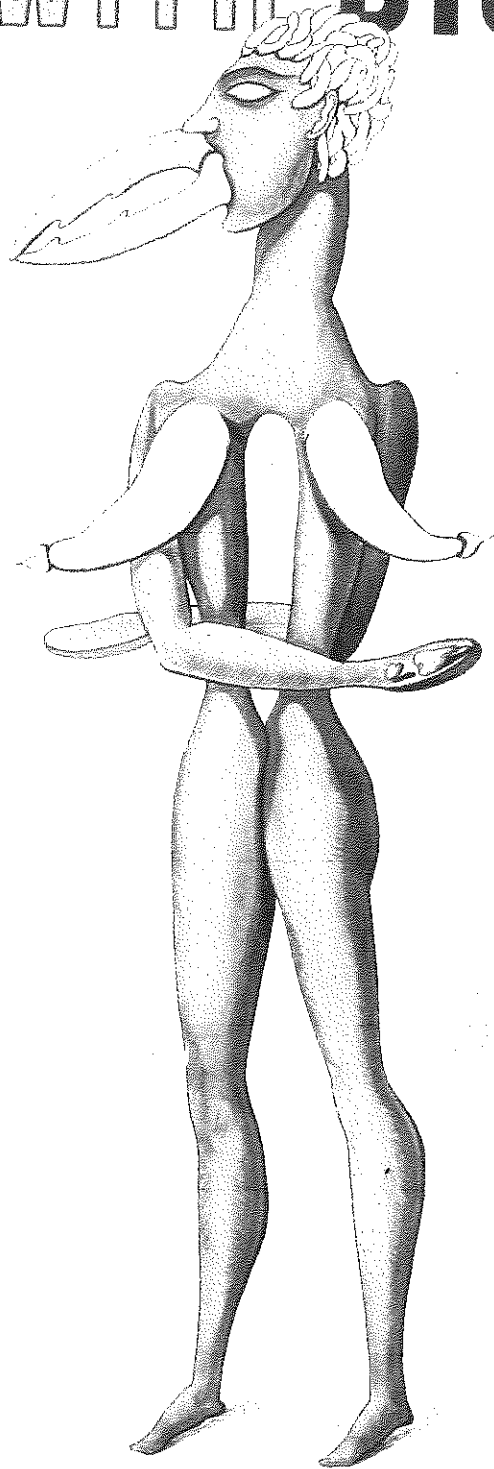


# BEGINNING WITH DISABILITY A PRIMER



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ROUTLEDGE  


# Disability and Sexual Objectification

*Should disabled women be sexually objectified in the same ways as nondisabled women, or is all sexual objectification unjust?*

## A. LONGING FOR THE MALE GAZE

*by Jennifer Bartlett*

When I was in my early 30s, I practiced yoga at a studio in my neighborhood in Brooklyn. On most days, I walked there with two friends—one who was in her 20s and one about my age—but occasionally we each got to class on our own. There was a construction site across the street as part of the growing onslaught of gentrification in the neighborhood. My friends would often complain about being harassed and catcalled by the construction workers—even more so when they wore their yoga clothes. I passed the site day after day without incident.

When I was younger, in my 20s, I was a thin, slight woman. I have also always been beautiful and a nice dresser. I also happen to have cerebral palsy, which affects my motor skills, balance and speech, as it does with most people who have it. It is typically caused by damage to or malformation of the brain during birth or infancy. In my case, my mother's umbilical cord was wrapped around my neck *in utero*. As my mother was unable to have an emergency cesarean section, I was strangled by the cord, and born clinically dead. The temporary lack of oxygen caused damage to a portion of my brain.

Cerebral palsy is not uniform and manifests in a number of ways. It might affect all limbs severely, or just one side of the body; or the effects may be slight, making the disability barely perceptible. It can affect strength, balance and movement; some with the condition may not be able to walk unassisted or care for themselves in typical ways.

To put it bluntly, people with cerebral palsy appear to have strange movements. Since they are not in full control of their muscles, they may have facial expressions or spasticity that most people find surprising, if not unattractive.

People with cerebral palsy are often mistaken for having a mental impairment, although the two are not necessarily linked. I have a speech impediment and awkward gait. My disability is visible, but not necessarily significant. I do have some physical limitations, but am able to do most things that a typical person can do. My primary difficulty has been with people's negative reaction, or what disability studies scholars call the "social construction" of disability. This primarily means that the main challenges disabled people face come from societal prejudice and inaccessible spaces.

Recently, the popular feminist Jessica Valenti published a memoir titled "Sex Object," which focuses on the toll the "male gaze" has taken on her. She wrote an article on this theme for the *New York Times*, "What Does a Lifetime of Leers Do to Us?" Ms. Valenti describes a life of sexual harassment beginning at adolescence. She writes of what seems like countless instances of men exposing themselves to her on the New York City subway. She describes constantly thwarting unwanted advances from men in all areas of her life. Ms. Valenti currently has a 5-year-old daughter and she wrestles for a way to prepare her child for an onslaught of male harassment. She takes for granted that this will happen.

My experiences have been quite different, nearly the opposite, of Ms. Valenti's and that of most women. I was never hit on or sexually harassed by my professors in college, or later, by my co-workers or superiors. I have not felt as if my male teachers, friends or colleagues thought less of me because of my gender. I've never been aggressively hit on in a bar, despite the fact that I have frequented them alone throughout the years. In fact, I've rarely been approached in a bar at all.

I do remember being sexually harassed by a man on the street. Once. I was 16 years old. I was waiting for a bus, and a man pulled up and offered me a ride in his car. When I declined, he got hostile and asked me if I was wearing panties. I was more startled than anything, and I left the curb to go to the nearby movie theater where my friend worked. I didn't tell my friend what happened, but waited with him for the bus. This was very frightening, but I wouldn't say the incident traumatized me, nor is it something that deeply affected my life. And it happened only once.

Let me rephrase that: It happened only once while I was visibly inhabiting my own body. Virtually, it has been another story.

In 2013, I began experimenting with the dating website OKCupid because I wanted to explore this concept of being desexualized. I created a provocative profile. The photographs were recent, but in photographs, I look "normal." I did not mention that I have cerebral palsy. I wanted to use the opportunity to explore the sexual world as an able-bodied woman, if only online, and see what all the fuss was about.

As a pretend, able-bodied woman, I received all kinds of messages. Men wrote stupid things, aggressive things and provocative things. Often, while I was in a dialogue with a man who didn't know of my impairment, I would disclose it, and almost always, the man vanished, no matter how strong the connection had been beforehand. After a while, I changed the profile to reflect that I have a disability. Fewer men wrote. Sometimes, no men wrote, depending on the content. But overall, the messages changed. They could be called more respectful. The men who wrote primarily wanted to know how my disability affected me.

This all feels like a political act, and in some ways it is. Strangely, my disability makes me feel as if I have license to play with and deconstruct sexuality in ways I might not have the bravery to do as an able-bodied woman.

I watch men on the street. I will watch a man visually or verbally harass women who pass him. I am invisible enough to do this. Sometimes men look at me, but the reaction is different. There seems to be some level of shame or confusion mixed with the lust in their eyes. Does this mean that I am lucky? Am I blessed to be sexually invisible and given a reprieve from something that has troubled women for centuries? It certainly does not feel that way. On one hand, I know that I am "lucky" not to be sexually harassed as I navigate the New York City streets. But I am harassed in other ways that feel much more damaging. People stare. People insist that I have God's blessing. People feel most comfortable speaking about me in the third person rather than addressing me directly. It is not uncommon that I will be in a situation where a stranger will talk to the nearest able-bodied person, whether it be a friend or a complete stranger, about me to avoid speaking to me.

I also do understand what it feels like to get attention from the wrong man. It's gross. It's uncomfortable. It's scary and tedious. And in certain cases, traumatic. But I still would much rather have a man make an inappropriate sexual comment than be referred to in the third person or have someone express surprise over the fact that I have a career. The former, unfortunately, feels "normal." The latter makes me feel invisible and is meant for that purpose.

I like it when men look at me. It feels empowering. Frankly, it makes me feel like I'm not being excluded.

## **B. DISABLED WOMEN AND SEXUAL OBJECTIFICATION (OR THE LACK THEREOF)**

*from [crippledscholar.com](http://crippledscholar.com)*

Today in *The New York Times* Opinion pages there was a piece called "Longing for the Male Gaze." It is a personal account of a disabled woman's experiences of not being socially perceived as sexually desirable. I have mixed feelings about the piece.

On one hand, while it is reasonably well known that disabled people are viewed as nonsexual by default, there is very little available on the lived experience of not being accepted as an attractive, sexual being. This piece challenges that trend and does so in *The New York Times*.

