

Alternatives 2005: Leading the Transformation to Recovery
October 26-30, 2005
Hyatt Regency Phoenix, Phoenix Arizona

“Self Direction as a Route to Recovery”

I was one of five 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, uncoordinated, inflexible, untimely, and buried in criteria. People hopelessly cycled between crisis and minimal stabilization. It was difficult for anyone to take responsibility for their “mental wellness” when they must remain chronically, persistently mentally ill and indigent to receive services...services based on someone else’s perceptions and expectations of what they needed.

Florida Self Directed Care (FloridaSDC) was created as a fiscal program which allows 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.

Once the self directed care program was operational, I had an interesting reaction when I was asked if I’d like to be a participant. I’d been fearless in my advocacy and determined that this grassroots initiative would succeed so why was I feeling fearful now? My mind raced with questions like: Can I trust my decisions? How do I know if I can direct my own life? What if I make a mistake? What if I don’t know what I need? What if I have a relapse? What if failures are viewed as incompetence instead of lessons in learning? All of those questions have one common denominator...self doubt from years of dependency.

So why did my fearlessness turn into fearfulness? The answer was simple...change. The one thing that remains constant is change and yet it’s always met with the most resistance.

For years I feared change as a “disconnection” from what was familiar. Change in my life meant signing a different treatment document; starting over multiple times with a new case-manager; showing up for group therapy only to be told it had been terminated; having to move to another county to keep the same doctor; the endless changes in Medicaid formularies along with my brain’s chemical resistance to text book treatment. All the changes in my life that pertained to mental health lacked one important element...me.

SDC provided opportunities for me to “reconnect” with my potential and achieve a healthier life filled with purpose and hope. With the freedom to choose services based on my individual needs, I could now take responsibility for my recovery, and work within my responsible limits.

I didn’t really know what I needed, but I certainly had a wealth of information and experience about what I didn’t need. There were three important challenges for me: Setting goals, prioritizing the steps to reach them and learning how to use my quarterly budget effectively.

Setting goals: My first goals focused on discovering my abilities, hidden talents, needs and a vision for achieving them. One of my goals was to take a course on writing articles and stories for publication. It was a measurable goal in that it was a future source of earned income; it included education (#4 college credits) and challenged my level of confidence in my abilities. Having a choice in deciding which author I wanted to work with, made all the difference in my commitment to accomplish my goal. Her critiques and editing were carefully balanced with words of praise. We also shared a spiritual likeness which reinforced my ability to see myself as a “whole” person.

Developing and prioritizing the steps to achieve my goals: This was something I had to work on. I’d list the steps in my plan, but with no specific order in mind. It didn’t take long for me to realize that I quickly worked the simple steps for that immediate sense of accomplishment, and procrastinated working through the steps that were more challenging. That was like buying a pair of shoes because I liked them and it made me feel good, before I measured the size of my foot. Achieving a goal is like climbing a ladder. Each step supports the next step. When you get to the top of the ladder you have a better view of where you are going and the goals you will set to reach the next destination. I learned from that experience that ignoring the challenge kept me in the position of starting over instead of moving forward. I also learned that I have the potential to face any challenge.

Effective Budgeting: There are three types of services which are available for me to use.

***Traditional:** e.g. medication/symptom management, therapy, etc.

***Non-traditional/Service Substitutions:** e.g. more natural types of services that produce the same or higher levels of outcomes as the traditional ones. These services offer a more holistic approach to recovery; e.g. including dental, vision and hearing. Yoga classes may be a choice for exercise, reducing stress, discipline and for opportunities to learn about other cultures. Massage therapy has been helpful for people who have issues related to touching from abuse, PTSD, etc. These services provide a least restrictive environment and foster true integration into the community.

***Recovery Enhancements/Supports:** e.g. tangible items reimbursed at 50%; e.g. instructional guides/books, transportation related such as bus tickets for appointments, materials related to seeking employment, education, productive activities, socialization, stress reduction, etc.

I was born with the RPTPP gene that enhanced my ability to budget. Some of you may be familiar with that gene (**Rob Peter To Pay Paul**). Budgeting for many of us has been based on survival, not recovery. My treatment plans in the past documented my “disabilities” while my Life Action Plan is a document of my “abilities.”

Developing my quarterly budget allowed me to be creative, responsible and experience my potential. Every time I identify a service, connect it to a specific area of care, comparison shop, estimate the number of times I will need that service within a time frame, and define my own expectation of a positive outcome...I know that I am fully vested in my future.

I’ve been able to practice cost effective treatment by un-bundling services and comparison shopping for alternatives. The freedom to purchase only what I need created opportunities to select services that focus on prevention and recovery.

I chose to join a community weight loss program as a “service substitution.” I’ve lost 60 lbs. which has decreased my need for certain medications, while gaining a valuable support group. It has decreased a symptom of my illness...isolation. Since I discovered the word “recovery” six years ago in that first meeting to discuss the “concept” of self directed care, I haven’t needed any inpatient psychiatric treatment...saving thousands of dollars. I’ve learned how and when to challenge my “responsible limits” reducing my risk for crisis-care, and realize while satisfaction is important to me, it’s the quality of the service that moves my life forward.

Challenges:

***Reuniting your wholeness: mind, body and spirit.**

Realize that the ability to choose services that treat and enhance your mind, body and spirit is the first step in integrating “you” back into your life.

