

Relationships and Change

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On the bulletin board that hangs over my desk, there are various bits of things that I have saved as reminders to me about what I value in my work. Among the pictures and buttons, there are two hand-written notes that I read almost every day. One says "**Things Change!**" The other says "**Hey! There is enough to go around. There will be leftovers. Remember this!**" This is a paraphrased version of a longer quote by Henry Nouwen, a theologian. Both notes remind me to stay calm about things that are difficult. The full quote from Nouwen also hangs on my bulletin board. It reads as follows:

The opposite of a scarcity mentality is an abundancy mentality. With an abundancy mentality we say "There is enough for everyone, more than enough: food, knowledge, love, everything." With this mindset we give away whatever we have to whomever we meet. When we live with this mindset, we will see the miracle that what we give away multiplies: food, knowledge, love...everything. There will even be many leftovers.

Change is inevitable, and it is a core part of the work of providing support over the long term; it is both joyful and sorrowful. And scarcity: that is the riddle in front of us today. The funny thing is that in my 20 years of work at Options, scarcity has always been a part of it, and we have always found a way. The note is posted to remind me of that truth; we will find a way.

I have learned from people supported by Options that the best support occurs when there is an opportunity to form a relationship with the individual. In this context, I am defining relationship as a commitment to stick by a person. Forming a relationship means taking the time to know what is important to the person supported, to know their preferences, to know what their experiences have been, and to offer support in the context of that knowledge. There may be friendship as a result of a working relationship, but not always, and not even frequently.

If we expect *only* a service to be provided, or a transaction to occur when a support worker is with a person with a disability, we have no expectation for a relationship to form. We expect completion of a task. But, as I have learned over and over, the odds of successfully completing a task go up when there is a relationship between the worker and the person supported. Both parties are much more likely to be satisfied with the interaction. Transaction-based services *will* work, but only in the short run; there is little satisfaction for either party, and there will certainly be a long parade of workers in the life of the person with the disability if the work is centered on transactions instead of relationships.

Some would argue that relationships with support workers are too risky for people with disabilities. The worker will leave and the person supported will be hurt by the loss. Some might say the relationship is not necessary. The relationship gets in the way of objective service delivery. Some would say that we are wasting time. What we need right now in this time of scarcity is to find more efficient means of providing service.

It does hurt when relationships end. This is a part of life. But, the risk of not having the relationship is greater. And the risk to people with disabilities of a service system based on transactions is

enormous. I have talked to service providers who wonder about the wisdom of "allowing" a support worker and a person supported to live together for years. The general concern is that the worker will leave, and that the person supported will be hurt. Yes, the worker may leave, and there will be sadness and loss, but there will also have been a relationship that supported the person with the disability to have a full life. The need to rely on the service system will inevitably mean that people with disabilities will experience stressful changes; the hope is that relationships formed with support workers will make the intervening time meaningful.

Because we are all engaged in work that is long-term in nature, relationships become essential.

The number one reason Options workers stay committed to their jobs is what they get from the relationships with the people they support. We want workers to feel satisfied with their work and to stay with it. We want to be able to stay with our own work, not feel worn down, used up, unappreciated, unacknowledged. To accomplish this goal, we must think about how to **nourish commitment to the work of providing support to people with disabilities.** Workers should feel proud--not embarrassed--to say they have done this work for 3 years, for 5 years, for 15 years. People who are called to direct service work should not be perceived as low achievers or somehow not serious about building a career. The response to someone who's made a commitment to this work should be, "good for you! How lucky to have work with so much meaning and satisfaction."

We can accomplish this through modeling commitment to the work, and by developing leadership throughout organizations. Making the work sustainable over the long-term means offering support to co-workers by creating opportunities to talk about the work and reflect on what is being learned. Taking time to step back from the day to day work offers the possibility for reflection and recommitment.

To stay with the work, it is essential that we understand and recognize that **supporting people through relationships inevitably leads to change. And the experience of change may lead to feelings of loss and grief.** We forget this, we ignore this, and we often don't understand the emotion of grief that is experienced when changes in relationships occur.

Loss is felt by support workers, people supported, and their families. We understand loss when we grieve the death of someone we support. We don't always recognize other types of loss, such as when a long-time co-worker leaves her job or when a newly-hired support worker quits, saying the work is too hard. Because loss *is* hard, we may want to gloss over the difficulty a person supported has in making a transition between support workers. Sometimes we attribute the way they express loss to their disability rather than to the experience of loss.

The loss experienced when a worker leaves his or her job is not the same as when a person dies, but this is a loss that people with disabilities and their families must face over and over. Such loss requires considerable energy to move through, to be willing to start again with a new worker, to form a trusting relationship, to extend themselves, and to figure out the quirky aspects of this new worker. The scenario is the same for workers who must learn to build partnership and trust with a new person.

So, what do we do? We start by recognizing the inevitability that relationships lead to loss. We recognize when it is loss that we are feeling. I always bristle when I hear workers say they feel

burned out or used up by their work. What does that mean? It may mean that they feel they were not supported to be in relationship with people they supported. It may mean that they were not acknowledged for the important work they were doing. It may mean that there was no recognition of the losses that occurred. Any and all of those things will lead all of us to feel tired and worn down.

