P-05-812 We call for the Welsh Government to encourage trusts to implement the NICE guidelines for Borderline Personality Disorder or justify why they do not do so –

Correspondence from Petitioner to Committee, 08.05.18

For the attention of the Welsh Assembly Petitions Committee

Thank you for giving this petition your consideration. I note the response from the health secretary and while I shall make some specific points below I also enclose a blog written on the subject which will cover the points in more detail. It was first published about 6 weeks ago and has been read around 1000 times.

With specific reference to the Health Secretary's letter:

- While "many people recover fully without any intervention" may be true, this petition is about borderline personality disorder specifically. Around 2% of the population would meet the criteria for this diagnosis. 1 in 10 people given this diagnosis will die by suicide. These figures are too high.
- NICE produced guidelines requiring trusts to develop specialist services in 2009. Less than half trusts have done so.
- Borderline Personality Disorder is recognised as the most stigmatised diagnoses within mental health. It is widely acknowledged that those with this diagnosis are excluded from mainstream services. An example of this exclusion is that less than half of Welsh trusts have specialist services compared to 84% in England.
- Where welsh trusts have ignored the NICE guidelines for 9 years, they are likely to continue to exclude this group of service users unless there is pressure to do otherwise.
- Money for psychological therapy without a direction to meet the needs of excluded groups is likely to result in money being spent in the usual places.
- This client group has been excluded long enough. They are frequently people who have lived through childhood neglect and abuse. Despite this their histories are forgotten, the focus is on what is 'wrong with

them' and they tend to get blamed for the difficulties that they live with.

- If the ethical argument for not offering help is not enough, trusts without specialist services are over reliant on private services at a cost of over £150,000 per person per year.
- Trusts with specialist services have significantly reduced this expenditure.
- This is one of the few areas where more could be done with less. Ethical, compassionate support at a fraction of the cost that trusts are currently spending. I recently presented on this to the British Personality Disorder Conference in Cardiff in March and would be happy to expand on this for the committee members.

Again, Many thanks for looking into this matter,

Keir

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March is upon us and this is my first blog of this year. The main reason for that is that I've been desperately trying to get my dissertation finished and any writing that has not contributed to that 18,000 word total has felt like a betrayal. Anyway, it's handed in now and it's time to cast my eyes upon the land of my fathers as the British and Irish Group for the Study of Personality Disorder Annual Conference is coming to Cardiff on March 20th. With this in mind, it's worth looking at how Wales responds to the needs of those diagnosed with personality disorder and how we compare to our neighbours on the other side of Offa's Dyke.

In some ways, Wales has been quite pioneering in this field. While the NICE guidelines for borderline personality disorder were published in 2009, Wales laid out its own blueprint for services in 2005 calling for the provision of specialist services that were integrated into current provision. This was echoed in the NICE guidelines 4 years later. With Welsh Government guidelines and the National Institute for Clinical Excellence requiring trusts to provide specialist services you would assume that Wales would have ploughed ahead. You would be mistaken…

In 2017 Oliver Dale and his colleagues undertook a review of the provision of personality disorder services in England. They found that 84% of trusts provided a specialist service. In Cardiff in 2016, at a conference that gathered people from all the trusts in Wales, we very quickly replicated Dale's study. We found that less than half of Welsh trusts (3/7) had specialist services. This was odd because 2 had services that were recognised as being very effective while areas that didn't have specialist services talked about "the privatisation of PD" – how those diagnosed with a personality disorder were 'not their business' and were sent to expensive independent hospitals miles away.

Given the potential for specialist services to reduce the amount of people sent (and they go under the mental health act so they are literally sent) out of area I began to wonder why the Welsh Government wasn't pushing trusts to follow NICE guidelines, or even its own guidelines. I wrote to the Health Secretary asking if he could encourage trusts to follow his own and NICE guidelines or explain what they were doing that was better. The disappointing response was:

"I hope you will understand that neither the Cabinet Secretary nor Welsh Government officials can intervene in health boards' day-to-day operations"

This seems to me to be a preposterous answer. Not least because one of the Welsh Health trusts is under 'special measures'. This is defined as "Current arrangements require significant change. Welsh Ministers may take intervention as set out in the NHS (Wales) Act 2006." So in contrast to the answer I received, Ministers can not only ask why NICE guidelines are not being followed, they can take intervention to remedy it. In this case they merely choose not to.

If over half of Welsh trusts were refusing to provide treatment for people with cancer I suspect someone at the assembly would pick up the phone. If half of Welsh trusts declined to offer services to war veterans I'm convinced someone at the assembly would write a letter. Over half of Welsh trusts are ignoring Welsh Government guidelines and NICE guidelines for people diagnosed with personality disorder and the government doesn't even see it as within its remit to ask why.

We can have lots of ideas about why this might be. We could say it's because specialist services cost money, but the evidence is that they save money by reducing the need for expensive Out of Area placements. We might conclude that personality disorder remains a diagnosis of exclusion in Wales and that for some reason this is acceptable. Those in mental health tend not to shout very loud for their rights to be upheld. Those diagnosed with personality disorder are probably the most stigmatised and excluded within mental health. They are easy to ignore, easy to forget about and potentially paying £200,000 a year for them to be sent out of area is for some reason a better option than having to work with them at home. We can do better than this.

