Nadia Clarke’s cut in Support for Independent Living in 2021

Disabled People with High Level Support Needs are being further penalised as Councils are demanding they pay towards their Care Package which is vital to their Independent Living and enjoying a reasonable quality of life. Below is Nadia Clarke’s reaction to when she heard her Local Council were requiring her to contribute to her care package.

• Tell us a bit about yourself – what you like doing and how you’re supported.

“Hi my name is Nadia Clarke. I’m 29 years old. I currently live with my family in Halifax. However, I have my own bungalow, which is currently going to be adapted to meet my needs. Hopefully by the end of the year I will be living independently in my own home with support from a team of personal assistants! This is really exciting for me.

I employ a small team of Personal Assistants via direct payments. I receive a joint social care and health budget, which allows me to do this. I have received Direct Payments since I was 8 years old. I am dependent on my PA’s to meet all my personal care and daily living needs. They also support me to have full control of my life, and this allows me to have the fun, spontaneous and productive life that I wish to lead.

I am usually busy and active during the week, this involves studying disability, equality and human rights, giving speeches and supporting with research projects. I work as a travel consultant for INCLU Travel, where I support people with disabilities to find accessible travel and holidays. This job has taken me all around the world!

One of my biggest passions is travel and tourism, and observing different ways of life, different cultures. I love to travel around the world, which I have done independently with support from my PA’s. I have been to India, Dubai, Thailand, Singapore, Hong Kong, Australia, and Europe.

I love to have a good social life with my family and friends. I enjoy going out to eat good food, going to gigs and festivals, drinking delicious cocktails, walking with my dog Ted, going to stay at my Gran's house, weekends away and grabbing every opportunity I get to have fun!”

• What was your reaction when you read the letter informing you of the increase in charges for your care?

“I received a lengthy email informing me of my care charges raising from £15, 35 to £68.35 per week. I felt shocked. I did not understand what the email was saying. I felt really confused. I didn’t really understand what care charges are, or why I had to pay them. I wasn’t given any notice and prior explanation – I just received the email out of the blue. I thought what is this? I thought my care was free like NHS services are. I have been assessed as needing the support I receive, so why do I have to pay for the support I need to live a safe and independent life. My family and PA’s explained the email to me, but I still did not fully understand and I still feel confused now. The council have since said I shouldn’t have received the email yet, and are now asking me to explain to the council what my disability related expenditure is. I didn’t even know what this was – I haven’t heard of it before. I asked for the council to meet with me to discuss things further in a way that was accessible to my needs. I asked for large print, and also to have a BSL interpreter, and to be sent any policies and procedures to help me understand, but none of these things happened. You can’t just send me a complicated email written in English, and expect me to understand it. I am profoundly deaf, and my first language is British sign language. It has been down to my team and I to do lots of research and seek advice in order for me to be able to complete the work they want. I feel frustrated, I just want to get on with living my life. It has been a challenging and scary time due to the Covid-19 pandemic, so I think the council could have been more sensitive. This has all had a significant impact on my mental health and emotional wellbeing. The whole experience has been really confusing and upsetting for me”.

• What effect will the higher charges have on your life?

“Having to pay £68.35 in stead of £15.35, is a massive financial increase for me, and one that I have not planned for or chosen. This will affect my life significantly. For example, it will now be difficult for me to live independently in my own bungalow. I receive benefits – PIP, and won’t be left with much money to simply live off after paying my care charges. I currently go for specialist physio therapy every week, to a place called Rainbow Hub, which is near Ormskirk Lancashire. This costs me a lot in fuel, which I would no longer be able to afford. Due to my Cerebral Palsy, my body can get stiff and my posture can be poor. The physio is vital to promote a good posture and positioning. I love to have one holiday a year – I save up hard to be able to go. However, I have the extra costs of going away with 2 PA’s to consider. Paying increased care charges means that I will not be able to go away with my PA’s. I would have to go with my family, to save on costs. However, I am 29, what 29-year-old has to go on holiday with their parents!

Overall, the higher charges will have a detrimental impact on my life, I would lose my independence, and ultimately not be able to afford to live in my own home, which has been my biggest dream since I was a child. I also would not be able to go to the pub – ha ha ha! But seriously, I feel I would not be able to enjoy life and it would impact on my mental health – causing me to be stressed and anxious”.

• What would you want the council to know about the impact of their decision?

“It just doesn’t seem fair that I have to pay any care charges, let alone £68.35 a week. That’s nearly £300 per month - £3, 554.20 a year to be precise. I don’t live an extravagant life now as it is. I just can’t afford. I have to be very careful with my money. So how an earth can I pay £3, 554.20 per year? The council just don’t think about my needs, or the needs of people with disabilities. I want them to think about if they had a disability, or had a family member with a disability, who required support services to meet their every need. How would they feel if this happened to them? I don’t choose to require support services, and I wish I didn’t need them, but my life is such that I am dependent on 24 / 7 care. The council need to think about my human rights. I have a right to live an independent life, where and how I want. I feel the council, are discriminating against me because of my disability.

I also want to tell the council that they have not been accessible at all. They have failed to support me to understand this whole process, and failed to meet the requirement to meet my access needs, even after I specifically asked them to meet with me with a BSL interpreter, and to send me policies and procedures to help explain the situation, and to do so in large print.

I also want to stress that the council really should offer people with disabilities support and advice about care charges, and disability related expenditure. It is all so confusing. I have had to seek independent advice, and also received a lot of helps and support from my family and team of PA’s. But what about other people out there who don’t have family or people to turn to for advice. What about those with learning disabilities or who don’t speak or understand English. I imagine there are lots of people who are unable to challenge the council, and also those who don’t even realise there care charges have increased.

I want the council to know that their decision to increase my care charges, and the way they have gone about sending me an email to inform me of this, has caused me a great deal of upset and stress. I now feel really worried and uncertain about my future”.

Questions for UKDHM School Activity

• What impacts Nadia’s life?

• What could Nadia tell her local council and MP?

• Do you think it is fair for Nadia to have these care charges?

• What do you think Nadia can do to achieve her dream of living independently?

• Do you think the care charges are wrong? if so why?

• How can Nadia have her own voice and speak up for herself about her life?

• How do you imagine Nadia’s life would be without her AAC, how would you understand her communication?