

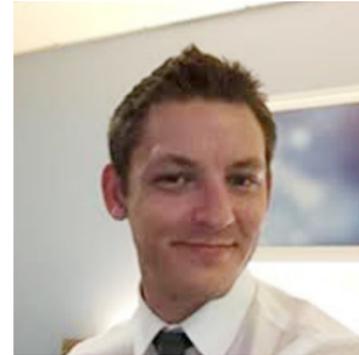
MEET THE INQUIRERS



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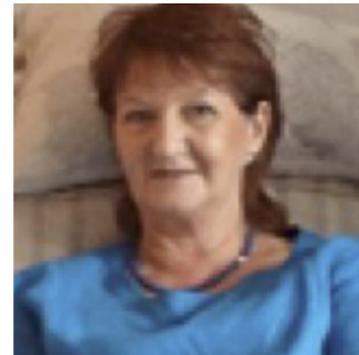
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Whose Social Care is it Anyway?

From permanent lockdown to an
equal life

#socialcarefuture



Introduction

BY ANNA SEVERWRIGHT, INQUIRY CONVENOR



Living through a pandemic over the past year, has made all of us appreciate more than ever how important the things in Social Care Future's vision are in our lives. They are what makes life worth living.

When the first lockdown started and many were talking about how hard it was being stuck at home, not being able to do the things they enjoyed doing, or not being

able to see friends and family, I remember thinking that it didn't feel that different for me. Actually I felt more a part of society than normal, because everyone was experiencing a life more like mine, unable to lead the lives they wanted to lead. Now with all the talk about lockdown lifting, I am left feeling that many will go back to their usual lives and along with others who share my situation, we will go back to feeling left out. **We can't let that happen.**

Because for me and many others who need to draw on social care for support, entering 'serviceland' can mean that things about our lives that we value are changed without our say, or lost altogether. For me, it's that I want to be able to go out more to see friends but don't have the support to do so. For others it may be having no option but leaving loved ones and their home to go into institutional care, or not being able to choose what time you go to bed in your own home.

**WITHOUT CHANGE
WE FACE LIVING IN A
STATE OF PERMANENT
LOCKDOWN.**

"We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us"

Social Care Future's vision

So why does this happen? And what would need to change so that we can all come out of lockdown together, no matter our age or disability? How can these important things be taken seriously and not pushed to the side when national politicians define the problem in ways to suit their agenda not ours, or when local leaders decide without us what social care should do and how?

Too often the debates and decisions about social care are happening behind the scenes without us – the people who draw on social care – or we are invited as an afterthought or just as a ‘tick box’. **Well we have had enough of that.** So we decided to lead our own inquiry called ‘Whose Social Care is it Anyway?’

As a group we have so much expertise, experience and knowledge to offer. We know what works and doesn’t work well and we know what needs to change to allow everyone to live good, equal lives and avoid permanent lockdown.

But we know we don’t know everything, so we asked everyone else what they thought too.

In this first stage of our inquiry, we heard from over 500 people, a huge thank you to everyone that spoke to us! Through a survey and online sessions we asked people to tell us about their experiences, the extent to which they experience Social Care Future’s vision in their life at the moment. Sadly the majority of people we heard from who draw on social care told us that their lives are restricted. Then we asked them what they think needs to change and their ideas for social care in the future that would mean living life the way they want to.

WE NEED TO BE HEARD

From what people told us, we have pulled out **5 key changes**; 5 things that we think if they happened would move us towards experiencing Social Care Future’s vision in our lives.

5 key changes

The 5 key changes to bring about Social Care Future’s vision are:

1. Communities where everyone belongs
2. Living in the place we call home
3. Leading the lives we want to live
4. More resources, better used
5. Sharing power as equals

We will explore each of these in more detail below. Although we and many others have raised these changes before, and they are not the only things that need to change, what is very obvious is how different they are to what the policy, political, media and sector-led discussions usually focus on. This might be why they are often ignored.

It is also clear that people experience social care unequally, with some groups more likely to receive poorer care. The **5 key changes** we suggest here need to be used to identify and challenge these unacceptable inequalities and to reduce them.

