Rethinking social care – fixing our broken health and care system

# Introduction

## Shaping Our Lives

Shaping Our Lives is a national service, user-controlled organisation and network. We are organised as a community interest company. Our aim is to increase the say and control of disabled people over the support they have and need and the services that affect them. All of us making the decisions identify as service users or disabled people ourselves. Shaping Our Lives has been around for more than 20 years, and we campaign and carry out research to spread and share the lived experience and knowledge of a wide range of disabled people and service users to bring about change in line with our human and civil rights. This includes people who identify as having physical and sensory impairments, learning difficulties, long term health and life limiting conditions and who use or may receive mental health services. We put a big emphasis on accessible communication and ways of working so that the wide range of people we seek to work with and support can be fully involved. We are also committed to involving and including people equally regardless of gender, ethnicity, age, culture, sexuality, belief and socio economic, housing or citizenship status. We call this inclusive involvement and we work to support it as key to the work we do.

## Our Principles and Values

We believe in the philosophy of independent living developed by the disabled people’s movement and embodied in the United Nations Convention on the Rights of People with Disability (UNCRPD). This means that we see the issues facing disabled people and service users primarily in terms of human and civil rights rather than of welfare problems and policies and believe that they should be able to live their lives on as equal terms as possible to non-disabled people, through having the support they need and access to mainstream society like others.

“People forget about rights-based social care. They talk about asset-based social care or strength-based social care. The problem with this is when having assessments, reviews, when doing support/care plans, to have an asset-based assessment is fairly meaningless and puts too much on the individual.” - Eleni

The philosophy of independent living follows from the social model of disability and we also believe in the importance of this. The social model makes a distinction between impairment, identified as physical, sensory, cognitive or emotional difference or limitation, and disability, which involves the negative, condescending and often hostile social reaction to such impairment, leading to discrimination, exclusion and oppression against disabled people. We believe that disabled people and service users, like other recognised minority groups, should have the right to speak and act for themselves rather than having other people managing their lives and choices.

# The problem of social care

The policy in Britain that is meant to offer disabled people the personal and social support they need is called social care. This is meant to include help with the daily tasks of life, like getting up and keeping clean and also support to live on equal terms with others in mainstream society. Many people, including many disabled people, are not really familiar with this policy which can make getting help from it particularly difficult.

“Social care is seen as a means of getting people out of a hospital bed; a short-term bridge to get old people back home (or at least out of the NHS). It’s seen as funding to relieve NHS of their care.” - Becki

This name, social care, is a relatively recent one and that is part of the reason people often don’t understand the policy and how it relates to them. People are more familiar with the health service or the National Health Service, NHS as it is more often known, and value its key values. These are based on the belief that:

* If you have a health problem then you can get help with it, which is free - as is said ‘at the point of delivery’, that is when you need to get it (this is not always true anymore, but it is for big things like seeing the doctor, going to hospital and getting treatment).
* The cost of the NHS is paid for out of general taxation by central government to make it fair and so that if you live in a poorer area they won’t have more difficulty raising the taxes for it.
* If more people need help than the help that is available, then you will go on a waiting list so that you will get that help as soon as is possible.

# What’s wrong with social care

Social care is not like this at all. It is based on a different set of rules or principles. In fact, these are the principles of the 1834 Poor Law, in effect well into the 20th Century, which helps explain the stigma many people feel towards them. These principles include:

* You won’t get free help from social care unless you are seen as poor (for example living on benefits) and then you may still have to pay something. This is called the ‘means test’. When she began to make reforms to the social care system in the 1980s, Margaret Thatcher, the Prime Minister, said most people should look after themselves and therefore pay for social care and it is still like that now.

“I want us to move away from seeing Social Care as a payment. The recipient is a customer and a provider, but we don’t get any overheads to meet legal responsibilities or recruitment costs.” - Mark

* You won’t get help from social care unless your ‘need’, that is, why you are seeking it - is seen as qualifying for help. There are so-called ‘eligibility criteria’ (sorry about the jargon) - that exist which are supposed to show if you qualify or not. But reality is different to this. Whether you are assessed as qualifying for help at all, and how much help you will get depends not on your actual ‘need’, for example, in the same way as if you go to casualty and you have a broken leg or a bad cut and the doctors will therefore treat it. Instead, it will depend on how much money the local authority - which is in charge of social care - has to spend on it and how they manage their budget.

“Visually impaired people don’t often get social care, but they are entitled to some minimal provision – for example, a white cane. Sometimes, though, something small can actually make the difference, and that should be recognised." - Becki

For a long time there has been a widespread concern that there is not enough money spent on social care. All councils have a lot less to spend on social care now because of the years of cutting public spending in the name of ‘austerity’ and some also want to spend a lot less than others.

So the fact is that although you may have suitable needs as a disabled person, you may well not get the help you would to expect to get from social care. This is because councils will get into trouble with government if they overspend and therefore they are more worried about doing that than they are about not meeting your human rights and needs. We know this from legal court cases that have gone to the highest courts. Age UK, the charity for older people, has calculated over the years that fewer and fewer older people are getting help from the social care system even though they have needs that you would expect would qualify. Their last calculations showed it was over one million people who didn’t get help but should.

While there are differences in social care arrangements between the four UK countries all are basically affected badly by this situation.

“Someone independence should not depend on where I live. Whether that a flat or a residential home or rural or City to give a couple of examples A disabled person should be able to live where they want to, without having to give up on their vision of independence. So the social care system should be to support a degree of independence whatever option people choose or more likely whatever care setting people find themselves in” - Mark

For a long time, many people, especially family carers and service users, have been saying that the social care system is in crisis, doesn’t work and is not sustainable. Yet government after government has done nothing to change this and we are still waiting for reform to happen.

