Disability studies applied to disability ministry

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Abstract
Ministry that includes persons with developmental disabilities should grow out of an understanding of disability. The models most often used to understand disability are the medical model and the social model. Each is described briefly. We then take these models and unpack how they would lead to the development of ministry. As in human services, we too often develop ministries that are exclusively based on the medical model. However, what would a ministry that grew out of a combination of these models look like? The focus of ministry would be on both developing the individual and changing the environment. This article looks at strategies for facilitating this type of "mature" ministry.

Persons with developmental disabilities as a focus of ministry

A good starting point in the development of disability ministry would be a solid understanding of disability. Contrary to what the reader might think, this is actually not a simple question. There have been thousands of pages written devoted to defining and understanding the concept of disability. So-called "models" of disability abound. Nonetheless, many researchers in the variety of disciplines intersecting with disability studies think disability can be understood through a combination of what have become known as the medical model and the social model. Let us think about each of these briefly to help us in our understanding of what disability ministry might be.

The medical model considers disability as a characteristic of individuals. In order to address issues related to disability, one therefore focuses on individuals. The idea of the medical model comes from the way that medical services are typically provided. Yet one should not be confused by thinking this model is just about doctors or medical procedures. It is also the basis for education, rehabilitation, and physical therapy, among other good interventions in the lives of persons with impairments. For example, through special education, people with difficulty learning to read can learn to read. Through physical therapy, people who have difficulty with movement can be assisted to develop movement. These interventions are in no way wrong within themselves. The problem

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comes when they are the sole way in which to understand disability. One can attempt to improve someone's skills with all the education or rehabilitation possible and still not achieve significant enough changes to cause one to become "typical" in their performance (assuming one wants to be or act in a typical fashion). Also, one could wrongly think that disability is exclusively a characteristic of individuals that only needs to be prevented, corrected, or ameliorated. Barnes has observed, "In most developed societies, it is now widely recognized that the severe economic and social deprivations encountered by disabled people cannot be explained simply with reference to individually-based functional limitations."[1] Thus, there is a second part to understanding the definition of disability.

The second component has developed under the heading of the social model of disability. This perspective basically says that disability is discrimination by those in the social environment and the environment itself. That is, one has this characteristic called "impairment" and as a result of having this characteristic, one experiences all kinds of mostly negative social consequences. Some limitations actually may be due to the impairment—for example, physical and communication barriers. Many barriers, and probably most, however, result from how one has come to be seen by the society, i.e., attitudes and stereotypes. As Tremain states, "Disability is then a form of social disadvantage, which is imposed on top of physiological impairment."[2]

Societies develop an understanding of disability that may or may not be based upon reality. This is referred to as a social construction, i.e., society has constructed it rather than its being inherent in a physical characteristic itself.[3] Thus, disability, as understood by a culture, is constructed in a particular way. Depending on how it is constructed, an impairment elicits positive and/or negative behaviors from the environment towards the person with that characteristic. As a result, one's life experience cannot be explained solely on the basis of the functional impairments that one's bodily impairments produce. Rather, one's experience is at least partly due to the social consequences of being a person with a disability.

Once one comprehends this understanding of disability, it is easy to see how ministry efforts can no longer focus solely on individuals with disabilities through the lens of a medical model. Of course we develop training programs that assist in teaching individuals about the Bible, prayer, Christian behavior, and so forth (medical model types of approaches in that they seek to improve the individual). But we must also develop programs that address the discrimination and social consequences of disability projected by social environments (social model), including the Christian church. There are a variety of ways this might be implemented.

Wolf Wolfensberger, easily one of the leading social scientists on disability in the last half of the twentieth century, spoke about this two-pronged approach as competency enhancement and image enhancement as critical aspects of his social role valorization theory (SRV).[4] Generally speaking, this theory describes the potential benefits to devalued individuals when they are provided the opportunity to take on socially valued roles (e.g. friend, worker, leader, etc.).

1. C. Barnes, *"Cabbage Syndrome": The Social Construction of Dependency* (London, UK: The Falmer Press, 1995), 9.
2. S. Tremain, "On the Subject of Impairment," in *Disability/Postmodernity: Embodying Disability Theory*, ed. M. Corker and T. Shakespeare (New York, NY: Continuum, 2002), 41.
3. Peter L. Berger and Thomas Luckmann, *The Social Construction of Reality* (Garden City, NY: Doubleday, 1966).
4. Wolf Wolfensberger, *A Brief Introduction to Social Role Valorization: A High-Order Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services, 3rd ed.* (Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agentry, 1998).

