

Article

Chronic ill-health, disability and societal attitudes

Background

At a time when we could be discussing how to support the development of the social model of disability, we are fire-fighting the worst dismantling of disability rights the UK has seen in nearly fifty years.

Successive Governments have badly failed to understand the collective impact of political policies and the role of social media on public outlook which is encouraging a populist view against disability. The chronic skill shortage in the NHS hides a lack of understanding about shrinking services outside the front door of a Hospital. This marginalizes people who need information, knowledge and skilled support to manage their disability. A school curriculum no longer teaches society mores to forge understanding about chronic ill health and disability. This has fractured the moral compass of the next generation. The powerful rise of the influence of social media on every-day life has lit a touch paper. Ill-informed, pre-conceived judgements spread negative rhetoric to target chronically sick and disabled people as 'scroungers' and a 'burden on society'.

Under early signs of the marque of austerity, the dissolution of the National Strategic Framework for Long Term Neurological Conditions in 2010 gave a clear signal that the neuro client group were an untenable economic burden on the NHS. The cull of public sector employees in 2010/11 reduced networking ability and the pool of neurological knowledge by 90%. By March 2016, the dissolution of the National Clinical Director for Neurological Conditions post and the removal of Neurological Conditions from Strategic Clinical Networks further isolated the client group from any strategic representation, with sinister implications. In December 2018, there is no NHS neuro 'lead' in the developing Integrated Care Systems for the new NHS Plan in the whole of northern England. With an estimate of over 75,000 people living with a neurological condition in the region, lack of inclusion since 2010 equals a clear systemic failure towards an entire NHS client group.

Indications of failure to protect the rights of the Chronically Sick and Disabled;

1. Medical

- a. In 2012, the World Health Organisation (WHO) reported that neurological conditions were the leading cause of disability in the UK equating to 1/3 the burden of all diseases and representing more than heart disease, cancer and diabetes combined. The WHO considered neurological disorders were seriously underestimated, largely defined by mortality rates not disability rates¹.
- b. This was echoed in a Public Health England (PHE) 2018 report underpinning the issues about mortality and providing evidence that life expectancy for people with a neurological disability has been decreasing since 2001².
- c. The UK has one of the lowest ratios of neurologists per head of population compared to most of Europe, *one* neurologist per 100,000 people in the UK contrasts to *four* neurologists per 100,000 people in Greece and *seven* neurologists per 100,000 people in Poland³.
- d. People are being badly marginalized away from a timely diagnosis with a 40-week waiting list to access a Neurology clinic at James Cook University Hospital, Middlesbrough. Neuro-psychology services rarely see a new patient within a year. This removes the recognition and right of need for timely clinical care and subsequent care pathways to access community services such as rehabilitation and psychological or crisis management. Employers have poor understanding of what reasonable adjustments they can apply whilst an employee waits for a diagnosis.
- e. With the likelihood of neuro-disability, GP's in Primary Care lack knowledge about neurological symptoms or case management. Couple this with a historical lack of in-service training and severe reductions in NHS capacity and the neuro client group can no longer guarantee skilled healthcare at the first point of contact.
- f. Reports from service users and caregivers indicate GP's advising their patients that 'you cannot get Multiple Sclerosis (MS) in your arms' and 'you may get better next year' after being diagnosed with lapsing remitting MS. This lack of knowledge is isolating people from appropriate and adequate care. (Neuro Key 2015-18)
- g. People with rare conditions or long-term unexplained symptoms who cannot refer to a national 3rd Sector organization fare very badly when trying to secure a clinical diagnosis or knowledgeable support. (Neuro Key 2015-18)
- h. People with neuro-developmental conditions also fare badly when GP's have little comprehension about the impact of Tourette's, autism or Attention Deficit Hyperactivity Disorder (ADHD) when the patient is in their late 40's. (Neuro Key 2018)