I wasn't particularly satisfied with the answer I received, so I emailed again. Part of my letter said:

"I take your point that neither the cabinet secretary nor government officials can intervene in the day to day running of health boards, but I wonder if the Welsh government could avoid being complicit in the exclusion of people diagnosed with personality disorder by strongly encouraging trusts to follow its own guidance. My understanding is that NICE clinical guidelines continue to apply in Wales so I'm curious why it's acceptable for less than half of Welsh trusts to follow them. Given that trusts have been sued for not following NICE guidelines would it be prudent for the Welsh Government to call on trusts to justify why they are not following the guidelines rather than have to pay the legal bills when somebody opts to take matters to court?

I welcome the extra money that the Welsh Government has put into primary care however the clientele I was speaking of tend to manage their distress with potentially lethal self harm. This is generally not seen as a primary care role and an absence of specialist services means that they get sent to largely *unsuccessful out of area placements at a cost of around £200,000 a year. This is £1,000,000 to treat 5 people where a specialist team at a fraction of the cost could provide better treatment without the necessity to send Welsh people to England"*

My response to this one was equally uninspiring. I was told that despite seeing no role for itself in highlighting that less than half of its trusts follow NICE guidelines for a particularly stigmatised group, the government had signed a pledge to reduce stigma. I feel like actions might have spoken much louder than words here.

I was also told "The Welsh government's main role is to set the strategic direction for health services and hold the NHS to account". For me 'Strategic Direction' might include writing guidance. 'Hold the NHS to account' might include ensuring that guidance is followed. I'm baffled why this is the case for some areas of health but not the realm of personality disorder.

The reply finished with **"Health boards must regularly review their services to ensure they meet the needs of their resident population you may, therefore, wish to consider contacting the individual health boards directly on this matter"** – my interpretation of this was "We have produced guidance, NICE has produced guidance, half of our trusts are ignoring it and if you want to know why, you can ask them yourself". Again, this seems an incredibly vague interpretation of setting strategic direction and holding the NHS to account.

I did an experiment and opted to contact one of the health boards to find out why they didn't follow NICE guidelines. They replied that Dialectical Behaviour Therapy was available in some areas and that intervention was offered through generic services. "That's not what I asked" I replied, "Where are the specialist services that NICE recommend?" They replied something along the lines of "We know we're not following the NICE guidelines and we're working on it as a priority". Given that it's 13 years on from the Welsh government guidance and 9 years from the NICE guidance you have to wonder how far down the list of priorities it must have been. There is also the worrying response that "we need additional funding to create specialist services" when the reality is that a service could be paid for immediately by not sending one or two people out of area. If the health boards are happy to spend £1,000,000 providing treatment to 5 people for a year, why not provide therapy to hundreds of people in the community for the same money?

Frustrated and wanting to know the extent of the problem the trust was ignoring I tried one more time. A freedom of information request asked:

1. How much does the Health Board spend on residential treatment for people diagnosed with a personality disorder?
2. How many acute beds are utilised by such patients who are often stuck on acute wards?

This resulted in the response:

"Unfortunately, the Health Board is unable to respond to your request for information as we do not record data on personality disorders to this level of detail."

"This level of detail" is an interesting phase. Another interpretation of this is "People we pay over and above £200,000 per year to receive treatment in private hospitals, we don't even record what we are paying for".

No Longer A Diagnosis of Exclusion was a document published 15 years ago highlighting the discrimination people diagnosed with personality disorder experienced within mental health services. 15 years on, despite an early call for better service provision, the Welsh dragon must hang its head at the ongoing systemic discrimination that goes on. This is a client group of whom 10% will die by suicide. The National Confidential Inquiry into Suicide and Homicide by people with a Mental Illness found that none of the 10% who died over the period of their study were receiving care that was consistent with NICE guidelines. Perhaps a high proportion were living in Wales where for some reason the NICE guidelines don't apply or, for this client group, there is no will for trusts to implement them.

It was about 2 years ago that I asked the Welsh government to encourage trusts to follow the guidance it had written around personality disorder, let alone the NICE guidelines that apply across England and Wales. That 84% of English trusts have a specialist service compared to our 43% is shameful indeed. It would be less shameful if we saw it as a travesty to be addressed rather than an issue to contact individual trusts about if you are interested.

I've asked Mind Cymru, Time to Change Wales, Hafal, Gofal and other groups with an influential voice to try to make some noise about the current exclusion of this client group in Wales. Perhaps with the British and Irish Group for the Study of Personality Disorder Conference coming to Cardiff in March, the Welsh Government might reassess it's position on encouraging trusts to follow its own guidance. Perhaps it might start counting the amount of money spent on sending people to England for treatment they don't want. Perhaps 15 years on it might reread No Longer A Diagnosis of Exclusion and consider that the difficulties experienced by those diagnosed with personality disorder have a legitimate place in our health service after all. I hope they do.