

Perspectives of life managing a neurological condition

1. Lived experience from a patient/carer in DWP review assessment;

I established the legal precedent of my disability with a successful Personal Independence Payment (PIP) appeal made to HM Courts and Tribunals with the help of an advocate in 2017. The evidence I offered for the PIP review is identical to the evidence I presented to HM Courts and Tribunals service. The PIP review assessed my ability to plan and follow a journey based on a phone call to my home with my wife/carer to assist me. My wife had to prompt me. This was ignored by the assessor and they failed to record pertinent information about my day-to-day life. My mental health disability has been exacerbated by the Covid-19 pandemic and I must manage my 5 co-morbidities 7 days a week, not just for a phone call.

I have PTSD due to an Adverse Childhood Experience (ACE) and have an acute 'fight or flight' response which was intensified during the phone call because I felt under attack. I was extremely anxious during the PIP review phone call and the stress and anxiety lasted several days afterwards which my wife/carer had to deal with and resolve, yet she has chronic anxiety and depression and I take care of her. We take care of each other but no-one understands that.

The assessor clearly had no qualification or professional skill about neuro-diversity/mental health disorders because her attitude and the subsequent PIP refusal was nothing short of discriminatory.

2. Lived experience from a kinship carer of someone with FASD;

First-hand experience of the justice system advocating for a person with FASD, an organic brain injury has proved there is lack of skill, awareness, knowledge and an endemic lack of support. Whilst it is difficult dealing with an offender not knowing their circumstances, there must be a database of local support services to tap into to see what services could support an individual and their carer's rights.

Despite the fact our young person explained brain damage and mental health diagnoses, leaning on pre-conceived ideas, the justice service failed to contact us to get any background help to support him. He was not offered an advocate or signposted to anybody with knowledge of FASD and mental health comorbidities such as limited concentration or sensory overload. He has a short attention span due to the FASD but was labelled non-compliant.

It is painfully obvious that the cognition, memory or knowledge of judicial jargon and protocols will not be understood by anyone with a neuro-diverse condition which leads to stereotyping and coercive behaviours that subsequently only lead to accepting false statements and charges based on presumption of guilt.

Our experience has left us with the impression of the system not caring enough to look further into the problems our young people have. The system is in a hurry, target-driven not appropriately outcome-driven. Such poor knowledge and associated skill along with constrained capacity means the Police want to charge or caution and move on to the next person, knowledge or compassion is a luxury. No-one is accountable for the harm they cause when a person's mental health deteriorates because of the attitudes shown to them or deliver professional psychological support the carer needs when trying to resolve the subsequent anger and mistrust and in particular, repeated behaviours leading to the perception of recidivism.

3. Lived experience of a patient /carer

On 23rd December 2020, a parent carer was hospitalised leaving the cared-for isolated and alone for Christmas. Although 50% paralysed, the person was also a carer for the parent with a mental health disorder. Services did not receive notice of events until 29th December but the 72 hour emergency care package which should have been triggered by the emergency carer's card was not implemented.

The carer will be in hospital for several months.

The person did not receive their domestic care visit on the appointed day in the New Year and was extremely upset. No-one had been in touch to explain but the Social Care department had sent him a new standing order mandate to claim the fees. The person was distraught.

With the help of an advocate, the person was able to resolve immediate needs and discuss how to manage the situation moving forward. Ordinarily, the person was not only vulnerable through several co-morbidities but felt a duty of care in shielding the parent. The advocate worked through a risk strategy to improve independence and after discussions with finance and care, was able to improve the management of care routines and additional actions such as food and pharmacy.

Due to the loss of the parent's support, the person's mental health has deteriorated over this period of time and measures have been put in place to receive social calls and twice weekly phone chats by the advocate.