2. Crime

- a. In June 2018, a news media outlet (BBC) reported that disability hate crime, targeted hostility towards the disabled, had increased by 51%. ⁴
- b. The rise of cyber bullying against someone with a disability is a nasty subversion yet the Police are powerless to act beyond the bounds of 'recording an incident'. Posts are targeted and personal to the point where the person who has been targeted must withdraw from social media in fear. Suicide attempts are not uncommon. (Neuro Key Advocacy service - March 2016 and September 2018)

3. Accessibility

- a. Following successive cuts to Local Government spending, Borough Councils removed a key aspect of accessibility and closed Dial-a-ride services for people with chronic ill-health and disability. The Government blamed 'local priorities' but Local Government is the system for delivering Government policy in the regions.
- b. Access to the Blue Badge scheme is specified in policy to comply with the right to accessibility, assigned under the Chronically Sick and Disabled Persons Act (1970). We now see Borough Councils and Hospitals enforcing parking fees for people with Blue Badges. Whilst the Blue Badge is not an entitlement to free parking under the Law, charging parking fees provides a deliberate barrier against disability which breaches the Chronically Sick and Disabled Persons Act (1970), The Disability Discrimination Act (1995) and the UN Convention on Rights of Disabled Persons (2009). There is a drip-fed politicized narrative that endorses the idea that able-bodied people have equality with disabled people.
- a. The recent case of a person feeling warranted to leave a message on a car windscreen to inform the driver of suspected misuse of a Blue Badge parking space is a reflection of what society has become (Facebook, November 2018). Even though the driver had a very legitimate reason for having a Blue Badge and parking in the space, the contender felt within rights to publically humiliate the driver and act in a discriminatory way, with anonymous impunity.
- b. Ten years ago, we had accepted societal beliefs that promoted understanding that chronically ill and disabled people have a right to live safely and independently. Today, we have judgmental and highly prescriptive mindsets with an increasing rate of discriminatory behavior. Blue Badge Fraud and misuse are serious offences contrary to The Fraud Act 2006 and the Road Traffic Regulations Act 1984. Blue Badge parking prosecutions have risen by 84% in a year.

Borough Councils in England took legal action against 985 people in 2014-15, the majority for using someone else's Blue Badge, compared to 535 in 2013. Thefts of Blue Badges have also risen with 2,056 cases, compared with 1,756 in 2013.⁵

This data is not generally reported by the media to support the political messages.

We are witnessing able-bodied people extort parity with disabled people.

- c. The UN Convention on Rights of Persons with Disabilities (2009) states that Governments have a duty to ensure that human rights are '*Universal, indivisible, interdependent and interrelated*'.
- d. The UN Convention Article 27 states, '*the provision of access to appropriate and where necessary, specially tailored forms of transportation is crucial to the realization by persons with disabilities of virtually all the rights recognized in the Covenant*'.

People living with an acquired brain injury are being denied mobility points and access to the Motability Car Scheme because the Department of Work and Pensions (DWP) rule that they do not have a physical impairment and can walk. Yet, vulnerability from cognitive impairment is heightened dramatically without the right of accessibility that is, getting as close as possible to where they need to be. The DWP are ignoring the PIP amendments of 2013 across a range of neurological conditions which allow for someone to be safe and take into account whether a disabled person can complete a task reasonably, repeatedly and to an appropriate standard.

- e. Despite the concession, a Disabled Rail card does not entitle a disabled person to space or a seat on a train and if someone has placed luggage or a child's pushchair in the allocated space, a disabled person must go elsewhere. Southern Rail has informed staff not to assist someone with a disability if it is likely to hold up the train.⁶
- f. Likewise, bus companies will not remove parents with pushchairs from disability accessible seats to help people with walking impairments or wheelchairs. Operating transport policy on a 'first come, first served' basis is breaching the Law by imposing a barrier against disability.
- g. Parent and toddler parking spaces are sited as near to the front door of a supermarket as possible, taking precedent over parking spaces allocated for people with disabilities because parents spend more money, not because supermarkets have any legal duty. Self-appointed sentinels patrol supermarket parking spaces to actively prevent the disabled from using parent and toddler spaces (Morrison's, Teesside Retail Park - November 2018) which directly contravenes the Chronically Sick and Disabled Persons Act (1970) on accessibility. Blue Badge drivers can park on double yellow lines but Neuro Key has reports that Blue Badge drivers are receiving parking tickets if they park in parent and toddler spaces. This is discrimination.

