Disability When Viewed as Impaired and Unchosen Relationships

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Abstract

This article attempts to understand disability in the context of relationships. Persons with disabilities may be perceived by others as having impaired social abilities leading to impaired or unchosen relationships. We list societal responses to the perception of one's having impaired relational ability and offer a biblical pattern of relationship with broad application. Finally, human services programs are critiqued in terms of both (a) the manner in which they contribute to the perception that relationships with persons with disabilities are uniformly impaired and (b) the resulting medical model-based interventions which lead to relationships with persons with disabilities being unchosen by nondisabled members of society.

Keywords: *disability as impaired relationships, paid relaters, societal response to disability, unchosen relationships*

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Defining Customary, Impaired and Unchosen Relationships

We begin our discussion of relationships by defining the key terms we'll be using throughout. *Relationship* might be defined as "the way in which two or more people regard and behave toward each other."[1] Relationships might also be considered typical or atypical. *Typical* can be understood as "conforming to a type, having most of the characteristics of a particular taxonomic group"[2] whereas *atypical* might be "considered to be an example of some undesirable trait."[3] This notion of an undesirable trait may at best be considered uncommon or not ordinarily encountered, or at worst, unchosen. *Unchosen* obviously means not being chosen, whereas to be *chosen* is to be "selected from or preferred above others."[4] This action of preferring might be based on good or evil motivations. 'Chosen' also implies that something is thought of as desirable or undesirable, based on some set of criteria for desirability. The issues we are interested in thinking through here are why relationships might be unchosen, and whether that is because they are *actually* impaired, or merely unchosen. In our title, we use the term 'impaired relationships.' *Impaired* implies that something is "weakened, diminished or damaged," or it is "functioning poorly or inadequately."[5]

Arguably, certain types of relationships are desirable over others. In part, the typically or customarily occurring nature of some types of relationships implies they are desired, while the atypical or less frequently occurring nature of other types of relationships implies they are not desired. Being *customary* implies that which is "according to the customs or usual practices associated with a particular society."[6] Relationships with persons with disabilities may not be customary because they are portrayed or perceived as undesirable, involving uncommon characteristics thought of in a negative way. Therefore, what makes a relationship customary or not customary has to do in part with perspective and experience. Being "uncustomary" could range from having a relationship with someone from a different culture or religious group, to having unusual personal characteristics such as some form of impairment. Even within the category of persons with impairments there is a range: one

1. *Google.com*, s.v. "relationship," https://www.google.com/?gws_rd=ssl#q=relationship.
2. *Mobile-dictionary.reverso.net*, s.v. "typical," http://mobile-dictionary.reverso.net/english-definition/typical.
3. *Mobile-dictionary.reverso.net*, s.v. "atypical," http://mobile-dictionary.reverso.net/english-definition/atypical.
4. *Thefreedictionary.com*, s.v. "chosen," http://www.thefreedictionary.com/chosen.
5. *Dictionary.com*, s.v. "impaired," http://www.dictionary.com/browse/impaired?s=t.
6. *Google.com*, s.v. "customary," https://www.google.com/?gws_rd=ssl#q=customary.

individual might have intellectual disabilities, implying one form of relational difference, whereas someone else might have autism or mental illness, resulting in another form of difference.

Why Are There Impaired or Unchosen Relationships?

Why are there impaired relationships? Human beings are broken. Until we reach heaven, relationships will always have difficult aspects. "It is not good for the man to be alone," says Genesis 2:18. God created "relationship" with the first man and woman. To be Imago Dei is to be in relationship (Reinders 2008).[7] Yet, with the Fall came the immediate degeneration of relationships: Genesis 2 becomes Genesis 3, which yields Genesis 4—blame-shifting ends up in murder. God has overcome our murderous intent through the sacrificial gift of his son. Thus, we have been given a higher standard of relationship: biblical relationships are more than mutually beneficial, they are sacrificial. That is, one person in the relationship is ready and willing to give up personal benefits and even endure rejection to benefit the other. The presence of a disability can challenge the broken human heart and our ability to have healthy relationships. When confronted by such challenges, the human heart frequently comes up with selfish solutions.

