



New England (HHS Region 1)

**MHTTC**

Mental Health Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

# New England Mental Health Technology Transfer Center (New England MHTTC)

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Yale Program for Recovery and Community Health  
in partnership with  
C4 Innovations, Harvard University Department of Psychiatry, and the  
Center for Educational Improvement

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The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED  
AND HOPEFUL

INCLUSIVE AND  
ACCEPTING OF  
DIVERSE CULTURES,  
GENDERS,  
PERSPECTIVES,  
AND EXPERIENCES

HEALING-CENTERED AND  
TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS  
PARTICIPATING IN THEIR  
OWN JOURNEYS

PERSON-FIRST AND  
FREE OF LABELS

NON-JUDGMENTAL AND  
AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR  
AND UNDERSTANDABLE

CONSISTENT WITH  
OUR ACTIONS,  
POLICIES, AND PRODUCTS





# New England MHTTC

## **Mission**

To use evidence-based means to disseminate evidence-based practices across the New England region.

## **Area of Focus**

Recovery-Oriented Practices, including Recovery Support Services, within the Context of Recovery-Oriented Systems of Care

# Our Guiding Principles



# Respect, Collaboration, and Shared Decision-Making A Relational Approach

## **Presenter:**

Anthony J. Pavlo, PhD

Yale Program for Recovery and Community  
Health

## **Moderator:**

Graziela Reis

June 23, 2021



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Anthony Pavlo, Ph.D. is a clinical psychologist and an Associate Research Scientist at the Yale University Program for Recovery and Community Health. His research focuses on recovery-oriented and person-centered practices in mental health care, especially the role of collaborative relationships in care.



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- Larry Davidson
- Maria O'Connell
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  - *Construction and Assessment of a Tool to Support Collaboration and Shared Decision-Making in Chronic Illness Care*

# Why?

- Significant disparities
  - Access
  - Quality of Care
  - Outcomes
- Discrimination in mental health care
  - Lack of options and choice
  - Therapeutic Relationships
  - Education and Training

# Person-Centered, Recovery-Oriented Care

- Person-Centered Care
  - Agency, Choice, Self-Determination
- Recovery-Oriented Care
  - Peers
  - Person-Centered Care Planning
  - Advanced Directives
  - Citizenship (Rights, Roles, Responsibilities, Resources, Relationships)
- SDM as one Person-Centered/Recovery-Oriented tool



# Health Disparities

- Significant health disparities for persons diagnosed with SMI
  - 20-25 year disparity in life expectancy
    - Comorbid medical conditions that are not treated or poorly managed
    - 2 to 3 times more likely to have diabetes
    - 6 times more likely to die from cardiovascular disease
    - 2 to 3 times more likely to have a stroke
    - 2 to 6 times more likely to die from respiratory conditions
    - More likely to die because chronic conditions

# Disparities (cont.)

- Individual factors
  - Side effects of psychiatric drugs
  - Lifestyle (lack of physical activity, poor nutrition, excessive tobacco and substance abuse)
- Social determinants of health
  - Unemployment
  - Poverty
  - Social Isolation/Loneliness
  - Homelessness
  - Housing Insecurity
  - Food Insecurity
  - Discrimination & Stigma
- Inadequacies within the healthcare system
  - Fragmented healthcare system that medicalizes mental health concerns
    - Neglects the whole person & life context
  - Stigma

# Shared Decision-Making

- A decision-making process jointly shared by people and their health care providers
- “Neglected second half of the consultation” (Elwyn et al, 1999)
- Two “experts”
- Roots in:
  - Informed Consent (1980s)
  - Person-centered care
- Requires a shift in the role of the “patient,” the “doctor” and the relationship
  - Active partnership between doctors and patients
  - Patient as active and deciding agent
- Potential to radically redefine how people relate to one another

# SDM (cont.)

- Ethical justifications
- Empirical justifications
  - Enhanced clinical and patient-centered outcomes
  - Cost-effective
  - May be particularly effective in the care of “chronic conditions”
- Adopted into policy (ACA)
- Failure to implement SDM in routine care
- Increased pressure on providers to engage in SDM

