially and so believe they are not valued."

Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. Livingston and Boyd, Social Science and Medicine, 2010.

Self-exclusion is a culmination of lowered self-expectation, avoidance of risk, and loss of hope and vision.

Lowered Expectations

Expect to be invisible or excluded based on experience

Feelings

No feeling of belonging or validation as a whole person based on stigma and discrimination

Risk

Anticipation of risk depletes energy and motivation to attempt inclusion

Loss and Hopelessness

Lost sense of personal role and validity resulting from exclusion

EMPOWERING SELF-INCLUSION

Creating opportunity is not enough. Invitation is not sufficient. Resource fairs and lists won't impact action.

We must empower others by assuring them of their value as complex individuals and by supporting them toward self-determination and participation!

Reversing self-exclusion through growing self-determination

Why is BREATHING such a big deal?

	Stress	Calm
Breathing	Rapid breathing More inhale	Slow breathing **Longer exhales
What	Stress hormones	Decreases production of stress hormones
Emotional experience	Flight, fight, or freeze	Calmer and safer
Where	Sympathetic nervous system	Parasympathetic nervous system
Car analogy	Floor it!	Hi the brakes.

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TAKE TIME TO breathe

12

Exhale…

https://www.calm.com/breathe

Why focus on self-determination?

It is more than simply making our own decisions.

1 *It is an essential foundation for*
- *Empowering personal agency*
- *Seeing available options*
- *Seeking out more options*
- *Understanding which options are a "good fit"*
- *Communicating effectively*
- *Following through and making adjustments*

2 *Dynamics of trauma*
- *Self-determination theory is integral to many trauma interventions*
- *Self-determination aligns with SAMHSA's 6 key principles of a trauma-informed approach*

3 *Ethical obligation for helping professionals, e.g.,*
- *Peer Support (NCCPSS Values and Code of Ethics)*
- *Social Work (NASW Code of Ethics, Standard of Conduct, 1.02)*
- *Psychology (American Psychological Association, Code of Ethics, Principle E)*

Trauma and self-determination

Trauma can erode or interfere with the development of self-determination

- *Can create a sense of loss or void*

- *A need to grow or rebuild internal and external resources*

- *Overwhelmed by number or intensity of issues*

- *Motivation may run low because its components are impacted*

What is self-determination?

Self-determination theory

- *A psychological theory of **motivation**.*

- *For optimal growth & development people have **3 psychological needs** that must be met.*

Ryan, R.M., Lynch, M.F., Vansteenkiste, M., and Deci., E.L. (2011). Motivation and autonomy in counseling, psychotherapy, and behavior change: A look at the theory and practice. The Counseling Psychologist, 39(2), 193-260.

