



**Storm WCB / UCAN  
Productions perform at the  
Wales Eye Care conference**

As vision impaired people working on a young adults project with Wales Council of the Blind and of course being keen performers as a part of UCAN Productions, Mared and I were once again asked to perform at Wales Eye Care Conference. For the 3rd year running we were asked to create two separate 10 minute informative, thought-provoking and, of course, entertaining theatre-style sketches around the themes of accessibility, during the morning, and outcomes in the afternoon.

When we were given the theme of accessibility it was a little bit like deja vu. Mared and I, as a part of UCAN Productions, have devised sketches and performed at previous Eye Care Conferences.

During this time we've been asked to cover topics such as certification and registration, accessibility within the clinic, benefits, rehabilitation and employment, to align with the conference themes. We felt that creating something new around the theme of accessibility would be quite difficult as we've already covered this topic. Therefore Mared suggested we take short pieces that are the most relevant and thought-provoking from sketches we've already created and combine them together. This resulted in a script which we felt highlighted all the issues around accessibility whilst making the point that they are still very much relevant. As usual the morning sketch aims to be deliberately provocative

in order to challenge all of our thoughts and never to criticize the great services provided by the NHS. We hope people realise how important it is that we collect and share the voices and opinions of vision impaired people.

Our second performance in the afternoon at the end of the conference was centred on outcomes. For this we wanted real stories from real people. We used the method of 'verbatim' to deliver four pieces around patient experiences in the eye clinic.

Verbatim means we could deliver these stories in their authentic form but keeping the identity of the storyteller anonymous. This is achieved by the actor or actors wearing headphones and telling the story as they hear it. Although these stories highlighted some challenges they all spoke very positively about their individual experiences.

We were really pleased with the reaction we had from both performances. Several people came up to us during the conference and thanked us for raising the issues or thought that the points we made were very important and agreed there are changes that need to be made.

We'd like to thank everyone who contributed and shared their stories with us. It wouldn't have been possible without you. We look forward to next year's conference and the celebration of the NHS turning 70 years old. See you there.

## Verbatim 1

Ok, well so I was born obviously with OC1 Albinism, so it affects everything, so when I was born, diagnosed at six months old I was literally always at the health clinic; I was there every six months until I was sixteen.

Now, got to be honest, the whole way through personally for me I don't have anything bad to say its been a really positive experience. I was brought up pretty much in the eye clinic and by the time I was six and seven it was just a normal thing to do, I went through nursery, through reception, year one. The practitioners there were always respectful to me the whole way through. Like, the options I had for care and treatment was fantastic; the amount of glasses I was offered. I had bifocals and I can't fault the amount of options I had to try and improve my quality of life.

The only side when I was young that was missing would be missing the emotional side, I never really felt in the clinic I had anyone really to talk to as such. I was always treated like an adult and I didn't ever feel like I had a visual impairment, I was treated so spot on and perfectly, but there was never anyone to turn to, there was nobody I could ask for information to ask more questions and such, and although it was a really positive experience and smooth looking back when I kind of got to my teens it would have been a really helpful area to have.

As I grew older I've sort of had various issues with my eyes, and for the last four years I've had a problem that nobody's been able to solve and that's nobody's fault – that's life - you can know as much as you can know and I can't always find the answer to everything, can't expect everyone to know the answer to everything and I don't, especially with eyes.

I've been put on medication quite recently and I've been given like a six month course of treatment, I've researched them and found out they're antibiotics and eye drops and I don't even really understand the problem with my eyes to know why I'm taking this and I haven't really taken it at all because I'm really reluctant to take it because I don't know, and that concerns me to take medication that I don't know 100% what it's for and I don't 100% know what's wrong with my eyes.

But now I've recently heard that there's an introduction of something called an ECLO (Eye Care Liaison Officer) that you'll be able to ask more questions and I mean like for issues I've had like this, that would be fantastic if that is an option. Because really that's the biggest problem I've had, because not understanding is a good thing, because I understand optometrists are seeing hundreds of people a day but to be able to turn to somebody and have that would be a big thing. I mean especially when I was growing up I don't think it now but I had

a lot of troubles and the emotional side would have been a really good aspect to cover, I'm just really happy to hear that's being recognized for sort of the first time, I'm really happy to hear that.

## **Verbatim 2**

So I was diagnosed as Registered Blind, I must have been about 18 months old and from what I can remember throughout my life, my experience of eye clinic has always been really positive. I've always had the same consultant, all the nurses have always been really helpful and my mother's always taken me, so it's always been a comfortable experience for me and something I remember quite fondly. But my mother always tells me that it wasn't always that way, when I was diagnosed at 18 months old, I think the first consultant my parents met with was quite rude.