On the other hand, much of the framing of the piece is problematic. It focuses less on being seen as attractive and sexual within interpersonal relationships and more on not being treated as a sexual object. Jennifer Bartlett (the author) focuses on her lack of experiences with catcalling and other forms of sexual harassment.

This is problematic for a couple of reasons. For one it gives a lot of social power and validation to harmful social interactions. For another, the author actively plays "oppression Olympics" between sexism/misogyny and ableism. In so doing she fundamentally fails to comprehend the very real harm that can come from catcalling and other forms of sexual harassment.

I do understand her frustration with the fact that disabled women are left out of the sexual objectification faced by our nondisabled peers. It is a catch-22 of intersectional oppression that even being denied an oppressive force usually experienced by part of your identity as a result of its intersection with disability is in fact further oppression.

That disabled women are often denied sexual objectification only shows how disability has denied us the ability to live up to social and cultural understandings of gender presentation and punishes us by denying us not only the consequences of being sexually objectified but also of simply being seen as fully women.

That is a conversation that hasn't happened enough and needs to.

Unfortunately, Bartlett is not starting that conversation. She instead writes almost longingly of being sexually objectified as though being seen as worthy of catcalling would also mean she was worthy of being seen as a sexual being in healthier interpersonal interactions. Unfortunately, in this she is probably right.

That however does not negate the issue of her downplaying the seriousness and real dangers of sexual harassment and catcalling. She writes,

On one hand, I know that I am "lucky" not to be sexually harassed as I navigate the New York City streets. But I am harassed in other ways that feel much more damaging. People stare. People insist that I have God's blessing. People feel most comfortable speaking about me in the third person rather than addressing me directly. It is not uncommon that I will be in a situation where a stranger will talk to the nearest able-bodied person, whether it be a friend or a complete stranger, about me to avoid speaking to me.

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sexual comment than be referred to in the third person or have someone express surprise over the fact that I have a career. The former, unfortunately, feels "normal." The latter makes me feel invisible and is meant for that purpose.

She does acknowledge that attention from the "wrong" men can be scary but still positions it as preferable to the erasure of the ableist interactions she does experience more frequently.

I would however argue that catcalling and sexual harassment are an erasure of the humanity and personhood of women. They can also be deadly.

Like Bartlett I am a woman with cerebral palsy. However, I have not lived a life as free of catcalling and sexual harassment as she describes her life to have been. I have also experienced the stares, question, prayers and being ignored in favor of nondisabled companions. But I am not going to say that one is preferable to the other.

In every single incident of street harassment that I have experienced, I have felt either utterly dehumanized or genuinely threatened. I however cannot say that I have left every dehumanizing disability-specific negative interaction feeling totally safe either.

Being a disabled woman who has experienced street harassment, I can also attest to the fact that it hasn't done anything for my being accepted as a sexual being by society. In fact it is sometimes used to reinforce the fact that I'm generally not viewed as sexual.

As I've written about before, as a result of my disabilities I am not able to perform femininity to cultural expectations. This has resulted in men yelling questions like "are you a man or woman?" at me out of car windows or men foregoing the question altogether and simply loudly debating the question as I walk by.

When the harassment is actually sexually suggestive it's threatening. Like the time I was lost in downtown Winnipeg at night and someone came up to me while I was trying to get my bearings, told me I was beautiful and requested that I go home with him. Luckily when I visibly recoiled he moved on. This interaction was immediately followed by a second man who had witnessed the interaction using it as an excuse to get way to close to me in order to say, "Well, that was creepy wasn't it?"

These interactions didn't affirm my femininity despite my disability. They made me terrified. The fact that I am also disabled and less physically able to run away or fight only exacerbated that fear.

So while I agree that in many ways the ability to be viewed as a sexual object is also tied to the more benign assessments on who gets viewed as a sexual being, I do not agree with Bartlett's downplaying of the harm of sexual harassment.

crippledscholar.com

Sexual harassment, when coupled with disability, does not actually reinforce a disabled sexual identity in a culture that continues to ignore that disabled people are sexual beings. Downplaying the harm of street harassment not only erases the real harm it causes nondisabled women who experience it regularly but also ignores that some disabled women do experience it and that it only makes them less safe, not more fully human.

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## Sexual Surrogacy

*Should disabled people have free access to sexual surrogates, or is sexual surrogacy a form of sex work that potentially exploits both parties?*

### **DISABILITY AND PAYING FOR SEX**

*from [unlockingwords.wordpress.com](http://unlockingwords.wordpress.com)*

Firstly – is sex a right?

Are we all entitled to have sex? I firmly believe we should all have the option of having a good sex life. We should all be able to choose to have sex in the context of a mutually beneficial situation where no one involved is forced, coerced or has no real alternative.

Which brings me to sex workers. This is a huge topic with so many different perspectives, including from people who freely chose to work in the sex industry. There are, however, many people who are forced, coerced or have no real choice. Women can get trapped in the sex industry, and this has to be an important part of any conversation around the right to have sex. However they've entered, or whatever the reason they stay in sex work, we need to ensure that our desire for sex doesn't further exploit sex workers. Whether it's through trafficking or sex slavery, through being willfully misled or because they need the money, or whether they've got addictions which need feeding, or even in situations as complicated as a history of abuse which makes them feel like they have no other option, sex workers deserve the same respect as anyone else.



## Sex Workers and Sex Surrogates

Within the context of disabled people paying for sex, the phrase "sex surrogates" comes up a lot. What does this mean?

**Sex workers**—a sex worker is anyone who works in the sex industry (e.g. porn actors, prostitutes, lap dancers, phone sex workers, sex surrogates). The predominant definition requires the worker to be involved in "sexually explicit behavior."

**Sex therapists**—licensed mental-health professionals; think *counselor*. A sex therapist will not have sex with or engage in any sexual activity with the client.

**Sex surrogates**—a surrogate does engage in sexual activity with the client. They aren't (or don't have to be) medical professionals, but they do engage in work which addresses particular sexual difficulties such as erectile dysfunction, anxiety, or lack of confidence. Think of this more like a way of being able to practice sex or masturbation with the support of someone. There is an International Professional Surrogates Association which offers training for surrogates.

## Should Disabled People Be Able to Pay For Sex?

Firstly, who would be allowed? Would you have to show that you receive disability related benefits? Prove that you're disabled? How do invisible disabilities factor into this? Would it just be for people who've proven they can't find a partner? How would people with mental illness show that they were eligible? What would happen to people who faked disability in order to be legally allowed to use a prostitute?

OK, so that was a bit of playing the devil's advocate, but this is a hugely complicated issue. If you decide that yes, disabled people can pay for sex, you then have a whole load of logistics and specifics to sort out. Especially if you're also in a society where nondisabled people aren't allowed to pay for sex.

Rewinding a bit, let's look at the arguments for and against disabled people paying for sex.

## Arguments For

Rachel Watton, from the Australian organization Touching Base, believes for people with disabilities, being able to pay for sex is a right. She acknowledges that society should change but feels that in the meantime sex should be available.

Forty-four percent of people in a *Guardian* poll said they had never had sex with someone with a physical disability and probably wouldn't. Those odds don't work well for a disabled person looking for a shag.

Watton stars in a documentary, *Scarlet Road*, about her life with Touching Base and providing sex to disabled people. The film doesn't address the issues that some sex workers face in terms of exploitation; indeed, the white sex workers featured appear to dismiss and invalidate the experiences of exploited workers. I was pleased to see that disabled people were included in the documentary, but the language used about them wasn't always so positive. The word "they" to refer to all disabled people was used a lot, as was "deserving," which to me can conjure up ideas of pity and can feel demeaning. Why do I deserve sex more than the next person? Does my disability make me that special?

However, *Scarlet Road* wasn't all bad. It talked about developing training for sex workers who were working with disabled people. This included things like manual handling and ways of communicating. This has potential to lead to resources and a bank of knowledge for disabled people and their partners.

Within this discussion, the most important voices are those of disabled people and the sex workers. *Disability Now* conducted a survey in 2005 which revealed that 22 percent of disabled male respondents (compared to an estimated 10 percent if you look at the whole male population) reported having paid for sexual services, compared to just 1 percent of disabled women. Similarly, just 16 percent of disabled women had considered paying for sex compared to nearly 38 percent of disabled men. This figure increases if you ask about paying to see specially trained sex workers.

Would legalizing sex work for disabled clients make the industry safer for the sex workers? The pros and cons of legalization are far too big a discussion to go into in this blog, but it is an important part of the conversation so I'd highly suggest going away and doing some reading about it.

