

# Just Like One of the Others:

## Testimony of a British Student Living with Cerebral Palsy

**In the United Kingdom, disabled people are disproportionately affected by the reform of the NHS and the massive cuts in public spending undertaken by the Coalition government after it came to power in May 2010. Joshua Hepple, 21, is a young man with a physical disability who is one of the hundreds of thousands people with disabilities in the UK who are on the receiving end of the cuts. In February 2011 he wrote to David Cameron, the UK Prime Minister, but received no reply. ERT spoke with him about publicising his concerns and asked him to provide further information about the position of people whose circumstances are similar to his own. He provided the following testimony, part of which is based on a letter he published in the Times, in October 2011.**

I am Joshua, a 21 year old currently studying law at Stirling University in Scotland. I have cerebral palsy and am a keen disabled rights activist. In the past I have been heavily involved in the National Union of Students as well as other organisations, but now I concentrate on human rights campaigning with my student Amnesty International group.

However, I speak now purely from my own experience and not as affiliated with any organisation. I hope I echo the voices of the many disabled students that I have represented, but I want you to know how much social work funds mean to me: a very intellectually capable, but severely physically impaired young man. I wrote to David Cameron in February 2011. I imagined that as his son had cerebral palsy and died at the age of

six, David Cameron saw the role social work played for people with learning disabilities too. It is difficult for me to speak on their behalf, but I hoped he would understand my experience and see how critical social work funds are to disabled individuals. I received no reply.

One of my worst experiences that related to my disability was in high school.

Throughout my five years at school, I was not bullied. I was ignored by everyone, which I think is worse – at least when you are bullied, you get some kind of attention, which I craved. I used to go weeks at a time with no one even making eye contact with me, let alone having a conversation. I am aware that young teenagers are very image-conscious and anxious about being able to fit in – and

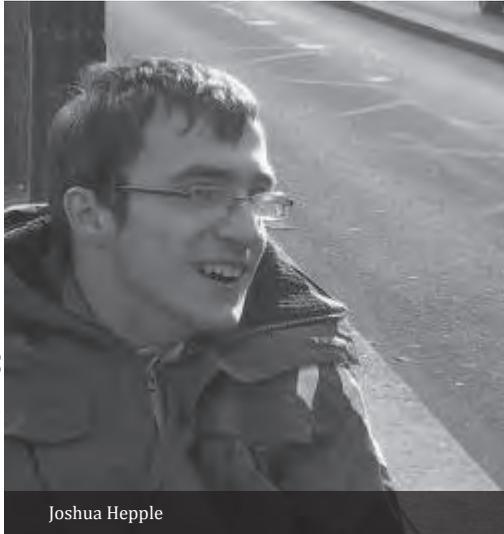


Photo credit: J. Hepple

Joshua Hepple

because I was different, my fellow students wanted nothing to do with me.

As if it wasn't hard enough to be disabled at school, I also found I was questioning my sexuality and was appalled by the lack of support my school gave me. I remember telling my guidance teacher that I thought about being gay: her response was "Oh dear", and she then walked out of the room. Two days later, she had a flyer for LGBT Youth Scotland, a fantastic organisation which I cannot applaud enough and have been in contact ever since. The flyer had a "post-it" note with my name on it, so during her drop-in session every person who came in saw this on her desk, which automatically outed and stigmatised me even more.

During the summer, when I returned home from university, my younger sister brought some of her friends over and they looked at me as if I was some kind of alien. This brought back so many memories from school and it really saddens me that these people are almost being taught to hate disabled people. I don't know why this is. My school was

known as a pond socially, which means you were either in the gang or not. If you weren't, you had no friends.

My teachers did very little to help and would quite often encourage the stigmatisation. On one occasion, a teacher told another pupil: "If you don't stop talking, I'll make you sit next to Josh." The girl almost started crying and said, "I would rather stand outside." That will be ingrained in my memory for the rest of my life.

There was not one day of school that I looked forward to, and I don't think there was ever a day in the five years I was there that a teacher ever told me to stop talking. It wasn't that teachers were frightened to discipline a disabled student, but rather that I never spoke in class.

I endured five years in my high school in Edinburgh before things eventually became too much for me and I left to join a local further education college. Thankfully, I found attitudes were very different there. At college, the tutors included me in classes, I made so many friends and no one seemed to care about my disability. I think I made more friends in my first week there than I ever did at school. After the isolation of school days, a move into further education helped me to leave a world of prejudice far behind.<sup>1</sup>

I have kept in contact with around five people from college, but not one from school. My grades were so much better at college, even though I was doing more Highers, because I was having a great time.

I am now studying law at Stirling University and have lots of friends. I do not feel that my disability is having a huge impact on my life. At university, academia is only a small part of

the whole package; university is more about finding out who you are as a person as well as making great friends and learning skills for life. This is also what secondary school should be about.

If you are a teacher and have disabled pupils in your class, I would really like you to think about whether they are included. And there isn't just one way to include disabled people in a classroom. What really helped me was being treated just like one of the others; being shown a positive attitude; and being kept an eye on to see whether I was being ignored in activities involving group work. Being asked questions in class is an excellent way of being included and stretched intellectually.

I have been so frustrated with people's perceptions of

disability that I am now working with the Edinburgh Festival Fringe and training all front-of-house staff on how to interact with disabled customers. I was also the disabled students' officer at Stirling University, which involved helping students with individual problems, as well as working with presidents of clubs and societies and training them to make the effort to involve disabled students in their clubs. I have also been the LGBT officer at Stirling and loved to challenge perceptions of sexuality



Joshua winning a carriage driving competition



Joshua spending time with pony after winning competition

Photo credit: J. Hepple

Photo credit: J. Hepple

and gender. I faced the exact same problems through having a different sexuality, as being disabled, with my classmates.

