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“The role of the Provider in Person-Centered Care practice”

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I'd like to share with you some of my recovery experiences as a participant in a “self directed care” program, along with my personal perspectives on what I feel are essential components for a recovery oriented system. This won't be a sad story of “suffering” but rather an insightful view of “living” with a mental illness successfully.

In 1999 I was one of 5 advocates in Northeast Florida who met in 1999 to discuss alternatives to a mental health class action law suit. With Florida ranking 47th in the nation per capita for mental health funding, service choices were limited, difficult to access, inflexible, untimely, and buried in endless criteria. People hopelessly cycled between crisis and minimal stabilization. With the knowledge that Developmental Services had already begun implementing cash and counseling pilot projects, we mounted a grass roots campaign to establish a similar pilot for people with psychiatric disabilities.

Florida Self Directed Care (SDC) was created by the Florida Legislature in 2001 as a fiscal program which allowed flexibility of service choice and how it's delivered. The fiscal management is based on self determination and the clinical foundation is recovery oriented. Individual needs are met through choice, responsibility, accountability and self direction which maximize the principles of self determination. I became a participant in 2002. In 2003 this innovative program won the Eli Lilly “Moving Lives forward reintegration award in Social Support.” In April of 2004 SAMHSA/CMHS (Substance Abuse Mental Health Services Administration/Center for Mental Health Services) used our program as a model as they planned the implementation of the President's New Freedom Commission Report which was released in July of 2004. This report placed person-directed behavioral healthcare as one of the top priorities in transforming the national system of care. Two things were very clear to me during our process of developing SDC: a lack of belief that people with psychiatric illnesses had the potential to direct their lives or make healthy decisions concerning their care, and the acceptance of a system design where the supply created the demand instead of the demand creating the supply. This brings us to:

TRANSFORMATION:

Why is it needed? Recovery is no longer wishful thinking...it's a reality for many people and it's happening all over the country. The role of the provider is changing from managing people's care to providing choice and assistance so people can manage their own care.

Webster's dictionary defines transformation as, “the act of completely changing or altering in nature, form or function”. How do we apply this to a system that provides mental health services? While this seems like an overwhelming question it simply requires creating a system of care that is recovery oriented (nature), person centered (form) and person driven (function). Equally important is the assurance that dignity,

respect, trust, safety, and quality are not compromised in the process. One thing I've noticed over the years is that change is the one thing that is constant, and yet it's met with the most resistance. One main difficulty in making changes within the present system is that we continue to layer positive changes and effective initiatives on top of an infrastructure that doesn't support them. Albert Einstein once said, "We cannot solve our problems with the same level of thinking that created them." Allowing what hasn't worked to be a part of any change is like spreading a computer virus...your system will crash. So, I guess you might say that transformation is an opportunity to "defrag," "delete" and "reboot." It gives us the opportunity to work together to download a new system of care that will promote a recovery oriented system.

WHAT IS MEANT BY RECOVERY?

The National consensus statement on Mental Health Recovery reads, "Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential."

People who are ready to move forward with their lives will define and seek recovery in a way specific to their needs and aspirations. The important thing to remember is that recovery is a life process with the same expectations that people without psychiatric diagnoses desire in their lives. Safe housing, food, meaningful employment, education, health care, social activities, and transportation are realistic and basic necessities that support quality of life. The ability to access these needs for people with mental illnesses remains challenged due to discrimination and lack of healthcare parity.