4. Welfare reform

- a. Under the banner of welfare reform, the Government has targeted people when transitioning from Disability Living Allowance (DLA) to Personal Independence Payment (PIP), particularly on Mobility points. DWP automatically remove mobility points, force people into stressful appeal processes or give up their claim. The MS Society (www.mssociety.org.uk) reported that 94% of people with MS received the higher rate of DLA mobility support, but that had fallen to 66% under PIP rules. This is echoed across a range of neurological disabilities.
- b. The Department of Work and Pensions (DWP) was forced to release updated Employment and Support Allowance (ESA) mortality statistics, in response to a Freedom of Information request from disability campaigner Gail Ward.⁷ The data revealed that 111,450 ESA claims were closed following the death of claimants March 2014 to February 2017 with more than 8,000 Incapacity Benefit and Severe Disability Allowance claimants who died over the same period.
- c. According to Professor Alston, (United Nations Special Rapporteur on Extreme Poverty and Human rights - Nov 2018)⁸, 3.45 million people are from families in which someone has a disability. People with disabilities are more likely to be economically inactive through unemployment and live close to the poverty line. The chronically sick and disabled are the hardest hit from austerity measures with Incapacity Benefit being reduced and DLA and PIP allowances being frozen. As a result of changes to benefits and taxes since 2010, some families with disabilities are projected to lose an average of £11,000 by 2021/22, more than 30% of their annual net income⁸. Benefits assessments are superficial, dismissive and ignore medical evidence in favour of making people compete with each other to see who is most deserving (Neuro Key Advocacy service 2015-2018).
- d. People in the PIP process are being forced to undergo repeated 'reviews' to keep them in the appeal process and not part of Government reporting data. Despite the harm being caused to applicants, there is also a very clear policy to prevent people receiving PIP beyond retirement age. Despite medical evidence and life-long neuro-disability, people aged over 66yrs are still being targeted, have mobility points removed at review regardless of prior medical evidence. This process is deliberately removing access to the Motability Car scheme (Neuro Key 2016-18).
- e. Borough Councils have the green light from Government to include Bereavement Allowance, Carers Allowance, Severe Disability Premium and Personal Independent Payment as sources of income to means-test service users for access to services (Darlington BC, November 2018).
These allowances are already means-tested and assessed which means the chronically sick, disabled or vulnerable are being pursued, scrutinized and means tested out of managing their condition and living independently.

- f. Older age adults with a learning disability and a mental age of a seven year old are constantly being scrutinized through Employment Support work capability assessments but valid medical evidence supplied by GP's is being ignored. This situation is causing elderly parents of a disabled adult considerable harm. Parents with responsibility for their son or daughter's financial affairs are often 70years plus and do not have the wherewithal to fill out lengthy forms. Parents live in fear of the brown envelope arriving or failing to secure what their son or daughter needs to live independently and receive suitable care. (Neuro Key Advocacy service 2015-2018)

This persecution falls woefully short of what a civilized society can claim to be cost effective.

5. Employment

'By emphasizing work as a panacea for poverty against all evidence and dismantling the community support, benefit, and public services on which so many rely, the government has created a highly combustible situation that will have dire consequences'.

