

Better living, higher standards: improving the lives of disabled people by 2020



Scope
About disability



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Living standards are not just about the amount of money in your pocket.

They are about whether you get a good education, have opportunities to work, have support to get out and about, whether you get to see friends, and play a full part in family life. They are about whether you can enjoy leisure activities and get to use public services. They are about the society that we are all part of.

We have choices about the type of society we live in and want everyone to be part of. With a General Election rapidly approaching, with signs of economic growth in the UK beginning to emerge – and importantly, with manifestos being written right now – we need all political parties to set out what they will do to rethink and reshape our communities, our work places and our support and public services. We need them to create a future that goes beyond the current economic crisis. We need them to invest in a society that is better for everyone.

This means a society in which living standards of disabled people are improved along with everyone else's so that they share in the benefits of economic growth and prosperity. A society in which disabled people can contribute to the economic recovery through being employed and paying taxes, can support their families, and can be part of creating stronger communities and networks that benefit all of us.

Let's make the most of the coming Election to set a new political commitment for social change. We must grasp the opportunities presented by emerging economic growth and political parties setting out their new commitments up to 2020 so that disabled people have the same opportunities as everyone else.

Let's make sure that disabled people are not left behind.

This report launches Scope's campaign to improve disabled people's living standards.

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Better living, higher standards



It's not just the money

Living standards are about a whole range of things that matter to people. Alongside their financial assets, income and jobs, people depend on being in good health and on having skills that they can use to learn or work. They rely on public services and on positive attitudes of, and relationships with, family, friends and wider social contacts.^[1] All of these and more make up living standards for all of us.

We've come a long way...

Disabled people have been at the forefront of driving big changes like the Disability Discrimination Act and the UK ratifying the UN Convention on the Rights of Persons with Disabilities. These show our commitment to being a fairer country and raising disabled people's living standards, such as by bringing in protections for disabled people against discrimination when using public services or in the workplace.

We have made progress towards everyone having the same opportunities in life – disabled or not.

...but we've got a lot further to go

In 2014 life is tougher than it needs to be if you're disabled.

Too often people feel awkward when it comes to disability.^[2] This makes people avoid conversations, overlook disabled people as potential friends, employees, work colleagues, neighbours or partners. In turn it affects disabled people's access to services, people's ability to live their lives, people's basic right to live in safety.

This awkwardness makes daily life tougher than it needs to be. Fundamentally we all – from employers, to politicians, to people at the local school, shop or pub – have an impact through the way we think, talk, and act.

This impact is not just on individuals; it affects the whole of society.

Awkwardness and lack of confidence around disabled people and disability undermines disabled people's opportunities and threatens living standards, creating the conditions where:

3/4 of non-disabled people have jobs

while fewer than

1/2 of disabled people do

- Getting a job can be far more difficult: "Disabled people do want to work, but if you can't get access to employment, because employers think it will be too expensive, too difficult, too challenging to employ you because you're a disabled person and that there's no help for employers, it's not going to motivate employers to employ disabled people." John, 51, Ardrossan (Living standards interviews, Scope)
- Taking an active part in the community is hard: 49% of disabled people report having experienced discrimination in shops, 31% report such behaviour when attending leisure activities, such as cinemas and theatres.^[3] In extreme cases, negative attitudes are responsible for 72,000 incidents of disability hate crime per year.^[4]

Disabled people are twice as likely to live in poverty as non-disabled people, and that's before the extra costs of disability are taken into account^[6]. This has been a persistent problem in the UK, showing that the progress we have made has not gone nearly far enough. Disabled young people are still less likely than their non-disabled peers to access higher education (33% as compared to 41%)^[6]. And many of the 3.7 million disabled people who will be affected as Government seeks to reduce expenditure on benefits,^[7] will end up with reduced financial security.

Three quarters of non-disabled people have jobs, but fewer than half of disabled people do^[8]. This gap is not closing fast enough – many disabled people who currently don't work, want to. Just looking at whether someone is able to work is not enough. Employment support comes with conditions and sanctions. It is important that these do not disproportionately push disabled people into any job available leading to poor outcomes for both workers and employers^[9] and decreasing disabled people's ability to shape their own working lives.

Too many people do not get the care and support they need. It should not be a privilege to decide when you eat, when you

sleep or who you live with – it is about basic independence. And there is a danger that this independence is being rolled back. Half a million older and disabled people who would have received social care five years ago now receive no support^[10]. More than 100,000 disabled people are currently at risk of losing the vital care and support they need to dress, wash, cook, work, study or take part in their community.^[11]

A demographic and economic imperative

Demographic and economic changes make it fundamental that increasing the living standards of disabled people is

“In general I feel like a lot of the focus and improvements of the 1990s are now being stripped away [...] it feels like we've taken a million steps backwards and the overall standard of living and quality of life is now back under threat.”