The Covid-19 pandemic showed how disastrous this situation is for disabled and other people. Tens of thousands of people have died as a result of the problems of social care and the failure of the NHS and social care to work well together. Many disabled and older people died after being discharged from hospital to residential homes and social care at home to make beds available for Covid patients in hospital. This is largely to do with the fact that, as we have seen, the two systems of social care and NHS are based on very different and conflicting principles so it is difficult to sort them out together to work well together, however hard their different workers and teams try.

# What Shaping Our Lives believes

Shaping Our Lives believes that the present systems of social care in the UK are failing and damaging and, in some cases, putting at risk the lives of disabled people and service users of all ages. We believe that social care must be radically and fully reformed so that all people regardless of difference, age and condition, have equal access to the help they need to ensure that they can live their lives with full human and civil rights.

To achieve this, we support an approach to social care in the UK that is:

* based on the same principles of free entitlement to support for all regardless of income and location
* stops relying on bureaucratic processes of assessment and supports the service user to work out what support they want
* treats people equally but values their differences and does not penalise particular groups of disabled people or ignore them or complex impairments
* does not assume people can rely on financial support from family, friends, etc. or any other source of income, but fully meets the costs of disability, frailty and distress
* recognises the value of specialised services but does not use this as an excuse for service fragmentation
* the full implementation of the Care Act’s original aims and goals, without the recent changes to guidance which does not support the intended outcomes
* funded by a system of progressive national taxation (the more you have, the more tax you pay and poor areas are not penalised by having to pay as much tax as rich ones) and free at the point of delivery on a universal basis as in the original principles of the NHS
* which takes full account of the costs of disability and treats diversity with equality in accordance with characteristics recognised by law
* which supports people equally regardless of who they are or where they live and respects their different priorities and goals in life and their right to define them
* is organised by a national social care/independent living service coproduced by government and disabled people/service users and their user- led organisations (ULOs) and disabled people’s user-led organisations (DPULOs).

The social care system has become mainly reliant on privatised services and insecure financial models. Neither of these has shown itself capable of ensuring a sustainable or effective system of support. The evidence has shown that service users particularly value support provided by small, local organisations, particularly Black and minority ethnic, community-based and user led organisations. These should be supported and given particular value in the commissioning process rather than the present system which encourages a race for the bottom in quality and the lowest bidders to run services being accepted.

# The importance of a valued social care workforce

To have good social care means treating social care workers properly. Social care workers are among those with some of the poorest working conditions and rewards in our society. Yet the work they do is some of the most complex, valuable and important in society. This must be reflected in improvements in the terms and conditions of service workers.

“Social care and health care practitioners are not ‘them’. They are equally frustrated and equally want change.” - Joanna

Zero hour contracts, 15 minute support slots and non-payment for time spent travelling must all be ended. Social care workers must also be supported, whether working as care workers or staff employed directly by service users as personal assistants, to have the appropriate training, supervision, other learning opportunities and employment prospects that they need.

# Social care as an important source of good quality employment for the future

With the advent of artificial intelligence (AI) and new technologies, many traditional jobs will be replaced by AI, automation and modern technological developments. Care work is based on the importance of people supporting people and the interpersonal and unique skills this requires, which will not be replaced in this way. Social care should also be seen as a key source of employment consistent with sustainability and securing the future of the planet, since it is not concerned with unnecessary production which causes environmental damage but with helping to maintain the wellbeing of human beings. The social care system should be committed to minimising climate change, carbon production and the inappropriate use of plastics and other consumables. Thus, for the future, it can offer a source of sustainable valuable employment and this should be developed in line with these possibilities and benefits. Social care support needs to be organised and provided in ways which are consistent with environmental sustainability.

# Social care reform means wider reform

Social care needs radical reform, but so do other policies which impact on the lives of disabled people and service users. The NHS is currently most concerned with acute medical problems – if we get a short term illness or need an operation – it’s good at that and is based on being technically advanced and on a medical model based system of treatment rather than primarily health maintenance and illness prevention.

“A broken leg or cancer is taken as a given, not contradicted. With social care, they can say you don’t have a need and keep saying that. We’ve seen this, in cases where people have to fight legally for their care.” - Peter

As a result of social change and improvements in health technology, in the UK and in other countries there are increasingly higher proportions of people of all ages who may have social care needs. The NHS needs to be revisioned in the light of this and the understandings which we have gained from the social model of disability and the philosophy of independent living.

Other policies - from employment and training to welfare benefits, social security, employment, education and housing etc. - must also be reformed in the light of these ideas to make possible a holistic not just single policy approach to disabled people’s and service users’ rights and needs.

# Making a start on changing social care

Currently, when the NHS does not have enough resources to meet the needs it encounters, we are able to see this through the existence of waiting lists and then policymakers can respond accordingly. There is no similar measure of shortages in social care. We suggest that in future local authorities record the needs that they are currently unable to meet to provide similar information. This will make it possible for the government to work towards filling the gap.

“We need to consider the language used: it’s emotionally manipulative and sentimental and covers up a lack of support. For example, when we see the term ‘heroes’ being used to describe ‘young carers’, when we’re talking about children who are being exploited, who are filling in when there is no provision forthcoming from the government.” - Michael

The United Nations for example, recognises that governments will not necessarily immediately be able to meet all existing needs. It does, however, expect states to take ‘concrete action’ to ‘progressively realise’ the resources required over time. Shaping Our Lives supports this position.

# Social care reform must be based on inclusive involvement

If social care reform is to be successful and improve the lives of disabled people and service users as it is intended to, then it must involve and include them fully, equally and from the beginning in all that is done. Thus all steps to take forward reform of social care and associated policies must involve disabled people and service users in all diversity and also our organisations, fully, equally and inclusively. The aim must be for coproduction in both the process and the outcome of change in social care.