

WORSHIP – SERVICE AND MISSION

A Just Community: Moving from the Old Story to the New Story

By Milton Tyree

DEI – Diversity, equity, and inclusion. Who's going to argue about that? Well... of course, some people *will* argue about that, but such is unlikely for anyone reading this piece. DEI *is* quite the popular idea nowadays. Businesses, universities, faith-based organizations, and others have created DEI jobs for people to do DEI things – aspiring to level the playing field for those facing unjust discrimination.

Interestingly, sometimes businesses, universities, faith-based organizations, and others instituting DEI initiatives need to be reminded that people with disabilities must be included in their DEI efforts. This will be my focus -- addressing unjust life experiences impacting people with intellectual and developmental disabilities. Moving from *aspirational* to *real*, from the *old story* to the *new story*.

I'll begin by describing an experience on a toasty June Saturday morning in Louisville, Kentucky. Most of the people gathered for the community run, walk or roll were wearing the official event T-shirt. The back of the T-shirt listed requisite corporate sponsors. Printed on the front, "Community is better when everyone is included." The slogan on a nearby banner read, "Real jobs. Real homes. Real friends. Real lives." Both sayings, on T-shirt and banner, seem reasonable enough. Downright ordinary sounding. Nonetheless, these are radical ideas for many people having intellectual and developmental disabilities.

The community organization hosting the toasty June fundraising event provides access to good jobs for people with intellectual and developmental disabilities, jobs like those of non-disabled people, and access to nice homes that are like non-disabled people's homes. Same with friends and people's lives. In other words, not "special," simulated, approximated jobs, homes, and friends. *Real* jobs. *Real* homes. *Real* friends. *Real* lives. These are expressions of the new story. Radical stuff indeed.

Real lives must include attention to people's spiritual side of life, perhaps including participation in faith communities. So, what's the role of our church when it comes to people with intellectual and developmental disabilities having access to real jobs, homes, friends, and lives? What's the role of community service organizations? What's the role of other community members – those who aren't church members or human service workers?

If we're going to address things getting in way of people having access to real jobs, real homes, real friends, and real lives, including real participation in the everyday life of the church, then I'm thinking we need to name some of the ways people with disabilities come to be captured in the old story -- *excluded, isolated, and distanced*. Why is it that belonging, inclusion,

and personal contribution continue to be absent, merely talked about or aspirational for so many people with disabilities?

Othering. This is the mindset, sometimes held quite unconsciously, that underlies so many of our social problems. Just turn on the evening news for evidence of othering. It's why we have diversity, equity, and inclusion programs. Othering is a regrettable facet of our human condition. Othering makes exceptions. It means that certain universal human needs don't really matter for some. Othering happens for varied reasons. There's cruel othering. The early 20th century spawned the popular eugenics movement in the US, scapegoating people with intellectual disabilities as the root cause of social ills. Institutionalization and involuntary sterilization followed, its legality upheld by the Supreme Court. Nazi Germany adopted our eugenics ideology with increasingly dire and deadly impact. Some decades later we had the horrific institutional exposés of the 60s and 70s. Burton Blatt's startling pictorial essay of publicly funded state institutions, *Christmas in Purgatory*, needled our country's conscience.

Othering denying humanity. Some making exceptions for others. Creating and emphasizing an "us and them." "If it weren't for those people." Like in George Orwell's novel *Animal Farm*, where Napoleon the pig changed the rule "All animals are equal" so that it read "All animals are equal, but some animals are more equal than others."

But there's another brand of othering, one that's much more common, everyday-like. This brand of othering is *not* rooted in any sort of bad intentions. No, more often this othering is delivered in kindly ways, or at least with kind intentions. It's more implicit about defining us and them. I call this *kindly othering*. Nonetheless it's a type of othering where there remains a significant cost to be paid – still preventing people with disabilities taking their rightful place in the world -- belonging, participating, contributing.

Kindly othering is an expression of the *old story*. The old story includes the old negative stereotypes believed to be true about people with disabilities. And it's common to see people stuck in the old story -- the stuck people being people with and without disabilities.

The old story. Kindly othering. "Jeff doesn't need to work. He gets an SSI check and Medicaid. And his family takes good care of him. Besides he's 23 but has the mind of a 5-year-old. He gets to go to the day program with his friends. They keep him busy and happy. Furthermore, this is what he chooses."

Jeff's experiencing one of the remnants of the old story, rooted in the Stanford – Binet Intelligence Scale and its utterly confusing and useless assignment of mental age and IQ scores. And the cost of this is high. For everyone. Certainly Jeff. But also, his family and community.

What's all the stuff we get from work. Money of course. Perhaps retirement. Dental plans. What about purpose? Contribution? Doing something that matters? Doing things for others? Relationships? Work is important for others, but not for Jeff?

Specialness is another common expression of the old story—one that's deeply rooted in our culture. While specialness has a long history, some of its contemporary seeds were likely planted through Public Law 94-142 in 1975 – mandating a free and appropriate public education for students with disabilities. *Special education*. I cut my teeth on Public Law 94-142 as one of its early special education teachers. And especially early on, but sometimes still today, it is translated as special schools for students with disabilities, or special rooms within typical schools – setting the stage for ideas around special places for people with disabilities to live, special places to work, even special places of faith formation and practice of one's faith tradition.

