

# Care for Equality

Making the case for inclusive social care reform



Leonard  
Cheshire



# About Leonard Cheshire

Leonard Cheshire is one of the UK's leading charities supporting disabled people. We support individuals to live, learn and work as independently as they choose, whatever their ability. Led by people with experience of disability, we are at the heart of local life – providing opportunity, choice and support in communities around the globe. This includes providing social care through supported living and registered care homes – supporting nearly 3,000 disabled people at 120 Leonard Cheshire services – as well as enabling disabled people to participate in educational and employment opportunities.

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**It is universally acknowledged that reform of social care is long overdue. What isn't universally understood is the life-changing difference social care makes for disabled people across the UK. Social care enables people to have the freedom to live, to be independent, to be equal. We're calling for urgent reform of social care, to ensure equality for all.**

## **1. Background**

Social care is defined by the Kings Fund as “the wide range of activities to help people who are older or living with disability or physical or mental illness live independently and stay well and safe.”<sup>1</sup> These activities include personal care – everyday tasks like washing, dressing and eating; and reablement support – the aids and home adaptations required for an individual to live independently. Social care goes beyond basic survival needs, giving support to enable people to remain active and engaged in their communities – including going to work, seeing family and friends and participating in leisure activities. Social care includes support accessed in an individual's home or community, in a residential or supported living setting, as well as advice, guidance and support for family carers.

The UN Convention on the Rights of Persons with Disabilities (CRPD), recognises that we are all equal. Disabled people have the same rights as everyone else to freedom, respect, equality and dignity. Article 19 of the CRPD enshrines the equal right of disabled people to live as independently as they choose, and to take part in their communities with the same choice and control as non-disabled people.

Over a quarter of a million working age disabled adults (aged 18-64) currently draw on social care,<sup>2</sup> with almost half (49%) of local authorities' expenditure on social care spent on disabled adults of working age.<sup>3</sup> Despite the clear mandate disabled adults have in working with governments across the UK to shape the future of the social care they draw on, disabled voices have consistently been left out of discussions on social care reform. With the UK Government committing<sup>4</sup> to bring forward proposals to reform social care in England (and potentially Wales) by the end of 2021, plans to create a 'National Care Service' in Scotland, and ongoing discussions about 're-booting' social care in Northern Ireland,<sup>5</sup> **governments need to urgently engage with disabled people who have lived experience of drawing on social care to shape their social care reforms.**

Having access to personalised and tailored social care can be truly transformative to the lives of disabled people. Leonard Cheshire has conducted interviews and focus groups with disabled people across the UK, with lived experience of drawing on social care, to inform this briefing. Participants told us that when they co-produced care plans and accessed person-centred and tailored care, they were able to “thrive” and not just “survive”.<sup>6</sup> Participants shared that drawing on the right social care for them enabled them to go to work, see family and friends, keep fit, gain qualifications and participate in a range of hobbies and leisure activities.



Social care reform has stalled over successive governments, in part due to economic factors. Our research demonstrates that enabling disabled people to live as independently as they choose is not just a fundamental right enshrined in Article 19 of the CRPD,<sup>7</sup> but also makes good economic sense. Improved access to well-funded social care can support more disabled people who choose to work to enter employment, and help to tackle the disability pay gap. Modelling from Frontier Economics<sup>8</sup> demonstrates that reducing unemployment for disabled people, eliminating the disability pay gap, and increasing the number of disabled people who are able to and choose to work, would **generate an additional £6-£20 billion in annual income across the UK**. More importantly, it would enhance the wellbeing of disabled people and those who provide care and support. The Health Foundation has calculated that it would take an additional £2.1-£12.2 billion a year<sup>9</sup> to bridge the social care funding gap. Alongside wider savings, for example on acute health care, it is clear from our modelling that **investing in social care has the potential to pay for itself**.