The quote that always sticks with me is that my mother was told that he will never lead a normal life, he will have to go to a special school, he'll never be able to kick a ball and he'll never be able to go outside and play with the boys.

Now I think when your child is being diagnosed with something, you know, that's quite serious, that's not what you want to be told, you want to be told in a confident way, you want to be told that it's not going to affect their life in a negative way, they're going to

get through it and lead a full life. But that's not what my parents were told, they were told the complete opposite and I think it all comes down to the type of people my parents are, especially my mother. It would have been quite easy for her to take that information and believe it and raise me that way, thinking I'm completely different that I'm going to be secluded the rest of my life. But because she's not that person, she said to the consultant that basically I never want to see you again, I want to see another consultant and that was exactly what happened, I don't think we ever saw him again. And we've been seeing my other consultant, Dr Laws, in Neath, Port Talbot Hospital ever since. And he's just a great consultant and it's been such a positive experience for me and my family.

But I do always think back to that time and how scared my parents must have been and how, what that one person said could have actually influenced my life so much but my parents were stronger and knew more, you know than that person did.

### **Verbatim 3**

I've been registered blind from a very early age. My condition, achromatopsia, is from birth. So I don't really remember my diagnosis or the process that my parents went through to get my diagnosis. I've heard stories that it wasn't easy, that they, my

parents weren't taken seriously to begin with, they weren't really believed and that it was very difficult for them. They also said at times they didn't feel there was much support for them. Visual impairment doesn't just affect me you know, it affects my whole family, particularly at that young age.

So, I've heard those stories from other visually impaired people I know. I've heard, dare I say it horror stories about what's happened to them in the eye clinics. But I guess I'm quite lucky, to my knowledge when we met Margaret Woodhouse, all of the pieces of the puzzle came together and so all my memories of going to the eye clinic, they're all quite positive because of her.

I know a lot of kids would have dreaded having to go and get their eyes tested - and at times quite intrusive tests - but I don't think I minded all that much and I still don't, I'm lucky, I'm aware of that.

## **Verbatim 4**

Ok, I suppose I look at eye health and I look at the NHS and one of the things I think of is, is that it saved my life. I was born blind I had no vision whatsoever and had a fantastic consultant who restored the sight in my one eye and, you know, a limited level in the other. But that transformed my



life, having that opportunity to having that excellent service there.

The one thing I will say in Wales is Emergency Eye Care is first class, it is superb but there are still concerns, I still have concerns around waiting too long for clinic for example, around glaucoma which I know have with cancelled appointments and the understanding of making sure your glaucoma treatment, that you continue to take drops appropriately to keep what vision we have.

The other thing I would reflect on is accessible information, there's been very little opportunities in my life within any Health department where I've had any information in my preferred format, that is until recently where the University Hospital of Wales Eye Clinic now provide a letter, an appointment letter to me in my preferred format of large print. It would be nice to have the option of having reminders around text and emails, which again is a format which I now prefer more than printed information, that wouldn't be accessible for everybody but it would be nice to have that choice of how we receive information.

There's still work that needs to be done, I must say I was recently admitted to hospital after surgery and the staff in the ward were very aware of sight loss and it was evident that they'd had awareness training and were very competent and very understanding but there are so many examples, so

many experiences of reception, ward staff, doctors that are not fully aware of - or do not understand - sight loss and not able to guide or understand some of the basics around sight loss. So there is still a need an outcome for Health Boards to continue to provide awareness training.

## Clinic

So I go to the hospital every few months for check-ups on my eye. About 3 years ago I was transferred from the children's clinic to the adult clinic in the Heath. You don't really realise how few 'young people' have eye conditions until you step in that clinic.

Every visit I make I'm without fail the youngest person there, it's an odd feeling. I feel like I can't be too loud cause I feel like I might say something to annoy one of the 'older' patients waiting, or when it's super busy you're paranoid about looking to see if anyone needs a seat – cause I was always brought up to give my seat to my elders – but at the same time, I'm visually impaired! I can't see if there's someone who needs that seat more than I do. I suppose it would be better if the waiting room was more cheery; it's dull and drab, the seats are uncomfortable and there's nothing to really entertain

you, except for pamphlets on sight loss. Like I said, cheery!

Although, my favourite part of that clinic has to be the terribly-made sign about no food or drink in the clinic. I only came across it by accident when I was standing right by it. A pale greenish wall, a small silver plaque, with small black (not bold) writing. It's an eye clinic; I think that some better contrast and bigger, bolder writing would've been obvious - apparently not.

It just makes you think how oblivious people can still be about visual impairment, I mean, the staff there are around people who have visual impairments everyday; you'd think they'd pick up a few tips on how they can make their clinic accessible. Though with the time it takes to get seen by a doctor there, I'm not surprised they haven't figured out a few simple changes. They've got some catching up to do.

Hannah Matthews, 22

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