Impairments can impact relationships. Some disabilities include characteristics of individuals that seem to impair customary social relationships. Relationships may be impaired because a person has a condition that makes it difficult to form customary social relationships. This is particularly the case, for example, for people who have autism and struggle with language or symbolic communication. These people have a characteristic that makes customary relationships difficult for them in their social environment. Impaired relationships may also be caused by social discrimination. These are the "unchosen relationships" described earlier. Here, members of society do not want to develop customary relationships with people who have certain characteristics called "impairments." These observations highlight the fact that both characteristics of individuals (impairments) and characteristics of environments (discrimination, lack of caring, etc.) come together to constitute the nature of disability.

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7. Reinders provides the following note about this idea:
   [Karl] Barth takes the Trinitarian relationship to be constitutive of the biblical view of human beings. Just as there is a "community of dispositions and actions in the divine essence," so there is also in humans a relationship between "I" and "Thou," a "face-to-face" pattern in human existence that mirrors the pattern of divine existence (Reinders 2008, 240 n. 31).

Environmental Responses to Perceptions about Relationships with Persons with Disabilities

When confronted with the possibility of certain types of relationships—in this case, relationships with persons with disabilities—the social environment responds in a variety of ways. Let us consider a continuum of ten responses from social environments, then look at how human services programs have set the tone for a significant understanding of what disability is, particularly as it concerns relationships. The following responses fall into three major categories: elimination (1-2), ostracism (3-7), and intervention (8-10).

1. Euthanasia

A 2016 article in the *New York Post* entitled "Europe's 'Cure' for Autism is Euthanasia" included the following statement:

> In early childhood, the Dutch psychiatric patient known as 2014-77 suffered neglect and abuse... He suffered terribly, doctors later observed, from his *inability to form relationships*... they treated 2014-77 for one more year, determined his case was, indeed, hopeless and administered a fatal dose of drugs (Lane 2016, emphasis added).

According to this report, doctors observed "suffering" due to "an inability to form relationships." Surprisingly, the doctors explicitly evaluated interpersonal relationships—but did they then work to facilitate the actual development of relationships? We agree that the inability to form relationships can lead to personal suffering. However, if people "suffer" from an inability to form relationships, on whom should the blame be placed for that experience? It is, as Reinders (2008) states, as if "most people in our moral culture do not want [people with impairments] to be part of their lives" (163). But if the combination of one person's impairment—some condition contributing to social skills deficits (which may be difficult or even impossible to change)—and others' eschewing of relationship with that person (something that is potentially changeable via addressing discriminatory attitudes) leads to that individual's being alone, ought we to place the onus for change exclusively on the person with the impairment? And, if she is unable to "change," should we then take her life? It's difficult to see how this is an appropriate response to one's suffering, particularly if that "suffering" is largely the result of others' attitudes and actions.

2. Abortion

As Weil (2006) observed, some parents choose not to be in a loving relationship with a child with a particular characteristic, specifically disability, choosing instead to avoid such relationships through prenatal diagnosis and abortion. With this in view, Barbara Katz Rothman, author of *The Tentative Pregnancy* (1993), states that "decisions to continue or terminate a pregnancy are never medical decisions. They are always social decisions" (1993, 63, cited in Roberts, Stough, and Parrish 2002). As an example of this, consider the fact that "[a]bout 90 percent of pregnant women who are given a Down syndrome diagnosis have chosen to have an abortion" (Harmon 2007), even though, as Reinders (2000) points out, if a person is "suffering" from Down syndrome, it is most often due to the way they are treated by society rather than the condition itself. Here, society's response to the suffering it imposes on individuals with Down syndrome is to "prevent" that suffering prospectively by ending their lives (through abortion).

3. Segregation into institutions

The development of institutions for persons with disabilities was initially based on the idea that they could be educated to the point that they no longer experienced disability. Over time, it became apparent that, for the most part, persons in institutions did not improve appreciably and ended up living a life of incarceration under inhumane conditions. However, for several generations before the horrors of institutions came to light, doctors would counsel parents of a newborn with severe disabilities not to hold or look at their child. It would be "better for you both," they insisted, "if she is placed in an institution." Interactions, after all, had the potential to lead to relationships, which might in turn lead a family to decide not to place their child in an institution (Scheerenberger 1987).

