

Mired in the Mud: What's Holding Us Back?

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Today I had the pleasure of listening to Lynne Seagle speak to a group of young leaders in North Carolina. Lynne runs Hope House Foundation in Norfolk, Virginia, one of the most progressive agencies in the country serving people with intellectual and developmental disabilities. Today Hope House supports 120 people to live in their own homes, have jobs and live rich, connected lives of meaning and impact. In the 1970s and early 80s Hope House Foundation looked pretty much like most agencies that provided residential services back then. They had a solid reputation for providing quality group home services. They could have taken pride in the decent work they were doing, rested on their laurels, but fortunately, they did not.

Starting in 1984 the Hope House staff began to question whether living in group homes and going to day programs was really what the people they supported wanted. They asked people a couple of simple questions, “How do you want to live? How would you like your life to be different?” These are the kinds of questions an agency shouldn’t ask unless they are ready to hear the answers and do the work needed to help people get the lives they want. What the Hope House staff learned must have been pretty demoralizing. Across the board, people said they wanted to live differently. People said they wanted to have their own place, live alone or with someone who was special to them, get jobs, make money, have a pet, be in charge of their own lives, do things for fun that they chose, have a girl- or boyfriend or partner, get married in other words, they wanted the same kinds of lives all of us want.

I don’t think most of us would be surprised by responses like these today. I imagine however, these answers must have hit the Hope House staff hard, especially because they worked for an agency that had (and has) a great reputation and in which staff put their hearts into providing quality supports. It’s hard to come to grips with the fact that while your aims were pure, while you had every intention of doing right by people, you were in fact limiting and underestimating and restricting the very people you were trying to support.

It was equally tough for Hope House staff to realize that the questions they had asked *before* of the people they supported may not have elicited the truth. *Before*, when those same people had dutifully said, ‘yes’ when asked if they were happy where they were living, it turned out they were just being polite, or maybe scared to speak their truth, or simply saying what they figured staff wanted to hear. Perhaps those times, staff had asked the right questions but in the wrong ways.

Some organizations back in the 1980s (and maybe even some today) might have filed away those ‘what-do-people-want’ survey results in the back of a file drawer, behind the task analyses for ironing and making a can of soup. They might have wished they’d never asked and given those uncomfortable responses no further thought. But those organizations weren’t run by Lynne Seagle. Once Lynne and her staff knew that what they were providing wasn’t what the people they supported *wanted*, continuing to provide services in the same ways would have been unconscionable. Or as Lynne says, “hypocrisy can only go so far.” It’s hard to imagine a manufacturer continuing to invest in and produce a product that almost no one wanted – what would be the point? ... but in our field, business-as-usual appears to have a powerful grip.

Hope House Foundation began closing their group homes and helping people to live lives of their own design in 1984, shortly after they came face-to-face with the knowledge that what they were offering, wasn’t what people wanted. The task wasn’t easy; they didn’t close their last group home, the thirteenth one, until nine years later in 1993. Lynne said in her presentation that if she’d known twenty-two years ago that she’d still be telling the story of why and how they closed their group homes all these many years later, she would have taken better notes.

Lynne travels all over the country speaking to audiences of people who work for agencies that likely don’t look too much different than Hope House did in the 1980s. Most of these agencies still run group homes and day programs and, unless the people they support are very different from the people Hope House supported (and still supports), they likely still are offering a service model that, if given the opportunity to *choose*, people wouldn’t.

Listening to Lynne today got me thinking about what *I* was doing in 1984 when Hope House began closing their group homes. It was in that year that I saw my first home computer. The guy who owned it proudly showed me one of the early Macintosh computers and said, “Someday, everyone will have a computer at home.” It seemed to me a ludicrous idea. What in the world, I thought, would I do with a computer in my home? About the time Hope House closed their last group home in 1993, I started hearing about the internet. People said that one day we would all have email addresses and communicate instantly through the air. This didn’t seem likely or frankly, even necessary to me. What’s the big hurry? What’s wrong with a phone call? Luckily for the people supported by Hope House Foundation, Lynne was far more visionary; she could see no path but to change.

All these years after Hope House Foundation closed its last group home, Lynne is still in great demand as a speaker. Audience members still want to hear her recount how Hope House closed their group homes all those years ago. And people don’t come to hear about the *history* of the field; the lessons Lynne shares are absolutely relevant to her audiences today. I’m pretty sure I couldn’t go on the road touting the value of having a home computer or trying to interest audience members in the efficiencies that email could offer. That ship has sailed. What keeps the shift to individualized supports so solidly mired in the mud at the water’s edge? Why has progress for people with disabilities crept so slowly when other kinds of progress have marched along as we would expect?