# Three Models of Decision-making

Paternalistic

Shared

Informed



- **Information Exchange**

- One way flow of information
- Doctor → Patient
- Medical
- Legally Required Minimum Amount

- **Deliberation**

- Doctor alone (or in consultation with other drs)

- **Who decides?**

- The Doctor

- **Information Exchange**

- Two way flow of information
- Doctor ↔ Patient
- Medical & Personal
- Anything relevant for decision-making

- **Deliberation**

- Doctor & Patient (potentially significant others, family, spouse, children)

- **Who decides?**

- Doctor & Patient

- **Information Exchange**

- One way flow of information
- Doctor → Patient
- Medical
- Anything Relevant for decision-making

- **Deliberation**

- Patient (others)

- **Who decides?**

- Patient

# Competencies

## Relational

- ▶ Develop a partnership with the patient by inviting them to participate in treatment
- ▶ Identifying the patient's preferred role in decision-making
- ▶ Eliciting patient's fears, questions, and expectations
- ▶ Checking frequently for understanding and questions and concerns
- ▶ Acknowledging transition from reviewing options to selecting a decision
- ▶ Generating concrete plan
- ▶ Arranging for follow-up to review strategies and effects

## Risk Communication

- ▶ Identifying and reviewing relevant medical information with patients using non-directive communication
- ▶ Determining the preferred mechanism(s) through which to provide relevant information to the patient
- ▶ Exploring how this information fits with the patient's own culture, language, expressed values, preferences and personal cost-benefit analysis.

# Collaboration Talk Model

- Team talk/choice talk
  - Communicate intention to collaborate and support deliberation
  - Highlight that reasonable options exist
- Option talk
  - Provide medical information
- Decision talk
  - Elicit preferences & integrate into plan

# Barriers and Facilitators

- Barriers
  - Time Pressure
  - Lack of applicability to patient characteristics
  - Lack of applicability to the clinical situation
  - Perceptions of patient preferences
  - Perceptions of patient characteristics
  - Too rigid
- Facilitators
  - Motivation of health care professional
  - Perception that SDM will lead to better patient outcomes
  - Perception that SDM will lead to a positive impact on the clinical process



# Barriers

- Doctor-centered rather than patient-centered
  - Medical model way of knowing/prioritizing
  - Ceding rather than sharing power (and responsibility)
- Research is largely dominated by research on the clinical side
  - Information Exchange and Decision-Aids
- Health Literacy, Decision support, Communication
- What about the relationships needed to facilitate & sustain this kind of decision-making?

# Barriers (cont.)

- Stigma
  - Stigma within the MH care system
  - Justifications for paternalism
    - Illness-model
      - Limited types of relationships
      - Reality-testing & Insight
      - Impaired judgement
      - Noncompliance/nonadherence
      - Patient's levels of satisfaction not taken seriously
      - Distrust

# Psychotherapy Research

- Rogers – Necessary and Sufficient Conditions
  - Therapist experiencing and effectively communicating *congruence*, *empathy*, and *unconditional positive regard*.
  - Not what a therapist does, rather the client's perception of the therapist drives outcomes
- Psychotherapy research
  - Elkins – Human Factors
  - Bohart – The Active Client

# Bohart and Tallman (1996)

Therapists are not the experts on the client, on the client's condition, or on how to treat that condition. Rather, therapists are experts on their own experience, and perceiving and reacting to the moment-by-moment process between themselves and clients. This includes the ability to help clients focus on and explore their values and experiencing. It also includes ***attending, prizing, and caring***... The therapist is a fellow traveler or a fellow struggler, and is not telling the client the truth from an expert's perspective. [We] emphasize client responsibility and choice, so the client is always the active agent.

