Thanks

Thank you to Diane Grieder and Lisa Meyer for their guidance and assistance.
Introduction

• Being Person-Centered is a holistic approach

• The following are tools and strategies to incorporate Person-Centered Thinking and Planning (PCP) into delivery of services for the brain injury community
PCP and Brain Injury

• Very little mention in the literature, what is available around PCP and brain injury concerns pediatric and adult acute care, and intensive post acute rehabilitation

• Three products developed over the past 10 years related to PCP and people living with traumatic brain injury (TBI)
According to Wayne Gordon of the Mount Sinai Research and Training Center on Community Integration of Individuals with TBI:

“... people with TBI who want to engage in PCP differ in many ways from people with developmental disabilities; a key difference is that people with TBI who want to move on after injury have to deal with ‘who I was’ in addition to ‘who I want to be.’”
• Stages of Change
  (Prochaska & DiClemente 1992)
  • Pre-contemplation
  • Contemplation
  • Preparation
  • Action
  • Maintenance

• Stages of Rehab in TBI Recovery
  (Ben-Yishay 1978)
  • Engagement
  • Awareness
  • Mastery
  • Adjustment and Acceptance
  • Competence
  • Identity

• Maslow’s Hierarchy of Needs (1943)
  • Affection, self esteem, food, clothing, shelter
  • Freedom, beauty, goodness, and justice
  • Self-actualization and Transcendence

Source: Applying Stages of Change Theory and Approaches when working with individuals living with brain injury
http://ohiovalley.org/informationeducation/materials/utilities/stages/
Critical Elements

Critical elements of implementing PCP with people suffering with TBI:

• Planning involves the person with TBI identifying their family, friends, and others

• The person’s voice and choices comes first

• Focus is on capabilities and strengths, not deficits and challenges

• The person’s hopes and dreams for the future are the starting point

• The plan is a statement of priorities, with small action steps defined, as well as commitments from family, friends, and other supporters

Source: Adapted from TBI Consumer Report #8, Person-Centered Planning, www.mssm.edu/tbinet
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Person-Centered Approach

“… Interact with your clients in terms of their biography, not their biology, focusing on their life experience rather than their disease.”

-Judith Felson Duchane
Professor Emeritus, University of Buffalo
Address to the graduates of the Department of Communication Disorders & Sciences, 2001
Person-Centered Approach

When people are initially recovering from a traumatic injury, they may be receiving intensive medical and rehabilitation interventions within settings where they are considered “patients.”
Moving away from policies and attitudes that focus on “fixing” to those that meet the person where they are now:

<table>
<thead>
<tr>
<th>Medical Model</th>
<th>Person-Centered</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The provider/professional knows best</td>
<td>• Person knows best</td>
</tr>
<tr>
<td>• Focuses on specific diseases/conditions</td>
<td>• Focuses on whole person</td>
</tr>
<tr>
<td>• Involves delivery of care to person</td>
<td>• Emphasizes self care</td>
</tr>
<tr>
<td>• Frequently focused on 1:1 meetings</td>
<td>• Encourages team approach to service delivery</td>
</tr>
</tbody>
</table>
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Person-Centered Approach

Even when people are just starting to recover and may still be in a state of post-traumatic amnesia, use person-centered approach when communicating *(in other words, don’t do this).*

While reporting on progress during a family conference with the person, her husband, and the rest of the rehabilitation team, the speech therapist turned to the husband and said, “*Jan is making fantastic progress with her deductive reasoning skills.*” This was stated as if Jan, a highly-educated and skilled professional, wasn’t sitting right there.
Person-Centered Approach

From *Themes and Subthemes From Structured Interviews With Individuals Living With TBI, Reflections on Person Centered experiences in Occupational Therapy* (2016):

• **Theme—Experiencing the client-therapist relationship:** “Seeing me as I the person I was; Getting to know me in the now; Making a positive connection”

• **Theme—Actively participating in therapy:** “Valuing the therapist; Being partners in therapy; Finding my place in life; Adjusting to who I am now and sharing my journey”
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Person-First Language

• Not a diagnostic label
• Person living with a brain injury
• Not a “brain injured” or a “brain damaged person”
• Focus on strengths, successes, talents
• Self-determination as a right
• Communicate a consistent message of hope

Source: Adapted from Diane Grieder
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Person-First Language

Where we are and where we need to go …

What’s wrong with this statement?

“The team decided to cut off his coffee early when at his residence, making the last cup decaffeinated at least two hours before bedtime.”
Person-First Language

Where we are and where we need to go . . .

