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Translating Transableism: when being able-bodied becomes a disability

Lara Irvine Ramp Up 27 Oct 2011

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In a world that affords a distinct advantage to the fittest and most able-bodied among us, it is hard to imagine that anyone would envy those of us with disabilities. But for some people, a disabled body is the one thing they desire most.

Anthony* is a pretty average uni student. He is nineteen years old and in the early years of studying medicine. He works hard, learning how to fix broken bodies and put people back together. He also plays hard and likes sports of all kinds, listing soccer, badminton, hiking, rock climbing and kayaking as among his many pursuits. And in the back of his mind, almost constantly, a part of him longs to be a high level quadriplegic. Yes, you read that correctly.

It does not mean he fantasises about how much fun it would be to scoot around in a wheelchair, nor does he think having a disability would be a good way to reap attention and sympathy. In fact, he envisions the condition and everything that goes with it in quite high detail; a lack of corporeal control and mobility, incontinence and even the need for a ventilator to assist with respiration are features of his desired body.

"I often see myself as not getting injured but more the disability being as a result of some condition such as ALS or transverse myelitis, but in saying that it is still more the end result that I desire." ALS, or Amyotrophic Lateral Sclerosis, is also known as Lou Gehrig's disease and is a form of motor neurone disease. Transverse myelitis is a neurological condition caused by an inflammatory process of the spinal cord.

Nick* is another university student. Since around the age of five, he has wanted to be in a wheelchair, and over time that vague desire has strengthened and clarified. He desires to be a T12 complete paraplegic, with complete loss of feeling in his lower limbs, continence and sexual functions. What makes his story particularly interesting is that several years ago he was involved in an accident that left him with a serious mobility impairment. He can still walk, but the process is slow and exhausting and he uses a wheelchair most of the time. This did not make the urges to be a paraplegic go away; he still feels his body is not what it should be, and that any ability to use his legs is too much.

It is a difficult concept for most people to get their heads around. In Western society, having a disability is often viewed as a challenge or struggle at best, and a tragedy at worst, by those who are able-bodied. Those who live with impairments know that these views can be misguided, but it's doubtful that even the most strident of disability activists would wish away any mobility or function they currently have. A quick internet search shows that Anthony and Nick are far from alone in their unusual desires.

They are known by a variety of names, not all of which mean exactly the same thing; Pretenders, Wannabes, transableists and, in medical parlance, sufferers of Body Integrity Identity Disorder, or BIID. What unites them is their intense need to acquire a disability, and the difficulty that can cause to their able-bodied lives. Apart from these similarities though, they are as diverse a group of people as you could expect to find. They come from all walks of life, from social workers to lawyers, homemakers to students, and many different nationalities. No-one really understands why they feel the way they do, and no-one really knows exactly how many people are affected. Sometimes there are feelings of sexual desire towards people with disabilities that pre-empt the condition, but for most it is a case of their internal body image not matching their physical bodies. Many parallels are drawn with transgenderism, and the idea of feeling that they were born into the wrong body; only in this case, it is not the whole body that is at odds, just one part.

Dr Christopher Ryan is a practising psychiatrist who also works for the University of Sydney as a Senior Clinical Lecturer, and is an Honorary Associate in the Centre for Values, Ethics and the Law in Medicine. "People with BIID, particularly the amputation variety but even the paraplegia one, are very focussed on that limb and perhaps because of that it's a much more focussed psychic pain, for want of a better word. They're really unhappy about that limb, it really makes them upset and depressed [...] I think one of the things that can be underestimated by people is the amount of distress that is associated with this. It's really awful for them."

He has seen a number of BIID patients over the past decade. "They do things, and this is quite frequent, they sit in such a way that they can't see their limb, so they tuck it up behind them and things like that."

