Voices

Access and Inclusion of people with a Disability

Issue 1 – April 2018

A free and open journal collecting together voices and opinions of people with a disability and those that support them.

Access and Inclusion Through Technology

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Editorial

David Banes
Director of Access and Inclusion

Welcome to the first edition of “Voices” a free and open collection of thoughts and opinions from across the world as written by people with a disability and those that support them. The idea of the magazine or journal was to provide a platform where the writings of the authors could be shared and to provide a channel to an audience who might never find the individual blogs and features reproduced. It offers a showcase of the rich diversity of thought and emotion amongst the community to broaden understanding and recognize the breadth of opinions expressed.

The idea behind “Voices” evolved from a series of focus groups and interviews held with people with a disability during the autumn and winter of 2017. The focus groups were undertaken across a series of projects around technology and people with a disability. From those events the need for greater information and the sharing of experience, challenges and responses emerged. “Voices” by drawing together diverse perspectives is one response to this.

In future issues we will be seeking to broaden still further the voices published and shared within the journal, inviting perspectives from people with a disability from across the world.

Details of how to make a submission to “Voices” can be found at the end of this edition.

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Reactions to Lady Gaga’s cancelled tour shows how little we understand invisible illness

Pippa Stacey
From Life of Pippa

Lady Gaga is without a doubt one of the most iconic pop legends of our time. Having dominated the music scene and headlined Coachella, given one of the most talked-about Superbowl halftime shows in decades, and of course left a lasting legacy on the world in the infamous meat suit, what could possibly dare to stop her in her tracks? The answer is simple: fibromyalgia.

Fans were first given a glimpse into Gaga’s struggle with chronic pain during her Netflix documentary, Gaga: Five Foot Two. We as an audience observed the daily battle she faced in trying to balance a thriving career with taking care of her health, and sympathised with her efforts to never let her fans down. To many, it came as no surprise when she later announced that she had been diagnosed with fibromyalgia: a debilitating physical condition causing widespread burning pain in muscles, ligaments and joints, unrelenting fatigue, and a whole host of other disabling symptoms.

Because Gaga is, well... Gaga, naturally she decided to embark on her upcoming grand-scale European tour regardless. However, the time eventually came when she reluctantly had to step back and put her health first, and in an emotional statement, her team announced that she was ‘suffering from severe pain that has materially impacted her ability to perform live’, and that she was ‘deeply saddened’ to cancel the final 10 dates of her tour, which included her London performances.

Although loyal fans were quick to offer their love and condolences in response to the statement, shared on social media on February 2nd, as well as in response to the reporting of the cancellation on other large news outlets, these tweets were noticeably peppered with some less than sympathetic responses.

About Pippa

Pippa, is 23 years old and based in Yorkshire.

She is a psychology graduate, currently splitting her time between freelance writing, working as a digital marketing intern for a disability charity, and running her own social enterprise, Spoonie Survival Kits.

In her free time she enjoys theatre, books and fundraising, and can often be found in her natural habitat: drinking tea and wearing pyjamas.

Her blog is Life of Pippa and you can read much more that she has written at https://www.lifeofpippa.co.uk

You can follow her on Twitter @lifeofpippa
'It’s just attention seeking that’s all’ declares Tracey from Bolton, in her professional analysis of the situation, ‘what a load of balls it really is’. Twitter user Damien agreed, stating ‘damn, the attention seeking got the best of her’. ‘This is not a real disease’ adds Jason, ‘stop being a baby and buck up for once’. Some users decided that the cancelled dates were a result of a ‘severe lack of ticket sales’, whilst others (who admittedly were trolls) shared GIFS and memes poking fun at and questioning her pain.

Meanwhile, another collection of social media users attempted to offer solutions to the situation, most likely intended to be helpful but again demonstrating utter misconceptions of the condition. ‘Just use some Tiger balm’ adamantly instructs Ashish, convinced that this will treat the complex neural abnormalities thought to be responsible for the condition. ‘Cut out sugar’ and use ‘herbal botanical treatment’ were among other suggestions, implying beliefs that the condition was a result of Gaga’s lifestyle choices, and something she had control over. [please note: all of the tweets mentioned above are embedded in the original MTV article.]

It was whilst reading some of the above responses that I couldn’t help but cast my mind back to when Ed Sheeran cancelled his own tour after breaking his arms in a motorcycle accident, so I decided to take a look back at the reporting of this news and the Twitter users’ responses to it. Unsurprisingly, not once did I observe anybody telling him that his decision to cancel his tour was attention seeking, or lecturing on lifestyle changes to treat his broken bones. Instead, these responses featured outpourings of love and sympathy, and thousands of well wishes from the Twitter community. Both Lady Gaga and Ed Sheeran developed physiological limitations that prevented them from performing, but why were these cases perceived so differently?

I think the difference in reactions to Ed’s broken bones encased in casts and Lady Gaga’s physical health condition tells us something important about the way we think about invisible illness. Is it because people can’t personally see Gaga’s suffering that they choose to question it? Is it because chronic pain isn’t visible that they think it’s something that she has any degree of control over? If she let people into her home when she’s having a pain flare and they saw her howl and cry, would that be enough to validate her illness? And why should she have to validate her illness in the first place?

As somebody with an invisible chronic illness myself, I’ve seen first-hand how people’s attitudes and knowledge seem to so widely vary between conditions they can see, such as broken bones and amputated limbs, and those they can’t see- not just physical conditions, but mental illness too. It’s unsurprising that people tend to know less about long-term conditions that they can’t see, but it does unfortunately seem that people are much less willing to learn about and accept them too. Whilst
having a disability of any nature (including visible impairments) is full of challenges, it’s endlessly frustrating to see how invisible conditions continue to be stigmatised by those who aren’t willing to learn.