## Hannah's story

**Hannah is 37 and moved out of her family home four years ago. She lives independently and employs a care team to provide support 24 hours a day.**

Commenting on the importance of accessing 'good social care' Hannah said:

"My social care is really my arms and legs! It gives me the freedom to live the life I want to live, to do what any other non-disabled person can, or wants to. Without social care it just wouldn't be possible. I would be reliant on my parents. Having a disability makes you feel restricted in so many ways, but if you have good social care, it changes your life forever.

It enables me to socialise and work two days a week at police headquarters. It means I can do lots of things just like anyone else.

My life has changed dramatically for the better because of the social care I use. It's enabled me beyond my expectations. Everyone should have that control and independence if they choose."

## 2. Why social care reform matters

Prior to the Covid-19 pandemic, the social care system was under significant pressure. In England alone, spending per person on adult social care services fell by around 12% in real terms between 2010/11 and 2018/19.<sup>10</sup> This led to unmet needs, with 1 in 5 adults reporting that they had gone without meals due to not receiving the social care they needed, and a third of adults not being able to leave the house.<sup>11</sup>

The Covid-19 pandemic has exacerbated the existing cracks in the system. Disabled people across the UK have shared with Leonard Cheshire that the social care they draw on has been impacted by the pandemic, with 55% of people accessing social care experiencing a change to their care.<sup>12</sup> Worryingly, these changes are becoming permanent, with 34% of disabled people reporting that they did not have their social care reinstated following the first lockdown.<sup>13</sup> There is therefore an urgent need to address these unmet needs and reform social care to ensure that disabled people are not just able to “survive”, but “thrive.”

Social care systems differ in each country of the UK. Scotland offers free personal care to adults, Northern Ireland offers means-tested integrated health and social care, and England and Wales offer free care up to a means-tested cap of £23,500 in England and £50,000 for residential care in Wales. Despite these differences in how social care is funded, disabled people from across the UK participating in our focus groups and interviews reported similar challenges and benefits to accessing the care they need.



## Equal access

Our research participants reported several issues around accessing social care support. In particular:

- Participants reported issues with the assessment process. Assessments were conducted too quickly, prohibiting social workers from developing an in-depth understanding of each individual's life. Participants also reported not being listened to and felt that staff conducting assessments should have better disability training, to enable assessments to be truly individualised and person-centred.
- There was also consensus that care workers should be paid more, and that improving their pay should be central to national and devolved government's plans for social care reform. Meaningful social care reform needs to invest in both the people drawing on care and the workers providing care, with remuneration for social care increasing beyond the minimum wage and real living wage.
- Participants also expressed concerns regarding the eligibility criteria to access social care. It was felt that disabled people had to 'prove' their eligibility for care, with one interviewee stating that she was told that she was "not disabled enough to have the social care support I wanted."
- Some participants reported losing access to their social care package when they moved between local authority areas. Others reported reductions in the number of hours they receive care for due to the pandemic, and experienced long waits for specialist equipment for their homes to enable them to live comfortably and independently.

## Equal choice and control

The disabled people participating in our focus groups and interviews from across the UK had strong views on what good social care should look like. Central to their views were the themes of choice and control: disabled people should co-produce their care plans, have choice about the care they draw on, and have control over how they manage their care.

**"Good quality social care is when disabled people are being listened to. We know our needs and difficulties better than any social care professional."**

**Sophia**

**"People need to listen and not make assumptions about the care I might need or want. Accessing and setting up social care is hard and demeaning and can put people off."**

**Simon**



**“I have a personalised plan of care that supports my needs. It’s really powerful and empowers me to live my life.”**

**Fiona**

However, the participants taking part in our research reported that they did not always have this choice and control over their care. In particular, participants highlighted barriers to making informed choices about their care, including the language used by social workers being full of “jargon”, creating a lack of “understanding” of the services available to individuals. Some participants shared that the full range of support available to them in their local area was not outlined by social workers, and others were offered very limited choice about the support available to them. One participant was told that they could only access support via a day centre. This was despite it being a legal requirement for local authorities across the UK to provide people drawing on social care with comprehensive information about the support available to them in their local area.<sup>14</sup> Accessible information about the full range of care and support available in each local area should be available to all disabled people, to enable them to make an informed choice about their social care.