Elisabeth is a US resident with two healthy legs, but has the body image of a double above-knee amputee. She falls into the category colloquially known as 'Pretenders'; that is, she pretends to have the disability she wants. This means she often (though by no means always) uses a wheelchair to get around for most of her shopping, trips to parks and sometimes to church. Although she does not technically need the chair, she says that it makes her feel happier and more free when she uses it, and helps to stave off urges of making a more permanent change to her body. That would move her into the category of a Wannabe; people who have tried, whether successfully or not, to self-inflict the amputation or injury they feel they need. "[I'm] not content as I am, but [I won't] go ahead with self-injury. If it happened to me it would be great to end up as a double above-knee amputee... I wouldn't want to be paraplegic. My image is definitely in the amputee category."

The ability to be so specific about what they feel is "wrong" with their body is one of the things that separates those with BIID from those who are simply curious about having a disability. It raises the question, exactly what kind of disorder is this? Elisabeth has a very clear view on this point:

"[The] point to stress is that I really don't want to have BIID and that I really don't want to have a disability. I fully realise that life without a disability is easier, though not necessarily happier, that there is plenty of prejudice towards people with disabilities.

People with BIID didn't choose to have it any more than somebody chooses to be bipolar, or have MS. It is a faulty wiring in the brain, a neurological, not psychological, disorder, and I have no control over it."

There is currently research being done in the United States that supports this theory. Dr Ryan believes that a group of neuro-scientists in California may have found an answer in the brain scans of patients.

"There is certainly some early evidence that points in that direction... They found a small area of their brain doesn't work normally."

That part of the brain is called the Right Superior Parietal Lobule, and it is responsible for creating and integrating an internal map of the body. It interprets sensory data such as sight and touch so that you know, for example, how many arms you should have, and where they are in relation to your body right now. On a brain scan, it should light up when the test subject's limbs are touched as it deciphers data coming from the nerves. In the BIID patients wanting amputation, however, this did not always happen. When the limb stimulated was the one they wanted removed, there was no response in that part of the brain. It could still feel what was happening through the nervous system, but the brain simply did not have it on the map as part of the body.

Dr Ryan is quick to point out that the research is in its very early days, and the number of patients involved in trials is so small they cannot be taken as definitive answers yet.

"It's one of the things you get with brain imaging studies is that things that look really swish early on, when you get more numbers just don't anymore. So we have to be pretty cautious about that but [...] I've got to say that so far it looks pretty strong."

If this theory proves to be true and a neurological cause for the condition can be proven, perhaps it will make life easier for some of the sufferers around the world, many of whom have faced prejudice and anger from those close to them, health professionals and people with disabilities.

Nick says that he is wary now of doctors, after one broke confidentiality rules and told his parents about his desire to become a paraplegic, one of the most traumatic events of his life. Nick says that since then he has tried speaking with six other GPs, all of whom insisted he was making it up. "I am now scared to go to a GP!" he says. "I get no support from anyone."

Like Elisabeth, he stresses that the way he feels is completely beyond his control, but says that he has received hate mail from people who have found him through online communities, and feels uncomfortable sharing his BIID diagnosis and symptoms with many people. This is where the online communities and forum have played a vital role in helping sufferers feel connected and less alone when dealing with a very rare condition.

"Yes, I've found that the online communities out there have helped me in accepting my thoughts and finding peer support," Nick says, going on to explain that he is active on many sites. He has never met anyone else with the condition in real life, so the cyber relationships have become important to him.

Whether the online connections that have happened to people have been entirely positive is an area that has come up for some debate. In a well-known article titled, *A New Way To Be Mad*, Carl Elliot poses the theory that a phenomenon like BIID could become almost contagious. He believes that people who previously would have dismissed the odd thought about paraplegia can now get online, find it's a real condition with many sufferers and feel encouraged, validated and fixated on the idea. Dr Ryan, however, dismisses the theory quite succinctly; "I don't think it has any legs at all, frankly."

