

***Service, Support and Success***  
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***Faith, Freedom and Fealty:***  
***Supporting People with Disabilities to Live Freely***

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Fealty!?! You may be asking why we'd use a word that's fallen out of popular speech in a newsletter that believes in the principles of 'plain language.' Well, the reason we're doing that is simply because it's the best word and the only one we know that works here. (And, of course, it looks nice because it starts with the same letter as the others in the title.) The synonyms for Fealty are: loyalty, faithfulness, allegiance, deference, homage, piety, commitment, constancy, sanctity, devotedness ... which makes it a lovely word to use in this context. This article is about showing fealty to people with disabilities who receive service by respecting their faith and their freedoms even when they differ from or even challenge our own.

All of us carry into our workplace our histories, our cultures, our faiths, our tastes and our preferences. Those things often are what make us good at what we do – being able to plumb the depths of our 'selves' makes it easier to understand the depths of other people, of other 'selves.' The best thing about being in 'human services' is that we are paid, in essence, to be human. Few professions offer the opportunity to constantly demonstrate character and the finer qualities of what it is to be humane.

The danger though is that, in serving, we can be tempted to lead, not follow. We can do damage with good intentions; we can hurt and justify hurt by believing that we know better how someone should live their life. Some situations that staff have found themselves in:

A group of staff refused to allow a Christmas tree in an apartment stating that it was against their faith even though those living there wanted one.

A young man had planned for months to go to the gay pride parade and, on the day of the parade, the staff refused to take him, telling him that he was sinful and that those in the parade were going to go to hell.

An older woman was forced to eat during a month of fasting by staff who said that the nutritionist's diet for the home didn't allow such a practice.

A woman with a disability, pregnant after being raped by one of her care providers, was refused support when she decided to have an abortion. Her staff called her a murderer and left her completely re-traumatized.

These are blatant violations of the support worker's role of ... supporting. What's worrisome, however, are the smaller violations, the interpersonal and often non-verbal coercive techniques used to reward compliance with staff's wishes, with staff's beliefs, with staff's points of view. Learning to be who you are, while allowing someone else to be who they are is perhaps one of the most important skills that a direct support professional can learn. It is a skill that leads to dignity in service provision and a life of freedom to adulthood for those with disabilities.

We have seven things for you to think about as you consider the complex interplay between faith, freedom and fealty.

- 1) ***It's Not About YOU.*** Setting boundaries is probably the most important, yet the most difficult thing that a support worker does. This is a job unlike any other job. Support workers are asked to be with and support people as they live their lives. Ordinary lives lived in ordinary ways requires extraordinary diligence. The job, while being very hard work, often doesn't feel like a traditional job. When you work in someone's home, when you work with rhythms that mirror your own life – breakfast, lunch, supper, watching television or going to a movie – it's easy to fall into the temptation to make the rhythm match the one you are most comfortable with, yours. Soon, you'll find yourself wanting the dishes done the way you do them at home, you'll want the laundry done on the day you do laundry, you'll want the person to experience the 'joys' and the 'routines' of your life. BUT IT'S NOT YOUR HOME, IT'S NOT YOUR LIFE AND YOU DON'T BEAT THE DRUM THAT SETS THE RHYTHM. The people you support don't want lectures on why the way they want things done isn't as good as the way you want to do them. The people you support have the audacity to want to set the pace and determine the direction. They want to choose the movie – saying, “Really, you want to see ***that***? Did you know that ***this*** is playing?” is coercion. Subtle, but it's coercion. Understanding that you are stepping into their life, not dragging them into yours is the start of ethical service provision.