Self Directed Care (SDC) allowed me to create a budget specific to my recovery needs, and to obtain services in a fully integrated way in the community. Taking control of my life through self determination, choice and self direction allowed me to see myself as a whole person...mentally, physically and spiritually. The ability to control the dollars for my care allowed me to practice cost effectiveness, focus on my abilities, discover my responsible limits and eliminate the blame game by being personally accountable for the consequences and successes of my choices. The long term goals I set when I became a participant were met in my first quarter. What I discovered was a new way of challenging my potential by setting goals that would move me beyond mere "survival" to actually creating a healthy and successful life. It included services that addressed my abilities not just my disability. Some of my successes included the completion of a writing course earning 4 college credits, participation in a computer education class, but the most rewarding was being able to access a non traditional service which was participating in a Weight Watcher's program. This provided me with a totally community integrated support system, nutritional education, kept me from isolating which is one of the symptoms of my illness, increased my self esteem, practice commitment skills, reduced the need for certain medications...and I lost 78 lbs. I learned the valuable connection between physical, spiritual and mental health and chose services with a holistic approach. Even the Neuroscience Institute at Shands Jacksonville support non traditional services such as tai chi, yoga and massage as therapies to improve energy, as well as emotional and spiritual well-being.

For me, recovery meant freedom...freedom to control my own destiny.

THE IMPORTANCE OF PERSONAL VALUES:

We make decisions in our personal life based on our value system. Our values are our personal infrastructure which determines our motives and motivation along life's path.

Before a successful mental health transformation can be achieved, it will require each of us to take a look at ourselves. What personal values, characteristics, experience, knowledge and talent can we bring to this process? It will require more than knowing that change is needed; more than the ability to analyze and intellectualize over it. We will have to have a conscience... to "feel" that it's the right thing to do in order to make the necessary commitment to make it happen. For some it will be a leap of faith, for another it will be a welcomed challenge, and for those us who will have an opportunity to experience a new future filled with hope, it will be a celebration of life.

VISION:

Whether you are creating a vision for your practice, business or your personal life it's essential to plan with an evolving future in mind. A vision isn't a destination. It needs to be flexible and adaptable to changing times. For instance, if your vision is to provide services that are recovery oriented and person driven for those you serve, then you are open to change in the future. Your goals will need to support that, which means...you will need to embrace and include the voices, talents and expertise of your customers.

INCLUSION:

There is a familiar saying that is heard throughout the country and that is, "Nothing about us without us." It's more than a simple phrase requesting inclusion. We have the expertise and knowledge from our lived experiences that can help you empower the lives of the people you serve.

A good place to start is to revisit the vision of your practice. Are you having difficulty reaching your goals? Are your projected outcomes unrealistic? Do you feel frustrated by funding issues? Do you feel like you can't be creative because of inflexible contracts, policies, regulations or other barriers? Do you feel like you are trying to accomplish "Mission Impossible?" If so then we share similarities. Over the years it's been difficult for me to develop meaningful goals because my "vision" focused on recovery. Until recently the vision for mental health focused on compliance and stabilization. I've also been frustrated with funding issues that didn't allow me to choose more cost effective and meaningful choices for recovery. My ability to be creative was entangled in access criteria and lack of choice. For years, recovery from where I stood was "Mission Impossible."

In order to access services for "recovery" I had to be persistently, chronically mentally ill and be impoverished. That's like asking someone to think outside of the box, but not allowing them to color outside of the lines.

The process of recovery becomes compromised when it is defined by someone other than the person seeking recovery. System and Practice change will evolve naturally when people receiving assistance are recognized as meaningful participants in the process.

What does person centered mean to you? Someone recently said to me, “I’ve been getting person centered care for years.” I said, “How?” Well when I sign my treatment plan I get to sit in the center of all these people.” That’s an example of the misconception for many of person-centered. It’s viewed as an environment not a process. Person centered planning is simply the freedom for the individual to create a plan of care specific to their needs. Person driven is the action needed to have person centered outcomes.

Peer Specialists are valuable employees. Their skills, personal experiences and understanding of what is needed will assure your practice remains person centered and recovery oriented. They are resourceful and mediate with a level of understanding unique among their peers. Larry Fricks from Georgia has developed a successful peer specialist certification program and is now helping to implement it in other states.

Help support Peer Networks whether local or state. They are the advocates whose voice will be heard. Agencies, practices and organizations that have self disclosed individuals with psychiatric illnesses on their boards understand the importance of quality, respect and positive outcomes. Peer Advisory Boards and Committees help you provide a level of service that empowers. If your vision includes recovery you will not hesitate to employ, incorporate, and invite the expertise of the people you serve.