In another article, Marc Tumeinski and I took Wolfensberger's SRV ideas and applied them to ministry.[5] Asking "What would be better?" we challenged the church on both medical and social model understandings of disability. Bryan McKinney and I felt this might be done through the development of what we called "social ramps."[6] Social ramps refer to developing personal skills while concurrently preparing, educating, and coaching the social environment so that the environment becomes more understanding, more inclusive and, hopefully, less discriminatory.

If, then, one desires to develop a ministry to a specific group, such as individuals with intellectual or developmental disabilities, how might this two-part understanding of disability guide what one would do?

The medical model and disability ministry—the focus of disability ministry is the individual

People will often question whether (i) the Bible should be taught to persons with some types of disabilities, and (ii) if so, how might it be taught? At the same time, people may not worry about teaching strategies, citing Isa 55:10–11, which states, "… so is my word that goes out from my mouth: It will not return to me empty, but will accomplish what I desire and achieve the purpose for which I sent it."

Clearly, there is an overriding spiritual element to God's word upon which one can count to accomplish God's purposes. I want to preface the following by saying a person does not need a college education for God to use him or her. God has used and continues to use people as they are. At the same time, however, people have minds that enable them to understand things about their world. Therefore, special education focuses on ways to teach people whose learning is impaired by disabilities. If one has the opportunity, one can therefore take advantage of knowledge about how people learn and apply that to teaching, or one could also, in an uninformed manner, just do whatever one wants, and rely exclusively on God to do a miracle whereby someone understands, accomplishing God's purposes, perhaps even in spite of the teacher. (If we only relied on that model, no one would get training to minister.)

One might also learn about how faith develops in individuals and put that into practice. For example, Fowler calls the first of six levels of faith, "intuitive projective faith."[7] This is the faith of 3–7 year olds. Yet, there is probably a phase even earlier than that. For those with very severe intellectual disabilities, faith and trust grow through interactions that are very direct, hands on, and inclusive.

What might ministry look like?

A friend of mine is a man who has a pattern he follows when visiting church. It might be said that this is how he receives and expresses "faith." Upon his arrival, I go up to him and tell him, "I am glad you are here" with a pat on the back. He signs "drink." I respond, "Do you want Agua or coffee with your donut?" He typically says "Agua." Later, in the midst of the Bible lesson, he will walk to

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5. Marc Tumeinski and Jeff McNair, "What Would be Better? Social Role Valorization and the Development of Ministry to Persons Affected by Disability," *Journal of the Christian Institute on Disability* 1 (2012): 11–22.
6. Jeff McNair and Bryan McKinney, "Social Ramps: The Principles of Universal Design Applied to the Social Environment," *Journal of the Christian Institute on Disability* 4 (2015): 43–68.
7. James W. Fowler, *Stages of Faith: The Psychology of Human Development and the Quest for Meaning* (New York, NY: Harper Collins Publishers, 1995).

the front where I stand to teach. He will reach up and put his hands to my head, pulling me forehead to forehead with him. He will then say, "Pizza" or "Hot dog," and I will respond, "Are you going to have a hot dog for lunch?" the key being the repetition of the food item he has mentioned. He will repeat the name of the food until I get it right and restate it. He then goes and sits down again. For him "faith" is the participation in a ritual with a group of people who are friendly and accepting to him. Expectations on my part as a facilitator of spiritual development are that he will feel loved and welcomed, that he will feel that he was listened to, that he will be able to express choices, and to ensure that the ritual he has associated with church occurs in the manner which he expects. Clearly, we all have certain rituals we expect to do when we go to church, be they who we greet or where we sit.

At times my friend will be confronted with actual "theological" content because he will occasionally hit someone. I will separate him from the group and say to him, "No hitting." But I also understand that there might be a communicative intent in his behavior, i.e., what was he trying to communicate by striking out? Hopefully, if this is the case, he is helped to learn to communicate in a more loving way with others what he is feeling or needs. People around him may be difficult for him to love, but he learns how to do that, in part through not hitting others. Christian behavior is something he learns (or has reinforced) at church that then applies across his life.

Does he have the ability to move to a higher level of faith? It is difficult to say. He does not repeat Bible stories but he will spontaneously take the position of folding his hands and lowering his head when he sees we are praying. I have attempted to teach him that we are all friends. He will point to the group, say "people," and make the sign for "friend," but his understanding of this concept is unclear.