In fact, he believes that finding people with a similar problem can help with the feelings of isolation that sufferers of such a rare condition can feel. Elisabeth started her own website, <http://ahiruzone.com>, and writes for other peoples as well. Her husband has never accepted her pretending and will not even talk to her about it, while her priest is more vocal in his disapproval. She believes that people who find BIID offensive or disturbing, "are not listening close enough," and started the website to find likeminded people who use wheelchairs for any reason, physical or otherwise.

Finding a way to treat the individuals affected by BIID is a difficult business. Many of the forum users say

that traditional psychiatric treatments, such as talking therapies and medications, do not work (although they can assist with the depression and anxiety that often accompany it.) Dr Ryan suggests, however, that this evidence is anecdotal and he would start with approaches like these that have little or no side-effects. In some people, it is a case of helping them learn to live with their disability, and finding ways they can be happy and fulfilled without damaging or changing the body they have.

However in his experience, "what people are saying they actually want, thanks very much, is to have an amputation, and I think you have to be open to that possibility. Now I don't think you should rush into doing it, for no other reason than amputations tend to be a little bit irreversible. You don't want to get this wrong. But I think if you say, no, that's not going to happen, first of all it's not going to help the patient, and second, I don't know on what grounds you would say that. Why would you rule that out of court?"

This response from a health professional could come as a surprise to some people. While there have been no elective amputations done in Australia so far, there have been several notable cases overseas where a patient's healthy leg has been removed. Robert Smith, a surgeon in Scotland, hit the headlines after completing two such operations and having a third booked in. There was a huge outcry, and claims that his actions went against the Hippocratic oath to 'do no harm'. The hospital he worked at subsequently banned any further surgeries of the kind. There are also harrowing stories in both the online BIID communities, and the broader media, of people who have taken matters into their own hands because they felt they had no other option. Cases of people packing their unwanted limb in dry ice so that a hospital is forced to remove it, blowing legs off with a self-inflicted shotgun wound, or travelling to third world countries as a medical tourist are certainly not common events, but they have all happened.

Perhaps though, offering an official and safe way to achieve their desired body image would eliminate some of the risks and pain these people endure. Certainly, in genuine cases, it would help their psychological well-being. Wannabes who have gone through with their desire body modification frequently discuss being happier, more at ease with themselves and society, and contradictory as it may seem, feeling 'whole' at last.

Paraplegia and quadriplegia, however, are much less straightforward. As Dr Ryan explains, "it's not actually the worst thing in the world to lose a leg. Prostheses are really good now. But to be paraplegic has an enormous amount of other consequences, including a decrease in your life expectancy. I don't think there would be a surgeon prepared to do that, although I could be wrong."

Whatever treatment they receive though, will have to be as highly individual as the patients themselves, and it will be a hard road to tread regardless of the ultimate outcome. It could be that in years to come, BIID will become far more widely known and understood. It may seem bizarre to people at the moment, but so did the now accepted notion of transgenderism even twenty years ago. For the time being, most BIID patients are just trying to get by, and find a way to live in our society and with themselves. Elisabeth plans to keep Pretending, and hoping that her husband will one day understand why she does it. As she says, "what sucks the most is when we are not happy with who we are, when we are in inner pain, when we can't be at peace."

Anthony's story is still very much unfinished, but he is working through it one day at a time. "I don't know why it is I have the desire for very high level, severe conditions, that is just what seems right to me, although at the moment I would settle for almost any physical disability." He understands that there is likely to be no help in the way of surgery or medical intervention and plans to finish university before exploring any permanent solutions for himself.

Nick is in much the same position. "I would jump on any safe surgery to become my body image. I do

think of self-harm a lot, but since many of the thoughts are dangerous I am most likely not going to act on them." He still very much wants to be alive, just in a slightly altered body.

The inner peace that Elisabeth spoke of, at least for the time being, will lie in all of them learning to live with their disorders. And, in the disability community at least, that makes them just like anyone else.

* Names and identifying details have been changed.



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