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E D I T O R I A L



Michael J. Sleasman, PhD | Editor
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In this issue of *Dignitas* we feature two essays by emerging scholars as part of our ongoing effort to cultivate and promote the next generation of thought leaders in Christian bioethics. This is one of the primary emphases of BioethicsNEXT, which we unveiled at our 2018 summer conference amidst our 25th Anniversary celebration. BioethicsNEXT emphasizes two strategic priorities that will guide the Center's work over the next several years: 1) inspiring young thinkers to courageously promote human dignity and foster human flourishing, and 2) helping pastors guide their congregations to wisely face difficult issues in medicine, science, and technology.

The first essay in this issue is by Koos Sieger Tamminga, MA, a doctoral student in practical theology at the Theologische Universiteit Kampen in the Netherlands. In his essay, "Countering Ableism through Embodiments of the Gospel: The Roles of Practice and Reflection," he explores issues of disability, social engagement, and counter-cultural community based on his doctoral research. In particular, Tamminga examines the case study of Hart van Vathorst (Heart of Vathorst), a Christian community in the Netherlands that includes two

residential care facilities for individuals with varying disabilities across the lifespan, a church, a children's center, and a restaurant in a single building. By sharing their lives and not merely a building, Heart of Vathorst and Encounter Church seek to be an embodied Christian practice "striving to become more inclusive."

Tamminga introduces those unfamiliar with scholarship in disability studies and ethics to the competing conceptions for understanding disability and social engagement before turning to an extensive analysis of the unique social practices of Heart of Vathorst that confront social norms through a radically different, inclusive experience. In so doing, he examines the ways in which this community of inclusion stands consonant with developments in Dutch society (going with the grain of values like a "focus on personal attention and locality"), while also highlighting the ways in which this unique community functions at times counterculturally, going against the grain of Dutch society (e.g., highlighting legislative obstacles and deeper questions of social values and politics). This complex relationship of "going with" and "going against" the grain of their social context is underscored by a more sustained

discussion of the ambiguities in the relationship.

Tamminga concludes his essay with reflections suggestive of how Heart of Vathorst and Encounter Church serve as Christian embodied practices of inclusion, invoking theologian Stanley Hauerwas and his reflection on the L'Arche communities. Such action—doing, not simply reflecting—creates "counter-imaginaries, based on the Gospel" that open the possibility of reshaping social imaginaries in relation to disability. In this way, he challenges Christian ethicists (and Christian bioethicists) not only to reflect carefully, but also calls for "faithful Christian practice in response to the experience of disability."

The second essay in this issue is by Dominic Mangino. Readers of *Dignitas* may recall that we featured an essay by Julia Bolzon, recipient of the CBHD's 2018 student paper competition award, in the Fall 2018 issue. Dominic Mangino was awarded second place in the 2018 student paper competition, and this essay is adapted from that paper submission. In his essay, Mangino explores the role of shame in healthcare. Beginning with a philosophical analysis based on the work of Eleonore Stump, Mangino distinguishes between shame and guilt and emphasizes that desire for love stands at the root of shame. Through a three-fold

taxonomy of species of shame, he then proceeds to characterize “illness *qua* illness” and “patients *qua* patients” as something “underserving of shame.”

Turning his attention next to autonomy, Mangino underscores “how prominent American values—like productivity, efficiency, and autonomy . . . predispose the sick towards feelings of shame.” In so doing, he highlights the purported deficiency that stands at the root of the experience of shame in the clinical or bedside encounter. The asymmetry of the physician-patient encounter further exacerbates this feeling through an inherent imbalance of power in the

midst of intense moments of personal vulnerability (physically and emotionally). Having established the root concern, Mangino concludes the essay by offering a constructive path to combating shame by focusing on celebrating the dignity of the patient’s life and, more fundamentally, recognizing the patient as created in the image of God.

As noted, Mangino is the second of two essay contest winners featured as part of the Center’s inaugural student paper competition, held in conjunction with our 2018 summer conference. Both award recipients presented versions of their submissions as parallel paper

sessions during the conference and were invited to revise their papers for inclusion in *Dignitas*. This student paper competition is one among several initiatives that the Center unveiled as part of BioethicsNEXT. To learn more about BioethicsNEXT and how you can partner with the Center in making a difference among pastors, young professionals, and students, please visit cbhd.org/bioethicsnext.

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03



Countering Ableism through Embodiments of the Gospel: The Roles of Practice and Reflection

K.S. Tamminga, MA | Guest Contributor

1. Introduction: The Social Construction of Disability

What do we do when we reflect on the human experience of living with a disability? As straightforward as the answer to this question might seem, it really is a highly complex matter. The emergence of and developments within the academic field of disability studies testify to this complexity. Disability studies as a discipline originates in the 1960s and 1970s, and can be understood as a result of three key insights. First, there was a growing awareness of the ways in which people with disabilities were disadvantaged in society, apart from their given physical or intellectual impairment. Second, it became clear that although the denominator “people with disabilities” signifies a group that is in many ways too

diverse to be called a group, the fact that all members of this group bear the label “disabled” entails that in some sense they *do* form a group—more specifically, a minority group. Third, as a combination of the previous two insights, disability was increasingly understood as a *social* phenomenon, rather than a problem of the impaired individual.¹ This story of the genesis of disability studies complexities our understanding of disability: it is not a problem of individuals, asking for mere reflection on the medical, ethical, or psychological issues people with disabilities and their immediate loved ones face. Rather, it is a socio-political phenomenon that prompts reflection on the way our societies are structured.

The insights developed by disability studies have led to the formulation of a

number of *models* of disability. These models each conceptualize disability in different ways and therefore guide reflection in different directions as well. This is most easily explained with the example of the two most well-known and opposite models of disability: the medical and the social model.² These models are sometimes illustrated by a telling cartoon.³ In the cartoon, we see a woman in a wheelchair at the bottom of a large staircase. A sign reads: “Way in, everyone welcome!” An arrow on the sign points upwards. The medical model suggests the woman must be cured in some way, or maybe she should be given robotic prosthetic legs, so she can walk up the stairs by herself. The social model, on the other hand, suggests that it is not so much the woman’s impairment that is the problem here, but the fact that somebody wrote that all are welcome, without realizing not all can reach the room; the stairs are the problem. In a primarily medical

K.S. Tamminga, “Countering Ableism through Embodiments of the Gospel: The Roles of Practice and Reflection,” *Dignitas* 25, no. 4 (2018): 3–9.

conceptualization of disability, solutions for problems surrounding disability are imagined mostly on the level of “curing” or “enhancing” the individual. Within a social conceptualization, solutions are sought in a much wider range. Instead of changing the individual, might it be possible to change the setting in such a way that space emerges for this individual *as she currently is* to participate? Much current policy-making regarding disability works from a social model of disability, and is therefore focused on creating *inclusive* societies, where people with disabilities participate in social life just as much as any other citizen.⁴

If the social model was an adequate way to understand disability, then these changes in policy should inaugurate a kind of utopian world for people with disabilities and, in fact, for everyone. Inclusion must then be the solution! However, as many disability scholars have concluded, unfortunately, it is not that simple. The terrain of disability studies has therefore shifted from a more advocacy-based approach towards deep reflection on the kinds of structures and thought systems that perpetuate the disadvantage of people with disabilities. These are understood as “ableism” or “normalcy.”⁵

The Australian ethicist Jayne Clapton has differentiated between different levels of inclusion as a way to understand why inclusive policy-making is not always the solution to the problems people with disabilities face in society. The first level is a state of exclusion, the status quo, so to speak. The second level is the level of technical inclusion, where inclusive policies like sending all children to regular schools are implemented. The third level is the legislative level, where these inclusive policies are no longer optional, but become mandatory and have to live up to certain enforceable standards. At this third level, it is possible that all children go to the same schools—their parents can even sue the schools if this is not the case. Yet there is no guarantee that children with disabilities aren’t bullied at school, or simply misunderstood. This is where Clapton introduces a fourth level: the ethical level. On this level, motivations

and attitudes are addressed.⁶ These levels underline the complexity of reflecting on disability: not only are we reflecting on a social phenomenon rather than an individual experience that should be “cured,” we must also study the underlying beliefs and assumptions, or social imaginary, of this phenomenon. To make matters even more complex, we must not only study this social imaginary but also reflect on how it can be influenced for the better.