2) ***It Is About YOU.*** The most important part of who you are as a person isn't really about when you do dishes or whether or not you think sauerkraut is German for "we can make you talk." The most important part of you and probably the reason that you were hired is the values you carry. Compassion. Generosity of spirit. Caring. Warmth. Gentleness. Patience. These are the traits that make great support workers. They are the things that, when given full reign, make decision making easy. Holding on to these things, however, can be difficult. Very, very, difficult. You see there is this other word, a word that can erase all the others. A word that isn't talked about quite enough especially considering the damage it does to hearts, minds and souls. The word? POWER. It is said that power corrupts and it does. The care providing role is an odd one; we are there to be of service which implies a hierarchy that doesn't exist, in fact, in service, we have power over those who need our care. Over time, we can develop the most corrosive attitude of all – that we know better how they should live their lives than they do. Power is in every interaction, in every decision, in every moment of every relationship between a support worker and a person with a disability. The only way to manage power is to hold onto YOU. The YOU at your best, the you that has ... let's review the list again ... compassion, generosity of spirit, caring, warmth, gentleness, patience. The ability to let go the reins of control is probably the most important ability when providing support to those with disabilities. (By the way, did you know that sauerkraut, according to Wikipedia is finely shredded cabbage that has been fermented by various lactic acid bacteria, including *Leuconostoc*, *Lactobacillus*, and *Pediococcus*?)

3) ***The Powerful Role of Faith:*** Ok, we've talked about choosing movies and cooking sauerkraut, it's time to get down to conflicts that go a little deeper. How we do things and what we like are difficult enough to deal with when power enters into a dynamic, but what we BELIEVE and WHAT WE HOLD TO BE TRUE and OUR FAITH ... are all things that can be a little more difficult to manage. You see, our compassion for the person can hold back our desire to insert ourselves into the decisions they make about day-to-day issues, movies, television, clothing choices, but it's also our compassion for the person we support that can be a motivator to direct their moral choices, their expressions of their own faith, their sexuality and choices in relationships. We want for them what we have for ourselves – a faith and a way of living that satisfies our intellectual or spiritual needs. From Atheism to Theism and back, staff have a diversity of beliefs. Every one of those belief systems leads to temptations to share and proselytize. A staff who is an atheist can be tempted to begin to debate someone's belief in God, dissuading them from attending church or synagogue or mosque. Christian staff may see a duty to condemn, through a 'sharing of opinion,' a woman's sexual relationship outside of marriage. More and more now, the issue of 'spiritual abuse' is being discussed in the context of the care provider relationship. The use of force or coercion in the area of

spirituality is simply another form of emotional abuse. Force and coercion are never to be part of the toolkit of care provision. Disallowing someone from participating in their personal faith or enforcing a moral code or structure that runs counter to a person's choice – is a misuse of care-providing ethics. Faith, whatever it is, that gives staff a world view of kindness and generosity and tolerance, however, is to be encouraged. We live our faith; we demonstrate our love of God, of humanity, of freedom, of kindness every day. Faith is the antithesis of abuse or it should be. A support worker's job is to support and, in understanding the power of humility which is woven through almost every faith doctrine we can learn to 'be' what we believe and 'demonstrate' the gifts of our faith.

- 4) ***Supporting At, Not Going To:*** One of the most important skills a support worker can bring to the job is an understanding of the difference ethically between “supporting the person” in their activities, choices and decisions, and “supporting” their activities, choices and decisions. This distinction is easy to stumble over. The first is what our job is about and the second is not. As long as the person is not asking for support to commit an illegal act, our role is to uphold the person's right to make their own decisions and have the physical support they need to participate in the life they choose to live. This means that we may support the person AT places we would not personally “go to.” If you have already sorted out what your role is, this will not be an issue because, you're right, IT'S NOT ABOUT YOU. Supporting someone at the casino does not mean that you enjoy playing the slots or agree with gambling, although you may, it just means that's where your job happens to be that night. Supporting someone in the Gay Pride Parade is simply just supporting someone in the Gay Pride Parade – ‘supporting at’ is not the same as ‘going to.’
  
