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FAITH4ALL
Inclusive Times

**Third Edition:**
The delivery of medical care to persons with disabilities.

Issue Number 3
January 2021

# The Delivery of Substandard Medical Care to Persons Living With Disabilities

By Kevin Pettit

Of course, unless you have purposely avoided news for the last year, there is no doubt that you have heard of the medical crisis and the overburdening of our medical system, which is stressed to the extreme by the COVID-19 crisis. Back on May 24th, under the headline "U.S. DEATHS NEAR 100,000, AN INCALCULABLE LOSS", the entire cover of The New York Times newspaper was covered with the names of 1,000 people that **in May** was less than **1%** of the people who had died in the U.S. from the COVID-19 pandemic**!**

At this time, many more than 330,000 citizens of the U.S. have died because of this virus and the entire health care delivery system is under ***extreme*** stress[i]. For almost one year, one unifying concern of the people in the diverse community of people living with disabilities (PWD) is that the struggle of PWD for fair medical treatment as human beings in need would be forgotten during this pandemic and, because of their disability status, they would be deprioritized despite the urgency of their medical needs.

This concern is certainly reasonable: by now, we've all heard of the limited supply of personal protective equipment (PPE), ventilators, and experienced and trained medical staff to care for those who fall drastically ill because of this virus.

The January/February edition of *The Atlantic* has excellent coverage of the urgency of these pandemic times, particularly the article "The Committee on Life and Death". In addition to these stressors, the seemingly human inclination to care for others similar to ourselves first and foremost would seem to indicate strongly the proclivity of medical care to be denied to a COVID-19 victim **because** of their perceived disability, irrespective of their need.

Though this is a very valid concern, the CDC has promulgated Crisis Standards of Care[ii] which call for equitable processes of care ensuring "consistency in application across populations and among individuals regardless of their human condition (e.g., race, age, **disability**, ethnicity, ability to pay, socioeconomic status, preexisting health conditions, social worth, perceived obstacles to treatment, past use of resources" (Institute of Medicine, 2009, p. 3).

Further, as the first of four ethical principles on which the document is based, the Colorado Crisis Standards of Care states that "[e]very healthcare provider should attempt to be fair to all those who are affected by the disaster, without regard to factors such as race, ethnicity, socioeconomic status, **disability** or region that are not medically relevant"[iii].

Despite the existence and publication of these lofty ideals, one wonders how well these goals are met. This reporter has interviewed the four members of his immediate family who are EMT technicians, ICU nurses, or emergency room doctors regarding their experiences providing treatment in this time of the COVID-19 pandemic. They all admit that they work every day under great stress, covered by considerable PPE, and only in environments that are tightly restricted to only the patient and the required medical personnel. However, after consultation with these family members and also employees of the Colorado Cross Disabilities Coalition, it appears that in Colorado thus far, at least, there haven't been reports of the denial of medical care to PWD in Colorado ***based on the disability status of a person in need***. Such denial of care would be against the clear guidance and legal restrictions of both Colorado and Federal law!

However, almost everywhere in this country, the difficult decisions that medical staff make every day regard **prioritization**, not restriction, of the distribution of medical care and effort. Doctors and nurses continually face patients filling ERs with people in need of care and their overriding concern is to deliver medical care first to those of the most urgent need. The minds of caregivers are not burdened by the concern of maximizing the life-years of the various people awaiting care in the ER, they rarely have the luxury of considering any more questions than this one: "*Who can I save from dying today by giving them my care and attention immediately?*" Thus far, it seems that our primary caregivers have done quite well distributing care ethically and fairly, in accordance with the state and national Crisis Standards of Care.

Readers of this article should not take these conclusions as a green light concerning the fair distribution of medical care in this time of the pandemic; these statements are meant to signal a ***flashing yellow light of warning*** about the delivery of healthcare to PWD. This issue is of concern, not because there has been an increased incidence of the unethical distribution of health care due to the pandemic, but because it is a **constant and common problem** facing PWD when interacting with the medical community. NPR reported a prime example of this recently[iv].

By listening to this story, one learns of Sarah McSweeney, a woman who lived with intellectual challenges and the inability to walk or speak with words. Caregivers at the group home where she lived, say Ms. McSweeney was a woman with a "vivacious personality" who "absolutely adored going into malls and getting her makeup done". She awoke with a 103˚F fever and was rushed to the hospital in possession of a clear legal document that a legal order that requires the hospital to take all measures to save her life (which she required because of her inability to communicate easily).