4. Segregation into community residences

When the living conditions in institutions came to light, many were shocked. They demanded that the institutions be closed. But as previously institutionalized persons were relocated to community settings, the meager government financial assistance they received often forced them to live in places plagued by poverty (and, in some cases, crime). Consequently, procedural and other barriers were put in place to insulate these persons from

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their surrounding communities. Presumably, those responsible for such placement decisions were motivated by a desire to protect these vulnerable individuals from the perceived dangers of the surrounding community. As a result, however, to this day persons in community residential facilities have a difficult time forming relationships with members of the broader community, in part because they are being "protected" from that community. Additionally, those vendored to provide such residential services fear litigation should they allow residents access to the community (and vice versa). McKnight illustrates the consequences of this "protection" in the following vignette:

> If one would say to the average citizen, "I want you to take five men and buy a house in a neighborhood in a little town where those five men can live for ten years. And then I want you to be sure that they are unrelated in any significant way to their neighbors, that they will have no friends, and that they will be involved in none of the associational or social life of the town." I think that almost every citizen would say that this is an impossible task. Nonetheless... systems of... community services have managed to achieve what most citizens would believe impossible—the isolation of labeled people from community life even though they are embedded in a typical house in a friendly neighborhood in an average town (McKnight n.d., 2).

This has been the situation for decades and, despite concerns voiced about these arrangements, the human services system appears to be satisfied with them. Moreover, little effort appears to have been made to alleviate fears of litigation related to allowing residents of these communities access to the broader community.

5. Paid relationships

Human services agency personnel might be enlisted to be in paid relationships with persons with disabilities. Baca and McNair (2013) described the paid agents in these relationships as "almost friends." They also found severe problems both with agency understandings of the notion of "friendship," and with what was or could be done in the pursuit or development of relationships, particularly friendships between people with disabilities and community members. We will discuss this at greater length later.

6. Relationships with other clients

One might also facilitate relationships with other persons with disabilities, particularly those under the care of state agencies. Issues related to this are discussed by McMichael-Pierce (2015). She describes how activities such as several group homes getting together for a joint activity or two sheltered workshops participating in a party together are considered "community integration." The Department of Justice (DOJ 2010), in its statement on the Integration Mandate of Title II of the ADA (Americans with Disabilities Act), states, "The preamble discussion of the 'integration regulation' explains that 'the most integrated setting' is one that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible..." In comparing integration programs with McMichael-Pierce's findings and the DOJ position, it seems evident that state agency-level and local human services providers lack understanding about what community integration actually is—namely, interaction that facilitates the development of unregulated social relationships.

7. Support families in relationship

Arguably, there is an overreliance on families to be the providers of social relationships for persons with disabilities. Society, including many within the church, appears to believe that persons with disabilities are almost exclusively the responsibility of families. Typical society members have bought into this perspective, thinking that if they pay taxes, government programs will be developed to support families in caring for their members with disabilities—and, therefore, they need not take personal responsibility to care for such persons themselves. (More on programs in the next section.) That this learned behavior is common is sad. That it exists within the church despite biblical passages referring to the church as a body (1 Corinthians 12) and to our responsibility to love our neighbor (Matthew 22:39 and Mark 12:31) demonstrates the degree to which the church reflects patterns of the world rather than scripture (Romans 12:2).

Clearly, there are many positive aspects of supporting families in their care for those family members who have impairments. This is not to disdain these relationships in any way. It is just to point out the degree to which families find themselves socially isolated and perhaps even socially abandoned. If members of the broader social environment feel no responsibility to support other community members who are facing challenges—operating

on the assumption that no external support from friends is necessary—this is highly problematic.

8. The development of programs

Related to number seven above, members of society (both within and outside the church) seem to opt for *developing programs* over *engaging in relationships*. Instead of developing friendships with persons with disabilities and their families, we develop programs to meet the needs that friendships might otherwise satisfy. We see this, for example, in respite programs. When families need a bit of a break, they will typically ask friends to watch their child and then at another time return the favor. Respite programs for families of children with disabilities are often created because these families do not have a sufficient number of relationships with friends who are willing to care for their children. If there is a "program," it apparently absolves us of responsibility to develop a relationship which might make demands on our own time and energies. Additionally, these programs can be highly segregated in terms of the children being served; in this way, respite programs may actually undermine the kinds of support that grows out of or leads to friendship. Churches should examine whether relationships are developing as a result of these programs. Are relationships allowed to remain "unchosen" because of the development of programs which do not demand their formation? If so, the program(s) in question may be problematic. To be sure, respite programs *can* become a vehicle to create interpersonal benefits from otherwise unassociated relationships. However, this is not necessarily something that develops organically. It will take specific effort on the part of program providers to encourage relationship development. Respite programs might be evaluated in part on the basis of the connections made between people, perhaps leading to a reduced need for such programs. The concern being raised here about reliance on programs is, again, that they have the potential to supplant relationships—not that "programs" *per se* are (necessarily) inappropriate or problematic.

