PASRR Technical Assistance Center (PTAC) Learning Module 4 Person Centered PASRR Transcript

Opening Slide

Welcome to PASRR Learning Module 4, Person Centered PASRR. My name is Julie Stanley, a Consultant with the PASRR Technical Assistance Center (PTAC). Today, I'll be your guide in learning about person-centered practices and how you can incorporate them into your state's PASRR program.

Slide #2

Just a quick reminder. Some of the material in Module 4 builds on the material contained in Modules 1, 2 and 3. If you have not already, we recommend that you review these three previous modules before proceeding.

Slide #3

The Centers for Medicare and Medicaid Services (CMS) and PTAC are committed to supporting state PASRR efforts. Through a 2009 contract, CMS asked PTAC to help CMS gain better knowledge about how state PASRR programs operate, research and study specific areas of focus, and help states improve their PASRR programs.

PTAC is helping states improve their programs in a variety of ways. The 2016 Regional Learning Sessions and the Modules you are reviewing now are a couple of the most recent efforts. PTAC is also available to provide free technical assistance to individual states upon request of the state.

Since 2010, PTAC has offered monthly Webinars (on the 2nd Tuesday of each month from 1-2:30 p.m. Eastern Standard Time), for which CEUs are available. Topics have included developing a more person-centered practice approach to PASRR, promoting ADA and Olmstead compliance, Minimum Data Set (MDS) and many other PASRR-related topics. PTAC consultants also facilitate regular regional calls that give participants an opportunity to showcase best PASRR state practices, discuss issues, and share learning with other states in the Region. PTAC publishes an annual report that provides insight on specific PASRR issues across the nation.

Through all of this activity, PTAC is helping CMS understand areas where greater regulatory clarity may be needed.

Please visit the PTAC website for comprehensive PASRR resources.

Slide #4

While PTAC acknowledges and supports the obligation for CFR compliance, we also understand the importance of PASRR being connected to much broader changes in the healthcare arena. When we look holistically at PASRR as an important component of integrated healthcare, the need for incorporating person-centered practices and continuous quality improvement into PASRR programs become obvious.

Slide #5

Change takes place over time. Stop for a moment to think about where your PASRR system is today, and where you may want it to be in five years or so.

CFR compliance is, of course, a basic "must." In this Module, though, we will assume CFR compliance and suggest ways you can build on what you already have in place take your PASRR program to a higher level by ensuring that you have person-centered practices throughout your Level I and Level II processes.

As you move your PARR program forward, you will find that the range of issues, support options and shared stakeholder values expand.

Slide #6

Think for a moment about the changes in your own PASRR program over time. As we saw in Module 1, there have been many milestones along the way, the majority of which place a much greater emphasis on community-based services and supports. The six questions on this slide can be a starting point to determining whether your state's PASRR program reflects these changes.

Do your PASRR processes:

1. Support and advance existing state initiatives, such as Money Follows the Person and Care Transitions?
2. Promote continuity of care regardless of where the individual happens to be living?
3. Support recovery?
4. Emphasize community integration when specialized services are being recommended?
5. Promote empowerment of the individual in all phases of PASRR?

And of course, do your PASRR processes reflect person-centered thinking and planning? We suspect you will be able to answer this question readily at the conclusion of this Module.

Slide #7

In 1992, the PASRR regulations were ahead of the curve because they incorporate many person-centered practices; we will examine some of these requirements in a few minutes.

However, if your state's PASRR program is focused solely on compliance with the CFR, it is all too easy to lose sight of the fact that PASRR is a powerful tool that can and does change the lives of every individual it touches. There are many ways to build person-centered practices into your PASRR program that both honor the CFR requirements AND assure positive outcomes for each individual.

Slide #8

In previous Modules we have stressed the need to avoid a "process-driven" PASRR mentality. This is important because the real power of PASRR depends on an alignment of the power that each entity has to make a positive difference in the lives of the individuals who touch PASRR.