Selfdeterminationtheory.org

Motivation

Autonomy

Competence

Relatedness
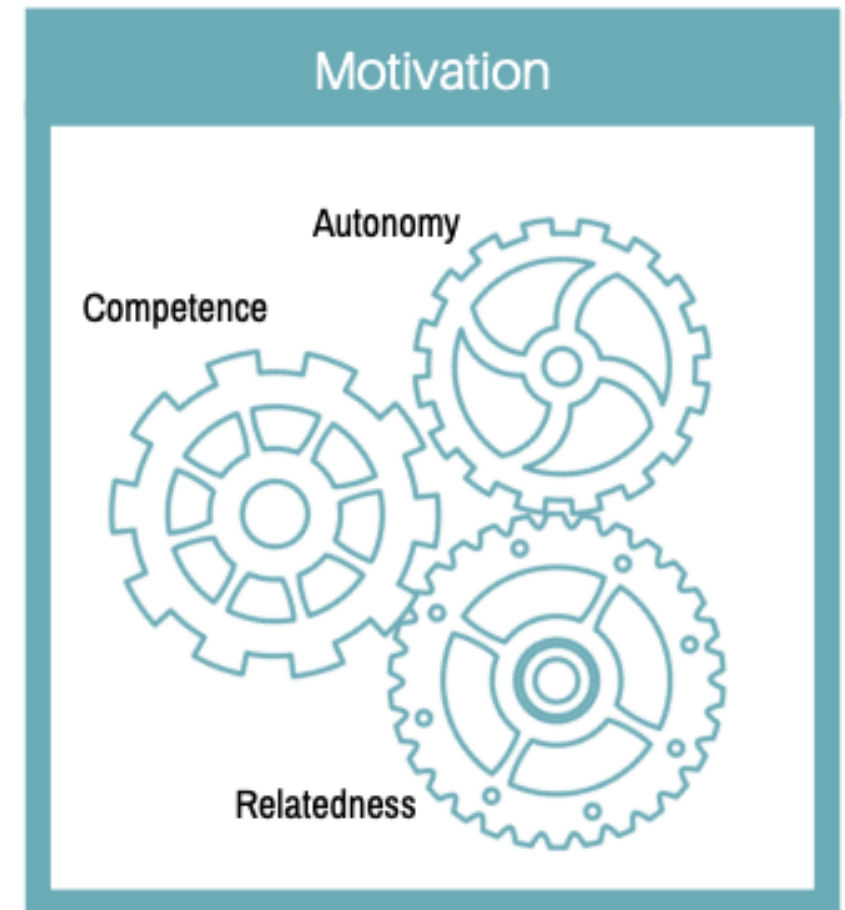
Poll – Let's check in about motivation

Autonomy

Trauma and impacts on autonomy	Autonomy in self-determination
Externally focused	*Self-awareness in balance*
Self-concept & regulation are dialed to survival mode	*Self-respect and boundaries*
Isolation and uncertainty	*Feel seen and heard*
Reduced or hidden options	*Have and see meaningful options*
Survival mode distracts from personal goals	*Set own goals (at level of "optimal challenge")*

Competence

Trauma and impacts on competence

Survival and coping drains energy from engagement

Feelings can make feedback experience difficult
- Vulnerability
- Shame
- Isolation
- Distrust

Question self & capacity to develop competencies

Competence in self-determination

Energy for new knowledge & skills

Practice

Receive helpful feedback & integrate into growth

Build confidence

Enjoy new learning and experiences

Relatedness

Trauma and its impact on relatedness	Relatedness in self-determination

Power & control

Isolation

Distrust, fear, hopelessness, numbness

Relational stress regarding coping

Challenges with setting and maintaining boundaries

Shared power and decision-making

Meaningful interaction with others

Compassion; trust and transparency

Boundaries that support balance among values and priorities of self and others in relationship

Ways to think about MOTIVATION

Sometimes people ask me, "I really like this self-determination, but what should I do when someone is resistant?"

Motivation is often thought of as an **attitude** *of caring about something or showing willingness*

