APPLYING PRINCIPLES AND PRACTICES OF PERSON-CENTERED THINKING IN BRAIN INJURY REHABILITATION

Presented by Sally Kneipp, Ph.D., CRC and Stefani Eichelberger, M.S.W., LCSW, CBIS, CESP at the Nineteenth Annual Conference of the Brain Injury Association of Pennsylvania Monday, June 24, 2019 from 10:45 a.m. to 11:45 a.m.

Session Objectives

At the conclusion of this session, participants should be able to:

• Define person-centered thinking and explain how the principles and practices can improve the quality of life for individuals with brain injuries and for their family members and friends.

Session Objectives (continued)

Participants should be able to:

- Understand how to use relationship mapping to enhance person-centered thinking and the development of services and supports.
- Develop a communication chart for an individual with a brain injury in a post-acute rehabilitation setting (home or facility).

Acknowledgment

The Pennsylvania Department of Human Services' Office of Developmental Programs has been offering a free two-day training program on Person Centered Thinking, in various locations across the state. As stated in the training description, the training "serves as a foundation for everyone" involved in supporting people with significant disabilities." The participants may include providers' staff, supports coordinators and supervisors, administrative and organizational leaders, people with disabilities, and family members.

Acknowledgment (continued)

The materials for the two-day training in Reading, PA, on December 3 and 10, 2018, were developed by staff of The Learning Community for person centered practices (©TLC-PCP 2012; www.learningcommunity.us). Excerpts from those materials have been incorporated into this presentation.

Overview of Person Centered Thinking

- Definition
- Principles
- Goals

Potential Issues in Brain Injury Rehabilitation

Definition

Person centered thinking is the process of developing plans that support choice while addressing issues of health and safety. It is based on acknowledgment by the individual, and the understanding of involved persons, of what is *important to* and *important for* the individual. It includes determining how to address significant issues of health or safety while supporting choice(s).

Principles/Goals

- Underlie and guide respectful listening which leads to actions, resulting in individuals who:
 - Have positive control over the life they desire and find satisfying;
 - Are recognized and valued for their contributions (current and potential) to their communities; and
 - Are supported in a web of relationships, both natural and paid, within their communities.

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Potential Issues in Brain Injury Rehabilitation

- Physical and cognitive impairments
- Lack of awareness (anosognosia)
- Poor emotional self-awareness (alexithymia)
- Guidelines of funding sources

Core Concepts

•Important TO

•Important FOR



Important TO

- People to be with/relationships
- Things to do
- Places to go
- Rituals or routines
- Rhythm or pace of life
- Status and control
- Things to have

Includes what matters the most to the person – his/her own definition of quality of life

Important FOR

- Issues of health:
 - Prevention of illness
 - Treatment of illness/medical conditions
 - Promotion of wellness (e.g., diet, exercise)
- Issues of safety:
 - Environment
 - Well-being (physical and emotional)
 - Freedom from fear

Meet JJ

JJ is a 49-year-old male who sustained a brain injury nine years ago (2010), as a result of a motor vehicle accident. He was a police officer involved in a high speed chase, and his vehicle hit a truck.

In the accident, JJ broke his ankle and sustained a severe brain injury. His brain injury caused significant cognitive, behavioral, and emotional changes. Following his acute hospital stay, JJ received residential brain injury services for about nine months. He then attempted to return home to his wife and two children. However, JJ had behavioral and other problems that led to his placement in a different residential brain injury program for about two years. He returned home in 2015, with the support of home- and community-based brain injury rehabilitation services.

Meet JJ (continued)

- Medical Diagnoses
 - Severe TBI
 - Type II diabetes
 - Hyperlipidemia
 - Thyroid disease
 - Gastroesophageal reflux disease (GERD)
 - Low testosterone
 - Bipolar disorder due to TBI

- Cognitive Difficulties
 - Attention/concentration
 - Memory
 - Planning/organizing
 - Decision-making
 - Problem-solving
 - Judgment
 - Reasoning
 - Anosognosia

Meet JJ (continued)

- JJ tells people that he is a police officer, and usually needs a reminder to remember he is a "retired" police officer.
- JJ is not left alone for extended periods of time. His wife is his primary caretaker, but he goes to his mother's and in-laws' home occasionally, when his wife needs a respite.
- JJ often perseverates about how much he loves his wife and how wonderful his family is.