As many scholars have observed, it is remarkable that the communitarian language of inclusion is used in a day and age when neoliberalism reigns over much of the western world.⁷ Neoliberalism constitutes much of what scholars have identified as “ableism” and “normalcy.” The idea of individual autonomy and responsibility, the valuing of life in mostly economic terms, and the primacy of cognitive capacities, to name a few examples—all of these disadvantage people with (at least intellectual) disabilities. Disability scholar Trevor Parmenter therefore suggests we need “ethical communities” where this social imaginary is challenged and an alternative is lived out.⁸ Theologian Tom Reynolds makes similar observations about the dangerous sides of neoliberalism for people with disabilities and concludes that a powerful antidote is for the church to live a radically different and inclusive life together. Reynolds speaks about “the ideal church,” even as the reality and experience church is often different.⁹ Although it must be said that Christianity historically has contributed to the current “cult of normalcy,”¹⁰ it is also true that the Gospel provides a powerful alternative way of thinking about the value of life, human worth, and the

nature and purpose of communities. Could churches become the kind of “ethical communities” for which Parmenter longs? Could churches be places where people with disabilities are not only tolerated because this happens to be the (inclusive) law of the land, but where they can truly belong?

If the social model was an adequate way to understand disability, then these changes in policy should inaugurate a kind of utopian world for people with disabilities and, in fact, for everyone.

In the remainder of this article, we will explore this question by looking at a case study of Heart of Vathorst (HVV), Vathorst being a neighborhood in the Dutch town of Amersfoort.¹¹ HVV is a co-op comprised of an inclusive day care center for children of all abilities, a number of disability service providers, including residential facilities for about 100 individuals with varying disabilities (ranging from elderly people with dementia

to young adults with intellectual disabilities), and a church: Encounter Church. The church used to be a “typical congregation” before it joined HVV and had no specific interest in the phenomenon of disability. However, when joining HVV, it decided to become a community in which all involved would not just share a roof but also their lives. They framed this desire in terms of striving to become more inclusive. We will study HVV and the church in particular against the backdrop of the surrounding society. While case studies are characterized by their contextual nature, nonetheless, much will be familiar to readers in their own contexts. This makes it possible to learn from case studies, even if generalization in a strict sense is not possible.¹² We will then offer some concluding reflections on the case, and specifically deal with the question of what the roles of practice and reflection are.

2. Case Study: An Embodied Christian Practice of Inclusion in Context

In its quest to become more inclusive, HVV and Encounter Church are influenced by larger societal dynamics: their macro context to which they try to respond. It is not possible to give a full account of the macro context, as that would mean we would have to paint a portrait of the twenty-first century Western world as a whole, and the Netherlands in particular. Instead, we will focus on elements of the macro context that explicitly appeared in the data gathered for my doctoral research. The macro context is not just an abstract and distant reality. Within the context of this research, for example, we encountered the macro context when political figures from the local authorities or the national government visited HVV and reflected on their experiences in the media. From their interest in this project and the way they spoke about it, we can gain significant insights into how HVV and Encounter Church are situated within their macro context.

When HVV officially opened its doors with a public celebration on September 30, 2016, mayor Lucas Bolsius of Amersfoort was present to conduct the official opening ceremony.¹³ When asked to reflect on the values driving this project, Bolsius clearly avoided religious language and spoke about the universal human need for connection to others.¹⁴ Apparently the project nonetheless left an impression on him because when he later hosted a visit from King Willem Alexander of the Netherlands to the city of Amersfoort, he referred to HVV and invited one of the founders of HVV to share something about the unique role of the church within HVV and the larger neighborhood.¹⁵ More political attention for HVV came in the form of a visit by the Dutch secretary of state Hugo de Jonge, who is responsible for healthcare. He visited HVV and spoke widely about his visit in talk shows and interviews.¹⁶ De Jonge posted the following on his Facebook page after his visit: “Everything in Heart of Vathorst is as normal as possible, and exactly that is

what makes it so exceptionally special.”¹⁷ When he launched a campaign to recruit new workers for healthcare weeks later, he referred to the way care and living together were organized in HVV and used a picture of one of the professionals who works in HVV as one of the faces of the campaign.¹⁸

These examples of the mayor, the secretary of state, and the King’s attention to HVV, the subsequent media exposure, as well as the attested impression their experiences with HVV left on them, gives us insight into how HVV is situated within larger dynamics in Dutch society regarding societal organization, healthcare, and how politicians think about the strength of communities. When we study the interactions between HVV and its macro context more in-depth, we can conclude that in some ways HVV seems to *go with the grain* of some societal dynamics. In a sense, the mayor and the secretary of state are very happy with what’s going on in Vathorst because it proves their points about how healthcare, for example, should be organized. There are other aspects of the project that *go against the grain*: they cause uneasiness or avoidance. In the following subparagraphs we will discuss some of the ways in which HVV both fits within the macro context naturally, and at the same time seems to be a counter movement to aspects of the macro context.

2.1 Going with the Grain

HVV fits very well in the societal developments with regards to disability inclusion that we described in the introduction. When the partners of HVV wrote their vision statement, they explicitly connected their plans to recent developments in Dutch society:

Health care in the Netherlands is going through a sea change. The classic welfare state is depleted and the government is taking a step back in many areas. Care providers are facing great challenges. They have to change the way they work, and do it for less money. The role of civic society, too, receives

much attention. How do Christians respond, now that the government places much responsibility in networks in society? In Amersfoort-Vathorst, we want to realize a new way of living together: *extraordinarily considerate*.¹⁹ As a church, a day care center for children, and two care providers we have found each other in the desire to combine encountering, growing, believing, and living together. We dream of a place in this neighborhood where everyone is welcome, and every talent is seen and honored. In this place our residents, fellow Vathorsters, volunteers, and professionals live and work together, seeking for new ways of taking care of one another.²⁰

It comes as no surprise that representatives of the government, local or national, mentioned in this vision statement are quite enthusiastic about this part of HVV’s vision. It seems to go with the grain of policy and developments in Dutch society that resonate with developments in many other Western countries. The responsibility of citizens to shape the good life together is highlighted, leaving lots of room for individual initiatives. HVV was mentioned in the media as one such initiative among others.²¹ Secretary of state De Jonge calls HVV “an example of how it can be done, because there are multiple shapes that work. At its root, it is all about more attention and time for each other. For people in care homes, too, normal life should continue as much as possible.”²²

HVV goes with the grain of developments in the macro context with its focus on personal attention and locality. It clearly presents itself as one possible solution for challenges that arise in the context of the transition from a classical welfare state to a participation society and is recognized as such. It also employs the language of inclusion that is used by politicians in the Netherlands and internationally as a motivational drive behind this transition.

2.2 Going against the Grain

It is precisely in the understanding of what living together in an inclusive manner really means, though, that HVV is also going against the grain of developments in the macro context. Governmental legislation, for example, meant that a number of elements in the original plans could not be realized, like the development of a swimming pool for residents and others in the neighborhood. Because the building was co-financed with a social housing organization that rents out its space to the care providers, this plan had to be terminated as legislation forbids these organizations to invest in anything other than living space.²³ This legal issue had an impact on some of the plans the developers of HVV had: the pool could have been a place of creative encounters, being both a place for people from the neighborhood to swim, and a place where some residents could receive physical therapy and exercise. Legislation continues to stand in the way of how the partners want to cooperate and shape inclusive ways of living together. For example: the daycare center likes to visit the elderly residents with dementia. This provides a chance for the “grandfathers and grandmothers” to read stories to the

children, and to do all kinds of activities together. It is these kinds of interactions that HVV wants to enable based on a conviction that such interactions are wholesome for all who are involved. This seems to harmonize well with the government’s ideas about an *inclusive society*. However, safety regulations often make it difficult if not impossible to arrange such interaction legally as the doors between the daycare facilities and the living space of the residents need to remain locked.