# Lessons

- We aren't as important as we think we are
- (To some extent)
- Expert model, Drug Metaphor
- Techniques have little to do with outcomes
- The relationship appears to play a much larger role
- The client is the largest factor
- Therapeutic Environment

# Our Research

- Overview
  - Engage Stakeholders
  - Secondary Data Analysis
  - Qualitative Interviews
  - Concept Mapping
    - Tool Development & Pilot

# Participatory Research

- Involve persons with lived experience of diagnosis and treatment for chronic psychiatric and physical conditions in all aspects of the research from conceptualization to data collection and interpretation to the dissemination of findings.
  - Co-researchers
  - Advisory team

# Qualitative Interviews

- 42 interviews
  - 10 people from community mental health
  - 11 people from primary care
  - 10 psychiatrists
  - 11 primary care physicians





Physicians

I follow sort of the rubric of ask-tell-ask. So, I usually will name a diagnosis, you know, this is the third time your blood pressure has been elevated. That means you have hypertension or a condition called high blood pressure. Then I ask, "What do you know about high blood pressure?" And they'll tell me and I might ask, do you know anyone who has it, just to get a sense for what they're lived experience with it is and with family or among their friends...And then, the tell of ask-tell-ask is me sort of filling in the gaps of their knowledge or correcting misconceptions, or taking what they've accurately described in bringing them up a nudge to where, an information level where I feel they need to be or could benefit from being over and above what they already knew. And then the second ask is to really ask for a teach-back in a way just to see how good I was in telling them about it.

So I ask the patients, they've come to me, they've been referred, what is it that they understand they're suffering with, the background for what has led to that understanding. I [think] out loud in the language of the patient, so it's an act of translation...[The diagnosis] may be threatening...so thinking out loud in the language of the patient, I present to them of facts. And it's important for me to elicit from them that they evidence understanding of what it is that I have told them, because one can discover that you come to the end, and the patient has shut down because of the burden, and the threat, or the fear of what, or of the implications of what it is that I'm attempting to communicate. So it's as much listening as it is talking.

I call it a chart diagnosis, doesn't mean they've been informed. I have to say I don't necessarily bring it up. I might, depending on the patient, so if the patient is somebody who's really aware, seems to be educated about their illness, then I will ask them, so the chart says, "[You have this diagnosis.] What do you think about that? Are you aware of that? Have you been told that?" If it's psychotic patients, that's the population I see the most, if they're actively paranoid of seeing me, or if cognitively they're quite impaired, then I personally don't see the point in hashing out the diagnosis with them unless they ask.

...we try not to talk about it, probably because we feel again that's stigmatizing, we don't want to tell somebody that has schizophrenia, because it's probably not going to be well received by patients, understandably so...as far as seriously mentally ill patients...I mean...It should be patient-centered care, obviously, and I should tell you about that, but patients don't always understand what really, what this means, even if you explain once, because...they don't have the wherewithal to either corroborate or contradict what we're telling them.

I don't know how to reconcile being patient-centered, but at the same time, patient-centered, respectful of their wishes, and that their wishes would reflect their needs, I don't know how to reconcile that with, quote, "insight."

...because he gets so sick, I'm not interested in his desire to go off medication...



Clients




It was a beautiful feeling. I think that, you know, he saved me from myself for the fact is that, you know, he didn't allow me to hurt. He made me feel that I could be safe with myself and that, you know, I didn't have to act out because I was feeling unsafe.

“I mean ‘You’re going to do what I say’ and I think that, you know, feeling like you’re hopeless when you walk out of [the clinic] just snowballs in the community... If I feel like I didn’t get any help while I was here and I walk back out there, then I knew there’s nothing else that could be done out there.”

“I’m being violated you know, and he’s not really that concerned. And I don’t feel like he’s really hearing me out. And I – then the distrust comes in and, you know, how do I move forward from that? I guess there’s a point of me that says, “Whatever, just take the pill and hope everything’s all right.”

“Well, I mean that if I’m in a delusional state and I’m having certain—my symptoms are so that I’m so delusional that’s not something I want to communicate with the doctor. Because he might just decide that, you know, I don’t need to be in public, right? So, some things—if my psychosis is that bad, then I wouldn’t tell him that. From learned experience, I suppose.”



