Young Mans Story Living With Aphasia

Okay it started. So yeah I've got like a list of questions and we're just going to chat I guess about this topic. I will sort of begin the conversation with just some more informal questions so that a listener can maybe have some perspective and then we'll progress into kind of more of the nitty-gritty. So how does that sound? Yeah that's fine. Okay great. So tell us a little bit about yourself. How did you come to have aphasia? So back in 2014 I fell down over 50 sets of stairs during a work event in Las Vegas and that caused me to have a traumatic brain injury causing me epilepsy and aphasia and at first when I was in hospital I just well to be honest in hospital I didn't realise that I had these hidden disabilities. It was only when I came out of hospital that I understood that I wasn't back to my original self and meeting friends, family, I realised that I did need more assistance and I learnt that these things were available accessing things such as PIP, freedom pass, X, Y and Z and I had to go to areas such as headway and all these other areas where people told me that they were available. Okay great so you had this TBI and then did the doctor tell you that you had aphasia and how aphasia was going to affect you or was that something that you discovered a bit later? The doctor, nope, many people, nope, said coming out of hospital I thought I was back to my usual self originally where I was. The hospital was perfect, I thought I was my normal self again when I came out of hospital. It was only when I went back and I thought when you leave hospital you're back to your normal self again say for example if you broke your leg or broke your arm you're cured in hospital and then you adjust yourself again when you leave. Yeah so you realised that you had to go through sort of a more long-term recovery and you realised that sometimes well maybe things had kind of changed and you kind of had to adjust to a new sense of normalcy.

Yeah so you then said that you was was can you remember who told you that there was potentially like benefits or welfare services or things like that that you could apply for do you remember when you first heard about that? Yeah it was when I first went to one of the headway groups someone in there told me oh have you got the likes of a freedom pass and that was when I was like what's a freedom pass and then they said oh do you know what pip is and that's when I started rolling the going through the process of finding out what some of the benefits are when being disabled and so obviously I went home I googled some of them and yeah just started the ball rolling there to find out what some of them were. Okay that's great so and headways are charity right is that for other people with TBI or? Yeah anyone who's had a brain injury yeah. Okay and that's super interesting so you learned from this community of people and then you started applying for different benefits and resources independently you weren't needed to be supported by anyone throughout that process? I was because going through that process by no means easy and takes a long time when I originally went into pip it took many many months and I did that first one by myself and as you can imagine it was an immediate no and I thought at first okay I've got no they said no so maybe I'm just not going to get it so I thought right just quit not quit just I'm not going to get it that's it maybe it's because I'm not disabled enough no so then I went back to headway and many people there said no no it's the case that you have to go again get someone else to go with you to sort of assist or every question have someone um say it's don't don't uh I don't know um imagine it's the worst day in life for every single question um say that and so I had my aunt go with me and help so just every single question imagine it's the worst day of your life every single question and she just over helped me with that okay so yeah so for doing the initial form you uh your aunt kind of helped you sort of strategize and come up with better written answers yeah um so that you fit the criteria that they're kind of looking for more closely yeah which to be honest I think is a joke but yeah that's the way it is yeah I don't blame you you know we've heard from a lot of people that like a lot of these uh criteria and things are are quite sort of like performative and um almost offensive in a way they are they are but I mean this is a typical government uh sort of approach um to kind of like try and look for uh criteria and rules and um try and get people to tick those boxes and then grant approval or not um when I think disability and the experience of disability is much more complex than that yeah um so your aunt was a super influential person who sort of helped you apply and then did she support you when you were eventually assessed or did or did you not have to be assessed or what happened next yeah when I first filled out the form that went through the process so then she actually came in um it might the one I got was in I think it was in um uh the area next to putney is um uh it kicks in no the other way going into london um sort of hammersmith no no no um you've got barnes putney uh I was going to say used not I go on that train every day um before onesworth onesworth that's the onesworth okay it was in onesworth so yeah I went in there probably even though it was um set to go at 10am as with anything I think we had to wait there until about 11 um waiting for ages and then I think it probably took about 35 minutes talking to people that seem to not understand disability because they're not disabled um which is something that I really think the government should understand that people who need disability benefits should be speaking to people who themselves are who are disabled because then they realize that you're not you're not is well obviously some people are physically disabled and visually disabled but it's not the case that you need to be and yeah I think they need to hire actual disabled people who understand being disabled um but yeah they weren't disabled and they just ticked bit boxes if you're not if you're struggling to eat it's not the case that you're struggling to eat every single day of lunch dinner and um whatever you had to just tick every box every day all year and overdo it okay so that's interesting so this was sort of in was it in a government building or like uh I think it was in one of the council buildings I think yeah so you went to a council building and then yeah you were met with this sort of office clerk yeah government yeah and they