The examples mentioned above might seem quite harmless. But the level of legislation is not the only level on which the practices of HVV sometimes go against the grain. In fact, it seems that the conflicts on that level are symptomatic of a deeper question: are the values that drive society and politics compatible with inclusion? And what is really meant by inclusion in the first place? In the introduction, we noticed how ethicist Luke Bretherton and others call attention to the dubious relation between neoliberal political systems and inclusion language. In Vathorst, we can witness this dubious relation in practice. Elements of Western society that work to exclude groups of people are often explicitly addressed:

prioritizing of rationality, valuing people in terms of economic worth, and high demands when it comes to productivity and success. These aspects all exclude people with intellectual disabilities and to a large degree disadvantage people with physical disabilities as well. However, as is often said in Encounter Church, these elements are unhealthy for every human being, regardless of (dis)ability. In this sense, HVV is going against the grain of its macro context.

2.3 Ambiguity in Relation to Macro Context

Although there are clear ways in which HVV and Encounter Church go both with and against the grain, there are also instances in which there is a kind of duality in how they relate to the macro context. On the one hand, alternative values are explicitly laid out. For example, instead of living for economic worth, people are valued because they are made in the image of God. Such a statement can be heard in sermons in Encounter Church, but it is also part of the daily experience of some church members, like church member Sam, who, in his own words, finds more fulfillment in



discovering all that he can learn from one resident in HVV than in his monthly bonus at work.²⁴ However, it is clear that Encounter Church is not a safe haven in which the surrounding culture does not play a part. For example, I noted during many of my observations of committee meetings and other more public events in HVV how much the setting reminded me of corporate culture, complete with expensive cars, tailor-made suits, and an atmosphere of seeing and being seen.²⁵

Encounter Church hence does not relate to the macro context in an unanimous fashion. A model developed by Helen Cameron, Deborah Bhatti, and Catherine Duce might help to grasp this ambiguity. In their *Talking About God in Practice*, they propose understanding theology as a conversation in which four voices can be distinguished: a normative voice (e.g., Scripture, doctrines that are normative within a given tradition), a formal voice (the theology of the theologians), an espoused voice (the theology that believers themselves express), and the operant voice (the theology that speaks from the actions of believers and communities).²⁶

An uncomfortable but clear example of how these voices can sometimes disagree can be seen in one traumatic event for HVV and Encounter Church in particular. One of the residents of HVV, who was not a Christian herself but had an important place in the life of HVV and was also a regular visitor of church services at Encounter Church, decided to pursue euthanasia. She felt her traumatic brain injury had ruined her life to such an extent that she did not find it valuable to live anymore. Her death came as a shock to many, especially to the other residents. In this unexpected situation, people were clearly in search of language that fit the situation. On the one hand, some felt that this resident had made a brave choice, taking matters into her own hands. Such a sentiment fits well with what is commonly accepted in the Netherlands. However, the formal and normative theologies within Encounter Church clearly point in a very different direction: life is a gift and should be received as such. Those in leadership were also concerned

about what an explicit approval of this resident's choice might mean for other residents who were, medically speaking, worse off than. For reasons of privacy, I will not delve into this example much deeper than this general description. Yet this example clearly shows how values that are commonly accepted in the macro context have an impact in HVV, even if their own values are very different. There is no hard border between the church, or a Christian community like HVV, and the world. This observation shows that there is clearly a difference between the normative and formal theologies and the espoused theology. In this example, the espoused theology seems to be influenced heavily by the macro context with its appreciation of individual autonomy. There can be apparent inconsistencies in the espoused theology: on the one hand approving and even almost praising the decision to commit euthanasia, while on the other hand being against it from an ethical point of view.²⁷

There are other situations in which HVV, Encounter Church, and individual members *do* clearly speak with one voice against developments in the macro context. A clear example is the interaction with debates about prenatal testing for Down syndrome and consequent abortion of babies with the syndrome, which has become a widely accepted practice in the Netherlands as it has in other parts of Western Europe. Dutch philosopher Marcel Zuijderland wrote a book in which he argued that with current prenatal tests, it is irresponsible to let babies with severe disabilities be born because their life is not economically profitable for society. He considers Down syndrome to be a severe disability.²⁸ Zuijderland's book was met with criticism by, amongst others, a mother of one of HVV's residents who has Down syndrome. In an open letter in the newspaper, she wrote about how hard it is for her as a parent to have to justify her son's existence. By pointing to the examples of Denmark and Iceland, where almost no babies with Down syndrome are born anymore, she sketches how it becomes increasingly expected to test and abort, leading to the feeling one

has to justify the "choice" to let the baby be born. She thus writes about her son:

Our son does not smoke, he does not use drugs, he rides his bike or uses public transportation. He does not curse nor does he discriminate. He doesn't post rude tweets. He is not a hacker and does not create insulting vlogs. He doesn't have dollar signs in his eyes. He has good teeth and never had to wear dental braces. He's never been committed to the hospital. He gives us loads of love and made us more beautiful people.²⁹

Many people from HVV responded to this mother's response with approval and encouragement. When Pastor Joost Smit preached about the sixth commandment (*thou shalt not murder*) a few months later, he invited the mother to interview her about her experience that had led her to write this open letter.³⁰

This uniform stance against the normality of aborting children with Down syndrome shows how HVV is clearly going against the grain of aspects of the macro context. On this issue, people involved in HVV find in each other a common conviction, shaped by the Gospel. Undoubtedly, that is the deepest reason why HVV goes against the grain of the macro context in certain areas. It is also the reason that the politicians we introduced at the beginning of our description of the macro context sometimes experience uneasiness with the exact role of the church in HVV. The Netherlands are a highly secularized country, as a recent study by the Netherlands Institute for Social Research confirms: only 31% of the Dutch population consider themselves a member of some kind of religious community. This number is quickly declining. This reduced involvement with religion also causes distrust towards religious organizations and declining knowledge and understanding of religious traditions. The report shows that at the same time, religious organizations are indispensable for civic society at the moment: 48% of committed church members regularly do volunteer work,

compared to 28% of the average population.³¹ There is a clear issue here: on the one hand, churches are needed for their social capital. On the other hand, their potential in terms of numbers and understanding by outsiders, including those in the government, is declining. This issue became more relevant towards the end of my data collection period. A non-Christian organization partnered with HVV to manage the restaurant which is located in its building, represents a work place for many residents, and serves as a meeting space for people in the neighborhood. Their participation brings to the fore tensions that come with working with a specifically Christian motivation. Such tensions are not felt only in relation to the context, but become a reality to deal with in everyday decision-making in HVV.³²

3. Concluding Reflections

As the case study shows, HVV fits naturally in the macro context in many ways: it is in line with societal trends of valuing the power of local communities over state-organized support. It also intentionally connects its practices to these trends, for example, by using the terminology of inclusion. At the same time, HVV goes against the grain of elements of the macro context on a number of levels. At the root, the tension between the macro context and HVV can be explained by pointing to the explicit Christian motivation of HVV in a highly secularized context. The Gospel presents an alternative way of valuing human life and an alternative way of thinking about community.

This alternative way is discerned as it is lived out. It is through actual encounters that people are changed in their perceptions. This presents a challenge for ethicists. How many ethicists can claim that in response to a book or article in which they criticized neoliberalism, someone

said their monthly bonus at work was really less worth his while than spending time with a friend who happened to have an intellectual disability? These things happen at HVV. People realize that the pressure that is put on citizens by the idea that life is a choice is crushing and in fact deadly for many. Once again, how many ethicists succeed in communicat-

it seems to be more promising to start by doing rather than by reflecting theologically, ethically, or otherwise.

ing this to an audience as large and diverse as Encounter Church, and on a level that truly has an impact on people's lives? Stanley Hauerwas writes in reflection on the L'Arche communities that they are not an idea put into practice, but that they are a set of practices, flowing from a simple desire to follow Christ, which in turn stirs reflection, leading to con-

cepts and ideas.³³ In the introduction to this article, we saw how significant concepts, ideas, and social imaginaries may be in relation to disability. The immediate response to this might be to design counter-imaginaries, based on the Gospel. However, as our exploration of HVV shows, and in line with Hauerwas's argument, it seems to be more promising to start by *doing* rather than by reflecting theologically, ethically, or otherwise.