What about the therapeutic benefits of sex? Orgasms can help reduce pain; being touched in a non-functional way can have mental-health benefits, and sex can be relaxing.

Would allowing disabled people to pay for sex normalize the idea of disabled people as sexual beings? Or would it make it easier to see us as "freaks"?

## Examples of Where This Already Happens

Mark O'Brien, a disabled writer, wrote:

I wanted to be loved . . . held, caressed, and valued. But my self-hatred and fear were too intense. I doubted I deserved to be loved . . . Most of the disabled people I knew . . . were sexually active, including disabled people as deformed as I. But nothing ever happened.

O'Brien went on to see a sex surrogate and lost his virginity with her.

In Holland and Denmark, support needed around sexuality and sex is something which social workers discuss with their disabled clients and have funded visits to sex workers or sex assistants.

A sexual assistant is a Dutch model which seems to offer a non-penetrative sexual service, instead more focused on erotic massage and teaching. Some sites suggest no kissing, no oral sex and no penetration. Perhaps a sex surrogate lite?

The horrifically named White Hands offer a masturbation service to disabled men in Japan (I'm hoping something got lost in translation of the name because there are some troubling connotations with its English version). The video I watched spoke of clients who didn't understand their sexual urges and desires and who got confused or ended up hurting themselves because they didn't know what to do with their feelings. The service appears to help clients understand how to react to sexual urges as well as providing masturbation for physically disabled men. From my perspective, it felt rather clinical, slightly reminiscent of the Victorian woman going to her doctor to have her hysteria treated by orgasm.

## And Against . . .

Returning to Rachel Watton's stance on the issue—society should change, but until it does, sex should be purchasable. An argument could be made that providing the service could hinder or prevent society from changing. It puts a bandage over the issue and means that it's less visible. Disabled people have a means of having sex, so society no longer needs to address discrimination or perceptions of disabled people.

Legalizing paying for sex for disabled people is a way of ignoring the issue of disability and sexuality; society doesn't need to change because we can get sex at a brothel (assuming it's accessible of course!). It's an attempt to pacify us. It also assumes that disabled people are only looking for the physical side of sex and that we don't want or don't deserve an intimate relationship. It feels like allowing sex work for disabled people checks off the box of the functional desire for sex and allows society to ignore the need for intimacy, which would require a lot more change and participation of society to achieve.

Allowing disabled people to pay for sex focuses heavily on the individual disabled people who may want to use this service and adapting things for them rather than on changing society. This approach feels much more in line with the medical model approach of disability: something is at fault with this person—let's fix them rather than addressing how disability is perceived and how we are disabled by society. If disabled people were seen as accepted members of the community, would we even be having this discussion?

In an *Atlantic* article, Alex Ghenis and Mik Scarlet echo this tokenistic gesture and the troubling implications on how we're seen by others.

Alex Chenis, an American disability advocate and former dating and relationships columnist says of paying for sex: "It commodifies sex in terms of an action. It makes it so society can check this box that men are getting laid, so we don't have to have broader social change—we are giving them sex through a brothel, so we don't have to change our social attitudes around socially excluded people with disabilities . . . And it pities and coddles us, as if we are being given things that will assuage us . . . rather than have society change around us."

Mik Scarlet, a disabled TV presenter and musician: "Imagine this, I'm disabled, growing up in Luton, and it's now legal for me to go to a brothel—to have sex for money—because apparently that's the only way I'm going to lose my virginity. Instantly, my relationship with sex is distorted, and it means that everyone I meet afterwards is going to say, 'He's disabled, that means he's paid for sex; I don't want to go to bed with someone who's paid for it.' You've reinforced the fact that you can't give it away because you've paid for it. We are reinforcing the idea that some people are too hideous and too disabled to have sex like the rest of us, and so they have to pay for it."

Paying for sex risks making us more "other." It could demean our (unpaid for) sexual experiences—the idea that if you're disabled, you've probably had to pay for sex and if you've paid for sex, the experience is therefore lesser. Paying for sex could further marginalize people with disability. It reinforces the idea we are too ugly, too broken, too disabled to have sex and not pay. It also makes us "special," a subset of society who are "allowed" to buy sex. It feels like a strange extension of the charity model of care.

Paying for sex is also expensive, especially if your disability means you can't work or you live in poverty. This could result in more division within the disabled community—a tier where more privileged disabled people can afford to pay for sex and less privileged can't. Some people would argue that benefits shouldn't be spent on sex, but I don't feel you can police what people do with their money. Some countries do pay for disabled people to access sex services rather than the disabled person paying themselves.

There is also potential for sex workers who specialize in sex with disabled people to be seen as a higher class of sex worker. An elevated role. Or by allowing sex workers for disabled people, the argument for sex work more generally could be justified.

When it comes to consent, there are the issues of the sex worker (are they freely consenting to the work they're doing?) as well as issues of consent for the disabled person. If you happen to have seen *Who's Driving Doug*, you may recall a scene where Doug (a disabled man) has been bought a prostitute by his driver. He seems reluctant to make use of this "present" but ends up going ahead with encouragement from the driver, his friend and the worker (who possibly wouldn't get paid otherwise?). Whilst I think it was a consensual act, it highlighted the pressures that

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can lead to coerced consent. Feeling that peer pressure means you can't refuse: spending the money and then changing your mind or feeling you can't call a stop to things. Consider the pressure society puts on people to lose their virginity, or situations where someone is nonverbal and someone else decides that of course this person would want to use a sex worker because it's "normal" to have sex. What about situations involving dementia or other memory issues? And what if someone appears to be consenting but actually doesn't have the mental capacity to do so? And communication issues?

## **All About the (Straight) Men?**

Perhaps unsurprisingly, most of the information around this topic I could find is focused on disabled men. From what I could find, there are far more female sex surrogates which suggests that it's easier for straight men to find someone. Something I read also suggested that disabled women felt more at risk of abuse from male sex workers than disabled men with female sex workers.

## **And in Conclusion . . .**

I'm not actually going to conclude anything. It's a complicated, multi-faceted topic and there's too much I still don't know and I still have too many questions. I hope that this post has raised some of the arguments for and concerns with the idea of sex workers for disabled people.

# Prenatal Testing and Abortion

*Should expectant mothers screen for disease and disability, or does this practice threaten the lives of disabled people before they're even born?*

## A. THE BENEFITS OF PRENATAL TESTING

*from WhatToExpect.com*

If you're nearing the end of your first trimester, your doctor has likely already mentioned prenatal testing. And if you're like most new parents, you might be wondering what it's all about—and whether it's for you. While most pregnant women receive high-level screens for some chromosomal abnormalities with their first trimester blood work, your doctor may suggest more specific screenings—including noninvasive prenatal testing (NIPT) and nuchal translucency (NT)—toward the end of your first trimester, especially if you're considered high-risk (you're over 35 or have a family history of genetic birth defects). These tests don't look for every possible disorder, though they do help identify the most common ones.

The decision to get tested is totally up to you, so talk to your doctor about your options. In the meantime, here are a few advantages of prenatal screenings to consider:

### **You May Feel More Relaxed If You're Informed**

In the vast majority of cases, prenatal testing will tell you that your baby is almost certainly developing normally, and that peace of mind is priceless. Luckily, the latest testing is more accurate than ever—so while a false positive result can happen, it's

M. Tennant

increasingly less likely. Keep in mind: a positive result on a prenatal screening still doesn't mean your baby definitely has a certain condition (prenatal screenings can't diagnose a condition; they only tell you your baby's risk of having it). If you test positive, your doctor will discuss best next steps, which usually involve meeting with a genetic counselor and opting for invasive prenatal tests (like amniocentesis or chorionic villus sampling) that can diagnose the condition with certainty.

If an abnormality is detected, there are benefits to knowing in advance of your baby's birthday, too.

## **You Can Arrange for Procedures During Pregnancy**

If your baby has an abnormality that can be addressed while you're still pregnant, *knowing before you go into labor can be a big advantage*: In some cases, you can take action. If your doctor finds a serious heart condition, for example, you may be able to opt for a pre-birth procedure to correct it, if necessary, rather than waiting until after your baby is born. Or, a specialist can be on hand soon after you deliver to help.