“So, you know, and it’s got to be a relationship, you know, both are agreeable on. Because then if it’s one-sided, then people don’t feel like they have a voice. And so, that’s why people just walk away from this.”

“Yeah, you know, but you know, it’s like more [medications] is better. No, more isn’t always better. But the communication between the two of them doesn’t always end. The person suffers between them... Then it’s like you people don’t know what the hell you’re doing so a lot of people just walk away... And so, you know, then you’re left with, you know, why people are - why do people become noncompliant to all this? Is because all the bureaucratic and red tape that people have to go through. They don’t want to be bothered anymore.”


“Then, the next time you go through something like that—you put caution. It’s like the wall goes up. And, you know, I’m not sure if I even want to hear you. So, also denial sets in because...I’m afraid of being vulnerable in a situation where you’re not telling me the whole story...So, if that happens a number of times, then I guess say [forget] it. I’m going to be noncompliant. And run away from the situation... denial on one hand is that, you know, [that] I have a problem. Number two is denying that I’m scared of the doctor.”

“I’ll tell you. They were trying to give me [inaudible: medication name] one time. I started the medication, but I kept getting ill. And I said, ‘This is the medication. It’s the medication. It’s the medication.’ But the doctors were saying, ‘You hear voices. You need to take the medication.’ I said, ‘It’s making me ill!’ He wasn’t going for it. And the only way I could get them to change it is to tell them one of the side effects that I wasn’t even having. And, he finally decided to change the medication... And so, to navigate through some of this in an intellectual way, I would have to say that, yeah, I’ve learned how to get through. How to manipulate the system to work it to my advantage, as you say, play the game.”



“And sometimes I think me as a consumer is left out of the conversation between them sometimes...And that doesn't always sit well with me either. And that, you know, they make - it's also that, you know, they'll make a change in your medication also and they won't always tell you...Why they do it, and thoughts about it...You may go to the pharmacy and then find out, you know, your scripts have changed and you say, why didn't he tell me this?”

“I was perfectly fine. I was stable for over a year. Why are you changing my meds?...“Well we feel...” Who are you to feel anything? I’m the one doing the feeling.” So, Dr. X here, I won’t even talk to. Now I take full charge of my meds.”



“It’s really like you feel—it’s really like feeling overlooked or feeling like what you’re saying to a doctor is being overlooked. So, you’re being overlooked in some way.”

“She was a pain, she accused me of drinking, I used the hand sanitizer, and she accused me of drinking...[the smell] from the alcohol from the hand sanitizer, so I looked at her I said, “Really?” And I said, “Let's go get a breathalyzer, and we went to this little nursing [station] with the breathalyzer and it wouldn't work—the machine. I said, “Go find a machine that works, and she goes, “Nah, I believe you.” And I said, “No, no, no, no, go find—we're not talking anything until you go find the machine. And she came down to the second floor and I guess there's an office over there with a machine in it, and I blew in it, 0.00. I said, “Don't you ever accuse me of that again.”

“The trust level had to go way down for that [to get to a point where I felt in control of my care] to happen. Before, like I said, I relied on doctors. I trusted their judgement. Now I don't trust their judgment, I trust mine.”

“And explain it, and again, because I've been on both sides, explain it on the client's level. Whether they are able to speak technical or street, explain it to them in a way they understand, that they can internalize.”

“The doctor needs to talk to the client. And it's not that you take the client's point of view in the decisions you make. It's that your decisions need to reflect the client's point of view, because it's about the client not about the doctor.”

Goal of SDM Intervention	Reduce imbalance of power in the doctor-patient relationship through supporting patient self-determination and agency in health care decision-making	
	Existing SDM Models	Relational SDM Model
1. Target of Intervention	Reduce informational asymmetry between patients and physicians; Increase information sharing	Increase elements of support, empathy, and mutual trust to facilitate information sharing; informational asymmetry is only one aspect of doctor-patient interactions that maintain this power imbalance
2. Definition of Success	Define success in terms of outcome, namely a mutually agreed upon decision regarding treatment	Define success in terms of process and quality of decision-making—involve elements of support, empathy, and trust
3. Focus of Decisions	Decisions about treatment	Decisions about accommodating for illness in their day to day lives, assimilating new aspects of identity related to chronic condition, and continuing to occupy meaningful and satisfying roles in their families and communities along with treatment decisions
4. Doctor-patient relationship	Relationship is of secondary importance to information exchange and treatment decisions; sole focus on patient trust and safety	Relationship is of primary importance along with trust in physician expertise and exchange of information; patients feeling supported, respected, heard, and engaged before (and during) formal SDM process