There is a lot of talk about “fixing” social care but it is mostly limited to the question of funding without asking what the funding is for, or how social care could be better organised to use the resources we have most effectively. We strongly agree more money is needed, but we worry that even with extra funding, it won’t end our permanent lockdown if spent on the wrong things.

Because for those of us who draw on social care, these are the things that shape our lives now, and **where change needs to focus**. We need them to be taken seriously and we ask that if you are serious about being our allies, you join with us in calling for these changes.



5

KEY CHANGES

to unlock an equal life

KEY CHANGE 1

Communities where everyone belongs

People told us that they feel disconnected from the world around them, without the support needed to be part of their communities or share their gifts and talents.

“ My care plan is very limited and restrictive. And although I was assessed as needing support to access the community I do not receive that support.”

“ There needs to be better opportunities for inclusion...”

“ I would like to live in an area where there are mixed ages. So families, young adults and elderly. All from different cultures. I would like to be able to look out of the window and see children playing and events happening on my street.”

“ Social care help me wash and dress each morning (9am). Social care help me wash and dress each evening (9pm) This is it. I live in a ground floor flat that is prone to flooding which means I spend periods of time homeless due to my flat being filled with water. My flat is surrounded by bungalows of elderly people. So I do not see anyone my age. I am 34. I am left with a TV and internet to entertain myself.”

“ Continuity of care would be greatly appreciated. Within a period of about 3 months the company send about 36 different carers.”

“ People who receive social care live in a ghetto!”



- We want to be part of our communities, helped where we need it to connect to people and things that give our lives meaning and purpose - relationships, friends, family, work, leisure – and to share our gifts and talents
- Social care must help remove barriers and offer assistance beyond traditional services to support such an ordinary community life
- This means helping us to access the places and things in our communities everyone else can use
- And it means offering support that is usually not about a “service solution” but that helps us connect in ways that others do, through shared interests, contributions and concerns in our communities

KEY CHANGE 2

Living in the place we call home

People told us that they did not always have a choice over where and with whom they live. Some people said that they are forced to share their living space with other people who they have not chosen to live with in order to access support.

“ (the) local authority want my brother to live with 4-5 other people to share the costs of his support. Living like this for almost 20 years has led to him losing skills, confidence and independence because he is overlooked. As a deafblind, learning disabled man, this shared support has meant he has disengaged from people and the world.”

“ I was put in a residential home 40 miles from home with no choice in the matter. I was the only person there without a severe learning disability and I ended up in hospital due to how badly it went.”

“ My Dad lives at home which is where he wants to be, but the walls on the stairs are not suitable for rails. I worry about him managing on the stairs as he has had a stroke. Also, the bath is not suitable for a bath board and he cannot get in and out of the bath. This means he can only have a strip wash with the help of his (self-funded) home-carer.”

“ (want to be) Living in ‘an ordinary home’; doing things that are of interest and meaningful to me and alongside people I know and like; being/feeling well connected with family and friends and feeling a sense of belonging in my community. It does NOT mean ‘living like a young student’- sharing a property with others/ groups of people, worse still people I don’t know and where most living space is shared meaning I have to fit all my worldly goods in my bedroom.”

“ I need more help when I come out of hospital, just temporarily, and this shouldn’t be something I need to fight for or organise myself when the doctors have said it is a condition of me going home.”



- We should be supported to live in our own homes, with the necessary adaptations, technology and flexible personal support directed by us
- If we move from our original homes, a good choice of housing and support options must be available so we are not simply “placed” in one size fits all institutional care
- If needed we should be supported to plan ahead for ourselves and our families with the information, advice, support and advocacy that helps us make good decisions and choose the right things for us – much of this best comes from our peers
- When we choose housing with support options we must be supported in ways that keep us as free to live as other people, not putting up with different rules and controls that no one else has to endure.

KEY CHANGE 3**Leading the lives we want to live**

People told us that the services they receive are extremely limited, amounting only to support with personal care, not to lead a full life.