(Professor Philip Alston, United Nations Special Rapporteur
On extreme poverty and human rights - Nov 2018)⁸

- a. The disability Charity SCOPE reported that just 35% of chronically ill and disabled people are employed⁹. However, over 80% of people with Multiple Sclerosis (MS) and 46% of people with Parkinson's disease are unemployed within 10 years of diagnosis (Parkinson's UK and MS Society). Whilst employment Law specifies 'reasonable adjustments', people are subject to 'constructive' behaviours by their employer to force them to leave employment before reasonable adjustments can be made (Neuro Key Advocacy service 2017-18).
- b. SCOPE also report 53% of disabled people have experienced bullying or harassment at work because of their impairments and over half of disabled people fear losing their job. Whilst the current Government made a commitment to halving the disability employment gap in the latest manifesto, the gap between disabled people and the general public has stayed static at nearly 30% for the past decade⁹.
- c. Today, severely restricted public services offer scant regard for the needs of people with neuro-disability trying to stay employed. This markedly increases vulnerability to isolation and poverty which is de-skilling, reduces self-esteem and narrows social and information networks that are needed to enable independent living.

6. Mental Health and Well-being

- a. We see first-hand the psychological burden on people with a neuro-disability; the ex-offender stigmatised and unable to afford high protein drinks to stem the weight loss caused by the constant muscle spasms of Huntington's disease; the older adult with Tourette's, socially isolated due to tics and anxiety; the ex-addict with Multiple Sclerosis where judgements were based on past addiction not neurological need; the person who lives in such chronic pain, suicide seemed the best option. All of these circumstances have caused chronic depression needing intervention. (Neuro Key)
- b. Quality of life is negatively affected in people with long-term neurological conditions; e.g. multiple sclerosis (Jones et al, 2013)¹⁰ and Parkinson's disease (Gordon et al, 2014).¹¹ Depression is also common in people living with a neurological condition (Bulloch, et al., 2015).¹²
- c. The growing body of research evidence such as, *Kılınc, van Wersch, Campbell & Guy, 2017*¹³ and *Kulnik, Hollinshead & Jones (2018)*¹⁴ all highlight how living with a long-term neurological condition can affect all spheres of life, physical, psychological and social.
- d. A report from the Neurological Alliance in 2016 found that the psychological needs of this population are not being met, with only 19% of those surveyed reporting that services to meet their mental health needs were "good" or "excellent".¹⁵

7. The Politics

We need a wholesale re-think about chronic ill-health and disability in the UK. It is time for a disability agenda to be bi-partisan, not subject to the mood swings of individual political parties or sidelined by 'local' priorities to deliver some long term robust development.

Current political propaganda exaggerates the reality of fraud perpetrated by chronically sick and disabled people whilst able-bodied people are politically encouraged to think the disabled get something for nothing. The media are complicit in projecting this politicized narrative. Lack of national strategic infrastructure is failing to protect the guiding principles and rights of people who need skilled, informed services. Universally pitched as the central tenet of a civilized society, how we take care of our young, the chronically sick, the disabled and the elderly but the UK needs to declare a collective shame at the way the principles of welfare for the vulnerable have been so badly debased since 2010.

Let us be really clear.

There is no Law on the statute books in the UK that protects the rights of able-bodied people against barriers imposed by disabled people. The Blue Badge is a legal right to accessibility. Parent and toddler car park spaces are a courtesy, not a legal right.

As the UN Convention on Rights of Persons with Disabilities (2009) cites in Article 4,

‘Member States must take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes’.

The specific removal of the neuro client group from national strategic planning leaves policy-makers, commissioners and health-care providers notably unprepared to manage the predicted rise in the prevalence of neurological and other chronic disorders and disability with ageing populations.

Anyone at any time can be diagnosed with a neurological condition, injury or impairment. The lack of forethought, knowledge and action is a serious issue. Chronically sick and disabled communities need someone to be accountable, someone who understands the Law and who does not put deliberate negative rhetoric above the welfare and rights of an entire NHS client group.

