Supporting Individual Choice

February 14, 2013

Colleen Eccleston, BSN, RN
Kathy Curtis-Rubin, RN
Goal of the NYS Care Management Training

To provide education, training, and ongoing support to care managers who are in transition of their workforce responsibilities in a way that utilizes their existing knowledge, skills and strengths so that individuals with complex needs can improve their health and wellness and realize their full potential.
Today’s Webinar Objectives

As a result of today’s webinar:

- Participants will identify common dilemmas with supporting individual choice as care managers.
- Participants will be able to identify “potholes” they can be prone to falling into when working with individuals.
- Participants will understand the critical role of culture on individual choice.
- Participants will learn 2 tools to use in their work: Supporting Individual Choice and Risk Analysis.
Purpose of Health Home Care Management

**Recovery:** To support individuals “improve their health and wellness, live a self-directed life, and strive to reach their full potential.”

- Improve quality of care
- Improve outcomes
- Decrease cost
Managing Risk in Community Integration: Promoting the Dignity of Risk and Supporting Individual Choice

Each of us makes choices everyday. With those choices often comes some kind of risk. Some risks are generally benign; others may have consequences, both positive and negative, that can be either seen or unforeseen. The bigger the decision, or the newer the choice, the more we need to weigh the possibilities of risk before we act.

From: The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric
http://www.tucollaborative.org/pdfs/Toolkits_Monographs_Guidebooks/community_inclusion/Managing_Risk_in_CI.pdf
“There is an inherent risk in most everything we do in our lives, this should not exclude us from participating, but rather ensure that we properly plan to mitigate harm that can be associated with the various domains and life activities.”

-- John Rose

From: The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities
John O’Brien
http://www.inclusion.com/jobrien.html

Five Valued Experiences for Individuals

• Sharing in meaningful exchanges
• Growing in relationships
• Experiencing respect for who I am; having a valued social role
• Contributing (what am I here for?)
• Making choices

Five Accomplishments of Person-Centered Work

• Supporting community presence
• Supporting community participation
• Supporting valued social roles
• Supporting contribution
• Supporting opportunities to choose
O’Brien’s 5 Valued Outcomes

Have Respect!
- poor reputation

Go Places!
- isolation

Be Somebody!
- low expectations

Make Choices!
- no power

Share Relationships!
- loneliness

8
What kind of dilemmas occur with supporting individual choice?

Valued Experience:
- Sharing in meaningful exchanges
- Growing in relationships
- Experiencing respect for who I am; having a valued social role
- Contributing (what am I here for?)
- Making choices

Example:
- Providers who’d rather tell people what to do
- Don’t foster natural supports
- Don’t encourage/support community connections
- Define people only by illness vs interests…
- Forget important to/for
What role does the Health Home Care Manager play?

- To collaborate with individuals and their supports (formal and natural) to develop both meaningful goals and a plan based on their interests and preferences.

- This process helps individuals make informed decisions about their choices.
We need to recognize that the people we support are the experts on what they want while we are their partners in helping them get it. We need to have relationships where we share control and continuously support people in gaining as much control as is possible.

~Michael Smull
Risk

An important issue raised by a shift towards individuals having responsibility for, and control over, their own lives is risk.

In life, taking risks is a necessary part of being human.
Differences in Risk

**Harmful Risk**
- Behaviors which are illegal or not socially sanctioned
- Behaviors that impact health/wellness
- Behaviors that jeopardize important community roles
- Harmful risk is to be avoided

**Healthy Risk**
- Behaviors which involve the person taking on challenges leading to personal growth and development
- Risk where there is benefit – even if it all goes wrong, resilience is developed through trying and failing
Addressing Risk

- Identify actions to reduce harmful risks collaboratively with the individuals we are partnering with.
- Address harmful risk as it will support individuals with developing personal responsibility for their actions.
- Recognize that engagement with services is much more likely if “recovery” goals rather than “treatment goals” are given primacy.
- While most systems are in place to assess and document harmful risk behaviors, ensure systems are in place to assess, develop and document actions involving positive risk-taking; this is what develops risk self-management skills.
Supporting Individual Choice

Managing risk is a discipline for dealing with uncertainty and supporting individual choice. It “involves developing flexible strategies aimed at preventing any negative event from occurring or, if this is not possible, minimizing the harm caused”.

From: The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities
Why would we use this tool?

- To help staff determine how to support the choices desired by the person while taking care of their core/paid responsibilities.
- This tool should always include completing an “Important to and Important For” exploration before.
Supporting Choice

Not Our Paid Responsibility
In the domain of the person, of family and friends

Judgment & Creativity

Core Responsibility
Opportunities for Supporting Choice

- **The comfort zone:** Client makes choice staff are comfortable with
- **The conflicted zone:** Client makes choice staff feel conflicted about
- **The non-negotiable zone:** Client makes choice that poses significant danger that is immediate or imminent

From: Intentional Care – Advocates, Inc & Pat Deegan PhD
The Neglect - Over Protect Continuum

It’s the client’s choice. We are supposed to support choice. Let him/her do what he/she wants.