“ *The local authority's system of Supported Living means that they take all my son's benefits and give him £25 a week to live on, to add insult to injury they would also remove his Direct Payments because they say he would be getting his care in the supported living house. My son would be left with no social life at all. No gym, no cinema, no music lessons and no social life in the community”*

“ *There needs to be trust in the system, no more demonisation of disabled people as 'scroungers' etc.”*

“ *When I first sustained my spinal cord injury in 2009 I had a brilliant social worker who sorted a 24h care package so I could go to uni and I could live a fulfilling life ... when I moved funding areas I had to fight to keep this care and every aspect of my life was questioned.”*

“ *Carers only undertake personal care, everything other than that has to be arranged and paid for personally. Many people cannot afford it or are unable to arrange it.”*



- People must be trusted to make decisions and direct their own support, with help where they need and want it
- Practices, systems, processes and rules that mainly control people must be removed and instead enable lots of creativity, innovation and flexibility
- This choice and control must apply to all forms of support – including personal budgets, support at home, housing with support
- When we choose to manage our own support we should be really free and supported to do just that. Councils should focus on the resources and support needed to make this work well, not restrictive rules and controls that limit our lives or make it too much of a burden

KEY CHANGE 4

More resources, better used

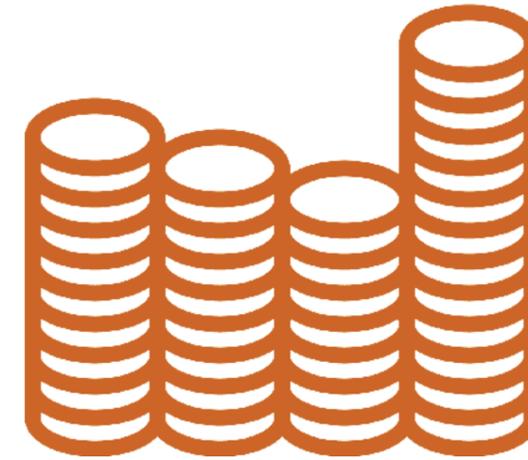
People told us that the support agreed by their councils is often completely inadequate to meet the cost of support with basic things like washing, let alone living a full life. Moreover, local authority charges for these limited services are taking away the money people might otherwise spend on living a life like others.

“...the assessment system blatantly underplays people’s needs in order to make sure they come under the threshold to qualify for social services-funded help. I don’t think it is acceptable to be unable to bathe properly.”

“(need) To be able to live our lives without worrying about how to manage physically, emotionally, financially, socially because the support to do so will not be rationed or impossible to access.”

“Direct Payments have become less and less flexible over the years. The system of assessments and reviews is no longer person centred. The charging policy of the County Council, with the use of the Minimum Income Guarantee is unfair. There is not enough money in the system.”

“We have some support to reduce the physical problems we face. We are fortunate that our (shrinking) savings and our teacher pensions have enabled us to pay for adaptations which make life easier but also mean we have to pay for the 2 hours per day of carer support.”



- Government resources must be increased to the level that allows people the funding they need to live a life like other people, where needed supported by staff who are properly paid and supported themselves
- Leaving people without the money they need for a life like others, through excessive local charges, must stop
- Local councils, their partners and support providers must think about and use resources differently – starting from asking how to support good lives in strong communities not traditional services
- All kinds of local resources should be used, not just social care money
- Money should be redirected to better, non-traditional kinds of support that help people find their own solutions in their communities, avoiding needing services where possible or being supported through ways that work for them

KEY CHANGE 5

Sharing power as equals

People told us that they felt that local councils imposed too many rules and restrictions on how they could organise their support, which in turn stood in the way of living the life they wanted to live. They also talked about not being trusted by councils and that they felt like they did not have the power or the means to challenge decisions made about their lives without their involvement.

“Social care in my area is restrictive and does not allow choice. The Direct payment contract needs to be more flexible and Social Care needs to be more flexible and more easily adaptable to ever changing life situations. It is a paternalistic system mired in red tape and long waiting times whilst a panel make decisions on whether a care plan will be approved”

“Social care needs to stop thinking of itself as an all-encompassing service and recognise its place in providing people with the flexible, responsive and caring support in ways that suit them and that help them live the life they want. Local authorities need to recognise the need for system and culture change in order to enable this flexible response - and focus more resource on communities, working with them in equal partnership.”

“I had an agreed care package with PAs that was then removed without any consultation and was told I would have to have an imposed agency package instead. I have severe physical and mental health disability and the agency had absolutely NO experience of mental health and could not guarantee to provide ANY continuity of care. It was unsafe. The local authority has not once responded to a single enquiry by email or telephone as to why this was done and that I challenge the changes imposed.”