However, if you take one thing away from this article, make it this: believe the sufferer. If Lady Gaga, arguably one of the most prominent figures of the 21st century music and celebrity scene, needs to cancel her tour in order to look after her health, then I stand by her decision and you should too. The only thing worse than living with long-term chronic pain, is living with long-term chronic pain and not having people believe you. You might not be able to see somebody’s suffering, but that doesn’t mean it isn’t there.

In the future, I’d love to see a shift in attitudes towards invisible illnesses, and people’s perceptions towards conditions that they don’t necessarily understand. Some targeted treatment and a cure for chronic pain wouldn’t go amiss either... if anything, just to ensure that we get to see our Gaga continue slaying the pop icon game in years to come.

Read more from Pippa at https://www.lifeofpippa.co.uk
Disability and Identity
By Holly
From Life of a Blind Girl

Here’s a question for you, when you think of me, what do you label me as?

Let me tell you the first things that come into my head... I’m a daughter, a friend, a cousin, a niece and a granddaughter. I’m a blogger, an Assistive Technology Officer, a disability activist and a premature birth survivor.

Oh, and I’m also registered as severely sight impaired (blind) so I’m disabled. I have no useful vision, so this has a rather big impact on my life.

Out of my many labels, being disabled is the first thing that people sometimes may identify me as when they meet me or see me walking with my cane or being sighted guided.

Some people don’t even think that I’m blind when they first meet me, or others think it’s such a shame and simply don’t know what to do, they talk to the person that I’m with rather than me. Some people pity me, expressing that “oh things must be so difficult for you”.

Yes, things are difficult, I have faced many challenges and continue to do so, but I do not let my disability stop me from getting to where I want to be in life, I do not let it control me or don’t let it stop me from doing the things that I want to do.

People also think it’s ‘inspirational’ or ‘incredible’ that I attended mainstream education, graduated university and now have a job. Think about it for a minute, why does having a disability stop me from achieving those things? It doesn’t. I have the same dedication, determination and drive than non-disabled people, some may say that I am more determined to achieve such goals. Others may be rather intrigued by my visual impairment and ask me questions, which I am always happy to answer.

About Holly
Holly is 22 years old and a York St John University Graduate. A lover of music, concerts and all girly stuff, she has been blind since birth, due to a condition called Retinopathy of Prematurity (ROP). Her disability has made her the person she is today and has given her so many opportunities which inspired me to start this blog. The portrayal of disability can often be negative, but she believes that there are so many positives of having a disability, in my case a severe visual impairment. My visual impairment is the reason behind this blog.

She created Life of a Blind Girl as a way of sharing experiences of living with a visual impairment in a predominantly sighted world as a platform for providing others with advice and support on all things visual impairment and disability. Tackling the stigma surrounding disability; she seeks to educate people on visual impairment and disability, portraying the fact that just because a person is blind, visually impaired or has another disability, it does not mean that they cannot get to where they want to be in life, it does not mean that they have to be treated any differently to anyone else and it does not mean that they cannot carry out everyday tasks and activities because truth is, they can.
Does my disability define me?

For a long time, I was caught up in the notions surrounding the saying “don’t let your disability define you”, I wanted people to look beyond my disability and see me for who I am, but thinking about it, my disability is part of the person I am, it’s helped shaped me into the person I am today. Would I be a different person if I didn’t have a visual impairment? That’s a hard one to answer, in some ways yes, I would, but in other ways I wouldn’t and that’s absolutely fine. What I’m trying to say is that it’s pretty obvious that my visual impairment has a rather big impact on my life.

Is being disabled part of my identity?

A project on identities got me thinking about my identity and whether being disabled is part of that. We all have an identity, everyone’s identity is different, it’s what makes us the person we are. My visual impairment is part of my identity. From the moment I wake up, I can’t see the world like everyone else, I have to do things slightly different, I need help with certain tasks and in order to get around as part of my daily routine, I use a cane. I can’t drive to where I need to get to, I have to get someone to take me or rely on other forms of transport. Therefore, my disability defines me and is very much part of my identity. Is this a bad thing? In my eyes, it most certainly isn’t.

Having a visual impairment has given me many characteristics that I may have not have had if I was fully sighted, it’s made me have a backbone, it’s taught me to never give up and fight for my rights and what I deserve, it’s made me appreciate things for what they really are, and it’s given me the desire and determination to help others.

What does being disabled mean to me?

When people think of the word ‘disability’, they often think of the negative connotations surrounding it, they often think of disabled people being sad, lonely, staying at home all day and not living fulfilling lives. However, these are often wrongly perceived ideas and very far from reality. For many disabled people like myself, having a disability can be rewarding, lead to new experiences, and can make you see the world in a different way. Don’t get me wrong, there are days where we often wish we didn’t have to face constant battles, and would love to switch our disability off like a light but this isn’t the majority of the time. That can’t happen anyway so you’ve got to get on with it, at the end of the day, life is what you make it.

Being registered as severely sight impaired (blind) has allowed me to learn skills such as braille in four variations – standard English, music, French and German braille, learn how to use various screen-readers, the ability to touch type and also use a long cane.
Having a disability has given me the chance to carry out some brilliant opportunities, both in terms of blogging and my personal life. I’ve also met some of the most important people in my life and that’s through having a disability so I am forever grateful.

My disability has also given me the chance to raise awareness through blogging, work with various organisations and charities, help others in similar situations and so much more! If I didn’t have a visual impairment, then I would never have started this little blog.

Having a visual impairment has never stopped me doing what I want to do in life, from getting a degree, gaining employment, going to concerts to see my favourite bands/artists and just generally living a normal life like sighted people. I may not experience it in the same ways as non-disabled people, but I’m okay with that.

I’m never going to be able to see, unless some miracle cure is invented, if it happens then that’s amazing, but if it doesn’t, then I’m okay with that. My disability will always be a part of me so why shouldn’t it be a part of my identity?