kind of went through forms with you it sounds like and were basically checking your um I think it was the form that I've sent to them yeah essentially asking me probably exactly the same questions um yeah okay and there was nothing nefarious because we've heard sort of horror stories from some people at the stage yours was generally okay uh I mean the first one that I did that I failed um but taking my aunt seemed to be okay um but yeah I'm now now that I can't remember how many years ago ages ago but as I said um before we started I just got another email back I had just another letter back I had to fill out the form again um and who knows what's going to happen now I thought once you got PIP that was it for life because you've known to be disabled a phase it doesn't go away um you've got it for life but yeah I got another letter having to fill out the form again so who knows what's going to happen am I going to have to go back in again so is this recently then that you've had to yeah it was I think if it was a week ago okay um I'm sorry to hear about that um but I so so yeah I I don't know from what I've learned from interviewing and chatting with lots of people it seems to be like something they do every three to five years I don't know if you've been receiving PIP that long um but yeah essentially they have this weird very nefarious understanding that they see maybe people's circumstances have improved so they kind of like randomly ask people to go back through the process or to reapply or to reprove and verify and it's kind of I think it's quite malicious um personally but um yeah you're not alone at having had this um someone I've been chatting to at phasia reconnect um who's also circumstances have not improved and has aphasia and things haven't changed um she's currently going back through a re-verification sort of process to get her PIP again um and yeah Sally and people are supporting her with that um so yeah I think it's unfortunately yeah pardon something that they do yeah um yeah who knows what's going to happen knowing the government I'm probably going to get a less amount of PIP or well either no PIP or less amount of PIP even though I've written that I still have seizures I've still got aphasia doesn't go away but yeah who knows who knows and outside of so so looking beyond PIP are there any other things that you've applied for and you'd recommend or uh on my let me get my wallet out um I've got the thing hidden disability card this one hidden disability sunflower because that people seem to know about that uh CEA card for entry into cinemas and um say museums if they're not free um so you can have a assistant uh with you um come for free um yeah trying to find out um see if you've had a brain injury a brain injury identity card um I think that's probably it and would you recommend any in particular I think hidden disability is one I've helped more so maybe the hidden disability card and getting one of those is not too tough no and it's more well known I've even got one that uh they've got a lanyard so you can wear the lanyard if you want to some people use it going on the trains and things like that okay no that's awesome or and actually that's useful if you're going on the all the airports use it nowadays so if you wear that going to the airport you can go through the disability um uh route yeah to sort of check in yeah yeah to check so it's sort of uh I guess more streamlined you don't have to necessarily queue and that sort of thing yeah and that's all around the world yeah no I yeah when I've traveled I've seen the sunflower lanyard sort of adopted everywhere yeah which is quite cool yeah um cool so that's we we can now broaden from your story and be a bit more um meta um so what would be your best piece of advice to someone who's just had a stroke or a brain injury and doesn't know about disability benefits speak if you can speak at that time um speak to groups or people that either that either your family or speak to people who've already had something similar to yourself because they'll know of these benefits and will be able to help you because it's something that I haven't I had no knowledge of when I first had my brain injury um and they they will help you okay that's great so so chat with yeah to develop a support network I think that's really important and then what in what in your opinion what is the biggest barrier that they should be aware of to accessing things like PIP is it emotional support confidence literacy and language the fact that you have to fill in a 40 page form or the deadlines or is it all of those I think it's all of those yeah to be honest the lack of the whole uk's accessibility um yeah it's just generally uh accessibility is such a large percentage of our country yet no one seems to care um yeah so yeah so so they should just be aware that it's going to be hard but it's worthwhile it's you know being on PIP it has that helped you a lot uh yeah because I can no longer with aphasia I personally can no longer be employed by someone else because well large organizations are not really accessible and no one understands aphasia so I've now had to well I personally have created my own business so yeah no one no no business that I know of knows what aphasia is so so yeah having access to that resource is a big help yeah okay awesome um and how would you advise someone who's maybe afraid to acknowledge you know their disabilities and they maybe have a stigma against fully representing how hard it is for them on their their sort of PIP form or on any of these application forms that's quite a difficult question I appreciate um I'd say reach out to people to help because there will be people similar to yourself obviously everyone is different disability um but yeah reach out to people groups or whoever um yeah because they will have been through similar situations themselves um yeah okay great yeah because what we found from chatting with lots of people is that people with aphasia and generally the uh applicants I've spoken to often minimize the the hardships that they face and perhaps don't fully represent themselves uh in the best way on on these sort of forms and applications and I think yeah as you said I think you gave really good advice I think chatting with people like um Sally and maybe more experienced people they just put in a lot better applications because Sally sort of snaps them out of that sort of minimization mindset which a lot of people have I think it's in general just being disabled it's something we have to do every day and we accept that we have to deal with all these barriers with