Though initially concerned of a COVID-19 infection, the doctors tested and ruled out this possibility. Soon they determined that she was suffering from a urinary tract infection. While still in the hospital, Ms. McSweeney developed aspirational pneumonia and was going to be put on a ventilator. However, before ordering that she be put on a ventilator, her doctors requested a new order that would say this disabled woman should not be resuscitated or intubated. For almost two and a half weeks, the doctors repeatedly pressured the directors of the group home where Ms. McSweeney lived (who retained her medical power of attorney) requesting that they do away with the legal documents that required them to provide all necessary medical care and sign a DNR. This was never done and after almost three weeks in the hospital Sarah McSweeney died of sepsis due to aspiration pneumonia -- a serious medical condition, but one that is usually treatable.

During the course of their (mis)treatment, doctors repeatedly questioned the validity of Ms. McSweeney's desire to live a life so impaired that they could not imagine ever wanting to live as she did. I note here that it is not for doctors to judge the ***value*** of a patient's life: they are ethically bound (and legally required) to save **all** lives!

As people of faith (**<u>all</u> faiths**), we all must agree that this situation is intolerable! We all should feel called to investigate and acknowledge these injustices that sometimes occur hidden away in hospital rooms. The delivery of substandard medical care to anyone because of their race, sexual preferences, income, religion, or disability is inhumane and illegal. As a forward leaning society, we cannot allow such treatment ever!

**CARE ABOUT EACH OTHER AND**
**STAY CONCERNED AND CONNECTED!!!**

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*Any questions or comment regarding this e-journal or this organization can be directed to kevin@Faith4All.org

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[i] For the current data, see this helpful site: https://covid.cdc.gov/covid-data-tracker/.
[ii] Institute of Medicine. 2009. *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations: A Letter Report*. Washington, DC: The National Academies Press.
[iii] See p. 11 of Crisis Standards of Care 2020.
[iv] Shapiro, J. (2020, December 14). "As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?" [Radio Broadcast], NPR.

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Inclusive Times

**Latest Edition:**

This edition will probe the relation between mental health challenges and disabilities.

Issue No. 4 April 2021

## Mental Illness and Disability

Frequently, in their casual speech and thought, many people conflate the issues of mental illness – or mental health challenge – and disability. There is frequent and sometimes heated debate on whether or not mental health challenges should be classified as a disability. I know that many people feel very passionately about these issues which means that it is very easy to step on others' toes! In this **Inclusive Times** article, I would like to address this issue with hopes that I can help everyone avoid frustrating and/or painful interactions in our community.

Sometimes a mental illness can be understood as the cause of a disability; however, at other times, it is not. To avoid disagreement and conflict, I've always found it helpful to stick with rather legal or professional definitions of disability and mental illness. One should be aware that these definitions are not universally agreed upon and we would do well to be open to hearing each individual's understanding of their own conditions or challenges.

### Disability

Very succinctly put, one helpful way of defining a disability is as a condition that one can have that limits their ability to live and perform essential functions or Activities of Daily Living[1] (or ADLs). Examples of ADLs include basic physical functions such as personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating.

Further, Instrumental Activities of Daily Living (IADLs) include more complex activities that are related to the ability to live independently in the community. These include activities such as managing finances and medications, food preparation, housekeeping, and laundry. Notice that both ADLs and IADLs are only lists of important activities and ***do not*** refer to the *cause* of the inability or limitation..

No matter their origin, challenges that restrict or limit one's ability to perform ADLs can be significant enough to lead to a disability. Precisely how many ADLs or IADLs must be restricted or limited in an individual in order to qualify one as having a disability is a legal matter. In the United States, according to the ADA, a person with a disability is "a person who has a physical or mental impairment that substantially limits one or more major life activities." The legal definition of disability doesn't state anything about the cause of the impairment.

### Mental Illness

Unlike the legal definition of disability described above, which has attained rather widespread acceptance as a useful definition of disability, the notion of "mental illness" is not commonly understood based on a legal definition of this condition or challenge. A more commonly accepted definition of "mental illnesses", as promulgated by the American Psychiatric Association, are "health conditions involving changes in emotion, thinking or behavior (or a combination of these). Mental illnesses are associated with distress and/or problems functioning in social, work or family activities."

According to this definition, "mental illnesses" are less precisely defined than the ADA definition of "disabilities" which, I believe, is commonly accepted and used by the public. Note, particularly, that not all mental illnesses are considered serious enough to be disabling. This is an important fact to understand and warrants repetition: **not all people challenged by a mental illness think of themselves as facing a disability**. (Personally, I have learned this fact the hard way: by being criticized for naming a person who admits to facing a mental illness as having a disability.) **Always allow people to name their condition and their own status themselves!**

While, certainly, more serious cases of depression, schizophrenia, and psychosis, for example, can and sometimes do restrict one's performance of ADLs and IADLs enough to qualify one as having a disability, a significant number of people who face a mental illness **do not** qualify as having a disability. They also do not consider themselves as having a disability.