- *"She's giving 110%"*
- *"I'm doing this for my kids."*

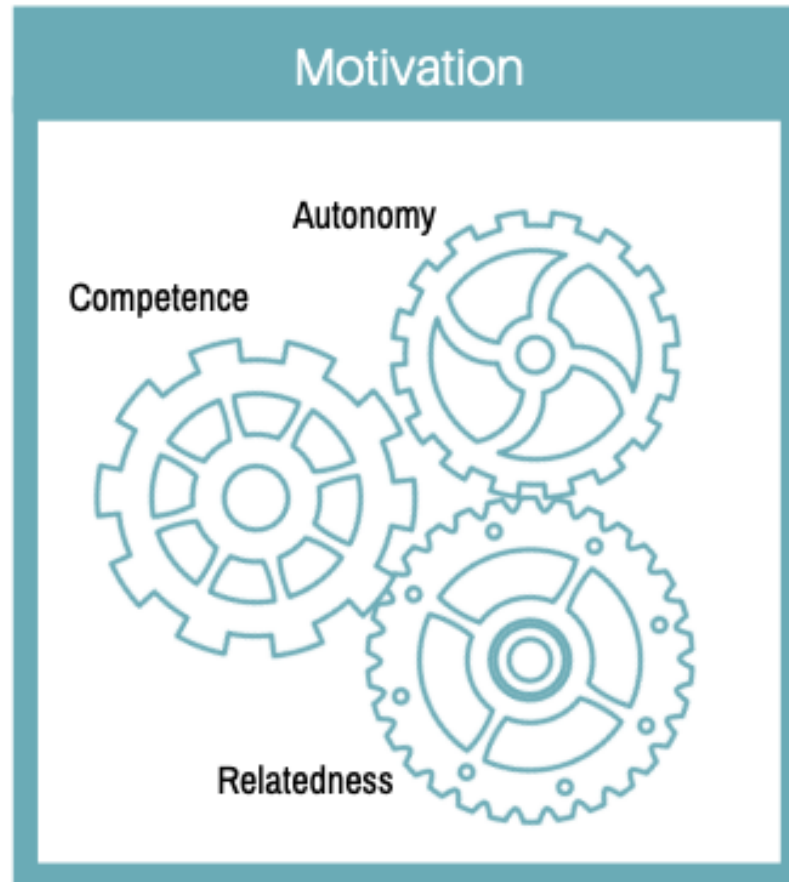*Frustration springs a trap of labeling the attitude, which often transfers to a characterization of the person.*

- *Stigma. "Resistant client" / "We shouldn't be trying harder than our clients"*
- *Shame. "What is wrong with me?"*

Self-determination theory changes the conversation.

Self-determination theory changes the conversation.

Operating within a system with other people and organizations who are also struggling against labels and have room to improve their autonomy, competence, and relatedness.

Attitude labels →

Motivation

Autonomy

Competence

Relatedness

+

Motivation

"People don't want to hear about a theory…"

Continuum	Fleeting · More lasting			
Amotivated	External	Introjected	Identified	Internalized
"I'm not doing this."	*"I have to do this."*	*"I should do this."*	*"I value doing this."*	*"I enjoy and want to do this."*

Ryan, R.M., Lynch, M.F., Vansteenkiste, M., and Deci., E.L. (2011). Motivation and autonomy in counseling, psychotherapy, and behavior change: A look at the theory and practice. The Counseling Psychologist, 39(2), 193-260.

A great place to start

Supporting validating relationships …

Relatedness

Broad and diverse network

Family, kin, or fictive kin

Life partner

Friends & social settings

Mentors, coaches, guides

Neighbors

Communities (identity, spirituality, geographic, etc.)

Occupational settings

Supporting validating relationships

PERSONAL RELATIONSHIPS

Trauma. *Understand the impacts of trauma & that it can impact people differently*

Well-rounded. *Protect space in personal relationships for topics other than mental health*

Shared Meaning. *Consciously develop a pool of shared understanding and meaning to expand mutuality*

Compassion. *For ourselves and others.*
Set aside time to REALLY SEE one another as humans, not just sources of each others' problems & stresses.

Supporting validating relationships

Communication

Language. *Talk about language and use language that is affirming*

Communication. *Set the stage for more effective and enjoyable conversations, including feedback*

Collaborative solution-finding

Acknowledge the struggle. *Understand the impact of control / power dynamics on a relationship & person*

Shared strategy. *Look for other ways to manage fear and risk*

Cultivate self-determination. *We can all benefit from growing our internal strengths and relational resources*

Supporting validating relationships

ORGANIZATIONS

Language: Talk about language and use language that is affirming

Feedback: Make it easier and safer-feeling to have meaningful exchanges

Organizations model behavior – what kind of "relatedness" example is your organization exhibiting?

