Taking Risks: Creating Powerful Dispositions for Professionals Working With People Who Have Developmental Disabilities and Their Families

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One of the buzz phrases in academia the last few years has been *professional dispositions*, the ways people act or think about their actions in their professional lives. Dispositions are wrapped up in values, both personal and professional, and in ethics: What, for example, are the norms for appropriate behavior and thought on the part of human service professionals? How to create powerful, positive dispositions in professionals working with people with developmental disabilities and their families, dispositions that lead to social justice and inclusion (not just physical integration), has been something I have had my eye on for a while.

Here I share. Let me tell you a couple of stories about that. I have been supporting people with disabilities, in various ways, for many years now, ever since the early 1980s, now that I think about it. I have worked in schools, a psychiatric institution, community agencies, and state bureaucracies. Over those 20-odd years, I have had a diversity of job titles: recreational therapist, case manager, project director, support person, researcher, instructional assistant, service coordinator, special educator, assistant teacher, independent support broker, consultant, inclusion specialist, and executive director. Sometimes those job titles (labels, really) described completely what I did; sometimes they did not don't really describe at all what I accomplished in my work.

These days, I work at a small university in the Midwest, teaching both graduate and undergraduate students, teaching them what it means to be special educators. I focus especially on special educators who work with families and people with developmental disabilities. I help them get student-teaching placements, educate them about the skills they will need in their jobs, advise them about how to wind their way through the various bureaucratic processes they need to work through in order to become certified special educators, and get them thinking about schools and what they do. I serve on some university committees and the board of a local organization advocating for families and people with disabilities. I write a little; in fact, maybe that is what I do best in my life. I do not write enough to keep me happy, but I try to squeeze it in where I can. All of this is the mundane work of a teacher educator. When people ask, I describe myself as a family member of someone with a disability; my daughter has been on an IEP for a couple of years now. I also describe myself as someone with a disability, one I keep mostly hidden from those around me. In terms of academic disciplines, if push comes to shove, I guess I would say that I am really more aligned with the emerging field of disability studies than I am with special education; but that's a story for a different day.

More than teaching my students the hard facts our state says they need to know in order to be educators, I try to infuse my teaching with experiences, both in and out of the classroom, that will get them to think about what disabilities are, what schools do in the lives of children, the roles people with disabilities fill, and how to work towards social justice and equality in educational and social communities. I offer them a charge, one I give every semester. Rather than "only" learning methods to teach individual skills to students with specific disabilities, I ask them to learn what they require in order to become what families and people with disabilities tell me schools and communities need more than anything else: community organizers, leaders, and change agents. Those, it seems to me,
are essential roles for professionals who want to work with people with developmental disabilities.

How do I do it in my own work? About 5 years ago, I decided to live my professional life (one could do worse in one's personal life too, I suppose) by three simple rules: (a) Show up. (b) Shut up. (c) Listen. I have posted those rules for myself in the several offices I have worked out of over those few years, and I tried to look at them daily to think about how they might apply in whatever I am trying to accomplish. I have pretty much decided that whatever good I might do by flapping my lips, I am almost always better served by listening to what people with developmental disabilities and their families have to say about what works, what is right, what should happen—and then doing it.

Some things I do might look silly, I suppose. When I worked as a bureaucrat (what one of my self-advocate friends calls “bureaucraps”) for a while, I looked around and found myself surrounded by suits: you know, people who come to work in a tie, power dress, and shiny shoes. I thought that if I were showing up to try to get supports and services, who would I want to talk to? Some wonk in a three-piece? So, I changed my wardrobe: never a tie, no button up shirts, and sandals with really weird socks. Also, I decided that if I needed to do the administrator thing (somebody has to do it, I guess, to keep the money coming, and better me listening to people than somebody who does not), then I wanted to be the kind of administrator I would like to work for: somebody who has my back, not the back of the system. My job, I decided, was to protect the people who worked for me (people with developmental disabilities and family members, for the most part), so that they could go out and do real work in the field, work that often made people upset. I decided to keep them safe and on the ground, running. I saw myself as working for them rather than they for me. The other day, a colleague sent me an e-mail. She asked me how I was, then wondered if I was “ready to talk about creating good mischief.” I knew what she meant. She was not talking about pranks or disrupting the status quo just for the sake of disruption. She was talking about developing a considered, thoughtful, pragmatic plan of action that would lead to real social and institutional change. I see that work, sometimes, as a kind of chess game: if I do this, then these actions will result, which will lead to these other actions. Is the initial action the right one to take in order to accomplish the end goal?

What are the unintended consequences, three moves out?

In working on those goals, I usually need to check in with family members and people with disabilities to find out how those actions might effect their lives. I do not always get it right. I do not always hear them right, I do not always analyze the situation right or see far enough ahead. I try to avoid the pitfalls inherent in what van der Klift and Kunc (2002) outlined as the politics of help, but sometimes I get it wrong. Sometimes, though Schwartz and Friedman (1992) warned, “Don’t get a big head about it” (p. 226), my ego gets in the way. Sometimes there is too much work to do, and I am tired and have to clean the house. Sometimes . . .

Over the years, friends, collaborators, colleagues, and partners with developmental disabilities have told me about their lives. They made it clear that because of the persecution, abuse, and stigma they face every day, their very existence—being alive, being on the planet, being in this culture—involves huge risks for them: emotional, physical, and psychological. For me, wanting to be in alignment with them, working for them, means putting myself at risk, too. I will never be able to live their lives, to truly understand their experience; but if I expect to work towards achieving goals of justice and equity alongside them, then I need to take risks as well, risks they take for granted just getting out of bed in the morning.

One way that I understand that risk, one way that I frame it for myself, is by believing, knowing, and feeling, ultimately, that if I am doing my job right (whatever that job is, today, tomorrow, or the next day), then there is a good chance that I am going to get fired when I show up for work. If I have the feeling in my gut when I get to work in the morning that I might get canned, then I know I am on the right track.

A state director of Medicaid services for people with developmental disabilities, someone I would describe as a colleague and mentor even when we were not always on the same side of things, once described me as an instigator. That is a label I can wear with pride. I tell my students at the end of class, mostly to their consternation: “OK, now, go get fired!” That’s the kind of professional disposition I would like them to live by. That is who I want them to be when they show up for work on their first day of school, all wound up and every-
where to go. (Hey, but listen: Do not tell my dean about this until after I get tenure, OK?).

References

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