Meet JJ (continued)

- JJ does not have a driver's license. He talks excessively about wanting to drive and the type of vehicle he wants to purchase.
- JJ loves food, especially "sweet treats," and will overindulge if the opportunity presents itself. He also likes to go out to eat.
- JJ receives functionally-oriented cognitive rehabilitation therapy, Monday through Friday from 9:00 a.m. to 12:30 p.m. He volunteers three days per week and goes to the gym twice per week, during his sessions.

WHAT IS IMPORTANT TO JJ?

Important To JJ

- Family especially his wife
- His career as a police officer
- Driving
- Food especially "sweets"
- Volunteer work
- Exercise

WHAT IS IMPORTANT FOR JJ?

Consider the following

- Medical Diagnoses
 - Severe TBI
 - Type II diabetes
 - Hyperlipidemia
 - Thyroid disease
 - Gastroesophageal reflux disease (GERD)
 - Low testosterone
 - Bipolar disorder due to TBI

- Cognitive Difficulties
 - Attention/concentration
 - Memory
 - Planning/organizing
 - Decision-making
 - Problem-solving
 - Judgment
 - Reasoning
 - Anosognosia

Important For JJ

- Healthy diet
- Exercise
- Compliance with medication regimen
- Volunteer work
- Supervision to ensure good decision-making and judgment
- Support from family members



Important To, Important For, & the Balance Between

Management Skills

- Donut Sort
- Matching
- Everyday Learning Skills
 - 4 + 1
 - Learning Log
 - What's Working/What's Not Working

- Discovery/Listening Skills
 - Relationship Mapping
 - Rituals and Routines
 - Good Day/Bad Day
 - Two-minute Drill
 - Reputation
 - Communication Chart

The Donut Sort

Management Skill

• Purpose

- Identify role-specific responsibilities.
- Determine how to handle a situation/experience.

• Process

- Identify situation and chart the following:
 - Core Responsibilities
 - Expectations without error
 - Use of Judgment and Creativity
 - Trial and error; learning what works and does not work
 - Not Usually Our Responsibility
 - Beyond expectations; "Keep your nose out of..."

The Donut Sort (continued)

Application

- Provide clear expectations.
- Develop job/volunteer descriptions.
- Use as a feedback/evaluation tool.

Scenario

At one of JJ's volunteer sites, he receives a free lunch in the cafeteria after his volunteer shift. Typically, during his volunteer shift, JJ finds out what is for lunch. Sarah, JJ's cognitive rehabilitation therapist, discusses with JJ, in advance, what he is considering for lunch, to help him have a plan for when he arrives in the cafeteria. JJ decides that he will get a cup of soup, a sandwich, one cookie, and a diet soda.

Scenario (continued)

However, when they arrive at the cafeteria, JJ sees that pizza, which was not initially on the menu, was added as an option. He immediately goes to the pizza station and selects two slices of pepperoni pizza. JJ then selects two cookies and gets a diet soda. Sarah attempts, unsuccessfully, to remind JJ of his original meal plan.

After the session with JJ, Sarah expresses concern to her supervisor about JJ's poor food choices related to his diabetes.

Use of Judgment and Creativity	Not Usually Our Responsibility

Core Responsibilities	Use of Judgment and Creativity	Not Usually Our Responsibility
Sarah provides CRT to assist JJ to carry out his volunteer job.	Sarah goes to the cafeteria before JJ, to see if the food choices match what is on the menu.	Sarah cannot tell JJ what to eat. Sarah cannot force JJ to select
Sarah educates JJ about appropriate food choices.	Sarah directs JJ to the previously discussed food choices, to try to	certain foods.
Sarah provides positive feedback for appropriate choices/behaviors.	divert him from making poor food choices.	

