Provider Panel on Self-Advocacy:

How we can foster greater self-advocacy when working with individuals in recovery from SMI?

Self-advocacy is emphasized by the recovery community as one of the most important elements of psychosocial recovery. “Speaking Out for Yourself”, a self-help guide published by SAMHSA, defines this concept as: “Taking personal responsibility for your own life—putting yourself back in charge and staying there. Speaking out means insisting that others respect your rights and treat you well. A little bit of hope and self-esteem can help you take the first steps to speak for yourself, and your actions on your own behalf will then increase your sense of hope and self-esteem. This upward spiral helps to relieve troubling psychiatric symptoms and supports you so you can do the things you need to do to make your life the way you want it and do the things you want to do. It all starts and ends with you; you have the right to ask for as much help as you need.”

We asked a national panel of VA providers to think about ways we can enhance self-advocacy in our consumers – here’s what they said:

1. How can self-advocacy benefit consumers in their recovery?

Self-advocacy is a core component of recovery. Needs are recognized and expressed leading to a stronger self-esteem and confidence. It’s a belief in oneself that “I matter” and “I can advocate for myself.” I have witnessed consumers who have been dependent on others and it is amazing to see the surge of positive energy when they accomplish their own tasks. As the accomplishments roll forward you see the blossoming of a new person. – Joseph Pacetti, LCSW (Social Worker; Hines VAMC)

Continued on page 2
In my opinion, the biggest hurdles a consumer faces in mental health recovery are not symptoms, but rather self-stigma and adherence to the old Medical Model. Self-advocacy works counter to each. I’ll never forget how profound I found it the first time I heard someone say that the turning point in their recovery was “when I realized that I was worth fighting for.” Even typing those words gives me chills. Because of self-stigma, many do not think of advocating for themselves. Either they believe that they are “not worth it” or that they do not possess the ability to be effective. Once they do begin engaging in self-advocacy, they are challenging those beliefs. This also allows my favorite psychological phenomenon to occur – cognitive dissonance. Cognitive dissonance occurs when your actions don’t match up to your beliefs, so you beliefs shift to be more in line with the actions. By fighting for yourself, even if at first you don’t believe you’re worth it, you can come to believe that you are. This also fosters increased sense that one can influence the direction of his or her life, rather than the belief that much of my life is out of my control (psychologists refer to this as ‘locus of control’). Regarding breaking free of the Medical Model, those who have graduated from our PRRC program all have at least one thing in common – they all report that they started really moving through their recovery once they realized that they had to take responsibility for their own recovery, that they couldn’t expect someone to hand them a magic pill or do it for them. This includes advocating for one’s self. – Tracii Kunkel, Ph.D., (Psychologist; Orlando VAMC)

In my own recovery advocating for myself became a sort of bench-mark. I didn’t want to advocate for myself and was uncomfortable doing it. Forcing myself into self-advocacy contributed to self-efficacy. A sort of feedback loop was created in which standing-up for myself in healthy ways told my mind that I was worth the effort, and the difficult work of recovery, including self-advocacy, became more possible, attainable and worthwhile. – Chuck Sanchez, CRPS-V (Peer Support Specialist; Orlando VAMC)

Self-advocacy is important in promoting a sense of self-efficacy. People advocate on their own behalf if they believe that they are agents of change in their own lives. Helping Veterans advocate for themselves sends a powerful message that we believe in them, even when they do not yet believe in themselves. It also encourages Veterans to be less dependent on the mental health system. – Amy K. Cuellar, Ph.D. (Psychologist; Houston VAMC)
Self-advocacy can benefit consumers by inspiring hope and improving self-esteem, though learning how and when to use words to elicit respect and emotion in others may facilitate more positive outcomes. – Kimberly Settle RN-BC, BSN (Registered Nurse; Bay Pines VAMC)

2. What can providers do to facilitate self-advocacy?
Encourage from the start. Let the Veteran identify what barriers they see in their ability to self-advocate and address them while providing opportunities to engage in regular practice. Rely less on modeling you advocating for them, and more on providing support while they are advocating for themselves. This is where Peer Supports can really make an impact. For example, there was a veteran attending our program who needed to seek out the services of a lawyer to help him with a fairly significant legal matter. He identified concerns that he had about speaking with the lawyer (one was that his anxiety would overwhelm him and he may interpret that as anger), and we practiced skills for those concerns. Then a Peer Support Specialist accompanied him to meet with the lawyer, not to speak FOR the veteran, but to be there to help him remember his tools should he need them. The Peer Support went with the veteran to about 3 meetings before the veteran told him that he was no longer needed. In this case, the Peer Support was never needed to intervene but his presence helped the veteran feel confident to overcome his fears about engaging in self-advocacy.” – Tracii Kunkel, Ph.D., (Psychologist; Orlando VAMC)

Being a good listener is key because you can help the consumer recognize and define their need. Initially, you might have to help assist a consumer who feels stuck and struggles in self advocacy. It is important to build a collaborative approach and brainstorm ideas together. As the plan is developed you might help assist the consumer in some of the tasks but it is key the consumer takes ownership of it too. Through the process, you continue to support and encourage the consumer to take on more tasks and responsibilities. It is important throughout the process to recognize their accomplishments and give them positive feedback on how they advocated for themselves. – Joseph Pacetti, LCSW (Social Worker; Hines VAMC)