Nonetheless, the case of HVV also shows the necessity of ongoing fundamental reflection on issues surrounding disability. As the uneasy example of Encounter Church's mixed response to a case of euthanasia shows, the alternative way of the Gospel is not always clear to people. Partly, this is a lasting element of the life of the church. Tensions between the different voices of theology and the surrounding context are not only inevitable, they are also potentially very fruitful, as they raise challenging questions. However, this does call for faithful practices of leadership to identify tensions between the different voices and address them. In this, the help of Christian

ethicists is indispensable. In the model of four voices, the field of Christian ethics is part of the formal voice. In situations like the ones we described in our case study, this voice is important as it may mediate between the normative voice and the espoused voice. The questions that Christians face today are often not directly addressed in the normative voice. Yet, if ethicists do their work well, they *are* addressed in the formal voice. A multidisciplinary approach in which, for example, practical theologians and ethicists work together in identifying key questions and answering them, informed by elements from the other voices, is hence of tantamount importance for faithful Christian practice in response to the experience of disability. As I have argued, it is essential that this reflection is not limited to a medical and individual perspective, but that the social context of (or: which constitutes) disability is reflected upon, including the imaginaries supporting this social context. ●●●

- 1 Alan Roulstone, Carol Thomas, and Nick Watson, "The Changing Terrain of Disability Studies," in *Routledge Handbook of Disability Studies*, ed. Nick Watson, Alan Roulstone, and Carol Thomas (London: Routledge, 2014), 3.
- 2 There are more than just these two models; Marno Retief and Rantoo Letšosa count as many as nine models. Recently, models like the cultural and identity model have gained popularity. However, for the sake of clarity, I only use the social and medical model here, because the differences between them prove that it matters which model one uses. Cf. Marno Retief and Rantoo Letšosa, "Models of Disability: A Brief Overview," *HTS Teologiese Studies / Theological Studies* 74, no. 1 (2018): 8.
- 3 See for example: Jamie Hale, "Disability Politics: Introduction," <http://jamiehale.co.uk/disability-politics-introduction/>, January 23, 2019.
- 4 A more in-depth treatment of how the word inclusion functions in current day policy-making in society and the church can be found in: K.S. Tamminga, J.H.F. Schaeffer, and John Swinton, "Potential Roles of Churches and Ecclesiology for Disability Inclusion," *International Journal of Practical Theology*, forthcoming.
- 5 Roulstone, Thomas, and Watson, "The Changing Terrain of Disability Studies," 4.
- 6 Jayne Clapton, *A Transformatory Ethic of Inclusion: Rupturing Concepts of Disability and Inclusion* (Boston: Sense Publishers, 2008).
- 7 E.g., Luke Bretherton, *Christianity and Contemporary Politics: The Conditions and Possibilities of Faithful Witness* (Chichester, West Sussex, U.K.: Wiley-Blackwell, 2010), 32–37.
- 8 Trevor R. Parmenter, "Inclusion and Quality of Life: Are We There Yet?" *Public Health Journal* 6, no. 4 (2014): 413–428.
- 9 Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids: Brazos Press, 2008), chapters 3, 7.
- 10 Kevin Timpe, *Disability and Inclusive Communities* (Grand Rapids: Calvin College Press, 2019), chapter 2.
- 11 The case study presented here is part of a larger case study of HVV, which forms the basis for my PhD thesis. In this thesis, I also elaborate on the chosen methodology, which consisted of interviews, document studies, and participatory observations. The data were analyzed from an ethnographic and grounded-theory perspective. Within the scope of this article, there is no room to discuss the methodology in more detail.
- 12 John Swinton and Harriet Mowat speak about this as "resonance," which according to them is often more transformative than theoretically generalized knowledge. John Swinton and Harriet Mowatt, *Practical Theology and Qualitative Research* (London: SCM Press, 2006), 47.
- 13 "Complex Met Gkv Kerk Vathorst in Gebruik," *Reformatisch Dagblad*, September 28, 2016.
- 14 *Fieldnotes*, September 30, 2016.
- 15 Tirza van der Graaf and Debora Dijkstra, "Heden En Geschiedenis in Eemland," *Nederlands Dagblad*, October 25, 2017.
- 16 Hilbert Meijer, "Trots Is Terug in Verpleeghuizen," *Nederlands Dagblad*, January 30, 2018.
- 17 Hugo de Jonge, "Everything in Heart of Vathorst is as normal as possible," Facebook, January 29, 2018, <https://www.facebook.com/hugodejongeVWS/posts/1085945771546575> (author's translation).
- 18 Hugo de Jonge, Facebook, February 5, 2018.
- 19 The working title for the project was Buitengewoon Zorgzaam or "extraordinarily considerate" (or "caring"). It was later changed to Hart van Vathorst (Heart of Vathorst).
- 20 *Vision Statement HVV*, April 1, 2014 (author's translation).
- 21 E.g., on the daily talk show 1 Vandaag, April 14, 2017 and in late night news show Nieuwsuur, December 19, 2018.
- 22 Meijer, "Trots in Verpleeghuizen."
- 23 Meijer, "Trots in Verpleeghuizen."
- 24 Interview with B13, April 4, 2018.
- 25 *Fieldnotes*, September 30, 2016; November 27, 2016; January 23, 2017.
- 26 Helen Cameron, Deborah Bhatti, and Catherine Duce, *Talking About God in Practice: Theological Action Research and Practical Theology* (London: SCM Press, 2010).
- 27 *Fieldnotes*, March 11, 2018; Interview with C3, February 12, 2018.
- 28 Marcel Zuijderland, *Gentest of geen test?* (Amsterdam University Press, 2017); Aaldert van Soest, "Mensverbetering Is Hét Debat van de 21e Eeuw," *Nederlands Dagblad*, October 6, 2017.
- 29 Jolanda Wolff, "Waarom Mijn Down-Zoon Er Is?" *Nederlands Dagblad*, September 21, 2017.
- 30 Observation notes November 12, 2017.
- 31 Joep de Hart and Pepijn van Houwelingen, "Christenen in Nederland: Kerkelijke Deelname En Christelijke Gelovigheid" (Den Haag: Sociaal en Cultureel Planbureau, 2018).
- 32 Conversation with C3, January 28, 2019.
- 33 Stanley Hauerwas, "Seeing Peace: L'Arche as a Peace Movement," in *The Paradox of Disability: Responses to Jean Vanier and L'Arche Communities from Theology and the Sciences*, ed. Hans S. Reinders (Grand Rapids: Eerdmans, 2010), 113–126.

10

A Conceptualization of Shame and its Remedies in Healthcare

Dominic Mangino | Guest Contributor

Editor's Note: An earlier version of this essay was awarded second place in CBHD's 2018 student paper competition and was presented as a parallel paper at the Center's 2018 summer conference.

As a patient-centered healthcare model has been adopted, there has been an increase in the literature describing shame in the clinical setting. Much of it has focused largely on social stigmas relating to specific afflictions: HIV, AIDS, lung cancer, addiction, and various mental health disorders. Somewhat neglected in these accounts is a comprehensive account of shame itself. This is not to say the various therapeutic suggestions and proposed solutions are ineffective. Rather it is to suggest that a more fundamental conceptual basis is missing or being presumed within the various solutions already proposed. A framework is necessary for providing a cohesive context in which a discussion regarding shame, its importance to healthcare, and its remedies may take place. In the rest of the paper, I present a notion of shame adopted from the work of Eleonore Stump to help illustrate conceptually the link between seeking medical care, illness, and feelings of shame. I then argue that any attempt to combat shame must attempt to defeat one of shame's two necessary conditions, which involve being deficient in or accepting as binding some objective standard of human attractiveness.