4 + 1 Questions

Everyday Learning Skill

• Purpose

• Learn from efforts and plan next steps.

• Process

- Develop the question.
- Answer the 4 questions +1:
 - What have you tried?
 - What have you learned?
 - What are you pleased about?
 - What are you concerned about?
 - +1 Given your learning, what will you do next?

How to keep J	J from foraging	for junk food!
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What have you tried?	What have you learned?	What are you pleased	What are you concerned
	-	about?	about?
1	2	3	4
Locking up junk food	• He can be sneaky.	• When he eats healthy	His behavior in
• Prompting him to eat at meal times	• He denies he is hungry until he is offered	foods at mealtime	uncontrolled environments
• Giving him pre- portioned sweets	something he wants.He always wants more.		• Health risks associated with diabetes and overeating
			• The children not lock- ing junk food closet

+1 – Given your learning, what will you do next?

- Continue to keep junk food locked in closet.
- Pre-portion sweet treats.

4+1 (continued)

Application

- Evaluate the process and effort.
- Facilitate review by the team members.
 - JJ and his wife
 - Home- and community-based program staff
 - Other identified persons (in-laws, relatives, or others in the community)

Learning Log

Everyday Learning Skill

• Purpose

• Gather information about specific activities and experiences over a period of time, as a means for ongoing learning and/or to identify what works best.

• Process

- Identify what you want to know (e.g., Why is a behavior occurring?, What activity does an individual like?, What is the best strategy to use?).
- Log dated entries (answering the same four questions) to determine what is working and what is not working.

Learning Log

Date	What did the person do?	Who was there?	What did you learn about what worked?	What did you learn about what did not work?
	What? Where? When? How long?	Names of staff, friends, others, etc.	What did the person like about the activity? What needs to stay the same?	What did the person not like about the activity? What needs to be different?

Increase JJ's Recall of Daily Activities

Date	What did the person do?	Who was there?	What did you learn about what worked?	Wat did you learn about what did not work?
6/01/19	Said "I don't know." With prompt, he looked at his watch.	JJ and Sarah (therapist)	With a verbal prompt, JJ checks his watch to identify the day of the week.	JJ's immediate response is, "I don't know."
6/05/19	With prompt, he looked at the calendar.	JJ and Sarah (therapist)	JJ follows directions to look at the calendar.	JJ needed additional prompts to identify the date.

Learning Log (continued)

- Use as a type of progress note.
- Track efforts related to changing a habit/behavior.
- Support learning, with a gradual reduction in services, over a long period of time.

Sorting: What's Working/What's Not Working

Everyday Learning Skill

- Purpose
 - Obtain/Organize multiple perspectives about an issue/situation
 - Leads to action planning

Process

- Identify issue/situation.
- Each participant identifies what *is* working for him/her.
 - Use the information to identify what is to stay the same.
- Each participant identifies what *is not* working for him/her.
 - Use the information to identify what needs to change.

Scenario

JJ's wife wakes him up by 8:00 a.m. She prompts him to take his medications. His wife gives him a single serving, pre-portioned bowl of Lucky Charms for breakfast. After breakfast, JJ watches television. At 9:00 a.m., Sarah, his cognitive rehabilitation therapist, arrives. JJ does not remember the plan for the session. When Sarah prompts him to check his watch for the day/date, he identifies that it is Tuesday and that means he is going to the gym. JJ gathers his items to go to the gym, but comments that he prefers to sit on the couch to watch television.

Scenario (continued)

With assistance from Sarah, JJ completes his workout. On the drive back to his house, JJ repeatedly states that he is hungry. When they arrive at the house, JJ asks his wife if they can go out for pizza (his favorite!). His wife says, "No," but offers to make him a sandwich. JJ then says that he is not hungry. His wife and Sarah remind him that it is important that he eat, since he has diabetes. JJ goes to watch TV.

How does Sarah assist JJ to manage his diabetes?