But the lesson here is that when the Bible is taught to the group, leaders recognize that Bible knowledge is not a significant focus of faith development for everyone. For some it is, but not for others. My friend's presence contributes to the faith development of others in their potential efforts to understand his gifting and in assisting and loving him. It may take a great deal of effort to find out the gifts of a person with a severe intellectual disability, but hopefully we take the time to learn. Because he has limited language, and sometimes engages in aggressive behavior, he is also "difficult to love." His presence, therefore, also challenges us to learn to love someone who is not necessarily easy to love, which increases his faith by experiencing the acceptance of Christ when he is not perfect, as well as the faith of the group in learning love and patience with someone who will probably not get much better.

In this kind of social setting, loving one's neighbor is something that I have to do to the persons next to me. Most likely, it will not be easy for me or them. People with autism sometimes have difficulty expressing love for others, and vice versa. I may need to learn to love you, but you also need to learn to love me. In fact, these issues are true for everyone in the church.

How would ministry be evaluated?

We would determine whether our programs are working in a variety of ways. We can determine if people understand biblical concepts by the comments they make. We can know if they are memorizing verses. We can recognize how they serve one another. We can see if they show patience when someone is having a meltdown, or engages in harmless though inappropriate (by social standards) social behaviors. We can look at the degree to which devalued people appear to be included by others or in the larger group and be befriended.[8] Evaluation begins, however, with a vision for the future. It is useful to think about what the best outcomes for individuals might be for a ministry. The benchmarks that come to mind become the goals towards which one is working. Marc Tumeinski

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8. McNair and McKinney, "Social Ramps," 43–68.

and I recommend thinking about where one is now in one's ministry relative to a particular vision and then asking the simple question, "What would be better?"[9] Self-evaluation leads one to the next small step toward the envisioned goal. Once that step is accomplished, the question is asked again, unveiling the next small step, leading to the next "new normal."

The social model and disability ministry—the focus of ministry is the environment

Perhaps one of the greatest blind spots in the development of ministry with people with disabilities is the degree to which the larger social environment of the church is the focus for change. It is also by far the most difficult part to achieve. This misunderstanding is reflected in segregated, silo ministries. A silo, of course, is a place in which grain is stored on a farm, which is separate and self-contained. If disability ministry were thought to be like the children's ministry, then there would be no expectation that there will necessarily be interaction between children and the larger congregation. But a child with disabilities would hopefully be integrated with other children, a teen with the other teens, and an adult with the other adults. A desirable vision is that a ministry that includes persons with disabilities is one that impacts everyone in the church at all levels. Shannon and Shannon reflect this sentiment when they state, "Would that every church were filled with "persons affected by disability"—typical and disabled—who have no family or financial relationship to each other and yet are mutually engaged in loving ministry together on a regular basis!"[10] Thus, a major focus of this aspect of ministry is changing the environment.

What would ministry look like?

How would a truly inclusive church environment look different than the types of environments we currently see in most churches? We are back to our vision of ministry and the "What would be better?" question. If we truly loved someone, we would likely desire them to be near to us. Friends who have not been together, when reunited, will typically say to one another, "I have missed you!" Thus loving someone implies both physical proximity and social proximity. It is the desire to interact with each other. When things go well, it is sharing good times together. When things are not going as well, it is the desire to be supportive, to drop everything to make another one's priority. That is what we do for and with others, but too often people with particular characteristics have no friends, even in a congregation.

In 1 Cor 12:22–23, Paul describes the Body of Christ by writing: "on the contrary, those parts of the body that seem to be weaker are indispensable, and *the parts we think are less honorable we treat with special honor*" (emphasis added). It is not difficult to imagine how we might treat someone who is loved with special honor. We have all probably done that at one time or another. Let me provide some examples from my own experience:

- Once over the Christmas holidays, my wife and I had made many plans for things we were going to do. But my daughter and her husband, as a surprise to us, showed up at a family gathering on Christmas Eve. Our response was that everything we had planned for the holidays was now tentative until we figured out what their plans were. We treated them with special honor.
- Towards the end of his life, my father-in-law had advanced Alzheimer's disease. Sometimes, he would spit his food out on the floor if he did not like it. But because of our love for him,

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9. Tumeinski and McNair, "What Would be Better?" 11–22.
10. Kevin Shannon and Karen Shannon, "Culture and Disability: It is Not that Simple," *Journal of the Christian Institute on Disability* 4 (2015): 85–86.

just about anything he might do, we overlooked. "I am sorry you do not like this food, Father. Is there something different we can get for you?" We treated him with special honor.