# Tool/Measure Development

- Concept Mapping?
- Statement Generation Groups Questions:
  - What has to happen for a visit to go well?
  - What has to happen for a visit to go poorly?
  - What do you wish doctors would do to improve the way they interact/respond to you?
    - Prompts: What have doctors done to get to know you as a person? To allow you to feel comfortable? To be honest? To make you feel hopeful? How can you tell when a doctor cares about you? How do you know a doctor is listening? Understand you?

- Understands what I'm going through
- Does not rush me
- **Knows my traumas**
- **Does not argue with me**
- Is kind
- Let's me "run the show"
- Is competent/Knows what he/she is doing
- Does not talk down to me
- Has a sense of humor
- Gives me time outside of appointments
- Trusts me to know what I need
- Listens to me
- Gives me the benefit of the doubt
- Sets reasonable expectations for treatment
- Does not waste my time
- Trusts my opinions
- Hears me when I am unsatisfied
- Is there for me
- Asks me "What else can I do for you?"
- Encourages me to ask questions
- Makes a difference in my life
- Inspires me
- Keeps their word
- Has a connection with me
- Makes me feel like I can be honest with them
- Lifts my spirits
- Acknowledges my accomplishments
- Empathizes with me
- Makes concrete plans about treatment
- Takes my problems seriously
- Turns chair to face me
- **Cares about me**
- Gives me enough time

- **Allows me to talk**
- **Enjoys what they do**
- **Believes me/trusts what I say**
- Does not say "I understand" without having been there
- Makes decisions with me
- Answers my questions thoughtfully
- Is honest about what he/she can and cannot do
- **Avoids distractions in appointments**
- Is knowledgeable
- Does not overprescribe medications
- Does not minimize what I have to say
- **Sees me as more than my history or diagnosis**
- **Does not force meds**
- Help me with referrals
- Asks direct questions
- Tells me about his/her personal experiences
- Is interested in what is important to me
- Helps me understand
- Lets me make my own decisions
- Provides information for me and my family
- **Is fair**
- Respects my confidentiality
- Offers constructive criticism
- Takes care of everything that I ask for
- Is truthful and direct
- Allows me to choose
- Takes a personal interest in my well being
- Asks me "How I am doing?"
- Takes the time to get to know me
- Asks me questions about me
- Believes in me
- Does not focus on his/her computer
- Calls me to see how I am doing

- **Shows his/her feelings**
- **Celebrates with me**
- Is open to feedback
- Asks me about other parts of my life
- Helps me with what I wanted help with
- Is confident
- Trusts what I have to say
- Allows me to get stuff off my chest
- Motivates and encourages me
- Listens when I disagree
- Does not judge me
- Asks me about what is helpful for me
- Is patient with me
- Is approachable
- **Knows details about my life**
- Is understanding
- **Knows my history**
- Is intuitive (has a sixth sense)
- Creates a relaxed atmosphere
- Is compassionate
- Sees my potential
- Lets me manage myself
- Takes input from family
- Looks me in the eye
- Helps me help myself
- **Realizes that I am unique**
- Is on time
- Treats me as an equal partner
- **Goes above the call of duty in care**
- Invites me to collaborate
- Is dependable
- Is consistent
- Focuses on my strengths
- Allows me to advocate for myself

## Competence/Transparency

- Calls me to see how I'm doing
- 42 Is competent/Knows what he/she is doing
- 39 Makes concrete plans about treatment
- 30 Sets reasonable expectations for treatment