Once we find ways to recognize loss, once we recognize how we and our co-workers respond to it, then we can take time to reflect on what we have learned from the relationship that's lost. We can remember and reflect on all that was good and all that was accomplished through the relationship.

Within organizations, we need to develop rituals to support remembrance, whether they are around the death of someone supported, or around the departure of a trusted co-worker. Through this, our organizations help us support each other, accept change, and grow through it.

At Options, one of the rituals that helps us reflect and remember is story writing. Here are two stories written by my coworker, Alice Sosinsky. The first story, written in 1990, describes Alice's experience with a person she supports. The second story, written in 2002, is a reflection on change.

Coming at This Through the Back Door

Driving along John Nolen Drive last Sunday morning, from out of the blue, a question entered my mind. "I've done this work for awhile. Why do I keep doing it?" At the moment I couldn't think of anything that I'd rather do *less* on this blustery morning. But there I was, heading into this work once again. Why? An interesting question to consider after working at Options for eight years, four days, and 37 minutes. Why?

I was on my way over to Wendy's house. Her life over the past year and a half has been filled with pain and misery. So much has changed. The problems seem endless. I think it is especially troubling to me as I can so vividly remember who Wendy used to be and what her life was like.

Autonomy, choice are common themes at Options. These were always of the utmost importance to Wendy, too...before. Wendy was most clear on what she wanted and was the most assertive woman I'd ever met. Today, it is a daily struggle. Making choices and taking control over her life are things that Wendy finds impossible to do. Instead, helplessness and dependency continue to grow, and we're forced to make the decisions, take the control.

Personal space is another difficult area to ponder. Options puts great value on helping people make good spaces and places for themselves--both in their home and out in the community. I remember when Wendy moved into her first apartment on East Johnson Street several years ago. That was her pad. She made friends with the neighbors and visited the local store. She loved that place. It was her first own real space. Now, after moving three times in a year and a half, Wendy is angry, afraid, and lonely. Unable to cope with the "problems" that neighbors cause (i.e., walking upstairs, saying hello in the hallway), Wendy sees those around her as enemies. She seldom ventures out of the apartment that she has detested since day one.

Wendy used to take great pleasure in eating. Now she eats only when, quite literally, she's forced to. And she used to love to cash her \$45.00 check every Monday – and come home exhausted after a big day of shopping. Money has become one of Wendy's many "obsessions" of late – a steadfast refusal to spend a cent. She had many friends and

acquaintances downtown that she spoke of often. She used to visit her best friend, Ed, at his home at least once a week. Now Wendy feels taken advantage of – and that her friends are stealing her money. Her beloved Ed is in a nursing home in Verona. The relationship that I felt so strongly with Wendy has changed as well. I feel more like her mother, her nurse--an enforcer, another enemy.

Working at Options has always felt right to me. It made sense. Working with Wendy over the past one and a half years hasn't felt very good – and it certainly hasn't made much sense. The values and quality of life that Options works for seem so remote from Wendy's personal hell.

In rereading this story, I still ask "Why?" Why do I keep doing this work? It probably isn't clear to anyone listening – as it isn't for me either. It somehow did make sense when I sat down to write this story. Right now, it's a perplexing question.

CHANGE

The dictionary defines Change as...."to make or become different"; A metamorphosis.....

Change has been on my mind a lot lately. Is there more change occurring now than usual?? Probably not, but it seems to feel that way.

Change, also defined as "money back", or "small coins," is somehow very much like a two-sided coin: heads or tails, winner or loser.

One side of the coin is change that we ourselves initiate. We plan for it, look forward to it, dream about it. It's thoughtful and deliberate. It's the side of change that's positive and hopeful. It's the kind of change I think that my co-worker who is about to be a new dad is looking forward to. And boy, is his life going to change. Things will never really be the same after having a child; you're a parent for the rest of your life– I guess this would be the heads side of the coin.

It's not that I have any resentment toward the tails side of the coin; but, there is quite a contrast between the two sides. Heads; on top, above. Tails? Well –you know where....

That damn tails side of the coin. It's different, a different beast. It's the stuff that hits you when you're looking the other way. You run from it, try to hide from it. It's your worst fears coming true. It's not welcome. It's not wanted. My other co-worker didn't ask to get slammed into the wall by a sudden near-fatal illness, she did not ask for her life to be turned upside down this way. While I know she is healing, it's still incredibly sad and painful. There's a lot of scary stuff ahead, and like the new dad, her life will never be the same. We just keep hoping and praying for the heads side of the coin to turn up.

And somewhere betwixt the two extreme sides of the coin, lie Jean and Ellen, two women about to move to their own home from an institution. From our perspective, of course, the changes about to happen for them are "heads" in life. Living in their own home has got to be 10 trillion times better than the institution where they currently reside. They'll be free, they'll make choices, they'll be happy. But we can't forget the other side of the coin for them. Those two women are about to have their lives turned upside down. They aren't lying in their beds at night dreaming about life in Madison. They will be leaving what they know, their security. They are in for a huge change.

All of the careful planning and thoughtfulness will, in part, be lost on them. We need to remember they will be scared and confused at times. Like my co-workers, their lives will never be the same. It's our job to help them transform, to embrace the change. A metamorphosis, of sorts.

Post script:

Another change, this one definitely the tails side of the coin. Funding shortfalls for our county have called off Jean and Ellen's moves, just one week short of it happening. We are grieving their loss. We are grieving our loss.

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