### A Shared Difficulty

Despite the significant differences between mental health challenges and disabilities, sadly people living with these conditions or challenges share the common attribute of being rejected by many others! This rejection is particularly pronounced in religious institutions. It would take <u>several</u> articles to explain how and why this occurs; here I will only note that most churches, synagogues, mosques, and temples are **exempt** from almost all of the requirements of the ADA. In addition to usually being settings of solemnity and reverence, with high expectations of proper etiquette and rigid social norms, many or most religious institutions commonly leave unsaid these expected appearances and behaviors. For this reason, the phrase "putting on your Sunday best" has obtained common parlance, even though religious rituals may occur on different days of the week!

### Common Solutions

This shared difficulty points to a few common practices that are applicable in essentially every situation and lead to a more inviting atmosphere for everyone – people living with disabilities, people living with mental health challenges, as well as those who are temporarily able-bodied. Here is a very brief list of guiding points for polite interactions:

- **Remember that people with disabilities and mental health challenges are humans, too.** You can acknowledge their differences as you would acknowledge anyone else's uniqueness.
- **As you would with anyone, speak with everyone at their own level.** Sit in a chair when you are speaking to someone who uses a wheelchair and respect the private space surrounding them, which includes any devices they might use.
- **Call people by their names!** Think of and refer to everyone as individuals first.
- **Both disabilities and mental health challenges are only <u>aspects</u> of a person, not the person themselves.** They are qualities only and do not define one's state of being. Everyone is more than can be described by a single word or even a single sentence!
- **Always use person-first language.** Note: that how someone claims their disability status shouldn't be assumed; always ask how this person prefers they are spoken of. (Hint: almost always, they prefer their names!)
- **If they need or want any assistance, people prefer to ask for help, not to have it forced upon them!** If you are unsure of how you should interact with anyone, just ask him or her. Just because someone has a disability, does not imply that they need your help!

More complete guidance is available from the organization RespectAbility and the “Ten Commandments for How to Talk About Mental Health”, an article published by **Psychology Today**.

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## Future Inclusive Times Topics:

- Stigma associated with disability and mental illness.

*Any questions or comment regarding this e-journal or this organization can be directed to kevin@Faith4All.org.

## Endnotes:

[1] Edemekong PF, Bomgaars DL, Sukumaran S, et al. Activities of Daily Living. [Updated 2020 Jun 26]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2021, Jan. Available from: https://www.ncbi.nlm.nih.gov/books/NBK470404/.

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# FAITH4ALL
## Inclusive Times

**Latest Edition:**

This edition will consider the use and consequence of **stigma**.

Issue No. 5 July 2021

## The Problem of Stigma

The word “stigma” originated from the relatively neutral Greek word *stizein*, a word for “tattoo”; but over the centuries this word has acquired a meaning which is quite negative. Today, the first definition of this word in the Merriam-Webster Collegiate Dictionary is “a mark of shame or discredit: a stain”. Even though stigmas are of limited usefulness and hurtful, people commonly stigmatize others who carry an identifying mark, often understood as a blemish. Stigmatization is almost always unjust and divisive, leading to negative feelings and hurtful actions; nevertheless, the stigmatization of others is quite common, so much so that it is often done subconsciously. As people who respond to a higher calling, we all might consider the limitations that a stigma ensures, try to always promote a more thoughtful connection to others, and enjoy the blessings of the diversity of the human family.

In fact, the word *stigma* in Latin took on the meaning of “mark” or “brand”, *i.e.* the purposeful scarring of animals to help distinguish livestock as the property of a single rancher. In the many intervening years between ancient Rome and today, the function of this word has changed in curious ways, including its Latin plural (*stigmata*) changing to mean, almost exclusively, the wounds delivered by the Romans to Jesus as they crucified him. But as commonly used today, the word stigma almost always implies a shameful defect – even if these marks imply little or no impairment of the person who possesses this distinguishing characteristic.

Stigmas are markers that are understood as encapsulating almost the totality of another person, or group of people. For example, in WWII, citizens of the United States of America who were of Japanese descent were understood to be dangerous people: the common facial features, dark colored hair, and Japanese ancestry of a significant number of US citizens – many who had never even visited Japan – all carried the stigma that lawmakers in this country understood as implying danger. Thus, did lawmakers justify the imprisonment of citizens of the United States who were of Japanese heritage in concentration camps as part of its war effort.