- 5) ***Balancing Rights and Making Decisions:*** A story will best illustrate this point. Four men lived together, receiving support from a team of staff. All four men in the house were of the Christian faith, few of the staff were. One of the men received the gift of an ornate crucifix for his birthday from his family. All those who lived there thought it was beautiful and it was decided by them independent of the staff that it would hang in the dining room. Some of the staff complained to the supervisor, who was of a differing faith, about the cross and asked that it be taken down. The supervisor spoke to the staff about the fact that this was the men's home and their decision to place the cross in the dining room was to stand without challenge. The staff took some time, but came around to realizing this was not their decision to make. When one of the men moved out and another moved in, the new fellow was not Christian. A new dynamic came into play; the dining room was a public area of the house and shared by all of them. The men discussed it and decided that the crucifix would be moved to the bedroom of the man who owned it. Interestingly, there was no friction between the men in making these decisions. Everyone wanted the new roommate to be comfortable and welcome. Sometimes staff need to

realize that their job isn't to dictate decisions, but to allow them to happen. The staff really had no role here – even though they tried to create one for themselves. Their role would have only come into play if support was needed ... if there had been conflict between the new person and the others over the cross, support would have been necessary. Sometimes the best support given is none.

- 6) ***Finding Options:*** Even with clarity on roles, nobody said it would always be easy to work in a role that supports people in living their own lives. There may be times when you feel strongly that to provide support in a situation would compromise you morally or spiritually. These situations should not be frequent because the nature of the job of supporting a variety of people means that there will be a range of personalities, lifestyles and activities. IT'S NOT ABOUT YOU. When you recognize that you have a problem by the gnawing in your gut about a certain upcoming situation, it is important to recognize that, in this case, IT'S ABOUT YOU. That is, YOU need to own the problem and take steps to resolve it without compromising the support the person has a right to receive. Creativity is the name of the game. Teamwork really comes into play here in facilitating the life of the person supported. Is there someone on the team who would gladly take on the role of support in the situation you find particularly difficult? Taking a vacation day is another possible solution and an ideal time to give relief staff a chance at working those hours. The nature of teamwork is mutual support. But a caution here—this is about extreme and infrequent situations. If you need an out from regular activities, it may result in a strain and uneven pressure on the team and maybe there's a bigger problem you need to look at and talk to somebody about. Whatever solutions you arrive at, it is really important not to convey to the person that their choices or their lifestyle are the problem, or to convey tacit disapproval.
  
- 7) ***It's In The Disagreements*** ... where you find yourself and discover the depth of both your humanity and your faith. Realizing that you are strong enough to remain who you are while supporting someone doing something or going somewhere that you wouldn't go, out of taste or out of belief, is a powerful thing to discover. Knowing that you are still you while they are being resolutely themselves gives you a freedom to provide excellent support. The relationship you have with someone with a disability doesn't need to be one of 'domination' in order to protect your faith – because your faith doesn't need protection! Your faith is simply, and utterly, yours. It's in the disagreements where your mettle is tested – will you resort to power or coercion or will you support wholeheartedly someone whose freedom truly matters to you.

**Conclusion:** Really, it's because all of this is about learning where *YOU* end and *ANOTHER PERSON* begins that it is such challenge. Understanding that line in any relationship is not easy. But it is where the real essence of support is tried and tested. The fact that it is difficult means

that you are getting close to answering questions in an ethical way. Yes, it is much easier to be sure that what's right and wrong for you should be the way it is for everyone, but that's just not the way the world works. If your job of supporting people seems easy, it probably means that you are missing something really important.

At the end of the day, getting this one big thing right—embracing faith, fealty and freedom—matters more than almost anything else we do in support of people, because being freed personally from limiting the freedom of others, means that, for them at last, choice can be fully embraced.

*Service, Support and Success thanks Belinda Burston and Christian Horizons for contributing to the newsletter. We remain open to receiving submissions for consideration for publication. You may contact either of the newsletter editors:*

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