Dean, 42, Nottingham (Living standards interviews, Scope)

seen as a priority for public policy. Older and disabled people are becoming an increasingly significant part of the total population. It is predicted that the proportion of people in their 50s self-reporting long term health problems or disability will increase significantly from 43% in 2004 to 58% in 2020.^[12]

Our communities, institutions and work places need to change to reflect this. Businesses cannot afford to lose workers who need greater flexibility in employment practices or because the social care support they need isn't available. Prosperity for everyone depends on everybody having the chance to contribute – through economic activity and paying taxes, through family life and strong relationships, and through participating in and shaping local communities.

There are great social costs to failing to act to build disabled people's independence and living standards beyond the struggle to make ends meet. The promise of economic growth creates both an imperative and an opportunity to make changes to ensure that everyone can contribute to the recovery and benefit from improved living standards.

Recommendations to improve disabled people's living standards

Scope's living standards campaign focuses on three areas that need immediate action nationally, to improve disabled people's living standards: extra costs faced by disabled people, poor access to the labour market and inadequate social care. At the same time we will be working to improve public attitudes towards disabled people.

Protecting against the extra costs disabled people face and providing good quality social care enables more people to work and be an active part of their families, social groups and communities. Doing nothing will lead to an increasingly financially unstable population going into retirement, and will affect the living standards of generations to come, potentially removing any future benefits of growth that we experience now.

The prospect of economic recovery in the UK gives us an opportunity to think differently. It is an opportunity to make society work better for disabled people by putting in place the right policies to support us all across the whole of our lives.

1. Life can cost more if you are disabled – let's end the financial penalty by 2020



We should have a society in which:

- the extra costs some disabled people face are no longer a barrier to making an economic contribution or to social participation
- the true extra costs of living as a disabled person are recognised and more disabled people receive financial help to offset these costs
- there are more innovative products and services that reduce the extra costs some disabled people face.^[13]

The importance of financial wellbeing

There are huge economic and social benefits to having a society where people are financially resilient. Individual savings are buffers against debt. But they also enable us to plan for retirement, unexpected financial shocks, pay for education, training and re-training, relocation in pursuit of career advancement, to save and plan for a family and our children's futures, and to make the most of what life offers us.

Challenges to the financial wellbeing of disabled people

Life can cost more when you are disabled and disabled people are at a distinct financial disadvantage because of the extra costs they face. Without taking extra costs of disability into account, disabled people are twice as likely to live in poverty as non-disabled people.^[14] And extra costs have a significant impact on the living standards of disabled people, who spend on average £550 per month on costs related to their disability.^[15]

Extra costs are unique for each person, but may include paying for home adaptations and disability equipment; taking taxis due to inaccessible transport systems; the cost of a sign

language interpreter; paying more for electricity bills because of running medical equipment, spending longer at home, regularly running hot baths for muscular conditions; and having to buy more expensive, ready-prepared food when cooking is difficult.

It matters for all of us

Creating opportunities for disabled people to lead independent lives, increase their own income and improve their personal financial stability is important for the health of wider public finances. As long as incomes are absorbed into the extra costs of disability, disabled people cannot contribute to pensions or build up significant savings,^[16] which in turn contributes to the challenges facing pension reform.

"I am not allowed to build up savings to be able to pay for this additional disability related

**Disabled adults
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per month
specifically on
costs related to
their disability.**



expenditure. [...] Even if you could save, the government doesn't allow you to have savings. This has the effect of keeping many disabled people in a perpetual state of relative poverty and drastically curtailing our aspirations." Dean, 42, Nottingham (Living standards interviews, Scope)

Not only does a failure to address the extra costs create barriers for disabled people to contribute to the economy, or to fully enjoy family life, or to play an active part in their wider community life in the present time, but it also

extends into the future, creating further problems for our economy by reducing opportunities to build their own financial resilience or pay into pensions.

We've come a long way...

Living with a disability shouldn't mean that the basics in life cost more. This is why over 20 years ago the Government introduced Disability Living Allowance (DLA) to recognise these extra costs – and to help cover them.

There have been a number of clear policy commitments to protect the value of extra costs

payments including exempting these benefits from the introduction of the £26,000 'benefit cap'.