As the gap between the bureaucracy of commissioning specifications and lived experience grows ever wider, we need to reaffirm some minimum standards;

- Margaret Thatcher established DLA, not as a benefit but to remove disabled people from the jobless data and recognize the need for a minimum level of income for people who were unable to work due to chronic ill-health or disability. PIP is being manipulated to achieve political targets, not acknowledge the State’s responsibility to ensure vulnerable people have a minimum standard of living
- Joint Strategic Needs Assessments should reflect local population needs and the metrics for Disability Adjusted Life Years - DALY. In the light of the WHO and PHE reports, lack of understanding about disability and decreasing life expectancy for people with disabling neurological conditions, DALY should be examined to ensure it is universal, fit-for-purpose, relevant and appropriate
- A multi-agency, multi-disciplinary approach is urgently needed to include the issues of disability on strategic agenda’s and commissioning cycles

The author is solely responsible for the views expressed in this article.

Joanne Cole is a disability rights campaigner living with two disabilities and 3 health co-morbidities.

She has been an advocate for people with epilepsy since 1997 and as a co-founder of the Charity, the Tees Valley, Durham and North Yorkshire Neurological Alliance (working title Neuro Key), guides service users or caregivers through welfare benefit applications, appeals or tribunals and mediates where people are being discriminated against in employment or denied access to public services. Demand for expertise has increased 200% since 2017.

Jo developed an education programme to raise the value of 'lived experience' to Occupational Therapy, Psychology, Counselling Psychology, Rehabilitation and medical students at Teesside, Durham and Sunderland Universities plus the Wolfson Institute to improve the care of people with neuro-disability. As a promoter of people with lived experience to influence research, service design and delivery, Jo has enabled service users and caregivers to underpin strategic developments and be participants in 2 MSc and 5 PhD projects. Jo is a co-author of a Self-management framework for long term neurological conditions.

Jo is recognized with three national awards for services to the community, Royal Humane Society for saving a life in 1979, from Epilepsy Action for outstanding voluntary work and NCMA Childminder of the Year in 2001 for supporting families with severe health conditions.

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References

¹World Health Organisation 2012

- *NEUROLOGICAL DISORDERS public health challenges*

²Public Health England (2018)

- *Deaths associated with neurological conditions in England 2001 to 2014 - Data Analysis report*

³ www.who.int/mental_health/evidence/Country_profiles_Europe.pdf

⁴ <https://www.bbc.co.uk/news/uk-scotland-44497881>

⁵ www.bbc.co.uk/news/uk-england-35408558

⁶ <https://www.theguardian.com/.../no-guarantee-of-help-for-disabled-passengers>

⁷ <https://welfareweekly.com/dwp-forced-to-admit-more-than-111000-benefit-deaths>

⁸ https://www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf

⁹ www.edf.org.uk/scope-report-the-disability-perception-gap

¹⁰ Jones, K. H, Ford, D. V., Jones, P. A., John, A., Middleton, R. M., Lockhart-Jones, H., Peng, J. & Osborne, L. A. (2013).

- *How People with Multiple Sclerosis Rate Their Quality of Life: An EQ-5D Survey via the UK MS Register. PLoS One, 8(6) 1-8.*

¹¹ Gordon, W. D., Khoo, T. K., Yarnall et al

¹² Bulloch, A. G. M., Fiest, K. M, Williams et al (2015)

- *Depression - a common disorder across a broad spectrum of neurological conditions: a cross-sectional nationally representative survey. General Hospital Psychiatry, 37, 507-512*

¹³ Kılınc, S, van Wersch, A, Campell, C. & Guy, A. (2017)

- *The experience of living with adult-onset epilepsy. Epilepsy and Behavior, 73: 189-196*

¹⁴ Kulnik, S. T., Hollinshead, L., & Jones, F. (2018) "I'm still me – I'm still here!"

- *Understanding the person's sense of self in the provision of self-management for people with progressive neurological long-term conditions. Disability and Rehabilitation, DOI: 10.1080/09638288.2018.1424953.*

¹⁵ The Neurological Alliance (2016)

- *Parity of Esteem for People affected by Neurological Conditions Meeting the Emotional, Cognitive and Mental Health Needs of Neurology Patients, www.neural.org.uk*