## **You Put Time on Your Side**

Knowing you're expecting a child with special needs gives you time to prepare—both emotionally and practically. You can:

- **Get informed.** Talk to genetic counselors and doctors specializing in your child's condition and ask where you can get more information. By researching the condition now, you and your partner will better understand it and feel better prepared for your child's arrival.
- **Seek out counseling and support groups.** A condition-specific support group with other parents in the same situation provides community and answers. St. Joseph's Hospital in Orange, NJ holds regular "perinatal collaborative conferences" to help parents realistically plan a course of action for lethal defects like trisomy 13. The 22Q Foundation helps inform and support families with a child born with the 22q microdeletion, while the National Down Syndrome Society links parents to local support groups.
- **Give birth at the right facility.** Depending on your child's condition, you may want to arrange to give birth at a specialized hospital. What's more, many of these hospitals that cater to high-risk births already have support groups in their community outreach programs.

- Arrange special care for your child. Lining up a pediatrician with specialized training while you're still pregnant guarantees care specific to your little one's condition from the day he arrives.

## **You Can Treat a Condition That Doctors Might Not Otherwise Detect at Birth**

Even if you'll love the baby no matter the results of a genetic test, some conditions aren't obvious at birth or even months later, like 22q. Without screening, your child could have symptoms that take longer to pinpoint and treat. Prenatal screenings, however, can help you to discover conditions early, so your child can receive treatment from the moment she's born. This, in turn, can sometimes help prevent symptoms. In the case of 22q, your child could have difficulty maintaining calcium or immune system deficiencies—but by knowing about the condition at birth, doctors can immediately begin monitoring your child's calcium levels or avoid giving her vaccines (which can be deadly).

Parenthood is always a journey into the unknown, but prenatal testing allows for a little more control and reassurance. Though it's very likely your baby will be born healthy and normal, modern technology can help you to make the choices that are best for you and your family.

## **B. DISABLED U.K. LAWMAKER: END ABORTION DISCRIMINATION AGAINST DISABLED**

*by Michael Tennant*

Declaring current abortion law in the United Kingdom "eugenic," Lord Kevin Shinkwin offered an impassioned speech urging passage of a bill he introduced to put an end to the law's "corrosive, unjust and deeply discriminatory" language that permits aborting a disabled baby right up to the time of his birth while restricting the time during which a healthy baby may be aborted.

"From this disabled person's perspective, there is a stark anomaly, an inconsistency in the law, whereby discrimination on grounds of disability is both prohibited in law after birth yet, confusingly, actually enshrined in law at the very point at which the discrimination begins, at source, before birth," Shinkwin, who has the genetic disorder brittle bone disease, said during his opening remarks on the second reading of his Abortion (Disability Equality) Bill in the House of Lords.

The U.K.'s Abortion Act of 1967 permits the abortion of babies during their first 24 weeks of gestation. Section 1(1)(d) of the act, however, also allows for abortion at any time prior to delivery, not just the first 24 weeks, if "there is a substantial risk



M. Tennant

that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."

"It is illegal for an unborn human being to have their life ended by abortion beyond 24 weeks, but if they have a disability their life can be ended right up to birth by law. Where is the consistency, the justice or the equality in that?" Shinkwin asked when introducing the bill earlier this year.

"If anyone thinks such obvious discrimination is acceptable, I respectfully invite them to imagine the outcry if the same were applied to skin color or sexual orientation. Such discrimination would rightly be regarded as outrageous."

Whether or not one finds discrimination on particular grounds to be "outrageous" and worthy of legal prohibition when applied to those who have been born, the fact is that the U.K. government does indeed have various laws prohibiting such discrimination while simultaneously encouraging discrimination against disabled babies in the womb.

"Our legislation currently affords unborn disabled babies significantly less protection than that which is afforded those who are able bodied," Lord David Alton said in his remarks supporting Shinkwin's bill. "Paradoxically, we will campaign and raise our voices for wheelchair ramps to be placed on public buildings but fail to uphold the innate right to life itself of the disabled person who uses that wheelchair."

The Lords are not speaking hypothetically. With the increase in prenatal screenings for various disabilities has indeed come an increase in abortions to prevent the "unfit" from being born—a practice "of which a particular regime of the 1930s and 1940s would heartily approve," Shinkwin pointedly observed.

"For unborn babies whose disability is detected, a mother's womb has become an increasingly dangerous place," he averred.

Citing statistics from the Department of Health—statistics that a 2014 review found were likely too low because of underreporting—Shinkwin noted that the number of abortions after 24 weeks on the grounds of disability had increased 271 percent over the last 20 years and 56 percent in just the last five. The overall number of abortions on the grounds of disability, regardless of the point of gestation at which they occurred, has grown by 68 percent over the last 10 years. Over one-fifth of the unborn terminated in 2015 were aborted because they had Down syndrome. Alton pointed out that already about 90 percent of Down syndrome babies are aborted; that rate is almost certain to rise even higher once the government implements a new technique that can detect the condition in unborn babies with 99-percent accuracy. In addition, Shinkwin said, last year 11 babies were aborted because they had cleft lip or palate despite the fact that such a condition can now be easily corrected via surgery.

"I find the contrast between the 0.3-percent decline over the last decade in the number of overall abortions and the rise in the number of abortions on unborn babies detected with a disability alarming and deeply offensive," Shinkwin added.

"What does it say about us and our society," inquired Alton, "when amniocentesis and other tests are used as part of [a] search and destroy mission with barely a murmur of dissent?"

Alton pointed to government reports showing that parents in the U.K. are routinely pressured into aborting their babies if prenatal tests detect any disabilities. Mothers reported that their doctors became angry with them for refusing to abort; one said her doctor "threatened that all medical help would be denied." Those who gave birth to disabled children claimed they were later criticized by their doctors for having failed to abort. One parent said, "I have heard views expressed that suggest my child is seen as a drain on resources."

This is hardly unexpected in a country in which the government owns and operates the health care system. And doctors, having become agents of the state rather than advocates for their patients, are only too willing to go along with the program.

"As a disabled person," said Shinkwin, "I am a prime candidate for abortion on the grounds of disability. I admit that I would like to say to the eugenicists in the Department of Health and those who obviously fail to appreciate the enormity of what is being perpetrated in our name: 'How dare you? How dare you wipe us out as mere conditions?'"

Of course, as Shinkwin well understands, they "dare" because the practice of aborting disabled babies has become "normalized," even expected. "I suggest that, collectively, we are in denial about the consequences of the choices we have made," he maintained.

One of those consequences, remarked Alton, is that the disabled who are born are viewed with disdain. "What does it say to the survivors—those who have been inconsiderate enough to avoid the perfection test and have somehow managed to slip through the net?" he asked.

Shinkwin recognizes that his bill, which would strike Section 1(1)(d) of the Abortion Act, will not put an end to the practice of aborting babies because of detected disabilities, but it will at least restrict the time period in which they may be aborted, putting them on an equal footing with nondisabled babies. Moreover, wrote *Live Action News*, "If passed, Lord Shinkwin's bill could be the most significant pro-life legislation since abortion was legalized in the UK."

# Assisted Suicide

*Should people be allowed to seek assistance in ending their lives, or does legalizing assisted suicide present too great a threat to vulnerable people?*

## A. THE DANGER OF ASSISTED SUICIDE LAWS

*by Marilyn Golden*

My heart goes out to Brittany Maynard, who is dying of brain cancer and who wrote last week about her desire for what is often referred to as “death with dignity.”

Yet while I have every sympathy for her situation, it is important to remember that for every case such as this, there are hundreds—or thousands—more people who could be significantly harmed if assisted suicide is legal.

The legalization of assisted suicide always appears acceptable when the focus is solely on an individual. But it is important to remember that doing so would have repercussions across all of society, and would put many people at risk of immense harm. After all, not every terminal prognosis is correct, and not everyone has a loving husband, family or support system.

As an advocate working on behalf of disability rights for 37 years, and as someone who uses a wheelchair, I am all too familiar with the explicit and implicit pressures faced by people living with chronic or serious disability or disease. But the reality is that legalizing assisted suicide is a deadly mix with the broken, profit-driven health care system we have in the United States.

At less than \$300, assisted suicide is, to put it bluntly, the cheapest treatment for a terminal illness. This means that in places where assisted suicide is legal, coercion is not even necessary. If life-sustaining expensive treatment is denied or even merely delayed, patients will be steered toward assisted suicide, where it is legal.

This problem applies to government-funded health care as well.

In 2008 came the story that Barbara Wagner, a Springfield, Oregon, woman diagnosed with lung cancer and prescribed a chemotherapy drug by her personal physician, had reportedly received a letter from the Oregon Health Plan stating that her chemotherapy treatment would not be covered. She said she was told that instead, they would pay for, among other things, her assisted suicide.

"To say to someone: 'We'll pay for you to die, but not for you to live'—it's cruel," she said.

Another Oregon resident, 53-year-old Randy Stroup, was diagnosed with prostate cancer. Like Wagner, Stroup was reportedly denied approval of his prescribed chemotherapy treatment and instead offered coverage for assisted suicide.

