

## Invitation to Dissent: Being Person-Centered in a Pandemic-Closing the Integrity Gap

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As we enter the second quarter of 2020 we find ourselves in extended quarantine because of the coronavirus 2019 or COVID-19. At the moment, there is no end in sight.

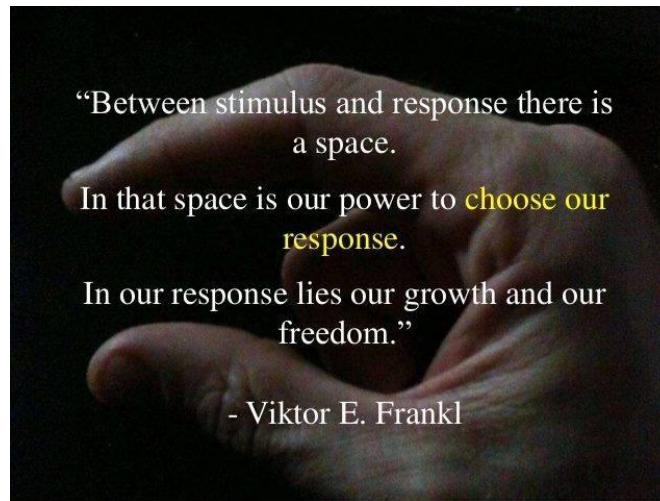
This virus does not discriminate. Everyone is vulnerable to the risk of illness and even death. As a result, we all must take precautions like practicing social distancing, frequent hand-washing and limiting forays into the community outside of our front doors. Around the globe, the freedom to come and go at will has been restricted and in some cases, revoked.

What does this mean for people living with intellectual and/or developmental disabilities who rely on residential service options? How does decision-making under pressure impact the supports- and the messages - they are receiving about their rights and responsibilities?

Research shows that, in the face of crisis, people tend to default to narrow or myopic thinking or revert to unconscious confirmation bias and groupthink. When this happens, bias becomes amplified despite prior training or other experiences that suggest we should 'know better.' An example of this can be seen in human service organizations that claim to be "person-centered" and value self-determination but in times of crises, revert to claiming full control over and in the lives of the people who are in their care. The result is an integrity gap; a phenomenon in which a response to a given situation goes in the opposite direction of espoused values. We say one thing but our behavior tells a different story.

In the midst of a crisis, it is easy to forget the promises that were made to be person-centered in the delivery of services to individuals with cognitive, intellectual and/or developmental disabilities. It is easy to forget that they are not abstract chess pieces, but human beings. It is easy, in the name of care, health and safety, to strip them of their right to make informed decisions about how they would prefer to respond to the conditions of quarantine and COVID-19.

Viktor Frankl, renowned neurologist, psychiatrist and Holocaust survivor is credited with the following quote:



Stephen Covey tells us in his book *The 8<sup>th</sup> Habit* (2004), that we are given certain “birth-gifts” – talents, capacities, privileges, intelligences and opportunities – that are unused and unopened except through our own decision and effort to take advantage of them. The first birth-gift, according to Covey, is Freedom and Power to Choose. The freedom and the power to choose how we will respond to any circumstance – in this case, COVID-19 and how we handle our relationship with people who rely on our support.

What does this really mean when we have no control over the coronavirus or the ordinances and laws being passed through to us from federal and state governments? It means we have to decide not *if* we will respond but *how* we will respond. We do not have freedom *from* dealing with COVID-19 but we have freedom *to* take a stand to maintain integrity to the promises we make in the name of being person-centered and reclaim the soul of our work.

Here are five steps that we can take to help close the integrity gap:

- 1) Engage in Self-Reflection – value statements, our own and those of the organization should be used to assess the strength of the link between words and actions. Are we enacting the principle of “nothing about me without me” in our relationships with the people we support or are we exercising command and control over their lives?
- 2) Tell the Truth – being truthful means owning up to the gap when it happens and taking steps to resolve it. Are we providing opportunities for the people in our charge to learn, understand and grow in their own decision-making authority to determine what good support is necessary to them in this time of crisis?
- 3) Be Accountable – look for concrete evidence (real examples) of how we are “walking the talk.” Have the people who count on us for support been invited to co-create with us their individualized support plan, including what happens if we or they get sick? How are they orchestrating daily routines and identifying ways to most enjoyably spend their days while under quarantine? Have staff created unnecessary rigidity around the person’s movements beyond imposed restrictions and mandates?
- 4) Resolve to be of Service – resolve to be of genuine service by honoring the person inside the consumer. Recognize, reflect and respond in ways that honor their dignity and humanity. How

are new and/or temporary support staff introduced to the person and their life? Are they “plugged” into a schedule and show up as a stranger in someone’s home/life? How are they introduced to the person? Is the individual given the authority to train new staff? Who makes the rules in the living environment?

- 5) Be Transparent – share the experience – we are all going through this crisis. Are we creating opportunities for communication to be a shoulder-to-shoulder exchange rather than a top-down command?

The word crisis comes from the Greek “to separate, to shift,” to keep only what is worthwhile. There is opportunity in every crisis. COVID-19 is offering an opportunity to deepen our resolve to honor our commitments to the people who rely on our support to truly be in this together.

Self-advocates in Vermont have put together a terrific resource called Tips for Working with Support Staff during COVID-19. It is worth sharing. [www.gmsavt.org](http://www.gmsavt.org)