By way of an example illustrating how programs can replace relationships, small churches will sometimes bemoan the fact that because they are small, they have only a few people with disabilities in the congregation and therefore cannot develop a disability ministry program. As a result, those few individuals with a disability are simply integrated into the regular flow of church life. However, these same churches may aspire to having a sufficient number of congregational members with disabilities so that they can have

a class or some special, separate program for those with impairments. In so doing, they may actually aspire to move from integration to segregation, from seeing people as the *subject* of relationships to the *objects* of programs.

9. Social skills development

One might also work on social skills development to address impairments that contribute to difficulty in social relationships (Snell and Brown 2010). This might be considered a "medical model" type of intervention (Silvers, Wasserman, and Mahowald 1998). In advocating this approach, the success of this "skills training" should be evaluated based on the degree to which persons with disabilities benefit by being chosen for integrated relationships as a result of the training. If this does not occur, then either the training needs to be altered or a different approach is required.

10. Cultural change

Social ramps (universal design for social environmental change) leading to inclusion has been described as an intervention by McNair and McKinney (2015). The goal of this intervention is to help social environments to do the right thing (Wolfensberger 1998). This might be considered a "social model" kind of intervention (Oliver 1990; Shakespeare 2002).

Cultural change is perhaps the most significant way in which impaired or unchosen relationships can be addressed. This implies broadening what is considered "customary" when it comes to our understanding of relationships, and seeking a change in the kinds of relationships that are chosen. From a Christian perspective, this is a matter of no longer conforming to the "pattern[s] of this world" (Romans 12:2, NIV). The "renewing of [one's] mind" which is mentioned in this verse is effected by a biblical understanding of who people with disabilities are. When embraced, this understanding leads to a cultural change in which people with disabilities are seen as created in the image of God, having a purpose, being gifted and falling under the scope of God's sovereign plan for themselves and for the larger body of Christ (McNair 2016). This perspective causes a pivotal change with respect to *which* relationships are customarily chosen, and with respect to how *all* relationships are understood: instead of seeing relationships as being impaired, they are now seen to have redemptive purpose through sacrificial behavior (even while acknowledging that all relationships are impacted by human sinfulness). This is not to deny that the limitations faced by people

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with severe disabilities can pose relational difficulties that require significant effort to overcome, nor to deny that those difficulties can result in suffering for those involved in such relationships. It is, rather, to say that people can learn to see these relationships as redemptive and even "customary." Sacrificial behavior can overcome seemingly insurmountable obstacles. The appropriate response to such relational challenges is not primarily to try to "change" the other but, first and foremost, to express unconditional love toward them. One who loves another will be willing first to change (and be changed) themselves. Often this is possible only through the power of God's spirit. The result of the working of the Holy Spirit is that people move to *choosing* and *being chosen* for relationship. The authors of this paper have experienced this change first-hand through their own efforts to be in relationship with persons with severe disabilities.

Importantly, sacrifice is required for any two people to be in relationship with one another. This is not exclusively a disabled/nondisabled or a valued/devalued dichotomy. In any bona fide relationship between two individuals, both are called to sacrificial behavior expressing love for one another. However, loving one's neighbor is hard. If one does not find it hard, then perhaps one needs to expand the sphere of those with whom they are choosing to be in relationship.

Why Are There Impaired and Unchosen Relationships? Redux

To recap: many people with disabilities have an impairment that impacts the formation of relationships, as a result of which a discriminatory society chooses not to be in relationship with them. Consequently, society must pay people to be in relationship with these individuals, because (often) no one in the society will choose to be in relationship with them otherwise. Such individuals have been referred to as "paid relaters" or "almost friends" (Baca and McNair 2013). Wolfensberger (1998) lists "artificial and boughten relationships" (19-20) as one of the "wounds" reflected in the social consequences of human devaluation. These paid relationships have largely been the principal state agency response (Baca and McNair 2013; McMichael-Pierce 2015) to the marginalization of such individuals. But these relationships are potentially problematic on a variety of levels. Minimally, they take the place of natural relaters or friends. Additionally, these interventions do not address the *lack* of friends, advocates, and acquaintances. Rather, they seem to assume that relationships are *necessarily* impaired (by virtue of bodily or mental

limitation), as opposed to being merely unchosen, with the prescribed "remedy" being professional helpers. The resulting cycle might be characterized in the following terms: because they are perceived as impaired, relationships are unchosen; thus, people are paid to be in relationship, as a result of which relationships continue to be unchosen. The result is an ongoing downward spiral toward social isolation and segregation.