Meanwhile, where assisted suicide is legal, an heir or abusive caregiver may steer someone toward assisted suicide, witness the request, pick up the lethal dose, and even give the drug—no witnesses are required at the death, so who would know? This can occur despite the fact that diagnoses of terminal illness are often wrong, leading people to give up on treatment and lose good years of their lives.

True, "safeguards" have been put in place where assisted suicide is legal. But in practical terms, they provide no protection. For example, people with a history of depression and suicide attempts have received the lethal drugs. Michael Freeland of Oregon reportedly had a 40-year history of significant depression, yet he received lethal drugs in Oregon.

These risks are simply not worth the price of assisted suicide.

Available data suggests that pain is rarely the reason why people choose assisted suicide. Instead, most people do so because they fear burdening their families or becoming disabled or dependent.

Anyone dying in discomfort that is not otherwise relievable, may legally today, in all 50 states, receive palliative sedation, wherein the patient is sedated to the point at which the discomfort is relieved while the dying process takes place peacefully. This means that today there is a legal solution to painful and uncomfortable deaths, one that does not raise the very serious problems of legalizing assisted suicide.

The debate about assisted suicide is not new, but voters and elected officials grow very wary of it when they learn the facts. Just in 2014 alone, assisted suicide bills were rejected in Massachusetts, New Hampshire, and Connecticut, and stalled in New Jersey, due to bipartisan, grassroots opposition from a broad coalition of groups spanning the political spectrum from left to right, including disability rights organizations, medical professionals and associations, palliative care specialists, hospice workers, and faith-based organizations.

Assisted suicide is a unique issue that breaks down ideological boundaries and requires us to consider those potentially most vulnerable in our society.

All this means that we should, as a society, strive for better options to address the fear and uncertainty articulated by Brittany Maynard. But if assisted suicide is

M. Golden

legal, some people's lives will be ended without their consent, through mistakes and abuse. No safeguards have ever been enacted or proposed that can properly prevent this outcome, one that can never be undone.

Ultimately, when looking at the bigger picture, and not just individual cases, one thing becomes clear: Any benefits from assisted suicide are simply not worth the real and significant risks of this dangerous public policy.

## **B. ASSISTED SUICIDE SHOULD BE LEGAL**

*by Rafia Zakaria*

On Oct. 12, 2014, Brittany Maynard, 29, who suffers from inoperable terminal brain cancer, announced plans to voluntarily end her life. Maynard's diagnosis means she will eventually lose all cognitive capabilities. Refusing aggressive chemotherapy treatment, Maynard decided to move to Oregon, where physician-assisted suicide is legal. Under Oregon's Death With Dignity Act, mentally competent terminally ill patients with less than six months to live can elect when to die by taking lethal doses of prescribed drugs. With only a month left to live, Maynard has made her death into a campaign for terminally ill patients' right to die.

However, her decision has been met with fervent opposition from disability rights advocates and religious conservatives. The freedom to live according to one's beliefs and choices is duly recognized and celebrated in the United States. But terminally ill patients who wish to choose death with dignity versus a painful and prolonged end often face an enormous challenge even to obtain life-ending drugs. Denying mentally capable individuals the right to end their lives in a peaceful manner is a denial of their individual rights to self-determination and freedom of choice.

Oregon is one of only five U.S. states—along with Vermont, Washington, Montana and New Mexico—that allow medically assisted suicide. In the rest of the country, assisting people with suicide (even if they are terminally ill) is a crime. Maynard's campaign highlights just how intrusive and unfair the laws criminalizing assisted suicide are for terminally ill patients and their families. For one, these patients must accept and live with their diagnosis. Second, asking a loved one to help end their suffering bears the cost of exposing them to the threat of prosecution and jail time.

The fear of prosecution for family members who help terminally ill patients is not theoretical. Last year Barbara Mancini, a 57-year-old nurse in Pennsylvania, was prosecuted for handing her father, John Yourshaw, a lethal dose of morphine. Yourshaw was a home hospice patient in failing health and had repeatedly expressed to family members his wish to die. Mancini was charged with a felony after an autopsy showed that her father died from a morphine overdose. The case was eventually dismissed but not before costing Mancini her job and more than \$100,000 in legal fees.

Fear of prosecution is not the only hurdle facing advocates of death with dignity. Disability rights activists and religious conservatives have been very vocal about the ethics regarding assisted suicide laws. "There are hundreds—or thousands—more people who could be significantly harmed if assisted suicide is legal," Marilyn Golden, a senior policy analyst at the Disability Rights Education and Defense Fund, wrote in response to Maynard's announcement. Golden maintains that prognoses of terminal illness are often wrong and the disabled or terminally ill may be encouraged to choose assisted suicide for cost reasons. She adds that dying from illness is not necessarily painful because of "palliative sedation."

To be sure, there may be terminally ill patients who wish to cling to the possibility of incorrect diagnosis. But most people are convinced of their fatal prognosis, given the advances in medical technology. Besides, there is scant evidence of misuse and no local movements to repeal the laws in states that have death with dignity statutes.

Golden's assertions regarding treatment costs as a factor in choosing assisted death, particularly for the poor, also do not hold up. A 2007 study published by *The Journal of Medical Ethics* found "no evidence of heightened risk for the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses, including depression, or racial or ethnic minorities" from the death with dignity statutes in Oregon and the Netherlands.

The criticisms of disability rights advocates suffer from one central contradiction. They claim to protect the terminally ill (who are also often disabled) by insuring that they do not get steered into ending their lives. But that argument takes the crucial decision of choosing death with dignity away from the very people they purport to advocate for. Death with dignity statutes such as the one in Oregon allow cognitively capable patients to decide when and how to end their lives, regardless of their physical abilities. Hence, opposing physician-assisted suicide denies those disabled by terminal illness the right to control their deaths despite the fact that they suffer no cognitive impairment.

## Support For the Right To Die

Religious conservatives oppose assisted death on the basis of their beliefs about the worth of life and the meaning of suffering. For example, Kara Tippetts, a devout Christian who is terminally ill, acknowledged in a letter to Maynard the pain of knowing one's days are numbered. "But it was never intended for us to decide when that last breath is breathed," wrote Tippetts. "Brittany, when we trust Jesus to be the carrier, protector, redeemer of our hearts, death is no longer dying. My heart longs for you to know this truth, this love, this forever living." As with most religious opponents of assisted suicide, Tippetts applies her own definitions of the transcendent

R. Zakaria

value of suffering and the existence of an afterlife on others, including those with differing views.

But none of these arguments are new. What is new, however, is the number of people who are engaged in the right-to-die debate because of Maynard's decision. A recent Gallup survey shows that seven out of ten Americans polled supported some form of physician-assisted suicide. It's a dramatic increase from just over 50 percent in 1970s. Legislatures in Hawaii, Kansas, Massachusetts, New Jersey and Pennsylvania have recently introduced death with dignity bills, with votes in New Jersey and Pennsylvania expected this year. Maynard's campaign may serve as the catalyst for other states to consider similar laws.

A handful of European countries—the Netherlands, Belgium, Switzerland and Luxembourg—have legalized physician-assisted death. But the U.S. doesn't have to look that far for examples. On Oct. 15 the Canadian Supreme Court heard oral arguments on reversing a two-decade-old precedent, which would decriminalize assisted death and even permit physician-assisted suicide.

As the representative from Quebec, which has already legalized the measure, rightly noted, death is part of life, and assistance in death is not suicide but should more accurately be described as end-of-life care. Unfortunately, that kind of thoughtful debate continues to be absent from our discourse in the United States, where death with dignity is often not an option for the terminally ill.

# Cochlear Implants

*Do cochlear implants endanger the future of the Deaf community, or should people use this technology to improve hearing?*

## **A. INFANTS MAY BENEFIT FROM ADVANCED COCHLEAR IMPLANTS**

*by Brian Owens*

Cochlear implants are powerful tools for people with hearing loss. Using electrodes implanted in the ear that transmit sound directly to the brain, they can give even the profoundly deaf a sense of sound.

But their success often depends on how early the implants are placed. People who are born deaf and receive implants as adults have worse outcomes than those who are fitted with the implants as children, said Andrea Warner-Czyz, an audiologist at the University of Texas at Dallas who studies development in children with hearing loss.

This is at least partly because as people with hearing loss grow older, the parts of their brain that are normally used to process sounds are reassigned to other jobs, such as visual processing. Once these reassignments occur, it is difficult to re-train them to do anything else.

The brains of children, by contrast, are much more flexible, and can adapt quickly to process the signals coming from their implants, so cochlear implants are most successful when implanted at a young age.