Never forget that your interaction with an individual in the PASRR process may well be the most important moment in the individual's life.

Slide #9

But before jumping into the meat of the material, let's first acknowledge the many strengths—and some challenges—of creating a person-centered PASRR program. The lists on the slide are not intended to be comprehensive—there are probably some that you could add.

The strengths that we want to point out are:

- You will likely be able to develop a more sensitive Level I screening instrument.
- Focusing on interacting with and understanding the individual considers the whole person, not just the person's diagnosis.
- Your Level II process will include ample opportunities for identifying the person's needs, interest and concerns.
- Plans of care will truly reflect the unique needs of the whole person, not just a "one diagnosis plan fits all" approach.
- Individuals will be able to access specialized add-on services that are more timely and more appropriate to their needs and preferences.
- Promoting expanded engagement with individual stakeholders creates many opportunities to not only improve their lives, but also to improve your overall PASRR program.

Some challenges we want to acknowledge are:

- It can take time: time devoted to reviewing and refining your PASRR tools; and time devoted to training and education on—and practicing--person-centered thinking, interviewing, and planning skills.
- It is also likely to require additional time for screenings and evaluations in the early stages.
- And this one may be a strength as well as a challenge: Use of person-centered practices and planning is very likely to identify service gaps in your state's current system of care.

Slide #10

Using person-centered practices can be challenging, especially considering the distinct perspectives of everyone involved.

Each individual has life and health experiences unique to them. When preparing to enter a nursing home and being suspected of having a PASRR diagnosis, they may fear and worry about many things: loss of independence, loss of control and power over their lives, loss of rituals and routines they currently enjoy, and the stresses of living in a different environment. The process itself may be confusing to them.

Evaluators are also unique in that they come to their positions with their own personal values and beliefs—which must be ignored when using person-centered practices. They have to balance their jobs with their personal lives. They have to meet schedules and timelines, and are limited to use of existing resources.

Hospitals must be concerned about bed utilization, managed care pressures, and remaining financially viable, including how to provide and pay for resources. Nursing homes have similar concerns, and additionally they must worry about population mix and their plan of care obligations.

States, of course, must constantly concern themselves with wise use of limited taxpayer money, compliance with CFR requirements, and accountability to the public, as well to and federal entities. Workforce demand and a skilled, trained workforce are also predominant concerns.

Slide #11

Now that we have looked at some of the strengths and challenges involved in building a person-centered PASRR program, let's step back and examine what it is we are really talking about. Traditionally, each individual's uniqueness was rarely (or not at all) taken into consideration by service providers, whose role instead was to "fix" the "disability "with whatever tools they happened to have at their disposal. This is the exact opposite of person-centered practices, which involve two basic concepts:

First, person-centered thinking is a set of values, skills and tools used in Person-Centered Planning and in the personalization of services used by people who need supports.

Second, person-centered planning is use of a set of approaches designed to assist someone to plan their own life and supports. It is used most often to enable individuals with disabilities to increase their personal self-determination and improve their own independence.

Slide #12

"For people being supported by services, it is not person-centered planning that matters as much as the pervasive presence of *person-centered thinking."* This is a hugely important point, made by the Learning Community for Person-Centered Practices. Person-centered plans simply cannot be developed without the use of person-centered thinking values, skills and tools.

As we all know, values can be difficult to change, and learning new skills and tools can be time-consuming. However, to create a truly person-centered PASRR program, states must commit to investing the time and resources necessary.

Slide #13

The Learning Community, which we just quoted, was started in 1989 at the University of Maryland with development of what was called "essential lifestyle planning" when Michael Smull and Susan Burke-Harrison were asked to help people to return to their home communities from institutions and residential schools. All people involved had a developmental disability and, because of challenging behaviors, had been labeled as "not ready" for community life. As it turned out, these were people who could live successfully in their communities but had been trapped by their labels and the "reputations" that they had acquired. Smull and Burke-Harrison found that typical ways of planning were not helping them successfully move to their home communities. A new way of describing who they were and what they needed was required.