## Respect

- Enjoys what they do
- 31 Is truthful and direct
- 41 Is kind
- 94 Is fair

## Whole Person

- Takes care of everything I ask for
- 26 Respects my confidentiality
- 52 Listens to me
- 60 Knows my history

## Consistency/Dependable

- 76 Is consistent
- 64 Is dependable
- 37 Is honest about what he/she can and cannot do

## Encourages Autonomy

- Encourages me to ask questions
- 27 Does not argue with me
- 5 Trusts what I have to say
- 89 Acknowledges my accomplishments

## Caring

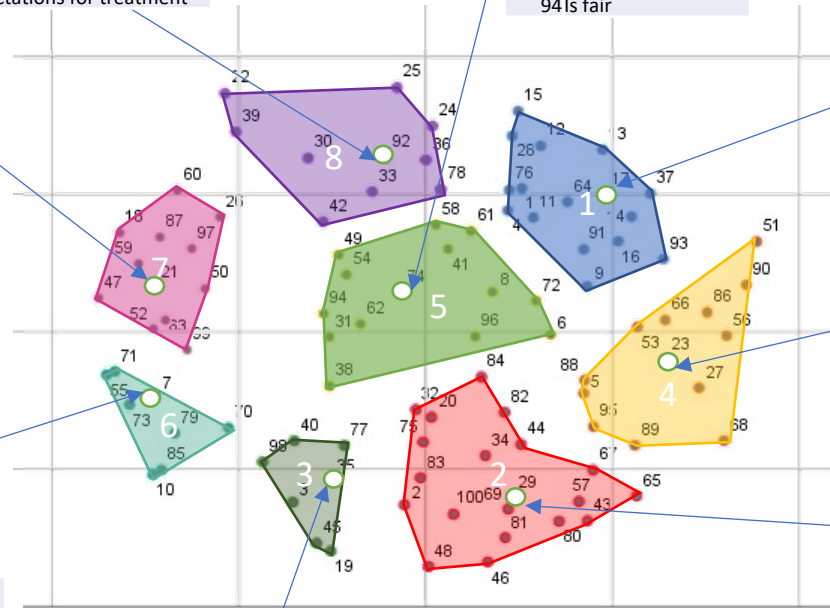
- Asks me "How I'm doing"
- 70 Cares about me
- 71 Is understanding
- 55 Takes my problems seriously

## Encourages Agency

- Lets me make my own decisions
- 43 Makes me feel like I can be honest with him/her
- 34 Allows me to talk
- 81 Helps me understand

## Trust

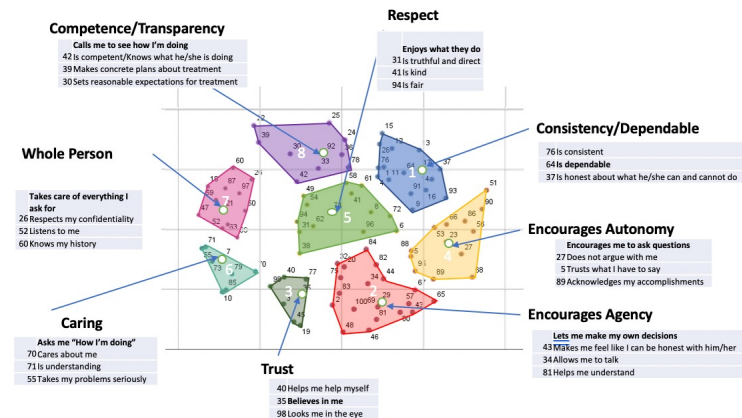
- 40 Helps me help myself
- 35 Believes in me
- 98 Looks me in the eye