The Food and Drug Administration advises that children should be at least 12 months old before receiving a cochlear implant, but Warner-Czyz wondered whether they would benefit from receiving the implants even earlier.



B. Owens

"We always want to push the envelope, we're trying to figure out if we get them implants before 12 months, is that going to be better?" she said. Some children do receive their implants earlier than the FDA-approved age.

The question that Warner-Czyz wanted to answer was: Can infants at that age properly process the information from the implants? She and her colleagues explored this question in a study recently published in the *Journal of the Acoustical Society of America*.

Cochlear implants have two main parts. First, sound is collected by a microphone that sits outside the ear like a traditional hearing aid. The sound signal is analyzed in a speech processor where it is coded for intensity, frequency and duration. Then, the coded signal is transmitted across the skin to an array of electrodes that have been surgically implanted in the cochlea, which is located in the inner ear. That array directly stimulates the auditory nerve to transmit the sound signal to the brain.

But the implants do not reproduce sounds exactly. The implant groups similar sounds into channels, collecting information on the sounds' general frequencies, but losing their finer details. The more channels there are, the more information is provided about the sounds. Typical implants have between 12 and 22 channels. Those are more than enough for adults, who only need eight or nine channels to understand speech. But younger people, whose brains are less developed, need more. Preschoolers need between 12 and 16 channels to reliably understand speech.

So Warner-Czyz wanted to find out whether infants, whose brains are even less developed, would need even more information to distinguish different sounds.

She took a group of 6-month-old children with normal hearing and played them one of two sounds, either "ti" or "ta." Once they became accustomed to that sound, they listened to a series of both sounds; this time, the sounds were played either through a normal speaker, or processed by an audio device known as a vocoder to sound like a 16- or 32-channel cochlear implant, to see if the children could tell the difference.

When the sounds were unprocessed, or played through 32 channels, the children could easily distinguish between the two sounds. But with 16 channels, they could not.

"Infants may need more information than cochlear implants are able to give them at this time," said Warner-Czyz.

Having more channels could help.

"If we can increase the channels, and improve the signal that they're getting, then maybe we can improve the outcomes for language and speech and hearing for those getting implants at early ages," she explained.

Mario Svirsky, a speech and hearing scientist at New York University in New York City, said that the work tells us important things about how infants understand degraded speech, but he cautions that the standard method of using a vocoder to mimic what a cochlear implant user hears is "woefully inadequate."

the use of ASL. In practice, this translates to teaching communication methods like lip reading, learning to speak (by imitating breathing patterns and mouth shapes) and, relatively recently, using cochlear implant technology.

AGB's reasons for their oral focus depend who you ask. When reached for comment, Susan Boswell, director of communications and marketing for AGB, told me that AGB "supports the development of spoken language through evidence-based practices focusing on the use of audition and appropriate technologies." When I asked Ruthie Jordan, a Deaf activist who runs Audism Free America and helped organize the rally against AGB, she told me the reason is much more bottom-line. (I spoke with Ruthie and other Deaf people at the rally through my interpreter, Drew Tolson, who was extremely helpful.)

Ruthie's take is that AGB "[Makes] money . . . by miseducating the parents of Deaf children." Like many others at the rally, Ruthie feels that AGB takes advantage of the fact that hearing parents may not understand how a Deaf child can lead a functional, fulfilling life. A hearing parent in this situation may be easily convinced that a cochlear implant and an oral-based approach is the only legitimate option.

AGB's "listening and spoken language"-based approach comes out of the school of oralism, which aims to educate Deaf children through the use of oral speech and lip reading (as opposed to manualism, which advocates for the primary use of ASL in Deaf education). The goals of oralism may not sound controversial to most hearing people, but oralism has a long and problematic history.

In the 1860s, Alexander Graham Bell was a prominent oralist, and to some, an important figure in the spreading of audism—the belief that it is inherently better to be able to speak and hear. Although he surely thought otherwise, Bell had an ugly relationship with the Deaf community. Though his mother and wife were Deaf, he was intent on wiping out "hereditary deafness." He removed Deaf faculty from schools, demanded the same schools stop their use of ASL, and advocated against "deaf intermarriage."

Bell was also involved in the Eugenics movement, serving for a time as chairman of the board of scientific advisers to the Eugenics Record Office.

In 1880, prompted by talks between Bell and other prominent figures in deaf education, 164 delegates met for the Second International Congress on Education of the Deaf. Only one of the delegates was deaf. At the conference, a resolution was passed that banned sign language in schools, in an effort to encourage spoken language skills, and thus "[restore] the deaf-mute to society." Other passages in the resolution urge us to "[consider] the incontestable superiority of speech over signs," and argue that teaching deaf people to speak English will "[give them] a more perfect knowledge of language." After its passage, schools in Europe and the United States ceased all use of sign language.

Given this history, some Deaf people feel that oralism is rooted in audism. Some argue that the sentiment of needing to "restore [Deaf people] to society" still underlies

the AGB and companies affiliated with them. In fact, many Deaf people and Deaf allies, like the ones at the rally, strongly oppose the AGB and their affiliates. These people argue that the AGB and its affiliates propagate practices that harm Deaf people, all for the sake of making money. And indeed, AGB has a financial stake in the sales of cochlear implants as well as other "hearing technology."

In addition to running an academy that trains teachers in oral-based educational methods, AGB "provides advertising opportunities to companies seeking to promote their products to individuals who are deaf and hard of hearing." According to AGB's website, one of their "partners in hearing" is Med-El, a large manufacturer of cochlear implants. As I mentioned earlier, the exhibitors and sponsors for their 2013 symposium include a long list of companies who sell or otherwise advocate for cochlear implant technology: Advanced Bionics, Cochlear America, the American Cochlear Implant Alliance, and many others.

Those who oppose the AGB's practices argue that this is a large coalition of companies that stand to benefit from the sale of cochlear implants. This, they argue, is a conflict of interest, and renders any information distributed by these companies untrustworthy. Ruthie Jordan told me she feels that AGB is "miseducating the parents of Deaf children . . . [AGB is] earning their millions by perpetuating misinformation. They are using the ears and the bodies of Deaf people to make themselves rich." She thinks AGB's actions are "only related to spoken language and 'fixing' Deaf people . . . they see Deaf people as sick, disabled, as having a deficit."

Many within Deaf culture feel similarly. They argue that the AGB harms Deaf communities by propagating large amounts of information about oralist methods—including cochlear implants—and treating ASL as "less than" spoken English.

The controversy is sometimes difficult for hearing people to understand. Hearing people often assume that Deaf people would naturally want to take advantage of any method that could lead them to become part of the hearing world—especially cochlear implants, the most advanced hearing technology we have. In reality, that assumption is far from true. To members of Deaf culture, American Sign Language is a cultural cornerstone. Because Deaf children who receive cochlear implants at a young age will likely be educated in the oralist method, they are less likely to learn ASL during their early years, which are the most critical years of language acquisition. For some Deaf parents, that would result in a child who speaks a different language than they do. Understandably, some see this as a loss of culture—one that, in some cases, has been passed down through generations. What may seem to a hearing person like an opportunity may be seen by some Deaf people as a loss.

The debate stems from a fundamental disagreement: one group sees deafness as a disability, and the other group sees it as a culture. The trouble is that the former group holds a disproportionate amount of power, and the latter group are the ones affected.

A. Ringo

Jeff DuPree volunteers with Audism Free America, and is a proud sixth-generation Deaf person. I spoke with him through an interpreter at the symposium. Jeff told me,

My whole life I've lived as a Deaf person. I married a Deaf person, I've worked and associated with Deaf people, and I've had no problem in this world. So why are organizations like this trying to take away my right to live the way I want to live, my right to raise my children the way I feel they should be raised?

It's not an easy question to answer. For their part, AGB maintains that they are simply advocates for the Deaf and hard of hearing. They point to the many people who, they argue, they have helped, by giving them information, grants, or general guidance related to cochlear implants and overall oral-focused education. AGB's website states that they "[Help] to ensure that every child and adult with hearing loss has the opportunity to listen, talk and thrive in mainstream society."

That's not a disingenuous statement. The question is whether the affected people are receiving the full truth about "mainstream society."

# Nondisabled Actors in Disabled Roles

*Should audiences reject nondisabled actors who “crip up” for roles, or should disabled roles be open to all kinds of performers?*

## **A. WE WOULDN'T ACCEPT ACTORS BLACKING UP, SO WHY APPLAUD “CRIPPING UP”?**

*by Frances Ryan*

“If you do a film about the Holocaust, you’re guaranteed an Oscar,” goes the famous Kate Winslet joke in *Extras*. The same can be said for an actor doing a film about disability. Unless you’re a disabled actor, that is. Then you’re lucky to even get the part.