The Concept of Shame

Eleonore Stump discusses the topic in her work dealing with the problem of suffering.¹ She believes it is helpful to investigate shame alongside guilt, as they are similar in their logical structures and are sometimes confused. First, it is important to note both are a response to an action or state of being. Second,

they both relate to things desired by the one who is experiencing shame or guilt. According to Stump,

it is helpful to think about the difference between shame and guilt in terms of the things desired and the penalties feared in each condition. The response on the part of real

or imagined others that is anticipated with anxiety by a person feeling guilt is anger, and the penalty anticipated with anxiety is punishment of one sort or another. But shame is not like this. The response that is anticipated by a person feeling shame is more nearly rejection than anger, and the penalty dreaded is ostracism or abandonment.²

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If desire is at the root of shame, it is natural

to inquire as to *what* is being desired. Answering this question adequately requires one to follow the logic back to the fundamental and most basic object of desire. For Stump this is *love*, understood as: (1) the desire for goods for the beloved, and (2) the desire for union with the beloved.³ Guilt is correlative with the desire for goods and shame is correlative with the desire for union.⁴

A shamed person and a guilty person each anticipates a repudiation, on the part of real or imagined other, of both the desires of love. . . . A guilty person . . . is anxious about things others may impose on him that are not for his good, at least not in his own view. By contrast, the shamed person anticipating rejection and abandonment . . . is anxious about marginalization or isolation; his anxiety is directed towards a distance, an absence of union, forced on him by others with whom he himself desires some kind of closeness.⁵

A 10 year old who disobeys his parents by not completing his homework when it is a well-established condition for playtime will feel guilt. The child knows (or believes) that his action will result in revocation of his playtime (contrary to his good) and frustrated parents (anger). On the other hand a 14-year-old child may feel shame when his parents find out he has been skipping school. He is not primarily concerned with the revocation of any particular good by the discovery, but he may feel anxiety about the prospect of rejection or abandonment by his parents. It is easy to see why the child in the first scenario may feel guilt.⁶ It is less clear in the second scenario.

Elaborating two necessary conditions of shame will help explain why there is shame in the second scenario. The first condition requires the individual to believe himself to be deficient in a standard that is deemed an objective measure of human attractiveness by a particular community. Let us call this the *deficiency criterion*. Second, the individual must accept the objective measure as ultimate and binding for himself. Let us call this the *acceptance criterion*.⁷ In the second scenario the child has identified and internalized as binding both obedience and studiousness as the objective measures of attractiveness set by his parents. By falling short of both, the child sees himself as a failure and worthy of abandonment in some sense. It is not necessary for the parents to actually abandon the child for the child to feel truly isolated. The abandonment deemed appropriate by the child can *in itself be* enough to isolate him. For instance it can temporarily lead to self-loathing and a type of willed loneliness.⁸

There are three species of shame in persons: (1) One may be worthy of shame who does not feel shame, (2) one may be worthy of shame and feel shame, and lastly, (3) one may be undeserving of shame and feel shame.⁹ All three varieties are

likely present in the healthcare setting, although the third will be the focus of this paper. Focusing only on the third species of shame limits the discussion to only those individuals for whom shame is an objectively bad state of being in nearly every sense. In doing this, I assume that illness *qua illness* is underserving of shame, and thus believe that all patients *qua patient* are also underserving of shame. I do not rule out the possibility that sick persons can be deserving of shame in other respects, but think it beyond the scope of medicine to make that determination. This assumption also seems consistent with the medical professions' commitment to caring (i.e., not abandoning) equally for all patients regardless of their past actions.¹⁰ Focusing only on those undeserving of shame also avoids complicating factors involved with the other species of shame that fall beyond the scope of this paper: for instance, if individuals are truly deficient in sound objective measures of human attractiveness, feelings of shame *might* be good in some sense.¹¹

Although the social stigmas related to certain diseases, such as lung cancer, are likely sufficient to bring about feelings of shame, I contend that there is a much more prevalent source of shame in healthcare. Analyzing the phenomenon of illness within the American cultural context will demonstrate how one who seeks medical attention may in many cases feel shame because of some commonly held values.

Values and the Nature of Illness

Productivity, efficiency, and autonomy are prevalent values in American culture.¹² The American obsession with productivity and efficiency has appeared frequently in the news, and the value Americans place on autonomy may be reflected by the fact that more than 90% of people who received physician-assisted suicide in Oregon cited "loss of autonomy" as one of their primary concerns.¹³ Autonomy has further gained prominence as a central principle of contemporary biomedical ethics.¹⁴



The source of these values is worthy of discussion, but their existence as important things for which humans strive (sometimes inordinately) is clear. This makes it plausible that many see these values as the objective criteria by which human attractiveness is measured. If this is the case, there are important implications for healthcare. The following discussion on the nature of illness will show how a sick individual who seeks medical care will likely fail to live up to these criteria.

Edmund Pellegrino notes four goods in which sick persons are deficient to some degree. These are (1) the freedom to act, (2) the freedom to make choices, (3) freedom from the power of others, and (4) one's self-image.¹⁵ He argues that the experience of a deficiency in these criteria constitutes an assault on that which differentiates human life from other forms of existence.¹⁶ It is easy to see how an inability to act will harm the ability to be productive. One may argue that this is a narrow understanding of productivity only accounting for physically laborious activities. However, this is a misplaced objection, for even if one was still

productive in other ways (i.e., writing, thinking, etc.) bodily integrity to some degree remains a necessary condition to carry out these or any human actions. To the extent faculties pertaining to an act are damaged, production resulting from that act will be hindered. This applies *mutatis mutandis* for efficiency.

Autonomy is hindered by deficiencies in choice making and freedom from the power of others. According to Beauchamp and Childress in their seminal work *Principles of Biomedical Ethics*, autonomy at a minimum requires self-rule free from both controlling interference by others and limitations that prevent meaningful choice (i.e., inadequate understanding).¹⁷ Acute or chronic illness hinders the individual's ability to act as stated above, and often times places an individual in a condition where he is incapable of healing himself due to inadequate knowledge, which then requires him to seek out the help of another.¹⁸ Any illness for which one seeks help from a medical professional requires, at the very least, the authorization of a stranger to probe the secret places of mind, body, or soul.¹⁹ This is the momentary surrendering of

oneself to another for the purpose of one's own good, and demonstrates a clear loss of autonomy to some degree. Moreover the inherent power imbalances between the patient and healthcare provider (the one to whom one is surrendering) can exacerbate this tension and lead to feelings of domination if the covenantal relationship between the clinicians and patient is not properly safeguarded. These aspects need not lead to feelings of shame, but they very well may.

The above discussion demonstrates how prominent American values—like productivity, efficiency, and autonomy—and the nature of illness interact strongly to predispose the sick towards feelings of shame. Any individual who accepts the values of productivity, efficiency, and autonomy as objective measures of human attractiveness and does not have a belief overriding these values is likely to experience shame whenever he is ill and seeks medical attention. This is because a sick person seeking medical attention is inherently deficient in those values to some degree, and the acceptance of the values as ultimate fulfills both the deficiency and acceptance criteria.



Combating Shame

In combating shame it seems there are two general approaches. The first requires a restoration or defeat of the deficiency the individual embodies.²⁰ This in healthcare is the medical means taken to restore bodily integrity. However, this approach is dependent on the technologies and procedures available at any given moment, which makes it materially limited. Material limitation and the more psychospiritual nature of shame seem to demand another approach. Rather than attempting to combat another's deficiency directly, one could assist a person in rejecting as ultimate the values in which he is deficient—in this case the values of productivity, efficiency, and autonomy.²¹ This happens in two ways: (1) by reordering one's objective measures of human attractiveness and by (2) celebrating the life of the shamed individual.²²

The first way is obvious—by not accepting the criteria denoting himself deficient in some respect, his ability to be shamed by it is removed. Further, since this discussion concerns people who *feel* shame but are *undeserving* of it, the problem of denying a sound objective measure of human attractiveness (i.e., one deserving of shame) is avoided. The “mode of action” for celebrating one's life is less apparent, but becomes clear after considering the kinds of things we celebrate. We celebrate things that are lovely, desirable, or dignified in some way. Therefore, when we celebrate a person's life, we acknowledge something lovely or dignified about him or her. This acknowledgement communicates some desire for union with that person and defeats the chief anxiety at the base of shame—the fear of abandonment.²³

There are at least two ways to celebrate another's life, which correspond with two varieties of the term “dignity” commonly employed in ordinary language.²⁴ First, one can celebrate another's attributed dignity, the dignity we attribute to another's life in virtue of having certain qualities.²⁵ We do this by celebrating

another's admirable traits, actions, and talents. For instance, a hospital staff might celebrate the harmonica skills of a patient by hosting a “mini-concert” in his room. Gathering together to celebrate the patient's talents clearly communicates to him that he is lovely in some way and that others desire union with him, and thus shame may be defeated.²⁶ Celebrating one's life in this way may often times be easy, however this is not always the case.