You can read more from Holly at https://lifeofablindgirl.com
When Accessibility isn’t Accessible
By Erin Hawley

From The Geeky Gimp

Society often frames accessibility as something abled people do to make the world easier to navigate for disabled folks, whether it’s an ambulatory contractor building a ramp at a restaurant, or a hearing employee putting captions on their organization’s videos.

But the reality is that disabled people are also making their spaces and creations accessible to other disabled individuals.

This is powerful because we know best the importance of having true inclusivity for community spaces, both online and off. The problem is, sometimes, making things accessible is not within our abilities.

For example, at The Geeky Gimp, I ensure all video and audio content posted includes a transcript and closed-captions. In the beginning, I tried doing the captions myself, but it was extremely tiring, taking hours to transcribe just three minutes of audio. I didn’t have the physical strength to type fast enough, so I started hiring folks to do this labor for me.

I believe it’s important to offer financial compensation for work if you can, especially to other disabled people, so I was paying $100 and up for the service per project. That’s why I stopped doing my podcast – even as a full-time employee, I can’t afford to put out this type of content regularly.

Many disabled folks rely on Social Security Income and would not be able to pay for the assistance if they couldn’t transcribe for themselves. Does that mean they shouldn’t make videos? What if that medium is most accessible to them? Where does the responsibility fall to make things accessible?

We should always make our creations and spaces as accessible as we can. Asking for assistance in a public forum, and being upfront about payment or lack thereof, is an option – folks may volunteer, yet it will prove difficult to find someone willing to do this on a regular basis for free.

In my example, even the process of finding a volunteer is time-consuming, strenuous, and unrealistic when doing a short video
or Twitch stream every day. There are fundraising options like Kickstarter and Patreon, but for most people, these sources are unreliable or financially insufficient to cover a regular staff of transcribers.

Many disabled folks rely on Social Security Income and would not be able to pay for the assistance if they couldn’t transcribe for themselves. Does that mean they shouldn’t make videos? What if that medium is most accessible to them? Where does the responsibility fall to make things accessible?

I used to think that if you can’t make something accessible, you shouldn’t make it at all. And now I realize how ableist this belief is when we apply it to disabled people – it can further ostracize us. We are already underrepresented in media and in the community, so we shouldn’t hide ourselves and our contributions entirely.

I am trying to be more solution-oriented in my thinking about disability issues, but there’s no easy solution here. We must continue pushing toward full inclusivity which will enable all of us to help each other out. It will take upending whole systems of power to make this a reality.

I’m hoping this post will start us talking about this openly. Through dialogue and an exchange of ideas, I’m hoping we can learn ways to navigate through inaccessibility.

You can read more from Erin at https://geekygimp.com
Hiya
By Gary Kerridge
From The Rebuttal

I think at 53 I am becoming more cynical and more insular. You know for 45 of the 53 years I have been deaf. You put up with a lot of shit when you are deaf. Not just deaf but if you have a disability of any type. People are either over the top in trying to meet your needs or they just exclude you all together.

Yes, I have had religious people come up and bless me when they have seen me signing with friends. I've had literally hundreds of people come up to me and sign Hi! This is either with an exaggerated wave or they finger spell it. The worst is the American alphabet H and I. With a broad grin people come up and do that awful wrist flick with a H and an I.

Is it entirely wrong for me to want to punch them in the face when they do this to me? OK, it’s a little bit wrong but believe me it’s very irritating. I swear it’s part of the reason a night or even week at home with Netflix is so much better than this kind of human interaction.

If you think that I sound old and bitter, you are probably right. But you know there is a campaign that is aimed at making people with a disability feel more included called Just Say Hi! There are heaps of videos just like the one below. For a laugh turn on the automated captions, it’s the only access deaf people have to this video. How do you make deaf people feel included? Just make videos like this with no or second-rate access!

"Instead it came across as go seek them out and say Hi! No one does that in real life. Ever!

Many people with a disability hate this campaign because they think it is really patronising and it is. Because, you know, we just walk up to complete strangers and say Hi every day. I want to make more Muslim friends, so I go out and find Muslim people and say Hi! I don’t know many Aboriginal people either, so I am gonna go to Redfern and mingle and say Hi to every Aboriginal person I
see. It is completely normal isn’t it? No, it isn’t. It is daft and patronising.

That is not to say you ignore people with a disability. It is to say you just talk to them when you meet them in life. Perhaps at a party. Perhaps at work. Perhaps in a bar because they are with your group of friends. You say Hi when you have common interests and you have a genuine interest in people.

I am sure this is what the designers of this campaign had in mind. They were trying to say treat people with a disability like any other. Instead it came across as go seek them out and say Hi! No one does that in real life. Ever!

But why were people with a disability so upset about this campaign? I’ll tell you why.

It’s because it gives non-disabled people a license to use people with a disability as a tool to make themselves feel good. John with CP over there .. Hiiiiii! I’ve done my good deed for today.

Stella Young hated these kind of campaigns. She despaired getting on a train or going into a bar because some well-meaning person would come over and say something like -“Hi, it’s great to see you out and about.” Inevitably someone will come over and think they are being kind by taking an interest in you. “What happened to you?” they enquire.

Sadly, this is often what well-meaning campaigns like just say hi! do. They just give people a license to satisfy their curiosity and do their good deed for the day.

“It is a truism that it is nearly always up to the person with a disability to lead the way.

Inclusion is never easy. It is a truism that it is nearly always up to the person with a disability to lead the way. They have to explain their needs and make endless requests for the environment to be adapted. This is because the needs of people with a disability are rarely considered in the design of things.

In my current job I spent some time teaching and informing my workmates as to what needed to happen for me to be included. I was very strong in letting them know that when they are chatting I often miss out on what is going on. Often what they are talking about is relevant to work and I need to know.