Let's explore a close cousin to specialness: *readiness*. Readiness is intended to be a temporary grouping together of people with disabilities. "Let's develop a program, so they can learn how to be part of our group. We can organize some things that are like what we do but simplified. Their group will help them get ready to join us." Seems like a nice idea, but in truth it hasn't worked out as intended. For a slew of reasons about things known related to teaching, learning and role expectations, readiness programs for people with disabilities have a terrible track record for getting people ready for anything – that is, other than continuation in readiness programs.

There's no doubt that specialness and its cousin readiness come from a kind impulse to do something for people sitting on the sidelines of life. And you might be thinking, I know people with disabilities who've benefitted from special programs. I do too. The problem is that grouping people together who are already at a disadvantage for learning, developing oneself, becoming known, and contributing find themselves grouped with others striving for the same things, so that their disadvantage only intensifies, all the while creating yet another dimension of "them." "Those people." Other community members are seeing this and learning to ask: "Isn't there a place for *them* to work? Isn't there a place for *them* to live?" Making it easy to jump to the conclusion that "they" are all pretty much the same and pretty much unlike "us." Kindly othering. You see? So, yes, there have been benefits of special programs for people with disabilities but "them" is a significant cost that's often not figured into the equation. Are there ways to have the benefits we've seen people get from special programs without the downside, the high cost of "them"?

Just one more thing, before we get to the new story, one more important caution of the old story to get our collective antennae up. This caution is *not* about grouping together people with disabilities. Because, it is, of course, quite possible for someone with a disability to be right smack dab in the middle of a group of non-disabled people and very powerfully experience isolation. Just a couple of ways that this happens, again, quite unintentionally, would be: First, the person with a disability is attached to a support person, the support person being a human services person like I am, or perhaps a regular congregational member in a sort of volunteer support role. Regardless, the person with a disability is attached to this support person as though with invisible Velcro, in such a way that others will distance themselves because of the message being communicated, the inadvertent, but powerfully communicated message that this

person is very much unlike me, and I really should have some level of disability expertise before approaching. The invisible Velcro can even lead to the support person being named as one who is in possession of the person with a disability. For instance, “He’s one of Milton’s people.” Yikes! That’s not the message desired at all – but nonetheless it’s what’s being said via the invisible Velcro. Or the next caution: Sue, a 28-year-old woman with an intellectual disability finds herself in the midst of a new situation, something she’s missed out on knowing about due to a lack of typical life experiences. She doesn’t know what to do or how to be involved and this gets blamed on her disability when it’s actually because she’s 28 years old and it’s her first time to go to church.

- So, what about a new story? What would be better? Is it possible to have a different starting point?
- What if, instead of starting with something special for *them*, we began with typical, ordinary, the tried and true, things that have worked through the years for *us*?
- What if, instead of readiness, instead of having people with disabilities do simulations and approximations of the real thing, we instead provided access to the real thing?
- What if, instead of planning *for* a group of people with disabilities, we began planning *with a person* with a disability? One person at a time.
- What if Jeff had another real choice besides the day program? And, instead of testing Jeff for his IQ and “mental age,” we devoted time to know his interests, things he’s good at doing, conditions that need to be in place for him to be at his best and negotiated a mutually beneficial job for him and a local business?

A few years back, I read a story in *Presbyterians Today* about First Presbyterian Church in Greensboro, North Carolina. One of the people featured in the story was John, a First Presbyterian member in his mid-to-late-20s. The story described his involvement as a lay leader, youth mentor, serving on the outreach committee, doing mission work on a Navajo reservation in Arizona, and doing rebuilding and landscaping work for Habitat for Humanity. Sounds like one of those congregational members we all seek, people active in living out their faith as devoted church members. While more active than most in a church, there was nothing else that seems especially remarkable. So, why is John featured in this story? The remarkable part of the story, and you may have already guessed this, is that John has a disability. I wish that Down syndrome had not been something remarkable enough to be at the root of this story.

Don't get me wrong. I appreciated the story. I'm glad it was written and published. We need good examples of personal belonging and contribution to move from aspirational to real. I'm just hopeful for the day when new story happenings like this are ordinary.

Perhaps John had a typical pathway growing up in his church, rich with opportunities for belonging and personal contribution. But, what about Sue, the 28-year-old woman who found herself being distanced from others, even though she was right in the middle of everyday church functions because she'd not had typical growing up experiences, or because she and a support person found themselves hitched together with invisible Velcro. From time to time, all of us, and especially people vulnerable to low expectations in a new situation, need what a colleague, Jo Massarelli, calls "a friendly guide in a foreign culture." Just like we'd want if visiting a new country for the first time -- someone familiar with culture, quietly and respectfully, and only when needed, providing information about what's customary, what's respectful, how to fit in to the culture that's new to us. You can see how the mindset and presence of a friendly guide in a foreign culture is very different than that of the Velcro support person.

The new story is not about imposing new things on people with disabilities. Rather it's providing access by making it feasible and safe to learn new things about themselves, meet new people and have kinds of involvement in life never previously considered. Being an ally to someone exploring the new story requires being gentle with ourselves and others while moving forward, keeping our foot on the gas.

The new story is an emerging story. And it can only emerge by recognizing the markers of the old story and the kindly ways it gets perpetuated: kindly othering, specialness, and its cousin readiness.

And the new story does not get everything right. We are, after all, human. But the new story does soften the edges of the aspirational, moving toward a more just reality. *For everyone.*

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