What’s right about this statement?

“R wants to continue her education.”
Reporting at a team meeting with a person with severe TBI, the residential case manager says, “Every time I walk in his room, I see his collection of plastic cups all over the place! He needs to clean up.”

This gentleman has a long history of alcohol addiction—currently sober—although expresses the desire to drink frequently. He was working at the time of the meeting and got along with his house mates.
Use in Documentation

• Dr. Nelson endorses the use of person-centered, non-judgmental language and for professionals to “consider the type of language you would find acceptable in documents describing the care provided to you or a loved one.” It is acceptable, she goes on to say, “to quote the person’s own words”

• As medical records transition to electronic formats, people will have increasing access to their medical records: “Use of patient-centered, nonjudgmental language will better preserve the physician/patient alliance”

Source: Kathleen J. Nelson, MD in Current Psychiatry, October 2011
Person-First Language

Systems often adopt a “checklist format.”

Checklists tend to be written in medical and rehabilitation jargon and are not person-centered or accessible.
In 2011, five of the executive directors of our Brain Injury Waiver programs completed a PCP provider self-assessment questionnaire, adapted from Tondora and Miller’s of the Yale Program for Recovery and Community Health (2009).

Source: https://medicine.yale.edu/psychiatry/prch/tools/practice_guidelines.aspx
## Person-Centered Planning Self-Assessment Questionnaire

We remind participants that they can bring family, friends, and other supportive people to their individual plan meetings

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
<th>Actions or examples/comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Each participant receives a copy of their individual plan</td>
<td>60 percent</td>
<td>20 percent</td>
<td>20 percent</td>
<td>“Goals posted in room”</td>
</tr>
<tr>
<td>The participant’s goals are written in their own words in their individual plan</td>
<td>20 percent</td>
<td>60 percent</td>
<td>20 percent</td>
<td></td>
</tr>
<tr>
<td>The participant’s strengths and talents are described in the individual plan</td>
<td>100 percent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The participant’s goals for their life are included in their individual plan</td>
<td>100 percent</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Person-Centered Planning Self-Assessment Questionnaire

<table>
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<th></th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
<th>Action or examples/comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe our agency encourages full participation of each participant in their individual plan meetings</td>
<td>100 percent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The steps and actions needed to reach the participant’s goals are clearly described in their individual plan</td>
<td>100 percent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Should the participant choose, their spiritual beliefs and cultural views are included in their individual plan</td>
<td>60 percent</td>
<td>40 percent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our agency has a process for working with each participant to prepare for their yearly individual plan meeting and to ensure their goals for themselves are represented in the individual plan</td>
<td>40 percent</td>
<td>40 percent</td>
<td>20 percent</td>
<td></td>
</tr>
</tbody>
</table>
To create person-centered plans, the assessment needs to be comprehensive in order to create a plan with meaningful interventions:

- Know the person’s mental health history. Were they ever diagnosed with or treated for a mental health disorder(s)
- Screen for a history of substance use/abuse
- Did they have an Individualized Education Plan (IEP) or a 504 plan when they were in school
- Do they have a history of traumatic or acquired brain injury, prior to the injury that brought them into current services
Plan Components

John is a person living with a behavioral health disorder and a history of TBI.
Plan Components

John is a 35-year old single man who has been diagnosed with major depression, characterized by low mood, punctuated by outbursts that seem to come out of the blue.

John had incurred several TBIs in his youth. One from a fall at six years old that resulted in a skull fracture and several nights in the hospital; a second fall from a bike at age 12; and a third—also resulting in hospitalization—from injuries received in a fight when he was 28 years old.

Both the first and third TBIs resulted in periods of unconsciousness.
Plan Components

John is working on a landscaping crew that has a contract at a public facility. He is valued for his excellent work productivity and the care he takes in getting the job “right.”

His boss wants to keep him; however his otherwise excellent work is punctuated by swearing at co-workers, and his boss on occasion, as well as other socially obnoxious behaviors.
Plan Components

GOAL:

“I want to keep my job.”

(Disinhibition and lability are common after TBI with Frontal and Temporal Lobe involvement.

From the Assessment and Narrative Summary, John and his team suspect his anger may be due at least some of time from his difficulty in understanding or remembering what is being asked of or expected from him in new situations such as working with a new supervisor).

OBJECTIVE: “John will yell and/or throw things less than three times per day.”

INTERVENTIONS

1. John and his case manager, Samantha will make an appointment for a consultation with a neuropsychiatrist within two weeks.