To their credit they’re terrific and when they’re chatting on the floor they will, often without me asking, just let me know what they are talking about. Even if they’re talking about what they did on the weekend. They do it naturally and easily and it makes me feel very included.

And that is the key – Do it naturally and easily. It cannot be false, and it cannot be forced. It especially cannot be orchestrated by well-meaning campaigns like Just say Hi!

I dare say if the designers of such campaigns took the time to ask us people with a disability what we thought before diving headlong into such campaigns they could have saved themselves a lot of pain and bother. Mostly they could have saved US, the people with a disability, the pain and bother.
Nevertheless, the struggles of non-disabled people to make us disabled’s feel included can be the stuff of much hilarity. Watch the video below and if you want to have an awareness campaign that works – Follow the format! Enjoy.

Read More from Gary at https://therebuttal2.com/author/adefty2/
My Ability to Spell, Stole by Brain Injury
By Michelle Munt

From Jumbled Brain

When I was growing up my parents made sure that at every given opportunity I continued to learn. I mentioned before in Number problems after brain injury, how weekends included spelling and arithmetic tests. Part of me found it laborious, whilst the other part enjoyed the challenge. I couldn’t spell as well as I could do maths, but I was still pretty sharp compared to my peers.

My mother, the human dictionary.

Actually, I was probably better than I realised, but I was using my mum as the benchmark. However, her grasp of the English language was astounding! She could give you the meaning of, and spell almost anything! It was a true talent as this was a lady who left school at 15. She needed to get a job to help support her mum and pay her own way. So, she had no qualifications, but you were the fool if you thought that was anything to go by!

I credit her with my understanding of how English words are constructed. Yes, my school teachers did their bit, but she had drilled it into me before they got a chance to have a go. So whilst I was never as accomplished as my mum, I still was one of the best spellers I knew. She’d given me confidence and the ability to break words down into their sections, so I could build words in the same way.

But my brain injury undid much of her hard work.

When my brain injury first happened, I couldn’t read or write. (Actually, the last conversation I had with my mum before she died was about how I didn’t know what would become of me as I’d lost these essential skills.) But in time, I slowly improved, thank goodness.

My progress meant my confidence grew too. But that also gave rise to a false sense of security. For years I had been the person in the office you could randomly ask how to spell something, and I could give you the answer, just like that. But I’m not that person anymore, although my confidence thinks I am.

About Michelle

In December 2014, Michelle had a car accident on her way to work. Driving on a dual carriageway she used everyday but doesn’t remember anything about it. Since she has learned that a Buzzard swooped down and smashed the windscreen of a small truck that was travelling behind me, approaching queuing traffic she had started to slow but the driver of the truck didn’t see that as he was struggling with his smashed windscreen. He hit the back of the company smart car she was driving and pushing her into the central reservation. The road was closed for hours and she was airlifted to the Royal London Hospital.

Speaking in a strange high-pitched voice she struggled to find words. Every day she was asked to remember 4 words: red, velvet, horse, church for a few minutes. But never once did she recall them all. In hospital for 10 days, she was never told within that time that she had a brain injury or what to expect.

Michelle feels that if she can help someone by making sure they have better access to information than she did by talking about her experience then she will have gone through it all for a reason.
Let me give you a really lame example that happened just the other day. My partner, James, and I were talking about the pronunciation of the word ‘full’. I over annunciate the U in it because it annoys me how often it is pronounced ‘fall’ or ‘fool’. James tried to point out that I can’t just base my assumption of how to say a word based on spelling. He pointed out ‘Gull’ makes quite a different sound, despite being only one letter different.

I immediately retorted that there was a reason for that..... "it's only got one L." I was absolutely certain of that ‘fact’ as I said it. But as the conversation went on, doubt started to creep in. And so it turns out I can’t even spell a 4 letter word.

My brain injury has made it difficult for me to spell.

My brain must be in denial.

If you have never been a confident speller, you’re unlikely to ever overestimate your ability to spell. You probably wouldn't give yourself enough credit to begin with.

Whereas because I had previously been confident, and it was pretty much warranted, my brain is prepared to believe it is again. However, that just makes me look like even more of a fool.

I know that with continued practise I will improve my spelling. Just writing this blog is helping I’m sure.

But I can’t tell you what I would give for my mum and her laborious spelling tests now.

Read more from Michelle at https://www.jumbledbrain.com

“The last conversation I had with my mum before she died was about how I didn’t know what would become of me as I’d lost these essential skills”
App of My Eye
By Luke Sam Sowden

From Luke Sam Sowden

I love being out and about, but being Visually Impaired I can sometimes get a little bit lost and disorientated. That’s why when I had heard that Microsoft had released Soundscape to help Visually Impaired people navigate their surroundings, I obviously had to give it a go. Well i’ve been using it for a little while now, and I thought that I would tell you what I thought of it.

A black iPhone, a silver pen, and a notebook next to a laptop on a white rectangular table, on a white background.A picture of an iPhone, a silver pen, a notebook, and a laptop on a white table.

Here’s what Microsoft say about Soundscape.

“When you’re ready, just go for a walk on a well known route and listen to the callouts to get a sense of how Soundscape works and how you may want to use it. Have fun!

Microsoft Soundscape uses 3D audio technology to enhance your awareness of what is around you, and thereby helping you to get around and explore your surroundings. Soundscape will place audio cues and labels in 3D space so that they sound like they are coming from the direction of the points of interest, parks, roads and other features in your surroundings. You will need a pair of stereo headphones that you feel comfortable waring outdoors. For example, bone conduction headphones, Apple AirPods and in-ear open headphones have proven to work well. Soundscape is designed to live in the background and provide you with effortless ambient awareness. Therefore, feel free to use it in conjunction with other apps such as podcasts, audio books, email and even GPS navigation.