All stigmas divide people and set apart those bearing this mark as “different” or “other”. In doing this, those endorsing this separation very frequently allow the distinguishing characteristic to monopolize their understanding of individuals bearing the stigma and often deny their full humanity. In this way, stigmas hurt and disrupt possible harmony in our society as well as reduce the full expression of individuals’ skills, abilities, and talents. The reliance on stigmas represents a lack of curiosity and intellectual passivity.

Stigmatization commonly occurs without significant frontal lobe processing, thus the use of stigmas often reflects the subconscious. The challenge is to convince individuals of their use of, or reliance upon, unwarranted stigmas that actually imply nothing about an individual. How can we best raise the awareness of people who rely upon and understand stigma as rightfully suggesting anything about others?

In a religious context, stigmas (either conscious or unconscious) frequently divide congregations into those members who display characteristics endorsed by the institution and those thought to less appropriately represent the institution. Organizers commonly do not invite Individuals bearing stigma to lead or to play any role in a service. The poorer and less properly attired, as well as those individuals living with significant cognitive deficits, are usually not asked to serve clearly prominent roles in religious celebrations or services. They are quietly and subtly shunned, even when they might be particularly good at accomplishing certain tasks.

The main solution to the problem of stigmatization is to raise awareness of harmful attitudes. This is almost never done effectively by directly blaming a person for their reliance on stigmas; however, every faithful community might help itself by delivering and receiving occasional reminders of the hurtfulness of stigmas. Helping to improve our attitudes and respect for others: is this not one of the primary functions of all faithful congregations?

Together, with the dissipation of stereotypes and stigma, we can engage life more fully. People are best understood as unique, with no single defining characteristic effectively encapsulating their being! In this beautifully varied and lively world, we are all very much more than is first apparent.

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## Possible Future Inclusive Times Topics:

- Forming an Inclusion Team

*Any questions or comment regarding this e-journal or this organization can be directed to kevin@Faith4All.org.

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# FAITH4ALL
## Inclusive Times

**Latest Edition:**

This edition will outline forming an inclusion team.

Issue No. 6 October 2021

## Forming an Inclusion Team

Given the fact that just about one in four citizens of the United States lives with disability[i], it seems apparent that **every** person in almost <u>any</u> faith community either has a disability themselves, or knows a close friend or relative who lives with a disability. However, as explained in earlier issues of the **Inclusive Times**, the participation in faith communities of people with a disability is remarkably low. Indeed, in her book ***Disability, Faith, and the Church***, Professor of Religion Courtney Wilder states "[d]espite significant theological progress on the part of Roman Catholic and mainline Protestant denominations, actual participation by people living with disabilities [PWD] in American churches is disproportionately low."[ii] Indeed, the primary problem leading to this participation gap is not the inaccessibility of the church building(s), as Ginny Thornburgh reminds us of her motto "A ramp is not enough!"[iii] The problem of the persistent participation gap has its origin in the attitudinal barriers of congregants toward PWD and the commonly evident disinterest of congregations in welcoming PWD who might stretch their "expected model" of a worshiper.

In order to see if your faithful community can grow into one compassionate and strong enough to include people who, because of disability, at first thought might not seem to "fit in" to your faithful community's congregation, first a small group of people interested in exploring this congregational transformation often forms. Even at this time, it is very important to remember at all stages of transformation the mantra embraced by the disability community: "**Nothing About Us Without Us!**" This means that it is important to include people living with a variety of disabilities at every step of the way in the process of a faithful community's transformation and after as these PWD are seen as an expected part of the congregation. Remember this dictum:
"***A congregation without people with disabilities is incomplete!***"

### Starting Small

An Inclusion Team or Disability Awareness Committee can be small -- even a couple or a few people can start the ball rolling! -- and a good first action item for this team will be educating its own members. This can be started in a number of ways; but one of the clearest and most concise guides for this is reading the "sacred scripture", ***<u>That All May Worship</u>***. Put together by Ann Davie and Ginny Thornburgh, this book is easily available online[iv]. This handbook is a masterful guide, written to help transform congregations of all faiths into places where children and adults with disabilities are welcomed, honored, and enjoyed. It is really a required reading for this work!