2. John will ask for clarification/paraphrase back instructions (“What you want me to do is …”) when given new instructions or when he does not understand/remember procedures on the worksite two times, per shift, as observed by Marc, his job coach and himself.

3. John will work with Marc to create a template of frequent job tasks and he will keep in his phone for easy reference within two weeks.

4. John and his psychotherapist will identify at least one meditation or mindfulness strategy (e.g. the application “Breath2Relax” or “Tactical Breather”) and learn how to use it to deescalate his anger within two weeks.
Being Person-Centered means being brain injury-informed.
Screening for TBI

Anyone seeking or receiving services for:

• Addiction or problematic use of substances including opioids
• Mental health/psychiatric conditions
• Intellectual disabilities

As well as anyone who has a history of:

• Domestic violence
• Military service
• Is homeless or has a history of homelessness
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Building a Plan

A Logic Model for building a plan—accommodating history of brain injury

Source: Adapted from Grieder and Adams, 2005
One-Page Description

The one-page description can be a stand alone document, useful to provide a overview of important “To/For” a person or a starting point to a comprehensive PCP that can be a product of the assessment and used to introduce the person to other professionals and supporters.

For those who have limited language/communication ability, it can serve as a quick, holistic picture of a person and a way for supporters to engage in a Person-Centered way.
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One-Page Description

What people like and admire about John:
- Dependable
- Honest
- Friendly
- Takes care of his mom

What is important to John:
- Family and friends
- Being a valued (and long standing employee)
- Time playing games on his devices
- Attending church
- Being independent in his community (learning new bus routes as needed)

Supports John needs to stay happy, healthy, and safe in the community and on the job:
- Know what to expect for the work week, schedule, who the shift supervisors will be, etc.
- Know that his mother is well taken care of when he is at work
- Be able to run situations by his employment specialist so he can think before he acts

For a good match, characteristics needed to be present or absent:
- Patient
- Really takes the time to get to know me and my mother
- Nice
- Honest—I don’t understand why I am feeling/acting angry sometimes
- Reliable for the long-term (hard to “break in “ new staff)
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One-Page Description

Jean loves:
• Getting her nails done and picking out earrings and bracelets to wear
• Her hair cut in a short style
• Cats, chocolate, and her grandchildren

People love Jean because:
• She cares about others
• Is a good friend
• Well respected oncology nurse, always a resource to others

It is important to Jean that staff:
• Honor her nursing career and experience
• Give her a heads up so she knows what to expect before any thing happens in her room or to her in the course of providing care. This helps manage her anxiety

Jean’s story
She grew up in Malden, MA. She spent her summers in Northern Vermont with her beloved aunts and uncles.

She and her husband of 45 years, Jim, moved to Connecticut as newlyweds. They raised four kids and have four grandchildren.

She is a proud Democrat.

She and Jim are very active in their church.

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MARYLAND
Department of Health
Video Resources
Learning About Support
Read the Narrative Summary based on the character of Chris and watch this brief clip from the 2007 movie *The Lookout*, based on your reading and observations generate:

- Two Goals
- One Objective for each Goal
- Three Interventions for each Objective
The Lookout

Based on a few scenes from this movie about a young man living with a brain injury, training participants are provided with a written assessment and asked to generate two possible goals, two objectives and 2-3 interventions keeping in mind:

• What are the character’s barriers?
• What are the character’s strengths?
• What are the strategies he is using to compensate?
Learning About Support

Gestalt Project—*Stop the Stigma*
“The Dog Days are Over” by Florence and the Machine:

[https://youtu.be/QficvVNIxTI](https://youtu.be/QficvVNIxTI)

This video illustrates the importance of person first language and how we need to see others as people not as their diagnoses.
Learning About Support

Bree Brown: Empathy vs. Sympathy: https://youtu.be/KZBTYViDPlQ
Learning About Support

Un-motivational interviewing: https://youtu.be/EAlWBhohDp4
SBIRT: Dr. A

Screening, Brief Intervention, and Referral to Treatment (SBIRT) is an evidence-based practice used to identify, reduce, and prevent problematic use, abuse, and dependence on alcohol and illicit drugs.

Using SBIRT Ineffectively: https://youtu.be/ZGETDcFcAbI
SBIRT: Dr. B

SBIRT is an evidence-based practice used to identify, reduce, and prevent problematic use, abuse, and dependence on alcohol and illicit drugs.

Using SBIRT Effectively: [https://youtu.be/ZGETDcFcAbI](https://youtu.be/ZGETDcFcAbI)
Thank you
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