Key Features.

As you walk, Soundscape will automatically call out the key points of interest, like roads and intersections that you pass. These can be adjusted and turned on and off.

About Luke

Luke is a visually impaired guy, technically severely partially sighted, who lives in the north of England. He likes to ramble about everything and everything all over the internet. He uses a white cane, so if you ever see a picture of him with something strange attached to my wrist, don’t worry, it’s just his big old white stick.

He puts his blog squarely in the category of lifestyle. From Health and Beauty to Food and Drink, and from Fashion to things that happen because he is visually impaired, there’s a little bit of everything.

Luke suffers from a hereditary eye condition known as Retinitis Pigmentosa, or RP for short. This means I also suffer from tunnel vision, and night blindness. He started his blog because of his YouTube Channel. He loved creating new videos, but blogging is much easier, and it takes up a lot less of time. Creating videos is a lot of work, but with a blog he can sit down and write a new post in about 20 minutes. Also, he finds writing extremely relaxing and if he gets a post idea, can write it on the go with my phone.

His blog is Luke Sam Sowden and you can read it at www.lukesamsowden.com
An audio beacon can be placed on a point of interest, and you will hear it as you move around. You can place an audio beacon on a point of interest that you would like to track, such as your destination, a point to return to or a landmark you are familiar with.

My location describes your current location and the direction you are facing.

Around me describes nearby points of interest in each of the four cardinal directions, helping with orientation. Try this out when getting off a Bus or leaving a Train station.

Ahead of me describes points of interest in front of you, for example when walking down the street.

We hope that you enjoy the experience. We believe that this kind of technology offers a new way to relate to the environment around you and we can’t wait to hear what you make of it.

It’s set up.

I really liked how easy this was to set up, as once I had downloaded it to my iPhone, and had given it permission to use my location and device motion, it showed me a little introduction video telling me a little bit about how the app works, including that it uses 3D sound to tell me what’s around me, like if something is on my right it will give me an audio signal emanating from that location.

It then showed me a few information screens telling me a little bit about it’s different features, including that I could place an audio beacon on my destination so that it can keep me informed of it’s location and my surroundings along the way, that when i’m walking that it will help me to stay aware of what is around me by calling out roads, intersections and landmarks as I approach them, and that if i’m unsure of where I am that I can hold my phone flat to explore the roads, intersections and landmarks that are ahead of me. It then said that I had to accept Microsoft’s terms & conditions, and then it was all set up.

I also really liked that it worked well with VoiceOver, as it didn’t stall or throw me out of the app whilst I was setting it up.

What it did when I used it.

I absolutely loved what this did when I used it, as once I had set it up, it loaded the main options screen, which was really clear and clutter free, and gave me seven different buttons. A menu button where I could set a reference point, manage call outs, get help, and change the settings, a set a beacon button where I could set my destination, a button telling me whether or not I had set a beacon, a location button which told me my current location, an around me button which told me what was around me like fields and parks, and an ahead of me button which told me what was in front of me.
I also really liked that once I had set a beacon to my nearest Bus Stop, that it gave me a little clicking noise that told me whether I was walking in the right direction or not, and that it also called out all of the different roads and places that I walked past. I did notice that I didn’t really have that many places to choose from when I was setting a beacon though, as I could only choose between schools, fields, and Bus Stops, but I think that this will change as the app grows.

I also really liked that whenever it called out the name of a road, that it told me the direction that I was walking in, the name of the road that I was on, and any intersections that I had passed.

I also really liked how responsive it was, as I was kind of expecting it to take a couple of minutes to recalibrate whenever I had changed my direction, but it only took a second or so to recognise that I had done so and change any call outs that it needed to.

I also really liked that it used 3D audio, which meant that it told me where something was by where ever the audio was coming from. So for instance, if a field was 250ft north-west away, the call out would only be heard from the right side of my right earphone.

Another thing that I really liked was it’s voice, as I was kind of expecting it to sound extremely lifeless and robotic, but it actually sounded really good, and strangely had a slight British accent to it.

**My overall thoughts.**

Overall, I would have to rate Microsoft Soundscape, an eight point five out of ten. I absolutely loved how easy it was to set up, and what it did when I used it, including that I could set a beacon depending on where I was going, that it told me my location and what roads, intersections and landmarks I had passed, that it told me what was around me, it’s responsiveness, and it’s voice, but I would have loved there to have been more places to choose from when I was setting a beacon, like local shops, banks or even bars and restaurants.

If you would like to check out Microsoft Soundscape for yourselves, then you can find it on the App Store.

Read more from Luke at [http://www.lukesamsowden.com](http://www.lukesamsowden.com)
Rethinking Disability

By Tania Principe

From Worlds of Education

Over the last 50 years, attitudes toward disability have changed. Whether viewing disability as a medical condition, through the prism of human rights or forms of exclusion, the understanding of disability has dramatically evolved. One could argue that we now know more than ever about disability.

Internationally, there are legislative frameworks such as the United Nations Convention on the Rights of People with Disabilities (CRPD) that outline, in depth, the role governments can play in eradicating ableism, where ableism is discrimination against disabled people or privileging able-bodiedness, and enshrining disabled people’s rights. Disabled activists have been successful in pushing a rights-based agenda that demands the right of disabled people to live life with freedom and dignity and they are articulating a new way forward in education, health, employment and economics.

Yet the reality for many disabled people globally is that much remains the same. More than half of the world’s disabled children never receive any formal education. On average, the unemployment rate for disabled people is five times higher than the national average.

The CRPD, signed and ratified in 2006, charted a new way forward. Yet in 2016, the Committee on the CRPD reported that implementation of its key recommendations has been painfully slow. The Committee recognized the enormity of the challenge ahead, stating that ‘profound challenges persist. Many millions of persons with disabilities continue to be denied a right to education, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision.