We see this evidenced, for example, in the provision of supports for workers in supported employment. Entry level human services workers are largely untrained people who are given a "service provider" label and paid to support disabled workers. A classic example is the job coach. In contrast to typical coworkers, these service providers arguably undermine natural workplace relationships and support, resulting in diminished employer investment, lack of opportunity for typical training potentially leading to friendships, and prescribed/assumed professional distance which does not allow friendship development between job coaches and those they support. In the end, genuine friendship is not a possibility between workers if one of them is a paid state agency worker.

Despite this reality, could it be that the state is, in fact, actually interested in *maintaining* disability as impaired/unchosen relationships rather than revisiting the use of interventions so as to facilitate the development of genuine friendships? After all, the notion of impaired relationships seems to justify the state agency's existence. Arguably, many of the things that human services workers decry or claim to desire to change are perpetuated by the manner in which their services are provided. Because human services agencies are in the business of providing and billing for paid relaters, the question arises as to what extent "disability as impaired/unchosen relationships" is in fact a *desired* model facilitated by them. By preventing people from having unpaid relationships, they may be complicit in relationships being unchosen. When community members support friends with disabilities, the unregulated nature of such unpaid relationships can translate into financial loss for these agencies. Additionally, as stated above, satisfaction with the status quo of unchosen relationships could simply be due to a lack of understanding about what community integration actually is—i.e., a process that facilitates the formation of *chosen* relationships (McMichael-Pierce 2015).

On a recent trip to Argentina, the authors of this paper were told of a service provided to individuals with disabilities. Called "*acompanante terapeutico,*" these individuals take people with disabilities to the movies or shopping or engage in a variety of other community-based social activities. Herr (2003) similarly describes a 1992 German law providing for a "betreuer"

who assists an individual with a disability in various life activities. Nussbaum (2007) expands on Herr's account, stating that

> other social services include that of "contact person" (kontakt), paid by public funds, who provides companionship activities for persons who would otherwise be isolated or inactive; the "personal assistant," hired and fired by the person with a disability, but paid by the government, also assists the person in many transactions; and the "escort person," who accompanies the person with a disability to cultural, sporting, and other leisure time activities, again paid from by the national government, in combination with municipalities (197).

Under arrangements such as these, the services provided are distinctively social activities, things friends do together. With such persons being paid for by the state, do typical (nondisabled) citizens feel the need to befriend a person with a disability? Underlying this approach, presumably, is the assumption (on the part of the state) that either (1) persons with (certain) disabilities are unable to be or make friends, or (2) people being paid to be in relationships with certain individuals with disabilities is the state's *desired* outcome for those receiving such services. Thus, although disability as impaired or unchosen relationships may not be rooted in objective reality, it has become a kind of "created reality." It is a reality socially constructed by human services providers, stemming from their commitment to medical model-based services and interventions.

How to Address Impairment

Clearly, bodily impairments impact function. But societies can make investments so that the effects of bodily functional limitations are (at least) mitigated, if not eliminated altogether. The classic example is the ramp which makes wheelchair usage no longer a functional impairment as it relates to entering and moving about in buildings. When it comes to impairments that affect the development of social skills, society's investment in helping to render an impairment something that does not lead to functional limitation can have a profound impact on increasing a person's range of opportunity for developing relationships with others. However, even if unintentional, I might still—through my actions—effectively orchestrate a particular type of functional impairment and then design human services in a way that (1) provides greater control over the commodity of disability,