We encourage you to visit The Learning Community's website for extensive information on the origins and various aspects of person-centered practices.

Slide #14

As we said before, traditionally, each individual's uniqueness was rarely (or not at all) taken into consideration by service providers, whose role instead was to "fix" the "disability" with whatever tools they happened to have at their disposal. We also stated that this is the exact opposite of person-centered practices. This is true because the presence of a disability is only a small part of a unique individual, yet we often view it as a major (or only) aspect of the individual. (As a side note, in recovery this is generally understood as the mental illness becoming a smaller part of the person's life.)

It may be helpful to consider a few questions here. Would you want only one aspect of your life to govern or take precedence over all other aspects of your life? Would you want to be known as a "diabetic", or rather a person who happens to have diabetes? Would you want to be called

a “crippled“ person, or rather a person who happens to limp? Would you prefer being a “disabled” person, or rather a person who happens to have a disability?

Parenthetically it is no small coincidence that, as person-centered practices emerged and have expanded, the terminology has become extremely important and has changed considerably.

Slide #15

Having a sense of being a whole human being and having power over one’s life is common to us all. We all have certain rights—and responsibilities. We all want to express what we want in our everyday lives. We all place a high value on taking and/or maintaining control of our lives and making our own choices. We all understand the importance of connecting and contributing to the community. We all want opportunities to improve our lives – to experience joy, happiness, and purpose. We all choose to see family members and friends as we choose to. We all want to manage our own money and other resources.

When we realize that people with disabilities are no different than we are in any of these aspects, we are well on the way to thinking in a person-centered way, and we are better equipped to learn the skills and tools needed to apply this thinking in our practice.

Slide #16

You are unique. Everyone you encounter in your PASRR work is unique, too. There is no room for “one size fits all” practices in PASRR. Rather, PASRR is a tool for recognizing that uniqueness.

Slide #17

By now we should have a little better understanding of both the uniqueness of every individual, as well as the commonly-shared desire of everyone to have maximum choice and control in our lives. In fact, choice and control contribute greatly to making each of us unique.

I’d like to share some choices I made today. I chose to sleep until I woke up this morning instead of setting my alarm clock, which I often do. I chose to eat granola bars and yogurt for breakfast instead of the French toast my husband ate. Because I had no appointments or set schedules to distract me, I chose to work on this Module today. I chose to take breaks during the day whenever I wanted to, which enabled me to do laundry and clean out the refrigerator at my own leisurely pace. I chose to call my mother to make sure she had taken her medication, and I chose to visit a neighbor this evening. I controlled all of my decisions all day long!

Take a couple of minutes to recall your own personal choices today and what you were able to control in your life.

Slide #18

Just as we apply person-centered practices, including choice and control, to our own lives, we can apply them when dealing with others in our PASRR work as well. How?

First—and most importantly--listen to people. REALLY listen to them. What is happening in their lives, and how do they feel about it? What do they say they want? What are their own goals in life? What choices can they make now, and what choices do they want to be able to make? They can give you more information than a screening or evaluation could ever give you—if you only listen.

Work WITH them (not FOR them), and whomever else they choose to support them. Some people won't want anyone else involved; others may want their entire family involved. Respect their choice.

Offer information about when, where, and how they may be able to get their supports—and honor their choices whenever you can.

Support them, don't control them, in:

- Developing their own plan for now and the future;
- Finding ways to work and/or contribute in other ways to their community;
- Being involved in groups, organizations, and social activities that interest them;
- Learning new things; and
- Staying healthy and safe.

Slide #19

The application of person-centered practices by single staff members is easier than it is for the entire organization for whom the staff members work to become a person-centered organization. While individual staff members can certainly influence decisions made by the organization, a true commitment to becoming a person-centered organization starts at the top.