The CRPD Committee report is a clarion call for societies across the globe to include disabled people in all aspects of modern life, including education. But it bears emphasizing what an enormous social change this would represent. Here, while academic and
rights based discourse on disability have shifted significantly, education has been much slower to follow this evolution. It is time to re-think disability in education.

Disability has been differently understood both formally, in medical science, in teaching pedagogy and informally, in social norms and attitudes. For example, a policy ensuring an increased numbers of disabled teachers are employed in schools does not necessarily translate into increased hiring, more respect from non-disabled peers or non-discriminatory attitudes towards disabled teachers. The same is true in the classroom.

Like other forms of exclusion—gender, class, race, sexuality—disability is not solely about one person’s impairment. It is the social context that makes one able or disabled. Like feminists and anti-race scholars before, attitudes towards the exclusion of certain bodies outside of the classroom (in business, employment, or cultural production for example) are re-created in the classroom. Disability is a dynamic category based on context. The impact of disability varies depending on intersecting factors such as gender, race, nationality, poverty, sexuality and citizenship status.

In the 1970s, UK activists with disabilities challenged the conceptualization of disability as an individual medical problem. Known as the social model of disability, activists and thinkers like Mike Oliver made the distinction between impairment and disability where impairment is a physical mental and psycho-social limitation, and disability is the social relational response to this impairment. To draw again on the parallel between gender and disability, gender inequality is not rooted in differences in sex, instead it is in the social relations of how that particular sex is viewed or understood. Sex is biological, gender is social. Efforts to include girls in schooling focus on the social, attitudinal barriers to schooling, and not barriers limited to ones’ sex, for example.

Disability activists argue that being blind or having low vision is not disabling, but living in a world created for and by sighted people imposes disabling limitations on the active engagement of non-sighted people. The social model of disability rejects the notion that disability lives within one body, or within one person, and instead puts the onus of disability on society. It asks educators to re-think their understanding of disability in education. Social model thinking puts all students including disabled students at the centre of learning. It expects the instruction, classroom structure and building architecture to change to accommodate students, and not the other way.

Social model thinking encourages educators, education ministries, and school boards to:

Understand disability differently and to change discriminatory attitudes,

Change their practices and policies to include all students,

Let disabled people direct their own learning, identify needs and strategies,

and in the process, it transforms organizations and institutions. (Rieser, 2013)
Understanding disability as exclusion and discrimination rooted in the social relations has significantly shaped legislative policy frameworks like the Salamanca Agreement and Education for All which advocate for inclusive education. Inclusion is the idea that all students and learners are able to grow and learn together in one space, irrespective of ability, race, class, gender, sexuality and caste. What kind of support for teachers is needed to create more inclusive classrooms that successfully accommodate disability is the topic of an upcoming Education International publication entitled Re-thinking Disability.

Read more from Tania at https://ei-ie.org/en/woe_homepage
Don’t Listen to Statistics. Because you are not one!

By Skyewaters

From Skyewaters

I’ve written quite a few posts about having Hydrocephalus signs and symptoms outside the norm. It really gets to me that if a patient doesn’t fit the statistical norm, then doctors simply switch off. Admittedly, saying this, I know is a generalized statement (it applies to other health issues and things in life too) and simply because there are others who will go above and beyond. Them, I commend. Absolute legends at best. Something I can say with conviction having experienced care from at least one of them in the last 10 years.

It’s like any other profession where you have the people who give their all, the ones who give only what’s expected of them and just the downright idiotic/ignorant and lazy. Except, in this case, it’s a bit more serious when it comes to people’s health and possible survival.

When you look up and search for information on Hydrocephalus, or consult with medical “professionals”, don’t make the mistake of “accepting”. We accept so many things when we are ignorant (I mean that in the nicest way possible), clueless or less informed. Something I definitely was at the start of my Hydro journey.

Don’t accept that what the medical professional is saying, is the gospel truth. They do make mistakes and don’t always admit when they don’t know or are out of their depth.

Don’t accept that because it happened to someone else, it will happen to you. (This is a tricky one though, so use discernment. Most times, I find myself listening closer to someone else’s experiences rather than to a doctor who dismisses it purely because it falls outside of their spectrum of knowledge).

Don’t accept that because your symptoms fall slightly outside of the list of known signs and symptoms that it should be ignored. Rather, use this list as a guide.
Don’t accept that there are timelines to determine your shunt/ETV as no longer being a problem for you. For example, the general lifespan of 2 years for shunts and 5 years for ETVs. Both of these treatment options can fail at any time.

There are just too many things to list as usual...

Statistics are great but there’s one difference...our anatomy is different and, we are all unique – FACT.

Would a statistic relax me simply because someone took the time to do the equation? No! That would be the same as taking things for granted and quite honestly, being dealt the Hydro card as an adult and what I’ve experienced since, does not afford me that luxury.

As an example, after my ETV, I was told that if it did close up, it would do so within 5 years of being done. Passing the 5-year mark, I was given the all clear and relaxed, thinking that it was all over and I had seen the back of this dreaded condition. (Remember, this is a journey and we don’t all know what we know about it – it’s a journey of discovery). Then, I started this blog and connected with others who have actually had their ETV redone because it had closed up or needed revising for whatever reason. I even know of a Hydro sister with her ETV open but still she needed surgery to implant a shunt. And, you guessed it, it was after the 5-year mark. The scares I’ve had since then have been nothing short of nerve wracking, constantly questioning, wondering and doubting...everything and everyone.

The number of years after surgery is irrelevant because it’s not a one shoe fits all condition. What drives this post, is the fact that these closures and failures are probably not part of the statistical equation.

Would a statistic relax me simply because someone took the time to do the equation? No! That would be the same as taking things for granted and quite honestly, being dealt the Hydro card as an adult and what I’ve experienced since, does not afford me that luxury.