This is NEGLECT, not empowerment

We can get the client to do the right thing. Arrange things so he/she she has to do it our way.

This is OVER PROTECT and is toxic help

From: Pat Deegan PhD & Associates © 2004
Conflicted Decision Making Zone

NEGLIGENCE

DO
Remain engaged
Remain Supportive
Brainstorm options
Discuss pros/cons
Teach re: alternatives
Talk with Supervisor

OVER PROTECT

Do NOT
Control

Do NOT
Abandon Client

From: Intentional Care – Advocates, Inc & Pat Deegan PhD
Avoiding Relationship Potholes

Carol Blessing's “Pothole Theory”
Or…
The Collateral Damage of Good Intentions
Collateral Damage of Good Intentions

BLOCK IT …
→ POWERLESSNESS

DETOUR….
→ IGNORANCE/MISTRUST

FILL IT IN…
→ LEARNED HELPLESSNESS

PUSH ‘EM IN…
→ HUMILIATION
Managing Provider Discomfort

“Knowing when to hold close and support and protect, when to encourage someone while offering support, and when to let someone try alone and perhaps stumble, and when to encourage a person strongly to push themselves is an advanced, but essential skill for practitioners to develop”

-Practice Guidelines For Recovery-Oriented Behavioral Healthcare: Prepared for the Connecticut Department of Mental Health and Addiction Services by the Yale University Program for Recovery and Community Health (Tondora & Davidson, 2006)
Alternative: Relationship Strategy

Use our appraisal of a potential pothole to provide the person with all the information and opportunities to make informed decisions.

Partner with the person to look at the possibility and explore the steps and barriers together.

Struggle with them to support them as they walk towards this potentially difficult goal and see where it leads.
Importance of Culture:

the way of life by a group of people with a common and enduring bond

Partnering with people we serve requires an awareness and understanding of who they are and what is important to them.

Culture shapes the way we see the world.

Understanding culture helps us to understand how others interpret their environment.

Understanding culture helps us avoid stereotypes and biases that can undermine our efforts.

Addressing culture contributes to: increased access to services, improved overall health, improved quality of care, and improved outcomes.
What can we do to address culture?

**Organization Level**
- Have a cultural competency plan
- Recruit and hire culturally diverse staff
- Provide training to staff
- Monitor outcomes by cultural group

**Clinician Level**
- Conduct cultural assessments
- Ensure language and communication skills
- Program strategies for trust and reducing stigma
- Provide services in cultural milieu
- Involve valued persons in process
- Make referrals/linkages to cultural valued settings/services and supports
Key Areas for Understanding Culture in your Work

Use a multi-dimensional lens: your perspective, the person you are working with, and each of the formal and informal supports

- Values and beliefs systems
- Perspectives on health, wellness and specific illnesses (MH/CD/PH)
- Perspectives on management
Beliefs that Guide our Work

- No one is just who we label or classify them to be.
- Who we are is inseparable from our racial and ethnic backgrounds but not strictly determined by them.
- All people are individuals regardless of the nuances of race and culture.
## End of Life Issues

- A “Good Death”
- Hospice Care
- Access to Care
- Pain Management
- Withholding/Withdrawing Medical Treatment
- Terminal Sedation
- Advance Directives
Areas Associated with a “Good Death”

- Adequate pain and symptom management
- Avoiding a prolonged dying process
- Clear communications about decisions
- Adequate preparation for death
- Sense of control, spiritual/emotional calm
- Affirming person is unique and worthy
- Strengthening relationships with loved ones
- Not being alone
Getting Back to Risk…

“In the past, we found clever ways to build avoidance of risk into the lives of persons living with disabilities. Now we must work equally hard to help find the proper amount of risk people have the right to take. We have learned that there can be healthy development in risk taking… and there can be crippling indignity in safety!”

-- Robert Perske

From: The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities
Staff/Supervisor Roles in Risk

- What do staff worry the most about regarding risk?
- What do supervisors and agencies worry about the most regarding risk?
- Using the Guidelines for Skillful Discussion when planning for a risk-related discussion in a staff meeting or supervision, can be very helpful.
A Tool for Health Home Care Managers: Risk Analysis

Why would we use this tool?
To clarify the possible outcomes of different alternatives when risk is an issue.

This tool...
Clarifies the concerns for everyone involved
Gives options of how to address the concerns
Helps to sort through options for responding
Provides clear documentation for liability
## Risk Analysis Tool

<table>
<thead>
<tr>
<th>What’s the issue</th>
<th>What can we try?</th>
<th>What’s the risk of trying?</th>
<th>Should we or shouldn’t we try?</th>
<th>What actually happened and when?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

From: Blessing/Meissner Consulting Group
Next Steps

- Please share your feedback via the webinar survey.
- Log on to the NYS Care Management Training Initiative website to review additional resources at [www.healthhometraining.com](http://www.healthhometraining.com)
- Practice using these tools with individuals you are working with- have conversations with your supervisor and co-workers.
Questions