and (2) maintains the form of intervention that requires me as the provider of that intervention. The question then is: if someone makes me aware of what I am doing, am I willing to stop or change my practices? If I continue, is it due to ignorance or to my propagating a deception, a lie? In the latter case, I will refuse to encourage natural relationships or community integration, because that might reveal that the separatist functional impairment I have created is in fact not real, that people may be able to function in the community with significantly diminished paid supports being provided by the government—i.e., they don't in fact need *me* as a human service provider. For example, returning to the comments made earlier, employment programs have developed to include the use of job coaches. These entry level human service workers often have no more training than do the entry level workers on the jobs where they are providing services. If job coaches do have training, it is not extensive. But rather than attempting to facilitate employer-provided support for workers with disabilities that is comparable to the types of support normally offered to other entry level workers in that or similar positions, job coaches are funded by state agencies to provide "special" support. The results of this arrangement can be confusing at best. Immediately, disabled workers are seen as being "different" insofar as they need "professional" trainers to help them learn their job. By their very presence in the workplace, these trainers undermine the usual investment of the workplace in the worker. Because of the outside trainer, relationships which might otherwise have developed as a result of new worker training do not develop. Each of these outcomes short-circuits the possibility of relationships developing in a workplace as they would for any other employee. From the advent of "supported employment" it has also been observed that the level of support provided is too often based upon which agency is providing the support, not the specific needs of the individual being supported (McNair 1991; McNair and Rusch 1992). Agency A provides four hours of supports per week while Agency B provides six hours of supports per week, so the individual receives either four or six hours of supports each week, regardless of how many hours she actually *needs* (whether more or less than these amounts). So, the supports provided by human services agencies are not necessarily based upon the specific needs of workers, and workers with disabilities have been defined as people needing training from perceived "specialists" who are not specialists at all. They are largely entry level human services workers. If employers were encouraged to provide their own training to disabled workers who need it, the entire system would change. Arguably, it would also become much less expensive.

Human services professionals sometimes decry any attempt at reliance on unpaid, community supports. These supports might come from friends, one's church, etc. Frequently, when these supports are recognized, the state attempts to regulate them. This "touch" from the state immediately transforms these services into something they were not prior to the state's touch. The state then claims that reliance on the community does not work. However, genuine reliance on the community has probably not even been attempted.

It has been our experience that efforts by community members to engage in relationship with a person receiving human services, such as those living in a residential setting, can be frustrated by the design of those services and the manner in which they are delivered. Whatever the motive in orchestrating such services, they can represent a barrier to community involvement. For example, should someone want to develop a friendship with an adult with an intellectual disability living in a group home, minimally they must be fingerprinted. Whether someone *should* be fingerprinted is not the issue being raised here. It is simply to recognize that there are impediments to the formation of relationships.

Might such barriers be motivated by compassion, with the intent of protecting vulnerable citizens? Perhaps that was the case originally, but the consequence of these sorts of barriers is that those living in residential facilities have few community relationships and experience social isolation. Perhaps at some point someone considered their options—social isolation and safety versus social integration and potential risk—and decided safety was the better choice. But who gets to make that decision for another? And what factors inform that decision making process? Are these decisions based on the preferences of those who are directly impacted, or are they largely financial decisions? Limited resources result in restricted options. So, persons who are under supervision are told that "this is just the way it is." Residential facilities, should they even desire to facilitate more extensive community involvement, fear the litigation which comes from people having real lives. After all, the reasoning might go, if you go with members of the community in their car, there might be an accident and you could get seriously injured. If you never get into a car, you will likely never be injured in an auto accident. So, you will not be permitted to get into a community member's car. If you never go to a restaurant, you will never trip on the steps going into the building and break your ankle. Therefore, to avoid litigation you will not be permitted to go to a restaurant with anyone other than a paid staff member.

Williams (in preparation) surveyed prison inmates regarding the freedoms they miss the most as incarcerated felons. She then compared identified

restrictions with those experienced by people living in community residential facilities for persons with developmental disabilities and observed that the restrictions were much the same. Her conclusion was that to "protect" people, we regulate their lives as if they were incarcerated felons.