But, if it works for you...then go for gold.

Read more from Skyewaters at http://skyewaters.com
I just cannot ‘make the grade’ in life. I’ve figured out a few things.
By Emma-Lucy

From Diary of a painfully shy introvert

I am starting to sound old here but I’m glad to have some peace. I’m sitting here without even the television on. I had to get up early this morning but later found out that the body shop had to rearrange my car’s appointment to have a new bumper (after someone hit it during an argument, one that I didn’t even participate in may I add). I couldn’t get the person that caused the damage to pay for it because they literally have no money. Insult to injury was added when I found things stolen from my flat. I don’t know if it was that person or the neighbours, but either way, I don’t like my things even being touched without asking my permission, let alone stolen.

I don’t like other people’s drama anymore, so they can just go and take it somewhere else away from me. I’ve had enough of my own issues, and as much as I am happy to help others out, I do not wish for anyone else’s crap. I’ve grown up. I no longer want to fight about who is right or wrong. The past is the past and it doesn’t matter what happened anymore. I’ve spent so many nights over the years feeling guilty for things that weren’t all my fault at the time. I’ve hated myself for reacting or over reacting negatively because I was so afraid of other people. It has taken me years to admit that I was petrified of other people. I’m sure that it won’t be enough for others not to continue thinking negatively about me for the rest of my life.

Avoidance fear is very intense, trying to pathologically control it when nothing is in your control is quite tiring to experience. The extreme lengths that people like myself will go to in order to avoid anything that they fear is not able to be understood by someone who doesn’t experience it. If the thing that the person fears the most happens, then they will just basically meltdown. I’ve been there many times in my life. It may look like a child’s tantrum but it runs deeper than that. I scream and shout but it’s more about trying to switch the situation off. Especially if I’ve explained that...
my behaviour issues can’t just be ‘switched off’ on demand and no one has actually taken that into consideration.

I’m a lot better now because I’ve learned not to care. That is difficult when you’re a person that feels everything. I will always care about someone who doesn’t want to see me. I’m legally enforced not to see them because they took my behavior in such a way that they thought I was a threat. It’s hard not to care about them when they’ve also inspired me to become the person I am. I get told by my friends that I am stupid for still caring because they treated me badly. I am more understanding than a lot of my friends. I’m quite laid back now. I even went out with dry frizzy pastel chalk colored hair which looked such a mess this morning, but I didn’t care whatsoever. As I’ve aged (feel a lot older than 30), I have realized that it isn’t always about the way you physically look. It takes a variety of things to make up a person. I must admit that I still have arguments with the scales in regard to my weight, but I think a lot of females wish that they were the weight that they were in their younger days. I wish for long hair again but it doesn’t grow well even when I don’t lighten it because of my anaemia. These little issues don’t frustrate me as much as they did a few years ago.

I’m off for a rest now anyway. I’m not well because I have a cold coming on. It started last night. I have a sore nose that is like a tap. I’ve had to take out my nose stud because it’s making it ten times worse. It makes it run more when it’s in. According to my Mother I am also too old to have my nose stud in any more. She thinks the pastel coloured hair streaks and the nose piercing are teenager things and that by mid twenties, let alone 30, I should have grown out of that image. She hates me bleaching my hair, if she had it her way I’d have boring brown hair. I can show my Mother quite a few adults who have that look who are much older than me. It’s not an age thing. It’s a how you wish to be thing.

I have a conservative Mother and it really shows in her views. She supports Theresa May and I’m all for Jeremy Corbyn. We are, and indeed, always have been complete opposites. She’s quite cold and reserved. I’m loving and open. I’ve never known a proper Mother’s love because of how cold she is towards us (all three of us). We weren’t brought up with physical contact like hugs. Even the warmth just wasn’t there. I look at others with their kids and can see that warmth. I get quite bitter that I couldn’t have had that and that it caused me so many issues in my life. I was close to my Dad but it wasn’t the same and in my later childhood I had to act as a carer for him because of his terminal illness. That can strain a bond because I would have to look after him when my Mother was working. I felt like I couldn’t go out and make friends because my life was at home looking after Dad. I weren’t...
very great at socialising so I just didn’t even try. I don’t even want to try right now to be totally honest. I’m happy with my own company. I don’t get lonely any more, and, above all, I do not fear a life of loneliness any longer.

Read more from Emma-Lucy at http://tinyurl.com/doapsi
YNOT Life Style: Story of Strength and Determination
By Hunter Kelch

From Come roll with me

Many people ask me the question, “If there was a cure for CP, would you seek it out?” My answer always surprises people. Unless CP is endangering my life, my answer is no. I have learned so much because I have CP. Most importantly, my path has crossed with some of the most amazing people on this earth directly because of my CP. Recently, my path crossed with Tyler Hogue, owner of YNOT Life Style Clothing Company.

In 2008, Tyler started YNOT at his family’s sign shop. He printed off stickers to give to friends and family. The YNOT motto was well received and a business/brand was born! YNOT officially became a company/brand in 2010. When asked about YNOT’s mission he stated, “I like to see the mission being a statement to just stay active. I hear the term used unconditionally daily and I think it is something people don’t notice. So if I can help people and motivate them in any way that is what makes me happy.”

Prior to 2011, Tyler was an avid surfer and skateboarder. He also loved riding on his motorcycle, as a matter of fact with a YNOT sticker on his helmet. His life changed in an instant when he was involved in a motorcycle accident. Tyler broke his C1, C2, T5 and T6. A fusion of his C1 to C4 was necessary and has limited his neck movement. The accident resulted in paralysis and Tyler is unable to feel from his chest down. Additionally, his wrist was shattered and he now has carpal tunnel.