	What Works/ Makes Sense	What Does Not Work/ Does Not Make Sense
JJ's Perspective		
Sarah's Perspective		
JJ's wife's Perspective		

	What Works/ Makes Sense	What Does Not Work/ Does Not Make Sense
JJ's Perspective	Eating Lucky Charms for breakfast	 Being hungry Not being able to watch television
Sarah's Perspective	 JJ receiving CRT JJ exercising 	 JJ not eating JJ watching TV all day
JJ's wife's Perspective	 JJ eating single serving pre- portioned cereal JJ Receiving CRT JJ exercising 	 JJ not eating JJ going out to eat for every meal JJ watching TV all day

Sorting: What's Working/What's Not Working (continued)

- Obtain a broader perspective.
- Use a problem-solving approach.
- Plan next steps.
- Use as an evaluation tool.

Relationship Mapping

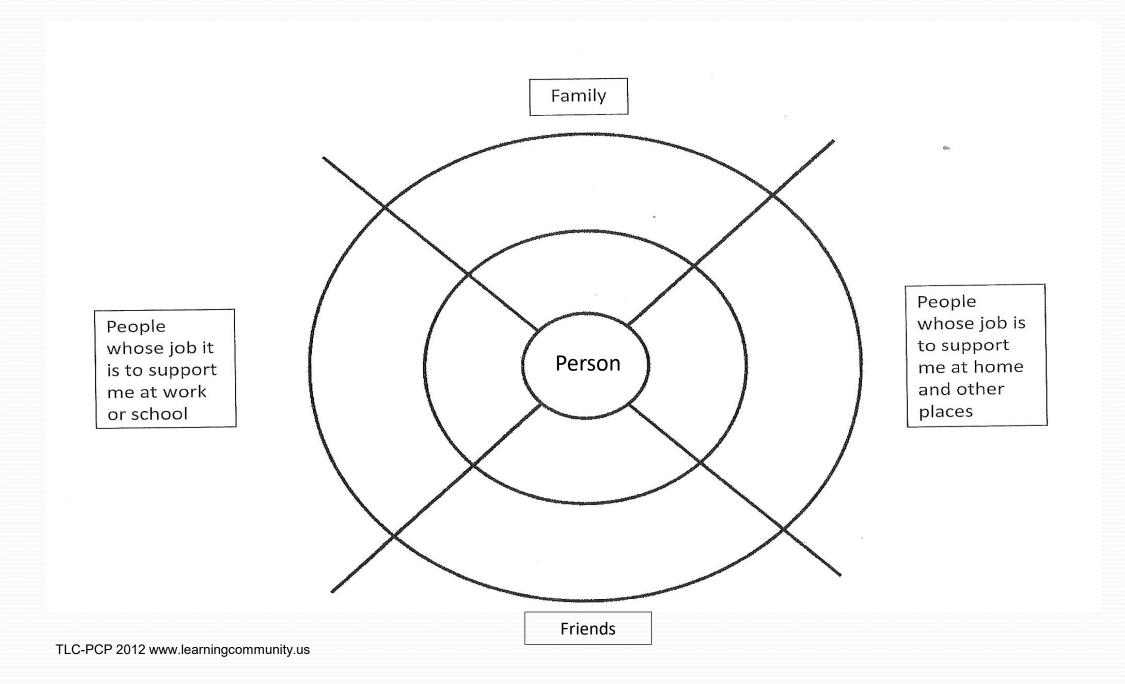
Discovery/Listening Skills

• Purpose

• Visual description of who is in the person's life

Process

- Indicate in the center who the map is for.
- Identify people in the person's life and the significance of the relationships:
 - Family
 - Friends
 - People whose job it is to support me at work or school
 - People whose job it is to support me at home and other places



Relationship Mapping (continued)

- Understand the roles and relationships of people in an individual's life.
- Identify the characteristics of a "good match."
- Help to identify people to provide support for the individual.