Providers can facilitate self-advocacy by offering information about community or online resources that provide opportunities for learning about self-awareness, communication and interpersonal skills. Also, by offering psychoeducational groups that teach these same skills including role-play opportunities. – Kimberly Settle RN-BC, BSN (Registered Nurse; Bay Pines VAMC)
Meet a person where they are, focus on strengths and self-determination in recovery, and set personal responsibility as the standard. – Chuck Sanchez, CRPS-V (Peer Support Specialist; Orlando VAMC)

Providers will first need to engage the Veteran on the rationale for why learning self-advocacy is helpful in one’s recovery. Providers then can teach Veterans social skills and problem solving strategies in order to advocate for themselves. – Amy K. Cuellar, Ph.D. (Psychologist; Houston VAMC)

3. What are some of the barriers to self-advocacy that you have noticed? Are they ways in which we as providers can inhibit self-advocacy? How can we be mindful of avoiding such practices?

In the hopes of being helpful to people and treating a whole person it is easy to slip into the role of thinking or feeling that we are supposed to “fix” or handle all aspects of a person’s recovery. I cannot do someone else’s recovery and neither can any other provider. I believe there is value in the struggle, and coaching someone through it, not taking it away, is giving a gift. – Chuck Sanchez, CRPS-V (Peer Support Specialist; Orlando VAMC)

The barriers I see are primarily related to self-stigma, stigma, or (often well-meaning) providers who attempt to do too much for their veterans. Regarding self-stigma, someone may believe that they are not worth the effort or that they do not have the ability to effect change. Providers can feed into this with unrecognized stigma of their own. We want our veterans to succeed and we want them to know that we care about them and want to help them, and sometimes may not recognize that we are doing things for them because we don’t believe that they can do it for themselves. Or we may advocate for a veteran because it may seem more expedient. For example, I may be able to call a veteran’s psychiatrist immediately and advocate for them, whereas it may take a few days for the veteran to get an appointment and see that provider to advocate for himself. If the matter is time-sensitive and needs to be handled immediately, my call to that provider may be more prudent. If it is not urgent and I make that call, I may have helped my veteran in one sense but hurt him by taking away an opportunity to practice self-advocacy. That would fit into the last barrier I mentioned – providers trying to do too much. In a sense, the provider is leaning too far into the medical model. I try to remember I am a coach, and I think about my high school football coaches. Their job at that time (as is mine now) was to teach me how to do for myself and put me in opportunities to use those skills, and to do as little for me as necessary beyond that. – Tracii Kunkel, Ph.D., (Psychologist; Orlando VAMC)
Low self esteem and a lack of confidence are strong deterrents to self advocacy. How can you advocate for a need if you feel it is unworthy or not necessary? A lack of knowledge of resources and advocacy tools will create obstacles in self advocacy. Sometimes the consumer’s support system squashes their self advocacy by tackling all of their tasks for them. They feel they are helping but they are only perpetuating the cycle of dependence and low self esteem.

Providers can derail self advocacy when they jump to resolve issues without the consumer’s input and/or allowing them the opportunity first to resolve the problem on their own. As providers, we might encourage consumers to continue to use their supports instead of branching off and doing the task on their own. We might also jump in to intervene after watching a consumer fail several times.

I believe the best way to not derail a consumer’s path to self advocacy is to take a long pause before jumping to a resolution for a consumer’s problem and to open the door to a conversation. Allow for the consumer to struggle and make mistakes. It’s part of the process. Encourage the consumer to take the driver’s seat in his recovery and ask him/her why it is important to them. Motivation is the key to change. If they are motivated to change. Change happens. – Joseph Pacetti, LCSW (Social Worker; Hines VAMC)

One of the barriers is attitudinal. As mental health professionals, most of us went into the field seeking a helping profession. However, the most common way we think of helping others is when we do *for* others. It can feel as though we are not being helpful if a Veteran is asking us to help them by doing something *for* them. One way to avoid this is to re-conceptualize helping as not doing for, but training someone to do for him or her self. This process takes more time and energy to implement, but is much more effective in promoting recovery for our Veterans. – Amy K. Cuellar, Ph.D. (Psychologist; Houston VAMC)

Some of the barriers that I have observed include: ineffective use of language, lack of a support system, living in a negative environment, and lack of computer skills or lack of access to computers. As providers, we can inhibit self-advocacy by not tuning in to our patients/consumers emotional world and their level of learning. If providers can practice more mindful navigation of the emotional and physical channels through which the communication flows, this can help the patient/consumer make the necessary internal adjustments in their emotions and be more successful in self-advocacy. Narrative matters. – Kimberly Settle, RN-BC, BSN (Registered Nurse; Bay Pines VAMC)
Resources for Self-Advocacy

- SAMHSA —
  Speaking Out For Yourself: A Self-Help Guide

- NAMI —
  Living With a Mental Health Condition: Disclosing to Others
  StigmaFree Pledge

- Wellness Recovery Action Plan (WRAP) —
  How to Self-Advocate

- Depression and Bipolar Support Alliance (DBSA) —
  Understanding Advocacy

- Other Organizations
  Bazelon Center for Mental Health Law
  National Empowerment Center

About the Author:
Members of our national provider panel include:

- John Pacetti, LCSW (Hines VAMC)
- Tracii Kunkel, Ph.D. (Orlando VAMC)
- Chuck Sanchez, CRPS-V (Orlando VAMC)
- Amy Cuellar, Ph.D. (Houston VAMC)
- Kimberly Settle RN-BC, BSN (Bay Pines VAMC)