I asked Tyler if he remembered his accident. “Complete. I remember from front to back nearly. Some give me the “you’re crazy” look when I say it, but I had an experience with death and it shed a bit of enlightenment on my life. Now I am just searching for me at any moment I can.” Tyler had a “painful 4 solid years” of recovery. He battled through bed sores, surgeries, therapies and adjusting to being a wheelchair user. Tyler summed up his accident and recovery with these inspiring words “I literally would say I’ve rolled into a perspective of life I NEVER imagined”
Transitioning from an able-bodied life to a wheelchair user is challenging. Tyler had to learn how to dress, do personal cares and drive as a wheelchair user. He also faced the challenge of “learning to deal with inconsiderate people who don’t know how to deal with people with disabilities.” However, he had a great deal of support along the way. Tyler’s main support came from his mom and sister. His grandparents, uncles, cousins, friends, co-workers and even strangers reached out to support him through this transition. “Till this day it’s nice to hear someone say how proud they are, although I hate stroking my ego, it’s nice to see someone notices hard work in life. Just as people should tell you how hard of a worker you are day to day encouraging people to keep rolling and keep smiling.” (Thank-you for stroking my ego, dude!)

Some thought that the accident and permanent injuries would “be the end to Tyler” He had different ideas, “So I turned my life around not only to show them, but more importantly to show my mom that it’s going to be okay. When moms see their children smiling and doing okay, they’ll be okay themselves. Nothing like a mother’s love and they deserve the best.”

Personally, I could not agree more. There have been hard adjustments, “Leaving my motorcycle, skateboard and surfboard behind. Hands down”.

However, Tyler continues to live a YNOT active life style. In fact, he is more active than some of his able-bodied friends. “I live about 30 minutes from the beach with mild traffic, so to enjoy some time to myself I walk my dog at the beach at any chance I get. I try to go on vacations and sight see when I can. Most people don’t do very much and they’re “able bodied” they work themselves into a grave much to earlier. But I sit and talk to anyone I meet for as long as they’d like. I always try to give anyone no matter their position, the time of day.”

Tyler’s disability has taught him some valuable lessons, “It’s taught me to seek the best in myself and also in others. It’s taught me my days are numbered. The number? Only God has that number. But I am not going to take for granted that it can be at any moment. So enjoy what you have. Tell people you love how much they mean to you. Stay active and always be sure to keep positive.” Plain and simple, no matter what curve ball life throws at you, “Be happy”.

Tyler’s disability has not stood in the way of his drive to build YNOT Life Style. Tyler initially started YNOT with the support of friends and family. However, he had to gain the support from his community to make it work. Competition from other local brands also posed challenges. Keep in mind, YNOT was created BEFORE Tyler’s injuries. I asked Tyler what motivated him to continue after his accident. Tyler credits his friends (along with the support from his mom and sister) for pushing him to move forward with his business. “I put them all through hell at some points but we all became stronger throughout and I couldn’t be happier they did what they’ve done.”
Tyler’s goal for YNOT Life Style is expansion. “Clothing is not the easiest thing I have tackled in my life.” He is currently seeking out stores to carry his clothing line, as well as creating new designs. He is beginning to put a friend’s advice into action by hiring “people smarter than you”.

YNOT Life Style has also changed Tyler’s life. “I’ve met many people. You are one of them. And when I see your motivation it gives me hope that people like you with such a tough attitude are still out there. And I’ve met others like you and also met many people who became good friends. I’ve used my lifestyle as a network of friendships. It been very important to me.” It is clear to me that YNOT is not just a business, it is indeed a Life Style that Tyler has embraced.

When Tyler reached out to send me a few awesome YNOT t-shirts, I never expected what would come from that gesture. Getting to know Tyler through this interview has enriched me and my outlook. My career as a blogger has been awesome, but it has also been challenging. His philosophy has reminded me that regardless of life’s obstacles, there is always a way to achieve your goals and dreams. However, along the journey you have to enjoy life and those around you.

Basically, live every day as it comes. Tyler summed up this very valuable message, “This has shown me to let go of things you can’t change. Taught me to visualize and understand differences in life. Taught me to enjoy the simple things in life. Enjoy family time as much as possible. Get out and smell the fresh air and enjoy the rain. I’ve had many hardships in life but this is what showed me durability”.

I am personally the owner of three YNOT T-shirts. I LOVE them. YNOT Life Style shirts are soft and comfortable. As a wheelchair user, this is so important. The designs are rad. However, what I like the most is the YNOT message my shirts represent.

- YNOT be active
- YNOT live life to the fullest
- YNOT enjoy what you have today
- YNOT take a risk
- YNOT enjoy those around you
- YNOT tell your loved ones what they mean to you
- YNOT stop and talk
- YNOT follow your dreams
- YNOT reach out to others
- YNOT listen
- YNOT DO!

“This has shown me to let go of things you can’t change. Taught me to visualize and understand differences in life. Taught me to enjoy the simple things in life. Enjoy family time as much as possible. Get out and smell the fresh air and enjoy the rain. I’ve had many hardships in life but this is what showed me durability”
• YNOT Keep Rollin’ and Keep Smilin’!!

You can visit YNOT Life Style website or find them on Instagram or Facebook

You can also read more from Hunter at http://comerollwithme.com
How to Contribute

Voices is a quarterly journal and the next edition will be published in July 2018

We invite anyone writing a blog or article to submit a link to the editors by email or by online form. We welcome contributions by people with a disability but also accept personal contributions by people with to support those with a disability.

Each issue we sift through the potential contributions to create a diverse and rich mix of stories and articles. The articles are reproduced in the authors own words and we do not edit terminology that an individual chooses to use. However, features and stories that are abusive towards an individual, organization or product will not be eligible for publication.

We do not accept articles that are seeking to promote a commercial product.

Other than this, we welcome submissions on all aspects of living with a disability, challenges and experience.

Email the editors at david@davebanesaccess.org

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