“I am so tight with the money, I wouldn't waste it. I would just get more out of the budget. I am the expert on me.”



- Real co-production ([what-is-co-production](#)) must happen at all levels; individual, service, strategic
- All unnecessary rules and bureaucracy that control rather than enable people must go
- Workers, properly rewarded, must be given the chance to use their creativity, skills and judgement in proper partnership with people
- The way councils arrange and buy services (commissioning) must become collaborative with communities - 'co-commissioning'
- Leaders must make generating a culture of openness and trust one of their highest priorities
- We need stronger assurance, accountability and forms of redress and appeal
- Particular attention needs to be given to increasing the power of some groups of people who draw on social care who get the worst deal and their voices need to be heard more.

Glimpses of the future

But more hopefully some people spoke of more positive experiences that could be built upon (though often with caveats around security and control)

“Overall we have a really positive experience. The council have sorted us well. We enjoy supporting our young person, he’s vivacious and rumbunctious. Sometimes we find the bureaucracy tricky.”

“My care package does give me the freedom to do these things but I had to fight to get this care and I live in fear that I will lose the care again.”

“The home carer from the agency is wonderful (always goes above and beyond).”

“I have direct payments which help me be independent and give my husband a break. My daughter however does not get any support and we are struggling to get the help she needs.”

“We feel this (the vision) is more or less where we are. I am worried that we will lose it in the future.”

The good news is we know we can do this – because some people in different places are already doing parts of it. We need to bring the jigsaw together. Here we will just share a few examples and places to look. Get in touch if you want to know more or be connected.

Think Local Act Personal (TLAP) with others, have pulled together a resource called [Innovations in community-centred support](#) which tells about lots of organisations and kinds of support that can help people with the **5 key changes**.

Examples include:

- Staying well and connected to others: such as Gig Buddies, Good Gym, the Cares Family
- Supporting people to contribute and do things they enjoy: like Local Area Co-ordination, Community Circles, Grapevine
- Living well at home: Like Buurtzorg, Community Catalysts, Wellbeing Teams, via cooperatives and community business
- New models of care and support with accommodation: Such as Keyring, Shared Lives Plus, Homeshare

TLAP and the National Co-production Advisory Group have also helped us with the Ladder of Co-production and [Making it Real](#) which is a brilliant tool for local people to come together to agree what is working and not working and plan positive change. It can be used alongside the Social Care Future vision to work out how to make big moves forward locally.

The Social Care Innovation Network brought people with lived experience, commissioners and progressive support providers together to look at the best ideas and examples for moving us on towards co-production, shifting power and using all local resources to improve lives and communities ‘co-commissioning’. They did a “Starter for Ten” here [Commissioning for a better future](#) and great guides on making direct payments better [Self-directed support](#) then TLAP added [Direct Payments - working or not working?](#)

The Housing Learning Improvement Network is a great place to look for alternatives to institutions and different kinds of housing with support [Resources - Housing LIN](#).

Our next steps

This is the end of the first phase of our inquiry. Our inquiry group came together and led it directly, showing how sharing power with people and families who draw on social care, can be done and achieves better results. We spent time together and asked those interested in a better future to help us think about what is most important and should be focussed on- our **5 key changes**.

But this is not a traditional inquiry which produces a report and stops and it isn't bound by rules about what it does or how- this is co-production in action!

Over the summer months we will:

1. With help from allies we are going to take a closer look at the **5 key changes**. We will be exploring them in more detail and thinking about what action we and others can take to start really shifting them.
2. We will be working with the wider Social Care Future movement to make sure the **5 key changes** are built into the movement's plans for action including practical support for change & key campaigns. Alongside people with lived experience this will include various professionals and system leaders, researchers, politicians, technical experts, campaigners and media experts. Want to help? Get in touch socialcarefuture@gmail.com
3. From this work we will set short and medium term goals for real change.
4. We will be growing a movement for change – bringing our voices together to demand change.

Are you in? Do you want to avoid a permanent lockdown?

Join the Social Care Future movement

Reading this you might be someone who draws on social care, a family member, someone who works in one of many roles, a politician, an academic or you may be a member of the public involved or concerned for another reason.