When these types of barriers are placed in the way of individuals who might seek to form relationships with those whom society has devalued—including portraying them as people unworthy of relationship at worst, or difficult to be in relationship with at best—significant effort is required to form such relationships. Should this effort be successfully undertaken, barriers still abound. People supported by government benefits have various rights, including rights related to living in residential facilities. However, without the opportunity to *exercise* their rights—the consequence of which might be the development of relationships with community members without disabilities—those rights are severely abrogated. By way of example, although I may have the right to religious expression, I may not be given the opportunity to go to a place where I can act on that right. The authors of this paper have been told that individuals living in a residential home could participate in community activities only if a staff member from the group home was present. If there are eight people in a residential home and two staff members, it is unlikely that everyone will be given their choice of where to go. Regardless of whether the ultimate solution is more funding for staff or greater trust of community members, the proximate result is that human services programs frustrate the formation of natural friendships with community members of faith groups (who are not receiving the same services). Whether by design or as the unexpected outcome of a particular way of delivering services, the result is that those designated as "clients" are limited to having either "paid relaters" or other service recipients as friends. Hence, as Eiesland puts it, "the locus of the problem of disability is neither the psyches [nor] the bodies of individuals with disabilities, but rather it is the system of social relations and institutions that has accomplished the marginalization of people with disabilities as a group" (1994, 62).

Can "Paid Relaters" be "Friends"?

"Paid relaters" can include everyone from physicians to teachers to social workers to job coaches and instructional assistants or other entry level human service workers. These faces in the human services crowd have at least one commonality: they need there to be something "wrong" with a person that "only they" can address—perhaps something that would prohibit the formation of social relationships. Whether what is "wrong" can be attenuated

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by means other than what they provide through their programs may, as a practical matter and to some extent, be irrelevant.

Whether their service attempts make a real difference may also be irrelevant. The services they provide may be "the only game in town"—so people can either go to them to receive services... or not. But are the services provided what is *best* for the individuals being served? The answer is arguable either way. For good or ill, services might be evaluated based on criteria set by an agency or service provider. Unfortunately, they are too frequently not evaluated based on what is best for the individual receiving the services.

"Paid relaters" are generally government workers from various agencies who appropriate relational positions which arguably ought to be filled by community members. Do human services agencies ever evaluate social environments to determine whether the "supports" they are providing might be filled by free agents in the community? Do they exert any effort to facilitate the development of community relationships? There is an expansive literature on natural supports (National Disability Authority 2011) which seems to have been either lost or ignored. It may be that, because of political or other proclivities, state agents are unwilling to find and take advantage of community supports where they are available. Faith communities, for example, offer significant potential for community integration, but are all-too-often underutilized.

What of friendships between service providers and their clients? These friendships may be real and beautiful. But arguably, they are not entirely natural because of the way they are regulated by service providers who determine what will and will not be permitted in the relationship. This is not limited to restricting untoward behaviors, but extends even to such things as providing opportunities for two people to take a walk together in the community or to go to church. We (the authors of this paper) have found ourselves in situations in which human services recipients— "clients," in the professional parlance—were not permitted to drink soda or smoke cigarettes. This regulation of lives is taken for granted by those working in human services. They regulate behavior in areas of life over which typical community members would never cede control; "clients" are subject to regulation simply because human services workers believe the person receiving services should not be able to make decisions regarding themselves. People "in the know" developed a "plan" for a person's life, and that document dictates all that can or cannot be done. So, for example, when one of the authors once asked a worker in a community residential facility if a resident could attend church with him, he responded, "It's not in his plan." Abridgement of personal freedoms limits

higher relational opportunities with others, such as corporate worship and community service.

Barriers limiting access to community members, intentional or otherwise, further impede the development of relationships through regulation. In their desire to protect, human services providers regulate all aspects of the lives of the people they serve. Because of restrictions imposed on client/professional relationships, there is virtually no possibility of genuine friendship between these individuals (Baca and McNair 2013). Thus, these professional "relationships" may preempt natural relationships, either unintentionally or perhaps because such genuine relationships are literally thought not to be possible for the individuals in question. This again contributes to an understanding of disability in terms of impaired relationships; ironically, though, development of relationships is impaired by the design of the very services ostensibly meant to "help" the recipients of those services.

From Programs to Relationships

The question, then, is to what extent existing human services regimes have developed through commoditizing disability in a particular way? And if this is the case, is disability as impaired social relationships in fact the result of the way in which human services have developed? Clearly there are characteristics of individuals which hinder customary relationship formation, and social environments are discriminatory toward people with certain characteristics—but is this understanding of disability exacerbated to facilitate the need for "human services" workers or programs? To what extent is the creation of *acompanante terapeutico*, paid relaters or "almost friends" tacit assent to the creation of disability as something that impairs social relationships? That is, rather than working to address impaired social relationships by changing both the individual and society, do we exclude people from community integration and pay workers to be in relation with them? In such arrangements, service providers benefit monetarily from the facilitation of disability as impaired social relationships. Whether this is the case or not, it is at least in part what is being offered as a justification for current human services arrangements. Therefore, human services programs will likely continue indefinitely to be based on a medical model (Silvers, Wasserman, and Mahowald 1998) because a medical model both maximizes paid professionals' knowledge of how to evaluate individuals (whether or not they know what to do with that information in terms of interventions, or actually care whether people are in natural relationships) and minimizes professionals'