# Relational SDM tool

- **Respect**

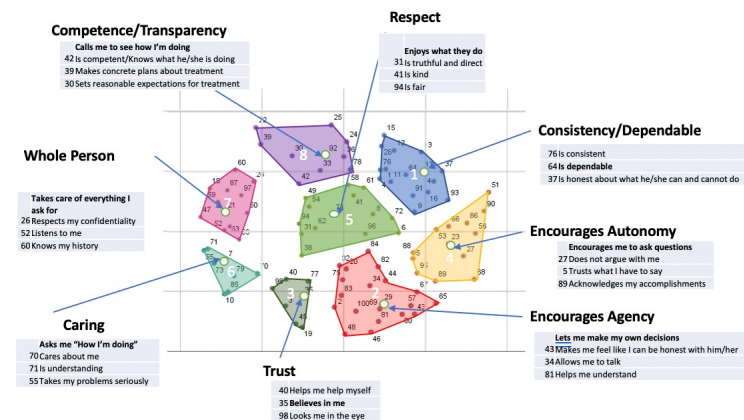
- My clinician enjoys what they do
- My clinician is truthful
- My clinician is direct
- My clinician is kind
- My clinician is fair



# Relational SDM tool

- **Consistency and Dependability**

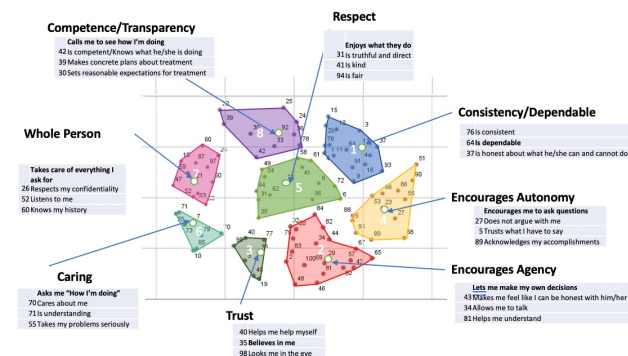
- My clinician is consistent
- My clinician is dependable
- My clinician is honest about they can and cannot do



# Relational SDM tool

- **Encourages Autonomy**

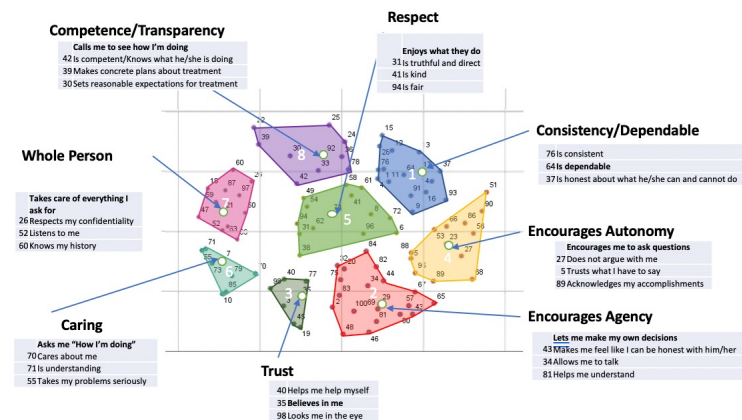
- My clinician encouraged me to ask questions
- My clinician does not argue with me
- My clinician trusts what I have to say
- My clinician encourages my accomplishments
- My client believes I encourage their accomplishments



# Relational SDM tool

- **Encourages Agency**

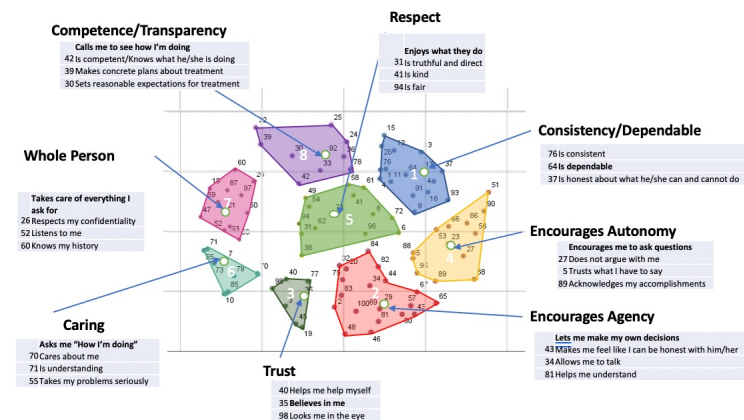
- My clinician lets me make my own decisions
- My clinician made me feel like I can be honest with them
- My clinician allowed me to talk
- My clinician helps me understand