- *Make sure options are visible*
- *Support staff self-determination*

Research and Articles on the Impact of Exclusion

'Prejudice, Discrimination, and Social Exclusion: "the belief of a biological basis for the condition (see below) and a discontinuity (rather than continuum) with normal experience have been added (as factors)"
http://www.jneuropsychiatry.org/peer-review/prejudice-discrimination-and-social-exclusion-reducing-the-barriers-to-recovery-for-people-diagnosed-with-mental-health-problems-in-the-uk-neuropsychiatry.pdf

On Being Invisible in the Mental Health System: IMPORTANT ARTICLE.
https://www.theannainstitute.org/OBI.pdf

The Pain of Social Rejection: "Long-term ostracism seems to be very devastating," Williams says. "People finally give up."
https://www.apa.org/monitor/2012/04/rejection

Stigmatization, social distance and exclusion because of mental illness: The individual with mental illness as a 'stranger' "Human beings suffering from mental illness often are recognized as 'strangers'. But, social-psychological and philosophical analysis of the recognition of 'strangeness' in mentally ill individuals as one of the main predictors for social distance towards them . . ."
https://www.tandfonline.com/doi/full/10.1080/09540260701278739?scroll=top&needAccess=true

How Does Stigma Affect People with Mental Illness? "Many people with mental health problems say that the biggest barrier to getting back on their feet is not the symptoms of illness, but the attitudes of other people". Australia
https://www.nursingtimes.net/roles/mental-health-nurses/how-does-stigma-affect-people-with-mental-illness-06-07-2012/

Research and Articles on the Impact of Exclusion

Understanding the Social Norms, Attitudes, Beliefs, and Behaviors Towards Mental Illness in the United States
https://sites.nationalacademies.org/cs/groups/dbassesite/documents/webpage/dbasse_170042.pdf

Discrimination and Support From Friends and Family Members . . . "Despite positive experiences being common, there is an ongoing need to reduce mental illness stigma and improve understanding of how to support a loved one with a mental health problem."
https://www.ncbi.nlm.nih.gov/pubmed/28477071

Stigmatizing attitudes in relatives of people with schizophrenia: a study using the Attribution Questionnaire "The high scores of coercion, pity, and segregation may reflect concealed stigmas that may influence the self-determination of the mentally ill, suggesting the need for psychoeducational interventions aimed at family members."
https://www.scielo.br/scielo.php?pid=S2237-60892012000400004&script=sci_arttext

Research and Articles on Self-Determination Theory

Ryan, R.M., Lynch, M.F., Vansteenkiste, M., and Deci., E.L. (2011). Motivation and autonomy in counseling, psychotherapy, and behavior change: A look at the theory and practice. The Counseling Psychologist, 39(2), 193-260.

The Center for Self-determination Theory has a website with information, research, validated measures, and articles on the evolution of the theory and its application in a wide variety of areas including health, parenting, sports, digital design, education, counseling, and more. Selfdeterminationtheory.org

Research on the impact of language on clinician's recommendations of punishment or treatment

Kelly, J. F., & Westerhoff, C. M. (2010). Does it matter how we refer to individuals with substance-related conditions? A randomized study of two commonly used terms. *International Journal of Drug Policy*, 21(3), 202–207. doi:10.1016/j.drugpo.2009.10.010

Seeing the Bigger Picture: Informative links with international perspectives

https://www.scottishrecovery.net/chime-diagram/

https://www.time-to-change.org.uk/blog/see-bigger-picture-jasons-story

http://rethink.org.nz/

http://selfdeterminationtheory.org

 Articles on breathing and how the Vagus nerve puts the brakes on stress

https://www.npr.org/2010/12/06/131734718/just-breathe-body-has-a-built-in-stress-reliever

https://www.bbc.com/worklife/article/20200303-why-slowing-your-breathing-helps-you-relax

Breathing video
https://www.calm.com/breathe

Some Q&A themes from our chat box

Thank you

FOR LISTENING AND CONSIDERING SOMETHING NEW!

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