The lack of control over how care is managed was also reported as a barrier. Disabled people told us that the limited hours of care they access, or the rigidity in the range of activities offered by some care providers, prevented them from being “spontaneous”, stopping them from seeing friends or participating in leisure activities. One participant commented that they felt that they were offered “a one size fits all system...to meet basic survival needs, because it’s nice and easy to budget for.”

## **Equal opportunity**

Despite the challenges to equally accessing, choosing, co-producing and controlling social care, many of the disabled people we spoke to were positive about its transformative potential. Participants shared their lived experiences of how good social care – provided through a multitude of avenues including direct payments, privately paid for care or family carers – enabled them to gain new qualifications, go to work, and participate in diverse hobbies such as swimming, horse riding and researching family trees. They shared that good social care enabled them to live the life they wanted to live – to live independently, see family and friends and maintain a social life. Accessing good social care provides many disabled people with a gateway to actively participating in their local communities, rather than being socially isolated at home. Good social care also has a positive impact on an individual’s health and wellbeing. One participant commented “it’s not just invaluable to maintaining my physical health and fitness, but to my mental and emotional health and wellbeing as well.”

It is crucial that social care reforms in each country of the UK deliver for working age disabled people. Accessing the right package of social care enables disabled people to live, learn and work as independently as they choose. These reforms can only deliver positive change for disabled people if they are actively involved in shaping them. **Governments must co-produce changes to social care with disabled people.**

### 3. The business case for investing in care

**Economic arguments are not the reason to reform social care, but equally they should no longer be the barrier to reform.**

It should be enough that it is a fundamental right through the CRPD, and also a legal right through legislation like the Care Act 2014 and the Social Services and Wellbeing Act (Wales) 2014, for disabled people to access the right social care support for them. However, the scale of investment to comprehensively reform social care has diminished the appetite of governments across the UK to undertake social care reforms. The 2011 Dilnot Commission's plans to significantly raise the means-tested cap on accessing free residential social care has not been implemented.<sup>15</sup> In addition, the Health Foundation estimates that by 2023/4 between £2.1-£12.2 billion<sup>16</sup> will need to be invested annually in the social care system in England. Similarly, the Scottish Government's own analysis has shown that its health and social care system will require £20.6 billion of funding by 2023/24, if it did nothing and chose not to reform the system.<sup>17</sup>

However, the scale of these economic challenges needs to be put into context. The adult social care sector in the UK contributes £46.2 billion to the economy. It represents 6% of total employment and the average full time equivalent worker generated £19,700 of value towards the economy.<sup>18</sup> Providing funding for social care reform should be seen as an investment in the economy and not just an expense. To demonstrate this, Leonard Cheshire commissioned Frontier Economics<sup>19</sup> (pro bono) to model the economic benefits of investing in social care. Their innovative modelling highlights how disabled people's unmet care needs, in terms of accessing the volume and quality of care they need, has a direct impact on their employment and earnings potential.

Currently, disabled people are twice as likely to be unemployed as non-disabled

people and earn 12% less.<sup>20</sup> If disabled people were able to better access the right social care support, this could contribute to reducing unemployment (for those who want to work). Accessing good quality, tailored and well-funded social care would also increase labour market participation to levels closer to the average for non-disabled people, and could also contribute to eliminating the disability pay gap. This would **generate an additional £6-£20 billion in annual income for the UK economy**. The economic benefits alone of social care reform are therefore clear for individuals and for wider society.

The lower end of this range reflects a reduction in unemployment and increase in wages to the levels prevailing in the wider population. The higher end of the range reflects increasing the number of disabled people who can participate in the workforce, from a level of 'economic inactivity' of 42.9% to one of 29.8% (which is still twice as high as the non-disabled population). This income would also generate returns for the Exchequer in the form of additional income tax. If taxed at the basic rate of income tax, **it would generate an additional £1.1-£4.5 billion**. This would pay for a significant portion of the additional funding for social care, as set out by the Health Foundation.<sup>21</sup>

Frontier Economics' modelling only takes into account the positive impact of social care reform on disabled people's employment. It doesn't take into account the positive impact on employment for unpaid carers, or the potential positive impact on the NHS due to reduced demand for hospital beds. Although the scale of investment in social care is vast, so are the economic benefits reaped from this investment. **Frontier Economics' modelling shows that reforming social care has the potential to pay for itself.**



## Chloe's story

Chloe is 33 and lives with her family. She commissions an agency to provide 15 hours of support a week.