Imagine a “locked-in” patient who may still be fully aware of everything around him but lacks the ability to respond in any way. Further, imagine that very little is known about the patient before his locked-in state—for instance, there is no knowledge of his past career, hobbies, or talents. How might this person's life be celebrated? How can a healthcare team show him he is desired by others? In this kind of case, it is not possible to celebrate the excellent qualities of the patient, so one needs to celebrate something more fundamental and inherently lovely about him—his intrinsic dignity. This is the kind of dignity an individual has simply by virtue of being the kind of thing he or she is.²⁷ It is more difficult to defeat shame in this way, for it is not always easy to communicate to another that he or she is desired and dignified simply for existing. One way may be to simply tell the patient she is desired and dignified. Another might be to devote time to a patient beyond what is professionally expected, perhaps by reading a book aloud to him. Further discussion on how to practically

We celebrate things that are lovely, desirable, or dignified in some way. Therefore, when we celebrate a person's life, we acknowledge something lovely or dignified about him or her.

celebrate another's intrinsic dignity in a way that aptly communicates that others desire union with him is warranted. Such a discussion would benefit by examining how early Christians operationalized their understanding of *imago Dei*—the theological concept that all persons are created in the image of God.²⁸ The *imago Dei* clearly has important ramifications regarding one's intrinsic dignity. For instance, how could one not recognize the inherent worthwhileness of caring for an elderly patient with dementia who struggles to eat, speak, and move, if he or she is made in the image and likeness of God? How might this concept motivate use to make advanced care planning decisions and mobilize resources for our loved ones? Further work needs to be done to spell out the implications of the *imago Dei* for combating shame.

Conclusion

A crucial point must be made regarding the defeat of shame in healthcare: its defeat does not preclude or necessarily defeat other forms of suffering. Shame—the fear of abandonment and isolation caused by one's deficiency and acceptance of some criteria—is only one type of suffering. It is an acutely existential and debilitating form of suffering; however, there are no doubt other forms to which the sick are subject: physical pain and suffering, the encountering of one's finitude, and permanent or temporary loss of things held dearly, among other things. These other forms of suffering must be absorbed into a larger context if they are to become intelligible, however this is beyond the problem to be dealt with in this paper.

I have proposed that a fleshed-out concept of shame is necessary to combat it in the healthcare setting. In the account offered shame is the real or imagined

abandonment of oneself or others caused by a deficiency in some objective measure of human attractiveness held to be ultimate by an individual. I then showed that common American values predispose any sick individual who seeks medical care towards feelings of shame if he is not committed to other overriding values. I argued shame could be defeated by remedying the deficiency one has, or by shifting the values one accepts as the objective measures of

human attractiveness. One way to do the latter is to celebrate the life of the shamed individual, which communicates to him that others desire union with him. I further argued this is done by celebrating the attributed and intrinsic dignity of the patient. Recognizing challenges in practically celebrating another's intrinsic dignity, I called for further discussion on how this may be done. Laying the conceptual groundwork for the defeat of shame is necessary but insufficient for

the defeat of shame in healthcare, so it is my hope that this discussion leads to concrete efforts to improve the lives of patients. ●●●

- 1 Stump's account was selected for this paper because: (1) she engages critically and builds on influential discussions of shame by notable figures like, Ruth Benedict, Martha Nussbaum, Douglas Cairns, and Moshe Halbertal, and (2) her discussion of shame is a constitutive part of her overall theodicy, which is one of the strongest and most analytically presented theodicy accounts on offer. Although she is not directly engaged with bioethics, her analytically sound theodicy and shame's large role in that account can provide many insights to bioethicists tackling shame in healthcare.
- 2 Eleonore Stump, *Wandering in Darkness: Narrative and the Problem of Suffering* (Oxford: Clarendon Press, 2010), 143–144.
- 3 *Ibid.*, 85–107. This is the two-desire account of love that Stump takes from Aquinas, which is able to encompass the two distinct features of love. Feature 1 is that we love others for their particular characteristics. Feature 2 is that our love for others remains constant despite changes in those particular characteristics. Other accounts like the responsiveness, volitional, and relational models are unable to adequately explain these two features. For a longer discussion see Stump's discussion in chapter 5, "The Nature of Love."
- 4 *Ibid.*, 144.
- 5 *Ibid.*, 144.
- 6 One might object that love itself is a good when desired. This is intuitive, but I believe the "good" one desires when she says "I desire love" is one of union rather than of some good in the ordinary sense.
- 7 *Ibid.*, 148.
- 8 *Ibid.*, 143–148.
- 9 *Ibid.*, 141. A truly shamed person is one who is worthy of being abandoned (in some sense) by others as opposed to one who only feels shame and only believes he is worthy of being abandoned.
- 10 Ofer Merin, Sara Goldberg, and Avraham Steinberg, "Treating Terrorists and Victims: A Moral Dilemma," *The Lancet* 385, no. 9975 (2015): 1289.
- 11 Within the delineation there is the implicit notion that there are sound and unsound objective measures of human attractiveness. It follows that if an individual is deficient in one of these sound measures he or she may benefit from the feeling of shame, which serves as a catalyst for change or reform. This notion of sound and unsound objective measures derives from an understanding of truth in which propositions correspond rightly with reality. It is henceforth assumed there are sound and unsound objective measures of human attractiveness, and that those in the category with which we are concerned are not deficient in them.
- 12 The definitions in this paper assume common and broad notions of productivity, efficiency, and autonomy. Productivity is the ability to produce goods or services. Efficiency is just a measure of how well one produces. Lastly, autonomy is the ability to be self-determining.
- 13 Melissa Gregg, "The Productivity Obsession," *The Atlantic*, November 13, 2015, <https://www.theatlantic.com/business/archive/2015/11/be-more-productive/415821/>; Jill Lepore, "Not So Fast," *The New Yorker*, October 5, 2009, <https://www.newyorker.com/magazine/2009/10/12/not-so-fast>; Lydia Dishman, "The Dark History of Our Obsession with Productivity," *Fast Company*, September 12, 2018, <https://www.fastcompany.com/90230330/how-our-obsession-with-productivity-evolved>; Center for Health Statistics Public Health Division, "Oregon Death with Dignity Act: 2018 Data Summary" (2019), <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>.
- 14 Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013).
- 15 Edmund Pellegrino, "The Humanistic Basis of Professional Ethics," in *The Philosophy of Medicine Reborn: A Pellegrino Reader*, ed. H. Tristram Engelhardt, Jr. and Fabrice Jotterand (Notre Dame: Notre Dame Press, 2008), 95–97.
- 16 *Ibid.*, 95.
- 17 Beauchamp and Childress, *Principles of Biomedical Ethics*, 101.
- 18 Edmund Pellegrino, "The Humanistic Basis of Professional Ethics," 94.
- 19 Edmund Pellegrino, "The Commodification of Medical and Health Care: The Moral Consequences of a Paradigm Shift from a Professional to a Market Ethic," in *The Philosophy of Medicine Reborn*, ed. Engelhardt and Jotterand, 101–126.
- 20 This would be the preferred method for one who is truly worthy of being shamed one way or the other. This is the case with moral and character deficiencies, for the shame would catalyze a positive change in an individual assuming that the objective measures of human attractiveness that individual accepts are sound.
- 21 I take it for granted that these concepts, as valuable as they may be, are not appropriate as ultimate values by which one should judge herself. One reason for this is that these values and capacities seem to be largely instrumental in character rather than ends to be pursued for their own sake, thus they do not seem to be the proper kind of values by which one should be shamed.
- 22 Stump, *Wandering in Darkness*, 146–47.
- 23 *Ibid.*, 147.
- 24 For a discussion of the three varieties of the term "dignity" used in ordinary language see: Daniel P. Sulmasy, "The Varieties of Human Dignity: A Logical and Conceptual Analysis," *Medicine, Health Care and Philosophy* 16, no. 4 (2013): 937–44.
- 25 *Ibid.*, 938.
- 26 Important to note this defeat might only be temporary. Celebrating one's life is an antidote to shame, but like many remedies it is unlikely to permanently cure the patient from feelings of shame.
- 27 *Ibid.*, 938–939.
- 28 Gary B. Ferngren, *Medicine and Health Care in Early Christianity* (Baltimore: Johns Hopkins University Press, 2009), 97–112.