- When my son was a little boy, he loved Sesame Street. I am not a big fan. When the Sesame Street live show came to town, however, we put his desires above our own and we went to see the show. One of the most fun memories of my life is my three-year-old little boy looking up at me after it was over and saying, "Thanks for the show, Dad!" We treated him with special honor.

In each of these cases, one person relinquishes his or her rights in deference to another. Maybe I did not want to change my Christmas plans or maybe I did not want to be patient with my father-in-law or maybe I did not want to see Sesame Street. Nevertheless, in each case people were treated with special honor simply in putting their desires over my own. Why? Because I loved them.

The verse starts out saying, "the parts we think are less honorable." Interestingly, Paul is writing in a way that implies that he also thinks they are less honorable by use of the word "we." In regard to disability ministry impacting the environment, maybe we do things we might not entirely like to do because of someone's presence. Maybe we are more patient with those who, because of a disability, are not entirely responsible for their behaviors/actions or because no one has taught them the unwritten rules in a congregation and they have not had enough practice to learn. Maybe we relinquish our rights in the name of facilitating something that will be a great benefit to everyone. Bryan McKinney and I recommend altering basic social skill traditions such that people are loved and accepted.[11] It is a Mark 7 kind of response when we do not exchange human traditions (i.e., our socially constructed environment) for the commands of God. We do change our traditions and show special honor in order to love our neighbor.

In *every* case, when someone comes into my sphere, someone to whom I must provide special honor, I cannot do the same things that I would typically choose to do. I have to change. By definition, if I do not change, I am not providing special honor. Suppose I told my daughter and her husband, "I hope you can work with the plans we have already made, because we aren't going to change them." Suppose I told my father-in-law, "I don't want you with me because you say and do things that are unusual." Suppose I said to my son, "You know, I don't like Sesame Street, so we are never going to a show." In every case someone, to the degree they were able to understand, would have justifiably felt unloved and disrespected.

What, then, of the people we think are less honorable? We already dishonor them by thinking them less honorable. Will we follow up that feeling by treating them less honorably, completing the circle? Or will we recognize that our feelings are wrong ("On the contrary," Paul says), and correct our negativity by treating them with special honor, an action that is for their sake but also our own. Can you see how this would be a corrective for them and us?

In *The Cost of Discipleship*, Bonhoeffer writes about how "Christ and Christians conquer by service"[12]—service in general, but particularly serving others within the church body. Earlier in the book, he describes the responsibility of the average Christian to other Christians, stating:

> To allow a baptized brother to take part in the worship of the Church, but to refuse to have anything to do with him in everyday life, is to subject him to abuse and contempt. If we do that we are guilty of the very Body of Christ. And, if we grant the baptized brother the rights to gifts of salvation, but refuse him the gifts necessary to earthly life or knowingly leave him in material need and distress, we are holding up the gifts of salvation to ridicule and behaving as liars … When a man is baptized into the Body of Christ not only is his personal status as regards salvation changed, but also the relationship of daily life.[13]

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11. McNair and McKinney, "Social Ramps," 43–68.
12. Dietrich Bonhoeffer, *The Cost of Discipleship* (New York, NY: Touchstone, 1959), 261.
13. Bonhoeffer, 256.

It is not clear whether he is referring to persons with disabilities specifically, but in order for the Body of Christ to accomplish what Bonhoeffer recommends, there needs to be in a change within that body. The church cannot remain the same and integrate persons with autism. The church cannot use the same practices for faith development for everyone, practices which were, one might argue, not the best in the first place. The simple presence of persons with various disabilities within the congregation makes demands on that same congregation. If people with disabilities are truly integrated throughout the congregation, it cannot remain the same. The facilitation of this positive change is a significant aspect of social model applications of disability ministry.