## Finding External Help

In addition, the inclusion team should remember to investigate possible guidance and help that can be provided by any group in your community's external hierarchy -- its association, conference, or denomination -- with expertise in this area. Often, helpful groups are hidden away in denominations' organizational structure. The concept of inclusion and welcome is common to almost all religious organizations and we should not hesitate to learn from other organization's experiences! I have found publications of the Disability Ministries committee of the United Methodist Church and the Jewish Inclusion Toolkit of the Jewish and Faith Inclusion project of RespectAbility particularly helpful in the work of building inclusive faith communities. In addition to these resources, there is the excellent interfaith Congregational Accessibility Network (CAN) that has done a lot to help faith communities improve their welcome and accessibility. Their guidance and consultation is helpful, as well.

After forming an inclusion team and educating its members as to the importance of including PWD in faithful congregations, church/synagogue/mosque/temple leadership can next be approached. Though advancement of the inclusion of PWD in faithful communities is possible without the support of clergy, it is extremely helpful to obtain the "blessing" of this group of people before your inclusion team gets too heavily involved with its planning. Your faithful community's leadership might also be a helpful source of information and support, especially regarding the theological mandate, made in most every religion, to include **ALL** people!

The basic requirements of the physical structure of an accessible worship space are described in ***Accessible Faith: A Technical Guide for Accessibility in Houses of Worship***, published by RRF Foundation for Aging (The Retirement Research Foundation) of Chicago[v]. However, this guide really describes only the "hardware" needs of an accessible faithful community; the theological and spiritual requirement for accessibility also need be addressed and can be accomplished by consulting ***The Disabled God*** by Nancy Eiesland[vi] and ***That All May Worship*** by Ann Davie and Ginny Thornburgh, which was referenced above.

## Obtaining Recognition

After educating itself and receiving the blessings of congregational hierarchy, the next step in the process of transformation will be to educate the congregation of the need and religious imperatives for such a transformation. This is often done by inviting a speaker with a disability to describe how PWD frequently shunned, left out, or forgotten by groups of people who are temporarily able-bodied and the spiritual importance of a faithful body's transformation to becoming a more widely welcoming organization. As the congregation becomes more aware of and sensitive to the welcome and inclusion of PWD, it will often feel called to obtain more or less "official" recognition of their status as a faithful organization which is welcoming and inclusive of persons living with disabilities.

This more or less "official" recognition can often be obtained from a faithful organization's denomination[vii]. Most major religious bodies have a group specifically dedicated to the inclusion of people living with disabilities. An excellent webpage listing many different faithful institutions is kept by the Faith and Disability Network. In addition, the Interfaith Disability Advocacy Coalition (IDAC) can be consulted, as can the American Association on Intellectual and Developmental Disabilities Religion and Spirituality Interest Network.

We hope that the text (and links) contained in this **Inclusive Times** edition efficiently guide all faith communities to begin the effort of including people of all abilities. Given that the the CDC has determined that about 1 in 4 (more precisely, 26%) the people living in the United States have some type of disability[viii], indeed "a congregation without people with disabilities is incomplete!" **Let's all work together to make all faithful communities more completely a reflection of their local community!**

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## Future Inclusive Times Topics:

- Stigma associated with disability and mental illness?

*Any questions or comment regarding this e-journal or this organization can be directed to kevin@Faith4All.org.

## Endnotes:

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[i] Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. **Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016**. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm?s_cid=mm6732a3_w.

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[iii] Mathewes-Green, M. (1995) **A Ramp Is Not Enough**. *Christianity Today*, 39(12), 68. DOI: https://www.christianitytoday.com/ct/1995/october23/conversations-ramp-is-not-enough.html.

[iv] Davie, A., Thornburgh, G. (2006). ***That All May Worship***: *An interfaith welcome to people with disabilities.* AAPD Interfaith Initiative. DOI: https://www.aapd.com/wp-content/uploads/2016/03/That-All-May-Worship.pdf

[v] Patterson, E.A. & Vogel, E.A. (2003). ***Accessible Faith: A Technical Guide for Accessibility in Houses of Worship***, The Retirement Research Foundation. DOI: https://rrf.issuelab.org/resource/accessible-faith-a-technical-guide-for-accessibility-in-houses-of-worship.html

[vi] Eiesland, N.L. (1994). ***The Disabled God: Toward a Liberatory Theology of Disability***. Abingdon Press. DOI: https://www.abingdonpress.com/product/9780687108015/.

[vii] In addition, Faith4All is considering adding a membership option for faithful organizations, which would include a seal of accessibility that would advertise an organization's commitment to invite, embrace, include and empower people living with disabilities as members and perhaps even leaders of its congregation. However, details of this membership option have yet to be determined. I hope that this can be the topic of the next edition of **The Inclusive Times**!

[viii] See Disability Impacts All of Us on the CDC website: https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html.