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TOP BIOETHICS NEWS STORIES: SEPTEMBER 2018–NOVEMBER 2018

Heather Zeiger, MS, MA | CBHD Research Analyst

“Infanticide in Kenya: ‘I Was Told to Kill My Disabled Boy’” by Anne Soy, *BBC*, September 27, 2018

Ms Njoki and Ms Kipchumba are not alone. A new study in Kenya has found that 45% of mothers interviewed by a leading charity faced pressure to kill their babies born with disabilities. The survey found that the situation was worse in rural areas—where the figure could be as high as two in every three mothers. (<https://tinyurl.com/y9gfms98>)

In Kenya, women are coerced into killing their disabled babies. Some of this is due to cultural beliefs that a disabled child is a punishment from God for a woman cheating on her husband or that a mother is “cursed” or “bewitched.” To some, killing the child is the most loving thing to do. Disability Rights International interviewed several women who decided to raise their disabled children despite societal pressure to kill them. These women work together to support children with disabilities. These situations in Kenya are just one example of the stigma many people with disabilities face around the world.

“Mosquitoes Genetically Modified to Crash Species That Spreads Malaria” by Rob Stein, *NPR*, September 24, 2018

For the first time, scientists have demonstrated that a controversial new kind of genetic engineering can rapidly spread a self-destructive genetic mod-

ification through a complex species. The scientists used the revolutionary gene-editing tool known as CRISPR to engineer mosquitoes with a “gene drive,” which rapidly transmitted a sterilizing mutation through other members of the mosquito’s species. (<https://tinyurl.com/ybvsv8erk>)

Malaria kills almost half a million people worldwide every year. It is a parasite that is carried in the *Anopheles gambiae* mosquito species. A controversial experiment genetically modified males in the species so that they are sterile. When let into a contained environment, the mosquitoes eventually died out. If successful, this will help curb one of the deadliest human diseases in history.

“Thousands of Foster Children May Be Getting Psychiatric Drugs Without Safeguards, Watchdog Agency Says” by Ricardo Alonso-Zaldivar, *STAT News*, September 17, 2018

A report released Monday by the Health and Human Services inspector general’s office found that about 1 in 3 foster kids from a sample of states were prescribed psychiatric drugs without treatment plans or follow-up, standard steps in sound medical care. Kids getting mood-altering drugs they don’t need is only part of the problem. Investigators also said children who need medication to help them function at school or get along in social settings

may be going untreated. (<https://tinyurl.com/yxejeow>)

There are many ethical concerns with giving children powerful psychiatric drugs. Often these drugs require professional monitoring and dose adjustment. However, many foster children receive drugs that they may or may not need while follow-up care is often lacking. Foster children have a higher incidence of mental health and behavioral problems more than non-fostered children likely due to past traumatic experiences. They are reportedly not getting the mental health care and support that they need, which is part of a larger trend in the US to over-medicate and under-treat mental health problems.

“CRISPR’s Epic Patent Fight Changed the Course of Biology” by Megan Molteni, *Wired*, September 11, 2018

After three bitter years and tens of millions of dollars in legal fees, the epic battle over who owns one of the most common methods for editing the DNA in any living thing is finally drawing to a close. On Monday, the US Court of Appeals for the Federal Circuit issued a decisive ruling on the rights to Crispr-Cas9 gene editing—awarding crucial intellectual property spoils to scientists at the Broad Institute of Cambridge, Massachusetts. (<https://tinyurl.com/y3oa8fj6>)

The patent battle between the University of California Berkeley and the Broad

Institute of Cambridge, Massachusetts, finally came to a close as the courts ruled in favor of the latter. However, the victory was somewhat anti-climactic. While the three-year legal battle progressed, scientists have been working on innovative ways to improve the CRISPR-Cas9 system. In particular, they have looked at enzymes other than Cas9 to make more precise edits.

“Cases of Mysterious Paralyzing Condition Continues to Increase, CDC Says” by Rob Stein, *NPR*, November 13, 2018

The number of children being stricken by a mysterious paralyzing condition continues to increase, federal officials say. At least 252 cases of acute flaccid myelitis, or AFM, have been reported to the Centers for Disease Control and Prevention so far this year from 27 states, including 90 that have been confirmed through Nov. 9, the CDC reported Tuesday. Most of the cases have occurred among children between the ages of 2 and 8. (<https://tinyurl.com/ybb7s5l8>)

In the fall of 2014 one hundred twenty children suddenly experienced paralysis after having cold-like symptoms. There had been reports of cases in 2012, but 2014 showed a marked increase in acute flaccid myelitis (AFM). In the fall of 2016, one hundred fifty-three children were confirmed to have AFM. Then, in the fall of 2018, two hundred thirty-six children were confirmed to have it. While evidence pointed to an enterovirus strain, it will not be until a year later, in October of 2019, that scientists confirm the presence of enterovirus D68 and A71 antibodies in these children’s spinal fluid.

“Chinese Researcher Claims Birth of First Gene-Edited Babies—Twin Girls” by Marilynn Marchione, *STAT News*, November 25, 2018

A Chinese researcher claims that he helped make the world’s first genetically edited babies—twin girls born this month whose DNA he said he altered with a powerful new tool capable of rewriting the very blueprint of life. (<https://tinyurl.com/y4yzbfnd>)

“He Took a Crash Course in Bioethics. Then He Created CRISPR Babies” by Sharon Begley, *STAT News*, November 27, 2018

For someone who has caused a worldwide uproar over what many fellow scientists consider an ethical outrage, He Jiankui of China spent a remarkable amount of time discussing his work—which he claims led to the births of the first babies whose genomes had been edited when they were IVF embryos—with bioethicists, policy experts, and social scientists. Two of them are father and son: Dr. William Hurlbut of Stanford University, a member of the U.S. President’s Council on Bioethics in the early 2000s, and J. Benjamin Hurlbut of Arizona State University, a biomedical historian. (<https://tinyurl.com/y2e8n2w4>)

(Editor’s Note: William Hurlbut is a Distinguished Fellow with The Center for Bioethics & Human Dignity’s Academy of Fellows, and J. Benjamin Hurlbut has been a plenary speaker at CBHD’s annual summer conference. Both disagreed with He Jiankui’s actions.)


The biggest bioethics story from Fall 2018 was the announcement that He Jiankui from the University of Science and Technology in Shenzhen had im-

planted two genetically modified embryos that were gestated to full term and born in August. He further announced that another pregnancy is underway. There was an international outcry over the experiment because the employed gene editing technology, CRISPR-Cas9, is still being investigated for safe clinical use. Additionally, the embryos He modified were healthy, meaning there was no therapeutic reason to modify them. Furthermore, there was controversy over whether He obtained proper approval from the university ethics committee and informed consent from the parents.

“Ebola Outbreak in DR Congo Now Second Worst in History,” *BBC*, November 30, 2018

The UN’s global health body says the Ebola outbreak in the east of the Democratic Republic of Congo is now the second-biggest ever recorded. A total of 426 cases of the virus have now been reported in and around the town of Beni, taking the outbreak past that recorded in Uganda in 2000. Beni is in the middle of a conflict zone and operations have been affected by rebel attacks. (<https://tinyurl.com/y2xt9yue>)

Containing the Ebola outbreak in the DRC has met some challenges because of an inherent lack of trust toward foreign medical workers administering vaccines and therapies. Rebel raids and in-fighting has even worsened the situation. The outbreak, which had over 400 cases in the fall of 2018, will eventually report over 3,000 cases in 2019.