Rituals and Routines

Discovery/Learning Skill

• Purpose

- Identify specifics of a particular time of day or event.
- Learn what is important and necessary.
- Let others know how to support the person.

Process

- Identify the ritual or routine and write a detailed description.
 - Examples
 - Morning routines, mealtimes, bedtime routines, vacations, celebrations, bereavement, transitions, birthdays, cultural/holiday events, spiritual routines

Rituals and Routines (continued)

- Learn what parts of rituals/routines are important to a person.
- Identify what is *Important to* and *Important for* the person.
- Identify supports that are necessary.

Good Day/Bad Day

Discovery/Listening Skills

- Purpose
 - Identify the details of what makes a good day and a bad day for the individual.
 - May include identifying *Important to* and *Important for*.

Process

• Identify what is being assessed – a good and bad day in general, or a specific type of day or aspect of the day. For example, a good and bad day at work, school, etc.

<u>Good Day</u>	Bad Day
 What occurred to make it a good day? What do you look forward to doing? Who do you look forward to seeing? 	 What made the day bad? What was frustrating or boring? What impacted your day?

Good Day/Bad Day (continued)

- Help to identify what is important to an individual and how to support him/her.
- Use information to increase the likelihood of more good days than bad days.
- Use as a reflection/introspection tool.

Two-Minute Drill

Discovery/Learning Skill

Purpose

• Provide critical information about an individual, in a limited amount of time, to allow the person you are communicating with to know how to best engage and support the individual.

• Process

• Verbally communicate an overview/summary of the most relevant and important information *in two minutes*.

Two-Minute Drill (continued)

- Communication between staff when substitute coverage is needed (especially unexpectedly)
- Information sharing with a family member or caregiver
- Information sharing with colleagues (e.g., grand rounds in a hospital)

Communication Chart

Discovery/Listening Skill

- Purpose
 - Provides key information about how an individual communicates.

Process

- "Listen" to behavior
- Record the communication
 - When _____ happens
 - I do _____
 - It usually means _____
 - And I want you to do _____

Communication Chart

2	1	3	4
<u>When This Happens</u>	I do this	<u>It Usually Means</u>	<u>And I want you to</u>
 Consider The environment What just happened The "trigger" 	What is the • Action/Behavior	 What is/are the Meaning of the action/behavior Emotions/Feelings 	Consider • What to say/do • What to <i>not</i> say/do

Communication Chart

What is Happening	What the Person Does	<u>What it May Mean</u>	<u>What We Should Do</u>
1/15/19-At horse farm cleaning feed buckets, I prompt him to use a different scrub brush.	JJ throws the feed bucket and says he is leaving.	JJ does not want to use that scrub brush. JJ is tired. JJ is cold.	Give JJ a minute to calm down. Try to reengage JJ or take him home.
1/22/19-At JJ's home, he is preparing to leave for the horse farm.	JJ says, "I do not want to volunteer today."	JJ is tired. JJ does not want go to the horse farm.	Engage JJ to find out why he does not want to go. Encourage him to participate.
1/29/19-At the horse farm, JJ is to fill water buckets, but the hose is frozen.	JJ walks to the car.	JJ thinks he does not have to do the task. JJ wants to go home.	Help him to problem- solve. When home, discuss JJ's interest in continuing to volunteer.

Communication Chart (continued)

- Share information between staff members assisting the same individual.
- Use it to get to know an individual better.
- Identify how to support an individual in challenging situations.

Matching

Management Skill

• Purpose

• Organize "people characteristics," interests, and skills/supports to make a good match between people.

• Process

- Create a chart.
- Identify the supports needed and the skills required to support those needs.
- Identify personality characteristics of important people in your life, and characteristics of people you want around; consider characteristics that are not wanted.
- Identify what common interests would be nice to share with another person.

Supports Needed	Skills Required	Matching for
		PERSONALITY CHARACTERISTICS
		NICE TO HAVE (SHARED INTERESTS)
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Matching (continued)

- Help the individual identify the type of people they want around them.
- Assign staff to clients.











ANSWERS