What if we identified another minority group – say for example, all the people of a certain nationality, and declared that for them, time would stand still. We would arbitrarily assign people of this nationality access to only the technology and healthcare options that had been available in the mid-eighties and force them to stay stuck while everyone else got to keep pace with progress. It's hard to imagine any group tolerating that kind of imposed stagnation. Moreover, it's hard to imagine family members or people whose job it was to support members of this minority group, standing by and accepting the very limited options that people of this nationality were offered. It is worse yet to imagine people who had been hired to be the champions of members of this minority, not only accepting the imposed limitations but making efforts to explain and defend them.

I wonder if there is any other profession that is as stuck. Is there for example, a heart surgeon who says, "Sure I know there are all these new technologies and surgical methods, but I'm sorry, I just like to do surgery the way I learned to do it when I went to medical school in the 70s. Well sure I lose more patients, but it's just the way I'm more comfortable." It sounds ludicrous but this is us. We might think this example is different, that our desire to do things the way we've been doing them all along isn't life threatening, but maybe it is.

After listening to Lynne today, I asked her how many people she thinks she speaks to in the course of a year as she travels the country doing presentations. She estimated she speaks to upward of a thousand people a year and she's been doing this kind of training for over twenty years. That's a whole lot of people who have heard Lynne speak (and if this doesn't include you, you should seek out an opportunity to hear one of the most compelling and thought-provoking speakers out there).

I asked Lynne whether she often has people contact her after one of her presentations. It seemed to me that if I was still running services, I would be giddy with excitement and want to call her the next day to say, "I can't keep doing what we have been doing. *Our* organization is going to do what you did" and ask her to mentor me through the process. "No," she sighed, "It's not like that. People like the idea. They get excited about it. They know it's what's right and they understand it's what *should* happen within their organizations, but I can think of only one or two people who made the decision to close their group homes and day programs and then really went ahead and did it. It's not an easy process, but it can be done." Lynne stopped and thought for a few seconds and then said, "The hardest part? The place I think people are stuck? It's just deciding."

What holds us back? What keeps us from *deciding* to make the changes we know are needed? It's not that we lack models and mentors. It's not that individualized supports are more expensive (unless we are holding on to the mistaken belief that most people need 24/7 support). It's important to note that Hope House made this shift in Virginia – a state ranked among the very lowest in expenditures for services for people with disabilities.

Individualized supports are not more dangerous nor are they beyond what people's families would tolerate. In fact, families, especially families of younger people who have benefitted from inclusive education, want and are demanding full, meaningful, engaged lives for their loved ones. We long ago learned that isolation and segregation are the biggest predictors of abuse. We know that people with disabilities who are supported individually achieve better outcomes, are more socially connected and that people want to be in charge of their lives.

It's hard to fathom then why the vast majority of people with intellectual and developmental disabilities who receive residential and day supports in this country still live in settings that are fairly indistinguishable from the group homes Hope House Foundation ran in the 1980s or the one in which I started my career in the mid-seventies as a direct support worker. Far too many people still spend their days being controlled in ways none of us would tolerate and do meaningless things in day programs, watch the clock until they can leave, then return the next day for more mind-numbing inactivity.

Certainly, the shift to individualized supports presents administrative challenges, but that can't be the whole answer to explain why we are so stuck. We're not in this field because we're afraid of hard work or a challenge. It is certainly true that states need to work on making quality, individualized supports a more easily achievable option but, in addition to Hope House, there are at least another seventy-five agencies across the country that offer only individualized supports. It can be done.

In our work through the National Leadership Consortium's Leadership Institute we have graduates who represent the leadership of hundreds of disability agencies worldwide. Everyone is motivated to change but sometimes Leadership Institute participants say something to the effect of, 'but you never told us exactly how; you never gave us the steps to take to make this change'. The answer can be frustrating. Even if Lynne had taken better notes those 20+ years ago, or even if we could document the exact paths of all the other agencies who have made this transition, their paths would not be the path that would work for any other organization. There is no magic – there are only two keys to success – agency leaders need to decide that this is the shift they are committed to making, and then agencies need to start, put one foot in front of the other, address obstacles as they encounter them and never waiver from the goal of free, full, self-directed lives for all. There is no greater human impulse than to be in charge of one's own life. It's true for each of us and we can accept nothing less for people our agencies support.

All I can think is that to make a major shift like this in the way we support people forces us to come to grips with the fact that, with the best of intentions, with every desire to do right by the people we support, we've been underestimating them, isolating them and holding them back. That's an uncomfortable thought, but surely not so uncomfortable that it justifies our allowing people to be stranded permanently in a time gone by.

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