lack of understanding of social environments in terms of facilitating changes in those environments such that they would lead to social relationship development (leading, in turn, to interventions which could be counterproductive to a medical model approach using paid relaters). Arguably, in theory and practice, existing medical model-based services remove the necessity for a discriminatory environment to change.

In times of fiscal constraints, menu-driven services could be attenuated; however, alternatives that would not require the services of those being paid to provide them are not explored. Human services agencies are probably not interested in cheaper services being provided by neighbors and community agents. This is evident if only in the manner in which the community is not engaged when it might be. As stated earlier in the quote from McKnight (n.d.), individuals with developmental disabilities living in group homes in the community may be totally socially isolated from the broader community in which they live. Sadly, human services providers appear to be satisfied with this arrangement. As McKnight (n.d.) goes on to say later in the same article, "community services are not tools that bring labeled people into community life. Indeed, the truth is more probably that activities called community services are the primary barriers between [labeled people] and their community" (3). McKnight continues:

> It is critical that we understand this process of incorporation because the primary problem of most people who are labeled is that they are excluded from the power and protection of community life. Paradoxically, they are excluded because they are said to be in special need while their special need is to be included in community life (10).

Unfortunately, however, for the purposes of service provision, disability is medical model-defined, such that there is no real reason for community integration. Perhaps it is thought that admitting the community into the life of someone with a disability invites the very discrimination which characterizes a social model (Oliver 1990; Shakespeare 2002) understanding of disability. Apparently, to avoid discrimination the best thing to do is to keep people away from the community and under the benevolent rule of paid human service workers.

Ultimately, what we should be after is transitioning from programs to relationships rather than transitioning from relationships to programs.

> While it is true that each of us has what might be considered deficiencies, each of us also has many capacities. Communities are those

social spaces where capacities are connected, expressed and manifested. Service systems are those social spaces where deficiencies are identified, adjusted, treated or cured... the tools of systems developed to deal with deficiency are structurally inappropriate and ineffective in communities because communities are social spaces for the expression of capacities. This is why most service systems never really become effective as agents for people entering community life. No matter how hard they try, their very nature is based upon deficiencies. Their name betrays this fact and their methods grow from that fact. Therefore, they are by their nature the inverse of community and unlikely places from which a person would enter community life (McKnight n.d., 13).

Final Comments: A Biblical Perspective

From a biblical perspective, the church is the *sine qua non* of community, the ideal context in which capacities can be expressed as the fruits of the Spirit are realized in each individual. In this way, church fellowship has the potential to overcome the stigmatizing effects of a devaluing society. Indeed, the church community becomes the sort of place in which a divisive focus on "difference" gives way to the nurturing and expression of capacities: in biblical fellowship, differences are "absorbed" through being celebrated. What does it mean to absorb differences? Galatians 3:26-28 says,

So in Christ Jesus you are all children of God through faith, for all of you who were baptized into Christ have clothed yourselves with Christ. There is neither Jew nor Gentile, neither slave nor free, nor is there male and female, for you are all one in Christ Jesus.

In the church, differences are absorbed by the social environment so that they become, in effect, "softer"—though still present, they are not treated as things that detract from the unity of the whole. Instead, differences that might otherwise divide have been transcended by the mutuality that comes through membership in the body of Christ.

Unfortunately, this unique opportunity to facilitate relationships through church involvement may too often be taken off the table by those providing human services. One means of intervening to remedy this circumstance is to figure out how to address the problem of unchosen relationships. To what extent are relationships unchosen as a result of characteristics

of individuals with impairments versus the presence of a discriminatory social environment? To what extent are unchosen relationships a natural outgrowth of the way human services are designed, funded and provided? Are existing services the way they are due more to a lack of creativity than to some sort of natural necessity? If our definition of disability revolved around relationships, then we might evaluate the success of interventions based on the presence of relationships with regular community members. Even then, given the nature of the human condition, sacrificial engagement will always be required to establish and sustain healthy relationship patterns.

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