***Breaking the cycle of dependency.**

Take the risk to make changes. Believe in your abilities. Practice self acceptance and positive self-talk. Know that change doesn’t have to feel right to be right.

***Learning to accept change as a challenge instead of a fear.**

Turn the “what ifs” into “why not.” Don’t focus on failure. See it for what it is...an opportunity to try again. Allow consequences to motivate not paralyze.

***Seeking services that focus on quality not just immediate satisfaction.**

Learn the difference between quality and satisfaction and how it affects your recovery goals. I created the acronym STOP as a tool to help me be more aware of the quality of my choices: “S” for safe, (does it provide protection from harm and is it in a safe environment?) “T” for trust, (does it provide a foundation for trust?) “O” for opportunities, (does it provide additional opportunities to advance my recovery?) “P” for promote, (does it promote self direction, self determination and choice?)

***Embracing consequences of choices as opportunities.**

Accept consequences as lessons not failures. Allow paths toward recovery to be flexible and guided by lessons learned.

***Embracing success.**

Take time to see, feel and experience each step toward your goals. Assume ownership of your success by acknowledging it. Don’t diminish your hard work by ignoring the right to celebrate your accomplishments. You earned it.

***Learning to monitor your progress through self evaluations along the way.**

Don’t wait to evaluate your progress quarterly. Make it an ongoing process. It’s not just the completion of a goal that defines your progress. How you handle a difficult choice, your attitude, a lesson learned, are some examples of making progress. Sometimes just the willingness to keep on trying indicates a major step toward moving forward.

***Learning to advocate for your needs.**

Understand your Constitutional, Civil and Human Rights. Empower yourself with assertiveness. Discover your own voice. Determine how you will communicate and interact with people. Present your opinions respectfully and never yield your opinion just to avoid conflict. Be willing to agree to disagree. Don't be afraid to speak...your voice is important.

***Learning the importance of person centered language.**

Acknowledge yourself as a person by not allowing others to define you by an illness. Any language that discriminates, labels, separates, or diminishes the value of any individual is unacceptable. Don't be afraid to share your preferences when it comes to language, while respecting the rights of others who may disagree.

The advantages of Self Directed Care are simply freedoms:

***Freedom to be empowered.**

SDC makes you the author of your book of life. Your choices are the chapters and your self determination is your publisher. The reality of empowerment comes in knowing that it's not an "end" result of success but an ongoing achievable process.

***Freedom to make choices based on individual needs.**

SDC encourages "you" to define and choose services that will move your life forward. The ability to un-bundle services creates responsible attitudes toward treatment as well as budgeting.

***Freedom to experience flexibility in seeking alternatives for recovery.**

There is flexibility in the choice of services, providers, settings, goals and time frames. People who choose to participate in SDC programs are more motivated to complete their treatment and experience recovery if they have control over what they participate in. They choose the least restrictive and often the least expensive route. They're able to develop a network of trust among professionals, family and friends.

***Freedom to discover your potential and your responsible limits.**

SDC eliminates the fear of taking risks in discovering your potential. You learn that failures are events not people. You also learn that stumbling blocks are not road blocks but detours on your journey of recovery. Responsible limits are merely resting places. Self evaluations of how stress affects your progress may determine when you choose to challenge those limits.

***Freedom to experience and expect success.**

The opportunities to experience success are guided by "your" choice of individual goals and the necessary steps to achieve them. "You" define your success. Success is no longer something that is hoped for, but is achieved through your own abilities and expectations.

***Freedom to be a part of changing the discrimination against persons with psychiatric disabilities.**

SDC is an opportunity to dispel the myths that people living with mental illnesses are irresponsible, incapable and unpredictable in directing their own lives. A person becomes responsible through experience; the experience to fail and to succeed. A person becomes capable when they are encouraged to believe in their potential and abilities. Concerning unpredictable...life is not predictable and it's a defeating goal that destroys individuality.

***Freedom to increase the quality of your life with a meaningful purpose and direction toward the future.**

Quality is often an assumed outcome of satisfaction. Satisfaction is the pleasurable feeling of gratitude when a need or desire has been met. Quality is defined as a degree or grade of excellence; a distinguishing attribute. An e.g., I'm very satisfied with my Psychiatrist, but inaccessibility to him in the public system diminishes the "quality" of care he can provide, do to the large volume of people he is expected to treat, in inadequate time frames.

***Freedom to reclaim ownership of one's life.**

The ability to make choices and accept responsibility for consequences and successes provides opportunities to embrace the vulnerabilities and strengths of our personal uniqueness. Self directed care returns to you the deed to the most valuable property you will ever possess...your life.

The freedom with SDC to make choices based on my wholeness as a person was the key to discovering my own personal path to wellness. Learning how to connect the mind, body and spirit as it relates to my recovery, has been educational and challenging. I believe in each of us there is an eternal flame. A burning desire to rise above life's difficulties; to become what we are destined to be; to believe that everything has a purpose, place and time; to "live with" not "suffer from" an illness and to know that we have made a difference. As you return home my burning desire for you, is to know that choice, self direction and self determination will provide you the wings to soar, a path to your future at the right time and place, the strength to endure and the knowledge that you have and will always make a difference.