VISIT BIOETHICS.COM, A PUBLIC SERVICE PROVIDED BY CBHD WHERE YOU CAN FOLLOW STORIES LIKE THESE AS THEY HAPPEN. 

BIOENGAGEMENT

The promise and perils of advances in technology, science, and medicine have long been fertile fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium or particular artifact. This column seeks to offer a more

expansive listing of contemporary expressions of bioethical issues in the popular media (fiction, film, and television)—with minimal commentary—to encompass a wider spectrum of popular culture. It will be of value to educators and others for conversations in the classroom, over a cup of coffee, at a book club, or around the dinner table. Readers are cautioned that

these resources represent a wide spectrum of genres and content, and may not be appropriate for all audiences. For more comprehensive databases of the various cultural media, please visit our website at cbhd.org/resources/reviews. If you have a suggestion for us to include in the future, send us a note at research@cbhd.org.

Primetime Bioethics



The Truth About Killer Robots (2018, HBO). *Robotics, Artificial Intelligence.*



Black Mirror Season 4 (2017, Netflix). *Virtual reality, consciousness uploading, privacy, human enhancement.*

Bioethics at the Box Office:



Ready Player One (2018, PG-13 for sequences of sci-fi action violence, bloody images, some suggestive material, partial nudity, and language). *Virtual Reality.*



Upgrade (2018, R for strong violence, grisly images, and language). *Human Enhancement, Therapy/Enhancement, Transhumanism.*



Gosnell: The Trial of America's Biggest Serial Killer (2018, PG-13 for mature thematic content including disturbing images and descriptions). *Abortion, Public Policy.*



Wonder (2017, PG for thematic elements including bullying, and some mild language). *Disability, Genetics.*

BioFiction:



Margaret Atwood, *The Maddaddam Trilogy* (Harper Collins, 2016).

Oryx and Crake (2004)
The Year of the Flood (2009)
Madd Adam (2013)

Genetic Engineering, Bioengineering, Research Ethics, Ecological Ethics.



Cole Perriman, *Terminal Games* (1994).
Virtual Reality, Consciousness, Artificial Intelligence.



Ernest Cline, *Ready Player One* (2011).
Virtual Reality.

UPDATES & ACTIVITIES

PAIGE CUNNINGHAM, JD, PHD

- In October, taught five sessions at 2018 Bioethics Conference at Sanford Health – Bismarck (ND).
- In the early Fall, taught bioethics training for ministry residents at College Church, Wheaton, IL.
- Published the chapter, “It All Begins in Genesis: Thinking Theologically about Medicine, Technology, and the Christian Life” in *Creation and Doxology: The Beginning and End of God’s Good World*, edited by Gerald Hiestand and Todd Wilson (IVP Academic).
- Interviewed in November about surrogacy with the *Christian Post*.
- Interviewed about China’s gene-edited babies and genetically modified pigs on “Brian and Kathleen” (Moody Radio Cleveland) and “Let’s Talk with Mark Elfstrand” (WYLL Chicago).

MICHAEL SLEASMAN, PHD

- Appointed to the Steering Committee on Bioethics for the Evangelical Theological Society.

MARIO TAFFERNER, MA

- In November, presented “Heirs in Conflict: The Rivalry between Cain and Abel in its Northwest Semitic Background” at the annual meeting of the Evangelical Theological Society.
- In November, facilitated the Fall Theological Bioethics Roundtable Discussion of Jean-Claude Larchet’s *Theology of the Body* (St. Vladimirs Seminary Press, 2017).

HEATHER ZEIGER, MS, MA

- Published “Boys Beating Girls” in the Fall 2018 issue of *Salvo*.



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Global Impact

One of the aspects of CBHD’s outreach that we do not highlight all that regularly is the global impact of our online resources. In 2018, several of the Center’s websites hit record highs for our online traffic. Our flagship site *CBHD.org* had more than **2.6 million sessions** through the first eleven months of the year. Our news site *Bioethics.com* had more than **1.5 million visits** with **7.4 million pages** viewed. And, for the first time ever, *EverydayBioethics.org* exceeded more than **500,000 sessions** in a single year. Even more encouraging, *CBHD.org* alone had visitors using our site from 187 countries, a tangible demonstration of the Center’s global reach.

Strategic Partnerships

CBHD continues our ongoing partnership with the Christian Medical and Dental Associations (CMDA) and their bioethics initiatives. In early November, CBHD once again hosted the Fall meeting of CMDA’s ethics committee, chaired by CBHD Senior Fellow William P. Cheshire, Jr., MD.

On the CBHD Bookshelf

For those interested in knowing what articles the Center staff have been reading and thought worth highlighting.

Articles of Note:

- Block, Brian, Alexander Smith, and Rebecca Sudore. “Universal Advance Directives—Necessary but Not Sufficient.” *Journal of Law, Medicine & Ethics* 46, no. 4 (2018): 988–990.
- Bryan, Charles, and Scott Podolsky. “Sir William Osler (1849–1919)—The Uses of History and the Singular Beneficence of Medicine.” *New England Journal of Medicine* 381, no. 23 (2019): 2194–2195.
- Dove, Edward. “The EU General Data Protection Regulation: Implications for International Scientific Research in the Digital Era.” *Journal of Law, Medicine & Ethics* 46, no. 4 (2018): 1013–1030.
- Foht, Brendan. “The New Kinship Engineering.” *The New Atlantis* 59 (2019): 3–12.
- Parasidis, Efthimios, Elizabeth Pike, and Devan McGraw. “A Belmont Report for Health Data.” *New England Journal of Medicine* 380, no. 16 (2019): 1493–1495.
- Rajkomar, Alvin, Jeffrey Dean, and Isaac Kohane. “Machine Learning in Medicine.” *New England Journal of Medicine* 380, no. 14 (2019): 1347–1358.
- Sabatino, Charles. “Overcoming the Balkanization of State Advance Directive Laws.” *Journal of Law, Medicine & Ethics* 46, no. 4 (2018): 978–987.
- Silverman, Ross, Douglas Opel, and Saad Omer. “Vaccination over Parental Objection – Should Adolescents be Allowed to Consent to Receiving Vaccines?” *New England Journal of Medicine* 381, no. 2 (2019): 104–106.
- Sim, Ida. “Frontiers in Medicine: Mobile Devices and Health.” *New England Journal of Medicine* 381, no. 10 (2019): 956–968.

STUDENT PAPER COMPETITION

Each year, CBHD invites undergraduate, graduate, seminary, and doctoral students to engage questions from a Christian perspective associated with foundational or emerging issues raised at the intersections of medicine, science, technology, and our common humanity.

PRIZES:

- Cash prize of \$250
- Paper published in the Center's quarterly publication, *Dignitas*
- Presentation of paper during a paper session at the conference
- Complimentary conference registration

TOPICS:

All serious proposals relevant to the study of bioethics are welcome, particularly those in the following subject areas:

- Biblical and/or Theological Anthropology
- Biblical and/or Theological Approaches to Cultural Engagement
- Biblical and/or Theological Ethics
- General Bioethics
- Biotechnology
- Disability
- Emerging Technologies
- End-of-Life Issues
- Ethical Theory
- Historical Theology and/or Perspectives
- Philosophy of Medicine
- Reproductive Technology and Ethics
- Technology Assessment

SUBMISSION DEADLINE | JANUARY 15

Visit cbhd.org/student-competition for guidelines and additional information.

INTERESTED IN SUBMITTING AN ARTICLE?

The editorial staff of *Dignitas* always welcomes the submission of articles for consideration. We are particularly interested in submissions for future issues in the following topical areas: Palliative & Terminal Sedation | Opioid Addiction & Chronic Pain Management | Organ Donation & Determination of Death | Genetic Testing & the Ethics of Reporting Incidental Findings | Disability Ethics | Research Ethics | Theological Bioethics.

We encourage you to contact us regarding your interest at research@cbhd.org

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University that explores the nexus of biomedicine, biotechnology, and our common humanity.

Dignitas is the quarterly publication of the Center and is a vehicle for the scholarly discussion of bioethical issues from a Judeo-Christian Hippocratic worldview, updates in the fields of bioethics, medicine, and technology, and information regarding the Center's ongoing activities. ●●●



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