Commenting on the how social care benefits her life, Chloe said:

"When my social care is going well, I don't have to think about it or worry about it, I can just have a normal day. Knowing I can rely on someone to support me to get ready helps the day get off to a good start and improves my productivity and happiness. Starting the day in the right way is really important for my mental health.

Being able to get ready and get dressed the way I want, and have my hair done how I choose, makes me feel good. I can get ready on time to catch a train into London and meet up with friends. Social care means I can lead the life I want to."



## 4. Recommendations for reform

The UK Government and devolved governments of Scotland, Wales and Northern Ireland need to urgently reform and invest in social care, to enable disabled people to be able to live independently and participate equally in society. Discussions on social care reform must be widened. The UK Government and Prime Minister must deliver on their commitment to bring forward plans to reform social care by the end of 2021. Based on the lived experiences of disabled people, Leonard Cheshire recommends the following:

- **Widen discussions on social care reform:** Discussions on social care reform must expand beyond care for older people, residential care and personal care. Discussions must ensure the needs of working age disabled adults are central to future reforms. Governments must demonstrate an understanding that the purpose of social care isn't to merely support individuals' basic needs, but to fulfil their right to live full and independent lives.
- **Invest in social care:** In the Comprehensive Spending Review we want to see immediate and sufficient funding to local authorities and care providers to stabilise the social care system between now and the end of 2021. We support the call of the Health Foundation for an immediate cash injection of £12.2bn in England to recover peak spending and stabilise the workforce.<sup>22</sup> This is essential to ensure working-age adults are able to access the care they need, and have any care reinstated which has been reduced or removed.
- **Deliver an ambitious reform plan:** We want to see an ambitious reform plan, that delivers a long term funding solution for all of us, commands cross-party support to be sustainable and creates the conditions for bold innovation in how social care is delivered.
- **Publish a clear timetable and plan in Northern Ireland:** We want to see the Northern Ireland Assembly publish a clear timetable and plan for the Department for Communities and Department for Health to co-manage the Supporting People programme.
- **Engage and co-produce reforms with disabled people:** Each government of the UK needs to launch an extensive consultation exercise to gain disabled people's views on how social care should be reformed in their country. As per Social Care Future's recommendations, subsequent social care reforms should be co-designed and co-produced with disabled people.<sup>23</sup>
- **Provide comprehensive and accessible information:** Disabled people require information about what care and support is available in their local areas to enable individuals to make an informed choice about their care. Although this is a statutory requirement, e.g. through the Care Act 2014, this information is not provided to disabled people in a consistent or accessible manner, limiting their choice and control over their care. Systems of care must be easier for disabled people to navigate.

- **Build in greater choice and personalisation:** Ensure that local authorities consistently co-produce care plans with disabled people so that they can put in place person-centred support tailored to their needs. This should also include widening the use of personal budgets and direct payments.
- **Improve workforce remuneration:** There must be funding available within the system to ensure the care workforce is rewarded and strengthened with a new deal for care staff and fair remuneration. Whilst we welcome the introduction of the Real Living Wage for adult social care staff in countries like Scotland and Wales, greater funding must be made available to achieve pay parity with NHS staff and alleviate the workforce challenges in social care. Reforming remuneration should begin with an immediate pay rise, including an agreement to move to parity with the NHS for the same roles, by a set date; a revised career structure; better training and development opportunities; and registration. Funded training would ensure quality of care provision and equip care workers to better meet the needs of people with complex conditions.

For further information on this briefing and our work on social care reform please contact [campaigning@leonardcheshire.org](mailto:campaigning@leonardcheshire.org)



# Endnotes

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