Another component of environmental change involves understanding the life experience of persons with disabilities. Wolfensberger states the following about what people learn when they engage in advocacy for devalued people:

> … advocate confesses to having been sheltered from contact with devalued people and the bad things that get done to them, and that the advocacy experience shattered this cocoon … many people start out assuming that the human service system is benign, facilitative and helpful. What they experience is often the opposite … one way advocates learn about the realities of social devaluation and wound-striking is that sometimes they come upon a scene where an arm has been raised to strike a devalued person.[14]

Interactions between people who have been valued and devalued change both parties, but particularly the valued. Their cocoon is shattered, the services assumed to assist may not, and they may be privy to actual abuse. Too often, however, our response seems to be something like those who pass by the man in the ditch in the Good Samaritan story. A modern equivalent is Gollum of the *Lord of the Rings*. In the parable, those who walk by see the man beaten and do nothing. We may not even see the people who are devalued. Instead we become like Gollum who, upon hearing about oliphaunts, frightening monsters in the *Lord of the Rings*, says, "No, no oliphaunts." Gollum continued, "Smeagol has not heard of them. He does not want to see them. He does not want them to be. Smeagol wants to go away from here and hide somewhere safer."[15] We imagine no persons who are devalued. We do not want to see them and we do not want them to be. We segregate them and hide ourselves somewhere where they are not present.

But that is not what loving one's neighbor, the greatest commandment after loving God, requires. A change needs to come to the social environment of the church. The ubiquitous presence of persons with various disabilities would cause that change and it would benefit us all. It would be a move toward loving our neighbors. An application of social model ministry strategies is at the heart of ministry to persons with disabilities, ministry that leads to diminished discrimination and isolation by the social (and faith) environment. That would be a true witness to the entire community.

How would ministry be evaluated?

We would know this has occurred simply by looking at the meetings at our churches. The US census says approximately 20% of the US population is individuals with disabilities. Do *all* of our meetings have about 20% of attendees as people with disabilities? That would express natural proportions we might expect to see.

Do we see valued persons befriending devalued persons, regardless of which of them has some form of disability? Are devalued persons invited for meals, or sat with over coffee?

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14. Wolf Wolfensberger, "Extract 17: What Advocates Have Said, 2001," in *Leadership and Change in Human Services: Selected Readings from Wolf Wolfensberger*, ed. D. Race (New York, NY: Routledge, 2013), 139.
15. J. R. R. Tolkien, *The Two Towers: Being the Second Part of the Lord of the Rings* (Boston, MA: Houghton Mifflin, 1965), 255.

Do our pastors talk about them as a group we need to include? Are we willing to do what it takes to include them? In the article cited earlier, Bryan McKinney and I ask whether we are willing to revisit basic social interactions that are so often the basis for exclusion of devalued people, and then change those traditions such that people might be included and loved.[16] We called the change the creation of "social ramps" and described how a group or congregational leadership might facilitate that change. This would be clear proof of our taking the parts that we think are less honorable and treating them with special honor.

How does this change occur? We cease the discrimination that leads us to think someone is less honorable. Instead, we change basic things about ourselves and our social interactions so that people are treated with special honor. This form of ministry will change those who are devalued, but the starting point is the change in those of us with power.[17] Through relationships, those with no power are given power. The medical model sees people as the object of ministry or work. The social model sees people as the subject of relationships. I probably do not need to change to teach you about the Bible, but I probably will need to change if I choose you as my friend as our friendship will make demands on me for my time, my service, and my love.

Conclusion

How does an understanding of disability impact the development of ministry? It broadens the focus of efforts to individuals and the environments they inhabit. It facilitates changes in the same. It focuses on helping people love their neighbors. Loving one's neighbor does not lead to segregation. It gives people the special honor we have been commanded to give. We are probably commanded to love our neighbors because we would not do it otherwise. It is often not easy, and that is true for everyone. I would not choose to treat someone with special honor as better than myself, or even as an equal. The change that can be brought by the presence of persons with disabilities when they are integrated throughout a congregation is a change toward obedience.

This process leads to what might be called maturity in ministry. A variety of criteria have been suggested for thinking through ministry maturity.[18] Facilitating increased integration, providing opportunities for the expression of gifting of those who typically are not present at church, loosening up social skill demands such that people feel more welcomed, changing the way biblical knowledge is taught and expressed, and broadening opportunities for service are all practices that will move a church toward ministry maturity. These and other criteria can assist the ministry leader to envision goals for a particular ministry leading to the development of next steps to move toward the vision.

Author biography

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16. McNair and McKinney, "Social Ramps," 43–68.
17. Jeff McNair, "The Power of Those who Seem Weaker: People with Disabilities in the Church," *Journal of the Christian Institute on Disability* 3 (2014): 93–107.
18. See the website http://whatwouldbebetter.com, which expands on the work of Tumeinski and McNair related to the development of maturity in ministry to and with persons with disabilities.