In 2014, when Eddie Redmayne won a Golden Globe for his portrayal of Stephen Hawking in *The Theory of Everything*, he became the latest in a long line of nondisabled actors to portray disabled characters. And to walk away—literally—with an award for doing so. From Daniel Day Lewis in *My Left Foot* to Dustin Hoffman in *Rain Man*, the ability to play “disability” is a definite asset for an actor, a source of genuine acclaim.

But is this as harmless as mainstream audiences seem to see it? While “blacking up” is rightly now greeted with outrage, “cripping up” is still greeted with awards. Is there actually much difference between the two? In both cases, actors use prosthetics or props to alter their appearance in order to look like someone from a minority group. In both cases they often manipulate their voice or body to mimic them. They take a job from an actor who genuinely has that characteristic, and, in doing so, perpetuate that group’s underrepresentation in the industry. They do it for the entertainment of crowds who, by and large, are part of the majority group.

F. Ryan

The explanations for “cripping up” are obvious. The entertainment industry is a business, after all, and stars sell. When Daniel Radcliffe played a disabled orphan in *The Cripple of Inishmaan* this won more headlines for the production than if a disabled, lesser-known actor had been cast. On a practical level too, perhaps hiring a non-disabled actor is easier. The ability to walk allows Redmayne to portray Hawking before being diagnosed with motor neurone disease. But I can’t get away from the fact that, if these arguments were made for white actors “playing black,” our outrage would be so great that the scenes would be left on the cutting room floor.

There’s a theory of why nondisabled actors playing disabled characters leads to success: audiences find it reassuring. Christopher Shinn, a playwright who had a below-the-knee amputation, describes the act of watching a disabled character being played by an actor who we know is really fit and well as allowing society’s “fear and loathing around disability” to be “magically transcended.”

When it comes down to it, Shinn says, “pop culture is more interested in disability as a metaphor than in disability as something that happens to real people.”

After all, disabled characters create powerful images and sentiments for audiences. They can symbolize the triumph of the human spirit over so-called “adversity.” They can represent what it is to be “different” in some way, an outsider or an underdog who ultimately becomes inspirational. These are universal feelings every audience member can identify with. And there is something a little comforting in knowing, as we watch the star jump around the red carpet, that none of it—the pain or negativity we still associate with disability—was real.

Perhaps that’s part of the problem. Perhaps as a society we see disability as a painful external extra rather than a proud, integral part of a person, and so it doesn’t seem quite as insulting to have nondisabled actors don prosthetics or get up from a wheelchair when the director yells “cut.” But for many disabled people in the audience, this is watching another person fake their identity. When it comes to race, we believe it is wrong for the story of someone from a minority to be depicted by a member of the dominant group for mass entertainment. But we don’t grant disabled people the same right to self-representation.

Perhaps it is time to think before we next applaud “cripping up.” Disabled people’s lives are more than something for nondisabled actors to play at.

## **B. ABLE-BODIED ACTORS IN DISABLED ROLES: MODERN-DAY “BLACKING UP” . . . OR IS IT?**

*by Tony Seymour*

Eddie Redmayne recently received a Golden Globe and a good deal of well-deserved praise for his role as the young Stephen Hawking in James Marsh’s *The Theory of Everything*. The film charts the young physicist, who developed motor neurone disease

(MND), whilst courting his first wife. It has already attracted critical acclaim around the world, notching up no less than ten BAFTA nominations and five Academy Awards nominations. However, it has not escaped criticism. Some have cited the film as yet another example where disabled actors have been overlooked in favor of their able-bodied counterparts. Is this true? Is playing a disabled character the equivalent of "blacking up"? Or a guaranteed way to secure a stash of accolades? Should disabled roles simply be the preserve of disabled actors?

Frances Ryan's recent article in the *Guardian* suggested that Eddie Redmayne's Golden Globe-winning performance of the disabled Professor Stephen Hawking was the equivalent to "blacking up."

I took this and the other points made in the column very seriously. After all, as a disabled person myself and writer of *The Mermaid in The Gherkin Jar*, I wrestled with similar issues when working with Northern Rose in bringing the story to the stage. Christopher, the disabled little boy in the book, is currently played by an able-bodied actor and I still wonder what a disabled person might think of this, were he or she to see the full studio production at The Lowry Theatre in September 2015.

The reality of casting the stage production of *The Mermaid in the Gherkin Jar* is perhaps similar to Eddie Redmayne's role in *The Theory of Everything*. In the film, Redmayne must play both the able-bodied Stephen Hawking before his MND diagnosis as well as the increasingly crippled scientist, once the disease starts to take hold. Similarly, the actor playing Christopher in *The Mermaid in the Gherkin Jar* must play able-bodied as well as disabled roles. Therefore the part of Christopher must be adopted by someone capable of slipping between disabled and nondisabled personas.

I thought reading Ryan's article might cause me to doubt this. On the contrary, it only served to assure me that disabled people are not the only ones capable of playing physically challenged parts.

A number of key points can be distilled from her column, which I will attempt to look at in turn:

1. An able-bodied actor taking on the persona of a disabled person is the equivalent of a white person wearing make-up to play a black person;
2. Playing a disabled character is a good way of securing an Oscar or some other such award;
3. Able-bodied people feel more comfortable seeing disabled roles portrayed by able-bodied actors;
4. Giving disabled roles to able-bodied actors is robbing disabled actors of a role which is rightfully theirs, denying them the right of self-representation and further perpetuating the exclusion of disabled actors from the stage; and
5. It is wrong for someone from a minority group to be depicted by someone from a majority group for mass entertainment.

T. Seymour

## 1. Is "Crippling Up" the Modern Day Equivalent of "Blacking Up?"

The first observation to make here is that Frances Ryan only seems concerned with physically disabled people. No mention is made of roles involving those with severe mental or behavioral problems. So, whilst it is acceptable for a mentally balanced person to play a manic depressive or paranoid schizophrenic, it is wrong to allow an able-bodied actor to portray a disabled character. Why? I'm not exactly sure. It seems to be an issue of perception and visual impact.

Writing as a disabled person with mild cerebral palsy, I have read the multitude of comments which followed Frances Ryan's article on the *Guardian* website. I have also researched a host of other opinions held by writers and social commentators on the issue. As such, I am only too aware of how serious and sensitive this matter is and how some disabled people may feel offended by comments which they perceive as going to the core of who they are.

However, having thought hard on this point for a couple of days, I have come to the firm conclusion that I absolutely cannot agree that the act of so-called "cripping up" is the equivalent of "blacking up" for stage and screen (at least not in the way that Frances Ryan implies).

### ***"Blacking Up" as a Derisive Act of Racism***

The practice of white actors donning makeup to assume the personas of black characters was widespread in the early 20th century where blacks were patronizingly perceived as simple, servile human beings or figures of comical derision. In other words, the roles perpetuated racism and the erroneous belief that black people or any ethnic minority for that matter, were somehow inferior to the white majority. Back then, society actively alienated and discriminated against black people.

### ***But Modern Day "Blacking Up" Still Occurs***

As Ryan asserts, the kind of "blacking up" that occurred all those years ago to poke fun and belittle black society has rightly stopped. But this is not to suggest that "blacking up" does not happen at all to enable an actor to more accurately assume a role. Sir Ben Kingsley won an Oscar for his interpretation of Mahatma Gandhi in the 1982 film of the same name. Perhaps the fact that his father was Indian helped to silence any critics, though the Yorkshire-born actor still had to wear a considerable amount of makeup for the role.

To say that wearing makeup to more accurately portray a role is an inexcusable act of bigotry seems rather exaggerated. The so called "blacking up" which occurred



in *Gandhi* was not some racist act aimed at arrogantly excluding ethnic minorities from cinema, it was the result of the late Lord Attenborough's desire to accurately depict one of the most famous freedom fighters of all time. In other words, to make Sir Ben Kingsley's characterization of Gandhi more convincing.

Eddie Redmayne was cast to play the brilliant physician because, like Sir Ben Kingsley, he is a talented actor with a proven track record. It is also apparent from the screen shots that his physicality is very similar to the young professor. He is a good "fit" and believable in the role.

For these reasons the so called "cripping up" of actors to play roles such as Stephen Hawking in *The Theory of Everything* or Christie Brown in *My Left Foot* is little if anything to do with the kind of motives behind "blacking up" which occurred so many years ago. It is in fact, more as a result of the actor's intention to transform him or herself into that role, in the same way as he or she might wear a befitting costume.