# Relational SDM tool

- **Trust**

- My clinician believes in me
- My clinician helps me help myself
- My clinician looks me in the eye

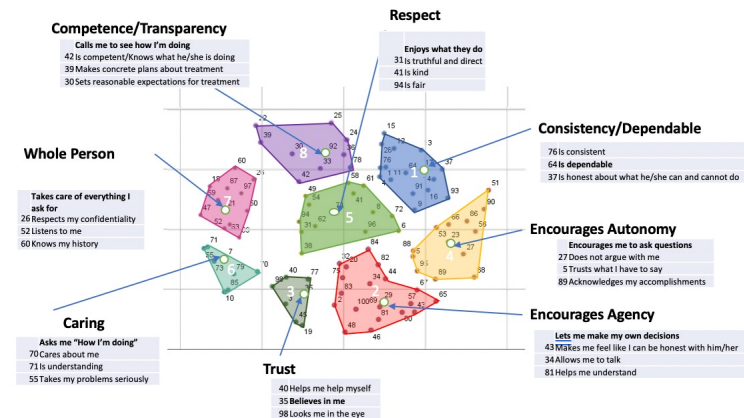




# Relational SDM tool

- **Care**

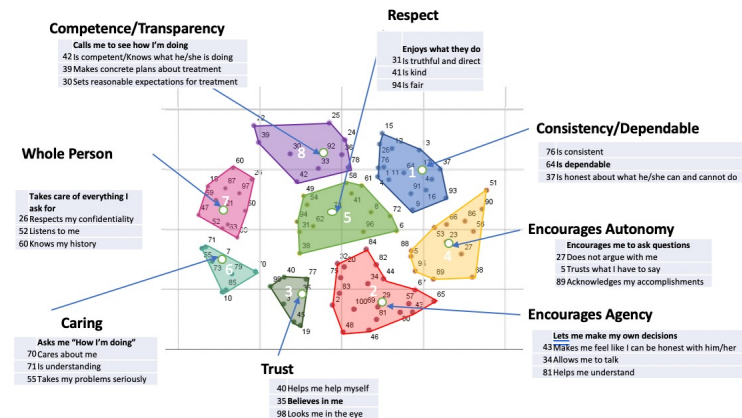
- My clinician asks “How I’m doing?”
- My clinician cares about me
- My clinician is understanding
- My clinician takes my problems seriously



# Relational SDM tool

- **Whole Person**

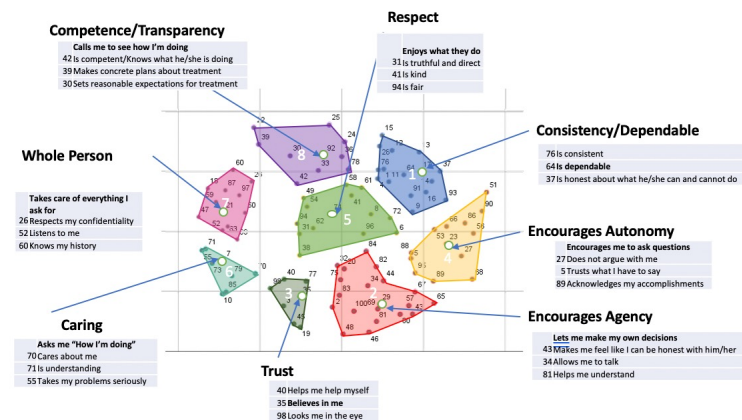
- My clinician takes care of everything I ask for
- My clinician listens to me
- My clinician knows my history
- My clinician respects my confidentiality



# Relational SDM tool

- **Competence & Transparency**

- My clinician calls me to see how I'm doing
- My clinician is competent/knows what they are doing
- My clinician makes concrete plans about treatment
- My clinician sets reasonable expectations about treatment



# Reactions, questions ...



**For more information and to join us in this work,  
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Thank  
you

# Contact Us

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New England (HHS Region 1)

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