Many of us are frustrated and tired at the lack of change but giving up is not an option because this is about our lives now. We started this unique inquiry because we need to come at change in a different way.

We are building a movement of people determined to make change – led by the voices of people who draw on social care. We know change is possible (see the 'the Glimpses of the Future') but the kind of change that is needed - will only come if we demand it, together.

Take Practical Steps

Whoever you are there are practical steps you can take to support and champion our **5 key changes**. Below we make some first suggestions to get started – you might also have other ideas. We will then move on to phase 2 of the inquiry and we hope you will join us.

We know people who draw on and work in social care want this change but there are many challenges making change hard - money, systems, historical ways of doing things, power. But we know you are our allies and we are yours - let's keep looking for all chances to build this change in our own lives and work and in how we influence and stand alongside others.

Some first asks

People who draw on social care and families, workers and professionals, concerned others:

- Will you be guided by the Social Care Future vision, looking for every opportunity in your own life and work and also with others to take action on our **5 key changes** ?
If so join us. Be part of our movement by [signing up here](#) and tell others that you know and on social media
Twitter: [@socfuture](#). Let's share and celebrate what we are doing and achieving together.
- Will you challenge and offer better solutions when you see practice and behaviour that keeps people in permanent lockdown?

Leaders in councils and support providers:

- Will you commit to use the Social Care Future vision to shape your local strategy and practice with a focus on our **5 key changes** and to use Think Local Act Personal's [Making it Real](#) to act in co-production with local people, to work out what's working well and not working and plan action?
- Will you commit to use the best learning about how to bring all local resources into play starting from the goal of good lives and strong communities, using co-commissioning, reducing bureaucracy and shifting power to people?

National social care organisations:

- Will you commit to use the Social Care Future vision to shape your efforts to both influence government and support councils and provider members to think beyond traditional services in your improvement and other work?
- Will you take direct action yourselves and support your members to act on the **5 key changes** ?

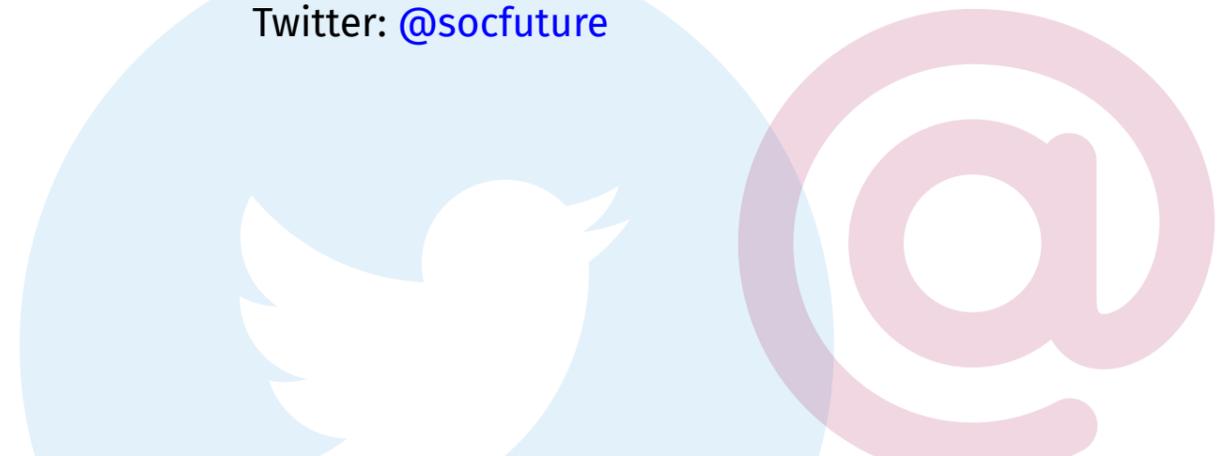
Government:

- Will you provide short term relief in the Comprehensive Spending Review to support recovery, stabilise social care and start transformation?
- Will you also make multi year investment, specifically for transformation and innovation, so that local authorities can not only meet their statutory requirements but also incentivise, support, evaluate and promote innovation in pursuit of our vision for the future?

If yes to any of the above please tell us

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