## 2. The Use of Disability to Guarantee an Award

There are many occasions where playing a physically disabled person has led to an award. The examples are numerous. However, there is a danger that pointing this out time and again begins to sound just a little cynical, if not bitter.

I don't know the criteria on which awards are presented, but I should guess they run a little deeper than an actor faking a limp or a stumbling gait. One thing is for certain, approaching topics such as disability is almost certainly quite a challenge, not just for the actor, but for the director and producers involved.

It must be the case that, in making a film such as *The Theory of Everything*, those involved wanted to be as thorough as possible in understanding the nature of Hawking's disease. That probably explains the months of research conducted by Eddie Redmayne. Amongst other things, he studied MND and visited patients who had this condition. Before even attempting to mimic the physical symptoms, a great deal of time was spent understanding what it was to have the disease. Surely that difficult challenge, if executed well, is worth an Oscar.

To turn the argument on its head, are we saying that a great actor, who happened to have MND, would stand no chance of an award were they to play a young Stephen Hawking with the same disease?

I would agree that many actors have certainly won awards on the back of portraying disabled characters, but this is not because it is not a cop out. It is because it is a tough challenge where the able-bodied actor must really be at the top of their game to carry it off successfully. If they do, it is only right that they receive the acclaim they deserve.

T. Seymour

### **3. Able-Bodied People Feel More Comfortable Seeing Disabled Roles Portrayed by Able-Bodied Actors**

I agree with Frances Ryan here. Hand on heart, there are times when I have found it hard speaking with people with severe physical impairments. It's a devastating reality with which we'd rather not deal, so I can understand how it's more reassuring to see an able-bodied actor walk away from a disabled part. Nobody likes to face a harsh truth. That does not mean we should not confront it at all, of course. Nevertheless, there are numerous films where the use of an actor and the illusion of make-believe elicits a sense of relief such as seeing brutal re-enacted scenes of the Holocaust or apartheid.

### **4. Giving Disabled Roles to Able-Bodied Actors is Robbing Disabled Actors of a Role Which is Rightfully Theirs**

I have already touched on the fact that there is more to playing a physically disabled character than simply "cripping up." Pretending to have the same physical handicap is not enough. The actor must be convincing. He or she must engage with the audience so that they buy into the story. In other words, they must draw on their subtle skills as actors to cast the magic that is necessary to make a tale genuine. If all that is needed to play a character with a given physical disability is personal experience of the same handicap, then this would give a very narrow, almost blinkered view of what it is to be an actor.

#### ***A Shortage of Disabled Actors***

Furthermore, one cannot ignore the financial perspective. Producers must make a film or theatre performance pay and so, like it or not, they require personalities who attract the crowds. To be fair, this is something that Frances Ryan readily understands.

But the criticism that able-bodied actors automatically win disabled roles over and above their disabled-bodied counterparts also seems to imply that there is a rich seam of well-known disabled talent just waiting to fill any role depicting physical impairment. This is simply not true.

The only agency which focuses on representing disabled actors in the U.K., of which I am aware, is the VisABLE Model Agency run by Louise Dyson. The agency represents well known disabled actors such as Colin Young, who played a key role in the BBC's *Call The Midwife*. VisABLE is an excellent resource for any casting director looking to hire a disabled actor, but that does not mean it is always easy to find someone for a specific role.

For instance, the role of Christopher in the physical theatre production of *The Mermaid in the Gherkin Jar* would require someone with cerebral palsy who is also capable of performing the other able-bodied elements of the piece. As someone with Christopher's condition, I can assure the reader that this is something which is really rather difficult.

On this point, one actor I did have in mind for the role of Christopher was R.J. Mitte, star of the hugely successful U.S. series, *Breaking Bad*. In many ways he would be absolutely perfect, but I doubt the production company could afford his fee. Not at the moment anyway! Furthermore, there is no guarantee that such an actor would want to audition for the part. An actor's career flourishes as his roles become more and more varied. Would any actor with a disability really be content being the "go-to" man or woman for any piece involving physical impairment? I think not.

The assumption that there is a multitude of eager actors who are missing out on plum disabled roles played by able-bodied, award-hungry actors is misleading. These roles are actually relatively few and far between and arguably not enough to sustain any acting career.

### ***Why is Disability so Precious?***

Perhaps the point that Frances Ryan made which I found most difficult to agree with was her comment that seeing an able-bodied person assuming a disabled persona is "for many people in the audience" the same as "watching another person fake their identity."

The obvious point here is that faking another identity is exactly what acting is all about. Moreover, why shouldn't able-bodied actors play disabled roles? Are these parts so sacred as to suggest that no able-bodied person could possibly interpret them accurately? I have watched a number of films depicting disability and I have never felt that my own identity as a disabled person was being faked. The idea is frankly absurd.

Mental disability has often been portrayed by healthy actors without the likes of Mencap taking to the street claiming the collective identity of their membership has somehow been faked. What is the real difference with physical disability? I just can't see it.

### **5. It is Wrong for the Story of Someone From a Minority to be Depicted by a Member of the Dominant Group for Mass Entertainment**

This statement would be beyond debate should any theatrical role be used by a "dominant group" to somehow belittle or undermine a minority. But, as I have already

mentioned, this was not the case in roles such as *Gandhi*. Far from being an insulting portrayal of the Indian revolutionary, Sir Ben Kingsley's interpretation was arguably a powerful and insightful piece of acting, worthy of great praise.

Similarly, Eddie Redmayne's portrayal of Stephen Hawking and Daniel Day Lewis's role in *My Left Foot*, to name but two, could hardly be argued in terms of a majority group capitalizing on a minority group for the sake of entertainment. I am personally thankful that actors and directors see these stories as so important that they must be told and I am happy to see them gain further publicity through their connection with famous faces.

### ***The Harsh Reality of Disability in Film***

There was a time when there were hardly any black actors in cinema, because the barriers toward them were so great. Over time the barriers to such actors broke down and more and more black artists as well as players from other ethnic minorities emerged.

The same will happen, to an extent, with disabled actors and stars like R.J. Mitte and Colin Young will, no doubt, lead the way. However they will always be few and far between. There is a very real and harsh truth to face—disabled people will always exist in far fewer numbers comparative to other minority groups, and the nature of having a disability will make it more difficult to play a wide variety of roles resulting in the majority of them losing out on blockbuster scripts.

An actor with severe cerebral palsy or MS might be able to play the role of Stephen Hawking in a wheelchair, but would find it impossible to pass off an able-bodied Cambridge student before MND took hold. An actor such as R.J. Mitte could have perhaps been a good call as an alternative for Eddie Redmayne, though bizarrely he would have to "crip down" for the first part of the film and "crip up" for the latter part. Is there any real difference? Also, as previously discussed, there is more to playing any role than simply being able to mimic the physical attributes of the character.

Similarly, casting Christopher for *The Mermaid in the Gherkin Jar* is not as simple as hiring the first actor one can find with cerebral palsy or a similar condition. After all, CP itself is a broad church that affects different people in different ways. Colin Young (although I thought about it) would have not been suitable as he wouldn't have been able to execute the more physically demanding able-bodied parts of the piece. This is a real shame as I think other aspects of his physicality would have been an excellent fit. Perhaps there are other actors out there with a milder form of cerebral palsy, but would they have had the same facial and physical characteristics as our current cast member?

The danger here is that in trying to use a disabled actor, the piece may alter in a way that was not truly intended. This, as a writer, I will always resist. Furthermore, and I may well be lambasted for making this point, if we focus on the disability itself too closely, there is actually the real risk that the piece becomes just about that—disability

## Conclusion

At first blush, Frances Ryan's article in the *Guardian* makes some strong points, but this is only because they appeal to our sense of outrage by hooking into emotive topics like racism. In reality, there is little in her article that holds water.

I've dealt with disability all my life and can honestly say I've never felt offended when an actor receives an award for "cripping up." Nor have I felt anger that the casting of an able-bodied person has somehow deprived me of my right to self-expression. On the other hand, I would feel far more disappointed if I watched a film that failed to deliver simply because of some misguided act of "positive discrimination."

Don't get me wrong, I would like to see more disabled actors in film. I want to see more talent agencies like VisABLE introducing actors into theatre casts and onto film sets. People need to see disability represented on TV and in the cinema as general roles. I can even see some disabled actors taking on far bigger parts.

But the reality of it is that those best suited to developing a mainstream career in entertainment are those at the periphery of disability, such as R.J. Mitte, who can keep their symptoms under control. This in turn allows them to play a wider variety of roles, even perhaps able-bodied parts. Having said that, the irony is that I doubt that any such individual would wish to base their career entirely on roles made possible because of their disability.