WALL OF AUTHORITY:

Another important step is “breaking down the wall of authority.” This isn’t about disrespecting authority but about creating trust and respect. I can remember in 1971 how terrified I was the first time I woke up in a hospital after a suicide attempt. That was my first experience with people who had “mental health” authority. I was told what to do, when to do it, when to be quiet, when to eat, when to go to bed, when to shower and when to sign on the dotted line for an unwanted treatment procedure. It was in those first minutes that institutionalized thinking was ingrained in my thoughts and spirit. I’d become useless and a blight on society. However, you don’t have to live in an institution to think and feel institutionalized. It’s a type of thinking that accompanies the loss of authority in one’s life. It’s the breeding ground for dependency and hopelessness.

How you portray your authority will have a huge impact on the people you serve. An authority that forces or only focuses on control and compliance will jeopardize “trust” which is essential in establishing healthy relationships. There is that spoken and unspoken message that says, “I know what is best for you.” The willingness to move from, “what you need is,” to asking “what do “YOU” feel that you need?” is a step in the right direction. The transformation process will allow all of us to move from a model of just compliance to that of building an alliance. Together we can discover what is needed and how to access it.

RESPONSIBILITY & ACCOUNTABILITY:

Accountability is more than organizing records and financial bookkeeping. It’s about being answerable to the quality of the services provided. It isn’t the immediate gratification of satisfaction, but the life building influence of quality that creates opportunities to become successful.

Believe in the potential of the people you serve. Share your needs and encourage people to participate in finding solutions. Provide safe venues for them to express their

needs. Peer Specialists would be helpful in doing that. Acknowledge their concerns and respond accordingly. Communication is a life line. No one wants to be a “silent” partner.

EVALUATIONS:

Evaluations that are used to determine the effectiveness, quality and satisfaction of your services must not be just measuring sticks. They are your most valuable tools for change if they produce accurate and meaningful data. It isn't enough to know where you are but where you are going to continue the ongoing process of transformation. Take a look at your evaluations. What does the data reflect? What do you do with the information you collect? Is it business as usual, a necessary contractual demand? Meaningful evaluations motivate the potential for change.

It isn't about who is the best service provider. Share your findings with other colleagues through networking. Evaluations aren't meant to judge but to teach all of us about the needs of people who are trying to live responsible recovery oriented lives. It's about improving and increasing opportunities for people to make healthy decisions based on their individual needs. You have a creative and valuable resource to assist you in determining if the evaluations are effective...the people you serve.

What are the hurdles and how high do I need to jump?

Each one of us who are willing to run in the transformation race has a unique track designed especially for us. Each hurdle will at some point seem insurmountable. Some of these hurdles will be financial, cultural, communication, parity of healthcare, regulations, bureaucracy, politics, discrimination and many more. I've never seen a hurdler look down before they jump. Some hurdles will be knocked down but the racer always looks up and continues forward. The best athletes practice as a team even though they may run individual races. We are all on the same team. We can successfully clear each hurdle and stand in the winner's circle if everyone on the team gets to participate.

What does the “Winner's” Circle look like?

For me, the winner's circle is the hope of a new future filled with opportunities to become a healthier, more confident and contributing member of society. I've been practicing my personal race on a “self directed care” track. I've cleared hurdles that I never dreamed were possible. I've been able to replace the negative “what if” to “why not.” I no longer allow others to validate who I am, or define me by my illness. My failures are detours not road blocks, lessons not judgments of competency. My budgeting, time management and prioritizing skills have become fine tuned. Change is no longer a fear but a welcomed challenge. Today, my success is mine and I don't let anyone still my thunder! When I look into the mirror I don't see a shattered image but a whole person. My smile is genuine and my hope is real. I have reconnected with the unique individual that I am...that I always was. Mind, body and spirit have been reunited. I'm now self employed as a mental health consultant and travel nationally to speak on self directed care and recovery. I don't have time to “suffer”...I'm too busy “living.”

It all began with someone believing in my potential to achieve great things through my own self determination, self direction and choice.