everything say even reading on a website we use tools to overcome it when we are writing something we use tools to overcome it and we probably have to pay for all these different things um no one accepts this and just thinks we managed to do this yeah if we had none of these tools which PIP helps with we would not be able to do them that's why PIP helps us yeah it's what us disabled people have to overcome every single day um and yeah that's why things such as PIP help so much um it's just another barrier that we have to face yeah I think those are really good points um what would you say to someone who's starting this process today and perhaps feeling quite stressed or nervous about the whole process first of all it's no it's by no means quick so don't worry too much uh you can just relax the government won't come back to you tomorrow um have someone help you um if you've got family member or friend or someone such as that bring them along um speak to someone say for example sally go with a group because they'll be have gone through similar situations um look on websites who've gone through the process either to help you um yeah things such as that no I think those are really good points um and yeah I think you know one angle people can maybe explore in these applications which they don't is you know the fact that maybe they are experiencing you know other challenges such as challenges with you know the their mental health you know maybe stress or anxiety is is also something that's had happened as a consequence of having had like quite a you know severe stroke or brain injury and that's something that you can potentially even mention in in your application yeah um which is something that people don't you know so when I've spoken with people they will say you know how they're so desperate to get pip and how they're not sleeping and it's giving them chronic stress the fact that they can't find work and these sorts of things and these are all things that you can mention I think yeah um in the form uh to try and further better argue for your case but people don't you know they they just discuss the as you said earlier the very physical aspects of their disability which with aphasia is very hard to argue for because yeah you're you're not necessarily blind or um deaf or yes an invisible well yeah a hidden disability so people don't understand it because you know it's one of those things that we look normal um yeah so people don't understand okay great um and I'm going to surprise you with this so we have uh some sort of contact with the DWP what would you say to the DWP or or these government organizations about improving their their processes um I recently also went to government and it's just the lack um I would like them to have some disabled people within government um because they they there's still that missing gap um that unless you are disabled yourself you have no real understanding of the struggles we face um yeah I don't really know what else to say so so you'd say to the DWP that they need to yeah hire more consultants and people something yeah who who've experienced disability yeah of all different types because everyone obviously a person just even if you have the same type of disability um even you have two people who have aphasia it doesn't mean you're that you're the same um you know one person with this phasia has completely different type of phaser as a person next to you two people with epilepsy have completely different types of epilepsy and you know xyz yeah um that makes complete sense um so we've seen unfortunately um sort of this really malicious um I guess media voice and also even political it's becoming more mainstream and political voice of like stigma and um negativity towards a disability and also be potentially depending on the government or using government benefits even though people who have disabilities are entitled to them and they are you know rights they are rights as a citizen of the country you deserve there seems to be a big mix of the I don't know what the other one is called those who don't work between that and pip um I think that's people's mix of pip and what's it called people that don't work they're unemployed um yeah their benefit yeah that's the mix of people their confusion um that's what I seem to think um the benefit that um I can't think of that one's um name is it universal credit universal credit I think that's what people are mixing up um because a lot of people are complaining oh yeah pip needs to be cut but yeah I don't see the big benefit of why people are shouting and it's on the media about pip and pip and why what is the big complaint because pip is helping people actually step into work um who have disabilities because it's barriers that we face being disabled you know um um universal credit is a completely different section and that's people who don't work um pip has people is for people who are employed and well it's actually it's for both things but yeah there's such a why is pips on the media and such a big thing at the moment because it's I don't know yeah I just think it's unfortunate that yeah there's this like stigma yeah um and yeah like look I don't think there is that much sort of fraud particularly from disabled communities so I just think it's yeah it's unfortunate but yeah as you said it's it's pip is really important and it can help actually get people into work yeah um so anyone who's applying should not be deterred and should not listen to sort of the stigma and stuff that they read online um great so I think to wrap things up uh one final question is there anything else or any other advice you'd give to someone out there who may be listening who's had a stroke or a brain injury um I think be confident and recovery takes a long time um but uh speaks as someone who potentially had a stroke or a brain injury who had it maybe I don't know let's say for example five or ten years ago and talk to them about their history and you know how they were after their stroke or brain injury and how they are now and you'll see you'll you'll understand that yes is a slow process but your progress you'll you'll you'll come a long way makes no sense it's a slow process but you will move forward yeah so so you're essentially saying that action's better than no action yeah and that um try to find people out there who can help and that um before you started any of these processes you wish you had just committed strongly to action yeah awesome well well thanks very much and uh I think you've really helped um uh with your story and um with some of the advice that you've given so cheers awesome