Organizations that are committed to being person-centered support all staff members in securing the necessary training and education, and in applying their skills in daily practice. These organizations recognize the need to match staff skills and personalities to individuals' needs, and make sure that staff members know both their responsibilities and where they can use judgment and creativity. They know what is private and respect privacy, are flexible and creative in the ways they support people, and frequently ask "What is working, what is not working, and what do we still need to learn?"

Slide #20

Here is one way to tell whether your current PASRR process is person-centered. As we go through these, be thinking about whether your processes capture any of this information.

We've already stressed the importance of how person centered practices and planning really start with listening to the individual. So exactly what are you listening for?

1. Positives about the individual. You will recall The Learning Center's finding that negative reputations and labels can lead to incorrect decision-making. When a person-centered plan is developed, it should always start with a positive description of the individual. Everyone has positive traits, and those are the ones that a person-centered process focuses on. Does your PASRR process focus on individuals' positive traits?
2. Who is important in the individual's life? Family, friends, neighbors, paid professionals? And why are they important?

3. What is important to the individual? What are their likes, preferences and routines?
4. What is important for the individual? What they need to stay healthy and safe?

Help the individual decide what others need to know or do to best support them. How do they prefer to communicate?

What personality characteristics do the people who best support them have?

Help the individual develop his or her own action plan that clearly states the individual's goals and who should do what, and when, in order to assist the individual in reaching those goals. Are key providers or support people identified as resources?

We all change over time, and the plan should also change to reflect the individual's changing needs and preferences.

Slide #21

Let's take a closer look at the concepts of what is important TO a person and what is important FOR a person.

The historical focus has been on what is important FOR a person; this is really the traditional "medical model," which of course aims at keeping people healthy and safe by addressing their problems. While there is certainly nothing wrong with that, it is only a piece of the person-centered puzzle. The missing links have been an equivalent focus on what is important TO the person, and achieving a good balance between "TO" and "FOR."

Slide #22

Consider the saying “An apple a day keeps the doctor away”—a classic example of a focus on what is supposed to be important FOR all people in order to stay healthy. But what if the person you happen to be working with likes only candied apples? Or much prefers bananas and grapes to apples? Or does not like apples at all? All of these are examples of what is important TO the person, and must be considered in finding the proper “FOR/TO” balance.

Slide #23

Here are some other examples of what may be important TO a person. They can be even more important when that person is preparing to leave home to enter a nursing home.

- Are there people you now enjoy seeing every day whom you will not be seeing any longer?
- Do you have a pet at home that you consider to be a part of your “family?” What will happen to it?
- Will you be able to maintain any of your unique daily rituals, such as the time you get up, when you brush your teeth or take a shower, or what clothes you want to wear?
- Will you be able to eat the foods that you are accustomed to eating and the brands of food you have grown to like?
- Can you have any control about how you spend your day? Whether you can continue to pursue your hobbies?
- Will you still be able to check out books at the local library, get a pizza at your favorite local pizzeria, go to your bank?

If you were faced with the reality of nursing home admission, what would you want in order to avoid losing all choice and control over your life? How could a proper “FOR/TO” balance be achieved?

Slide #24

This slide simply reinforces the fact that personal preferences (things that are important TO a person) can be balanced with the things that are important FOR the person. Balancing is so very critical, because it allows individuals to retain choice and control over their lives.

Everyone should eat breakfast. But what we eat and when can be our choice.

If medications are needed once a day for a certain health issue, how they are taken, and usually when they are taken, can be our choice.

Exercise is vitally important for everyone. But there are ways to exercise, so what exercise we do, when and how often can be our choice.

And importantly, everyone wants to feel safe—but everyone also takes risks in their lives. If you had a career as a fighter pilot, your idea of safety and risk will probably differ considerably from mine! Person-centered practices require that you put aside what you believe is safe for yourself, and focus on the individual's interpretation of safety and risk. The "dignity of risk" is available to us all, and care should be taken to make to available to individuals with whom we work.

