



Amanda Boxtel

Bionics: Wrong answer to the wrong questions

By **Annie Makoff** - 3 years 4 months ago

It has been hailed as the first real alternative to the wheelchair in over 500 years. Its developers at California-based Berkeley Bionics say it enables those with spinal cord injuries to stand for the first time since their injury. But, asks Annie Makoff, is the world's first bionic exoskeleton really the life-changing technological development its creators would have us believe?

Launched initially in the United States in 2010 and now launched for the first time in Europe and the UK, the battery-powered device uses sensors and cutting-edge technology to respond to the user's gestures and intentions, enabling them to walk with a natural gait. Featuring an "unprecedented knee flexion", the exoskeleton which solely benefits paraplegics who can self-transfer from a wheelchair, has helped nearly 100 people since its American launch. It is hoped that following its amalgamation into European rehabilitation centres, the device can be sold for use in the home as early as 2013 at an eye-bulging cost of around £100,000.

Yet disabled multimedia artist and activist Ju Gosling is highly sceptical of its relevance to disabled people. "Considering that only five per cent of disabled people are wheelchair-users, and even less than that are paraplegics, I would imagine that quite a number would be completely unsuited to wearing an exoskeleton," she says.

The author of the newly released book, *Abnormal: How Britain became body dysphoric & the key to a cure which explores attitudes towards disability and (ab)normality*, believes that despite common belief, the majority of disabled people wouldn't necessarily want to walk even if given the chance.

"Has this bionic device been developed because they truly believe that disabled people want to walk?" she asks. "In which case, I cannot believe they have done much market research. If you surveyed 100 wheelchair-users, I'd imagine very few of them would want to wear an exoskeleton. So did they invent this, regardless? Was their cultural belief enough for them to go ahead?"

According to Ju Gosling, there is the prevalent belief that disabled people just want to be

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"cured", and they are leading unproductive, sad and lonely lives with their disability. Wheelchair-users are seen as a "tragedy", apparently because they can't walk. Yet she says that society's obsession that everyone should be walking makes no sense.

"It's that nonsensical attitude where you see someone getting a bus or you see them walking because they can't afford a car and you look down on them, yet you look at people like me in a wheelchair and you think it's a tragedy," she says. "The ability to walk among non-disabled people isn't prized at all, so why should it be any different for disabled people?"

Yet paraplegic Amanda Boxel, ambassador to Berkeley Bionics, could not wait to walk. She told Disability Now that she would much rather pay for something which helps her walk rather than something that doesn't. Amanda, who was one of the first to train in and finally wear the device, found the experience life-changing.

"Our bodies are meant to be up and moving," she explains. "When I used to sit in my wheelchair all day long, I suffered really badly with oedema, so I used to get swollen legs and they were always cold and purple. I had a lot of trouble regulating my body temperature. Yet when I walk in the exoskeleton, the swelling goes. Everything in my body works more efficiently."

Having been paralysed following a skiing accident nearly 20 years ago, Amanda was told at the time that she'd never walk again. Yet all this changed when two decades later, she happened to meet the CSI of an Ekso Bionics company through a recreational programme she was running in Colorado to teach disabled people to ski.

"The CSI of Berkeley Bionics said to me one day, 'Amanda, I've got amputees up and running and winning races, yet I can never understand why someone in a wheelchair can't get up and walk. Yet someone who doesn't have legs is winning races – why can't we do something for them, too?' He told me that the technology he'd created was going to help me walk. He said it would change my life. He was right – I was walking within a couple of days. Walking for the first time in so long was indescribable – I can hardly put words to it."

But Ju Gosling remains unconvinced.

"Certainly since the 60s, there has been an obsession with engineering the body, but actually, we really need to ensure that everyone who needs a wheelchair has one, rather than assuming that every disabled person's dream is to walk. We need a more accessible world, not a world where disability ceases to exist.

"There is so much stigma about and a lot of disabled people can't afford decent wheelchairs even though they'd really benefit from one. Yet ironically, society's ideal is about avoiding walking. You sit down to breakfast, you sit in your car, you sit at your desk, and when you are at home you sit in front of the television. So this view that we all want to walk is completely topsy turvy."

Ju Gosling is of the opinion that everything we do is about despising this ability. She describes "body-extending" technology, such as smart phones (visual, hearing and memory aids), motorbikes and expensive cars.

"These are all highly desirable," she says. "Our society really prizes the extended body, unless it's associated with a disability or an impairment, then all of a sudden it's viewed as a tragedy. People will quite happily spend around £5,000 or more on cars, yet if I were to spend that on a spanking new wheelchair, people would really pity me."

Colin Barnes, Professor of Disability Studies at Leeds University agrees that body-extending technology for non-disabled people is highly regarded by society, yet his concern is more about the expectations which devices like the exoskeleton raise.

He refers to the case of Metropolitan police officer, Philip Olds who, after becoming paralysed as a result of a gunshot wound in the 1980s, underwent several technological interventions to improve his quality of life, but when they didn't work, he committed suicide.

"How effective is this particular technology going to be in enabling disabled people to lead normal, productive and active social lives?" Professor Barnes asks.

"By providing people with these devices you are raising expectations: people believe they can become 'normal', but so far, none of these technologies have actually achieved that."

He believes that the endless quest to become "normal" is about being part of a society which refuses to accept physical and sensory difference. We have become socialised into something resembling a non-disabled entity.

"The whole ethos of society is geared around the myth of the non-disabled ideal, and it has been since the ancient worlds of Greece and Rome," he says.

For Ju Gosling, even though the media plays a huge part in exacerbating the "non-disabled ideal", the medical establishment, particularly physiotherapists, subscribes to this belief as well.

"They are totally geared towards patients walking at all costs," she explains. "A physiotherapist asked me once what my goal was and I said I wanted to buy a lightweight wheelchair and learn how to use it. She said, 'oh no, once you get into a wheelchair, you'll never get out of it.' It was almost irrelevant that the wheelchair made me more independent."

The author and artist believes that disability aids – whether they are wheelchairs, crutches or walking frames, should be designed as aesthetically pleasing as anything else we use to



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extend our body and they should be seen as just as normal and just as desirable.

"That is the reason why we need to look at this," she says. "We need to look at our attitudes, because of all the people who are excluded because of the stigma of disability and their disability aids: they are not living the life they should be living."

Her main issue with the exoskeleton is more about its irrelevance to the majority of disabled people who can't even afford a decent wheelchair, let alone something that assumes wheelchair-users want to walk.

Professor Colin Barnes agrees.

"I have no problem with people developing tools to enhance disabled people's lives, but the reality is that technology is never evenly distributed," he points out.

"The exoskeleton will benefit a relative minority of the disabled population, whereas if you spent an equivalent amount of money in creating more accessible environments – which the Government claims they cannot afford – then you'd benefit everyone."

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