I wish there was a way of teaching young people not to be afraid to talk to people who are different. I would love to see a new breed of people leaving school who are open-minded, able to talk to new people and not care about differences.



Photo credit: J. Hepple

Joshua with a dog at the stables

Teachers of any subject need to think about how to welcome diversity in their classroom, whether it's disability, sexuality, gender or race. We are all people and no one should be treated less favourably than anyone else in any situation, especially not in school.

Up until three years ago, I did not have any interaction with social work, as my parents provided me with all the care that I needed. A friend told me about his personal assistants

that supported him and asked me why I did not have any myself. To begin with, I was very reluctant to have to pay people to support me with personal care, etc.

The money that I now receive from social work has had an extremely positive impact on my life. I don't know what the system is exactly in England, and around the world, but in Scotland I receive "Direct Payments", which are given to me by the government. This is a set amount of money every month with which I can pay for my own support in the way I choose to. At the moment I have around ten fellow students who support me, many of whom are in my university's hockey or rugby teams. These assistants allow me to do what I want and let me live a life which I do not feel is inferior to that of a non-disabled person. I am able to do anything that I wish when I am with them, be it horse riding, typing emails, or going to conferences in London. I am very lucky and grateful that I have assistants, but I do not feel that I should have any guilt for requiring them as they do not make my life any more superior to that of a non-disabled person.

If I didn't have these funds there would be no way that I could be at university or have any sort of life which did not heavily rely on my parents. Similarly, it has only been recently that my mother has been able to go back into work. It is not fair that she has had to wait so long. I am her son and I would like to hope that a parent should not have to make drastic changes to their life if they have a disabled child compared to a non-disabled child.

You may be aware that the Independent Living Fund is slowly being reduced and in a few years it will cease to exist and has closed already to new applicants. This fund provides me with half of my income for my personal assistants. I do not even want to think about

what will happen when this money is withdrawn. It is no one's fault that I have to pay for support and I really do not feel this should be something that I have to be concerned about. For instance, my parents live in Edinburgh and I am at university in Stirling. Quite often there will be a big event at the weekend in Stirling which I want to attend, but to save money I go home and rely on free support from my parents. This may seem trivial to you; however, no other students who aren't disabled would have to make a decision like this which automatically segregates me from the rest of my peers because of my disability. It also puts quite a lot of pressure on my parents to be there for me. If anything happened

to them and they were unable to support me, I would hate to think of the consequences.

If the proposal of a residential home ever came up, this would make me absolutely disgusted as I could not lead the independent life I am entitled to have and I would see this as a breach of my human rights. I am aware that the state has limited funds for social services; however, I feel they are the most important funds in the UK today. Without them, I could not have access to personal care such as eating or washing and could not live my life to the potential that I am able to do. I feel that without this money it would be degrading and easily count as a violation of the prohibition



Joshua on the top of The Empire State Building June 2012

Photo credit: J. Hepple

of degrading treatment under Article 3 of the European Convention on Human Rights.

Independent living is something that I feel extremely strongly about. I have many issues and concerns with the whole social work setup, from the way individuals are assessed to the way social workers treat their clients.

Regarding assessment, the process to receive direct payments is problematic. A request is made to social work for an assessment. This assessment is then made after around two months with a dedicated social worker and someone from the funding team. The assessment is dreadful. The individual is required to reel off everything they cannot do for an hour or two. Basically, the more the individual cannot do, the more money he or she will receive. This assessment is checked over by different people and goes to a board and then after a couple of months wait the money starts to go in to the individual's bank account. Some people decide to pay an agency that demands slightly more an hour to sort out their needs and gives them the support which they have been assessed for. The individual has very little say in who comes to help. I could never do this. I feel it is absolutely essential to get on with the person who is supporting me. In fact, 90% of the people I interview do not make it and when they do many of them do not make it past a month.

Regardless of the process for receiving direct payments and my criticisms above, I do want to reiterate how positive they are, I don't know where I'd be without them.

I feel that social workers treat their clients very much as numbers and make no effort to under-

stand their clients' needs or spend time getting to know them. The whole concept of reasonable adjustments is ironically non-existent within social care. For example, I cannot use a telephone due to my speech impairment but have no problem on e-mail. Not only do social workers phone up periodically to discuss my case, they also proceed to discuss extremely confidential matters with whoever answers the phone, normally my mum. At meetings, when social workers cannot understand me, they will automatically look at my PA (or "carer", as they insist on calling them even though I have explained my numerous problems with the term on many occasions) to translate instead of asking me to repeat myself which is much more empowering. If I could give disability equality training to one group of people it would be social workers, though they would never accept they needed it.

As you will know, I receive 12 hours a day support and unlike most disabled people, I employ my own staff instead of hiring an agency to provide me with people I don't know to help me with very personal care, which I think is very un-dignifying and very costly.

I don't think it's fair to limit the amount of funds any disabled person requires at all, as I feel it would be an Article 3 (with 14) breach of the ECHR. I need my staff for anything from helping with the toilet to giving me food. I don't think it would be difficult to argue that lack of food and personal care would amount to degrading treatment. I know it would not be as easy as this, as social work have very tight budgets which they keep unnecessarily reminding me about. I think this is an area which needs a lot of work done to it.

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<sup>1</sup> A version of the above paragraphs was published in: Hepple, J., "From school to college was a journey out of exclusion", TESS, 21 October 2011.