Slide #25

You may be wondering how all we have just been through relates to your PASRR program. At the beginning of the Module, we pointed out that the 1992 PASRR regulations were cutting edge in the field of person-centered practices. The regulations required:

- Adaptation to the individual's culture, language, ethnic origin and means of communication;
- Participation by the individual in the evaluation-- and the individual's choice whether to involve family members;
- An "individualized plan of care;"
- Level II findings to include the positive traits or developmental strengths in addition to weaknesses or developmental needs of the individual. (This is even more significant because, as you may recall, one of the keys to modern-day person-centered planning is developing a positive description of the individual); and
- Level II findings to be interpreted or explained to the individual.

But person-centered thinking and practices have continued to grow and evolve a great deal since 1992. Has your state kept abreast of this evolution?

Slide #26

We know from Module 1 that the CFR requires certain things for the Level I PASRR process. But let's look at what the CFR does NOT require.

Under the CFR, "the State's performance of the Level I identification function must provide at least, in the case of first time identifications, for the issuance of written notice to the individual or resident and his or her legal representative that the individual or resident is suspected of having MI or MR and is being referred to the State mental health or mental retardation authority for Level II screening." This, of course comes AFTER the screening has been completed. There is no requirement, however, that the individual even be apprised of the fact that a Level I screen is being conducted and why, let alone that the individual be consulted during or participate in the screening process. Imagine for a moment that you are the subject of a Level I screening. Would you want to know that? Would you want to know why it is happening, and the possible ramifications of the result of the screening? Might you have relevant information to share with the screener that that perhaps no one else knows about you?

The CFR requires no particular qualifications for Level I screeners. Would it be helpful for screeners to be trained in person-centered thinking and practices? Might it lead to more accurate Level I results?

The CFR requires that "a preadmission screening determination must be made in writing within an annual average of 7 to 9 working days of referral of the individual with MI or MR by whatever agent performs the Level I identification." Is computation by use of an annual average of all individuals a person-centered practice in any sense of the word? Is any consideration given to the impact it can have on a individual who has to wait 25 days?

And lastly, while the CFR requires that notice to the individual of the need for a Level II evaluation must be adapted to the cultural background, language, ethnic origin and means of communication used by the individual being evaluated, is the notice your state uses always clear to the individual? Is a written notice sufficient for the person to understand what is happening? The CFR permits—but does not require--the State to convey determinations verbally to the individual and confirm them in writing

Slide #27

Again the Level II CFR requirements have been addressed in previous Modules. Notably, however, states have much flexibility in assuring that Level II evaluations are conducted using person-centered practices. How can your state do this?

Provide training and education to Level II evaluators in the values, skills and tools used in person-centered practices and in the development of person-centered plans.

Involve individuals, and anyone of their choosing, in the evaluation in a meaningful way. "Meaningful" means:

- Listen—REALLY listen to them
- Learn who is important to them
- Learn what is important to them
- Understand what is important for them

Consider the individual's strengths and preferences to be high priority.

- Develop a positive description of the individual
- Determine what the individual can do, and what others need to know or do to support them

Assure that the individual controls the plan that is developed. The evaluator's role is to help the individual develop his or her own plan that says who will do what when. Over time, assure that the plan is being updated as the individual's needs and preferences change.

Slide #28

In applying PASRR requirements, we hope that your state can determine how best to keep the focus always on the individual whose life will be impacted by all decisions made. We hope this Module has given you some ideas about how to move your PASRR program from a compliance mentality to a person-centered one.

Slide #29

We encourage you to review these person-centered resources on the PTAC website.

Slide #30

And we also encourage you broaden your understanding of the materials presented in this Module by taking the time to explore the vast array of person-centered resources on the websites listed here.

Slide #31

Thank you so much for your time today. This concludes Learning Module 4. Please remember that PTAC is always available to assist your state in developing a more person-centered PASRR program. The assistance is free for the asking!