...but we've got a lot further to go

In April 2011, the way benefits are uprated changed – meaning that between 2010 and 2017, 3.25 million DLA claimants will be £1,000 worse off.^[17] In addition, these benefits will be included in the overall spending cap for welfare, jeopardising the help given to disabled people to cover their extra costs.

Little has been done to look at ways in which market and policy failures can be addressed to reduce extra costs faced by disabled people. Mainstream technology has become more affordable and accessible for many but this is not true for specialist equipment which is not held in check by market competition. The things disabled people need to buy are unjustifiably expensive, for example – a stair lift can cost upward of £4,000, a mobility scooter can cost up to £5,000 and an electric wheelchair between £900 and £6,000.^[18] And getting about is another area where disabled people encounter additional costs through needing to use specialist transport.^[19]

Between 2010 and 2017,
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"Christmas last year I had a problem with my wheelchair. [...] I went to the shop and it was like it's going to be a hundred pounds. And we were like 'Well where are we going to find the money for that? But we've got to find the money for it because I need it.' Helen, 39, South Bucks (Living standards interview, Scope)



Recommendations to improve disabled people's living standards

- Government should, and all political parties should commit to, protect the value of DLA, Personal Independence Payment (PIP) and Attendance Allowance (AA) by removing them from the overall welfare spending cap and triple-locking them just like pensions.
- In the next Parliament, political parties should commit to work in partnership with disabled people to reform PIP assessments, so that they properly reflect the extra costs disabled people face.
- Scope will launch a Commission on Extra Costs in June 2014 to examine the drivers of disability related costs and formulate concrete recommendations on how to tackle them. The Commission will explore extra costs across three key areas:
 - a. infrastructure (the built environment including transport systems, homes, towns and cities)
 - b. market structures – making the most of emerging markets and incentivising innovation
 - c. the future of financial inclusion.

2. Let's get a million more disabled people in work by 2020



We should have a society where:

- all types of work are available to everyone and where individual contribution is valued
- disabled people are able to work in roles that are meaningful to them and where they can contribute to the economy, develop and be rewarded on equal terms
- more employers feel confident to employ disabled people
- disabled people have opportunities to be drivers of, and benefit from, new employment opportunities arising from economic growth.

The importance of employment

Disabled people do work and they want to work. Nine out of 10 disabled people are either working or have worked in the past.^[21]

“Although I have been put onto the employment support allowance, I can see that I will eventually have to go back to work a) from a financial point of view but b) for my own sanity I think.” Helen, 39, South Bucks (Living standards interviews, Scope)

Having a job brings many important benefits, including providing a source of income, improving social inclusion, fulfilling one’s own aspirations, building self-esteem and developing skills and competencies. It also enables people to make a contribution to the costs of society and towards their local communities.

Challenges disabled people face in getting into and staying in employment

The living standards debate has been dominated by talk of wages. But we know that disabled people, throughout strong economic periods and times of recession, have been too often excluded from the labour market.

In work...“You feel like you’re contributing something again. I’m not going to be a dole scrounger, a welfare scrounger. That’s what you get tagged as, whether you like it or not, that’s what happens.”

Justin, 48, Newcastle-Upon-Tyne (Living standards interviews, Scope)

Today, disabled people are almost twice as likely to be unemployed as non-disabled people.^[22]

Staying in work can be hard without the right support from employers. Of people who become disabled whilst in employment only 60% are employed the following year, and 36% the year after that.^[23]

“I had a workplace assessment done [...] recommendations were made but not followed through so I had an accident and I am in great pain.” (Susan, 35, Living standards survey, Scope)^[24]

Once disabled people have fallen out of work it is much harder to get back into work – the average annual rate of disabled people making a transition from

economic inactivity into employment is just 4%, while the equivalent figure for non-disabled people is six times higher.^[25]

It matters for all of us

In order to create a fair, sustainable recovery that ensures that disabled people are part of the growth, disabled

jobseekers need greater support to find and apply for jobs.

The work force demographic is changing and work places need to change to reflect that if we are to ensure that everybody has the chance to contribute economically. This is demonstrated by almost 655,000 more disabled people assessed



Of people who become disabled whilst in employment...

only 60% are still employed the following year and just 36% have a job the year after that.

as fit for work through the change from Incapacity Benefit to Employment and Support Allowance. If this trend continues, we could see about a further 344,000 looking for work in the near future.^[26] As the population ages, older people are more likely to stay in the labour market, many of whom will also have conditions or impairments that require changes in the workplace.^[27]

We've come a long way...

Since 2001, the employment rate of disabled people has increased by 10%.^[28] This has been aided by Government investment in schemes such as Access to Work, which addresses the extra costs disabled people face in the

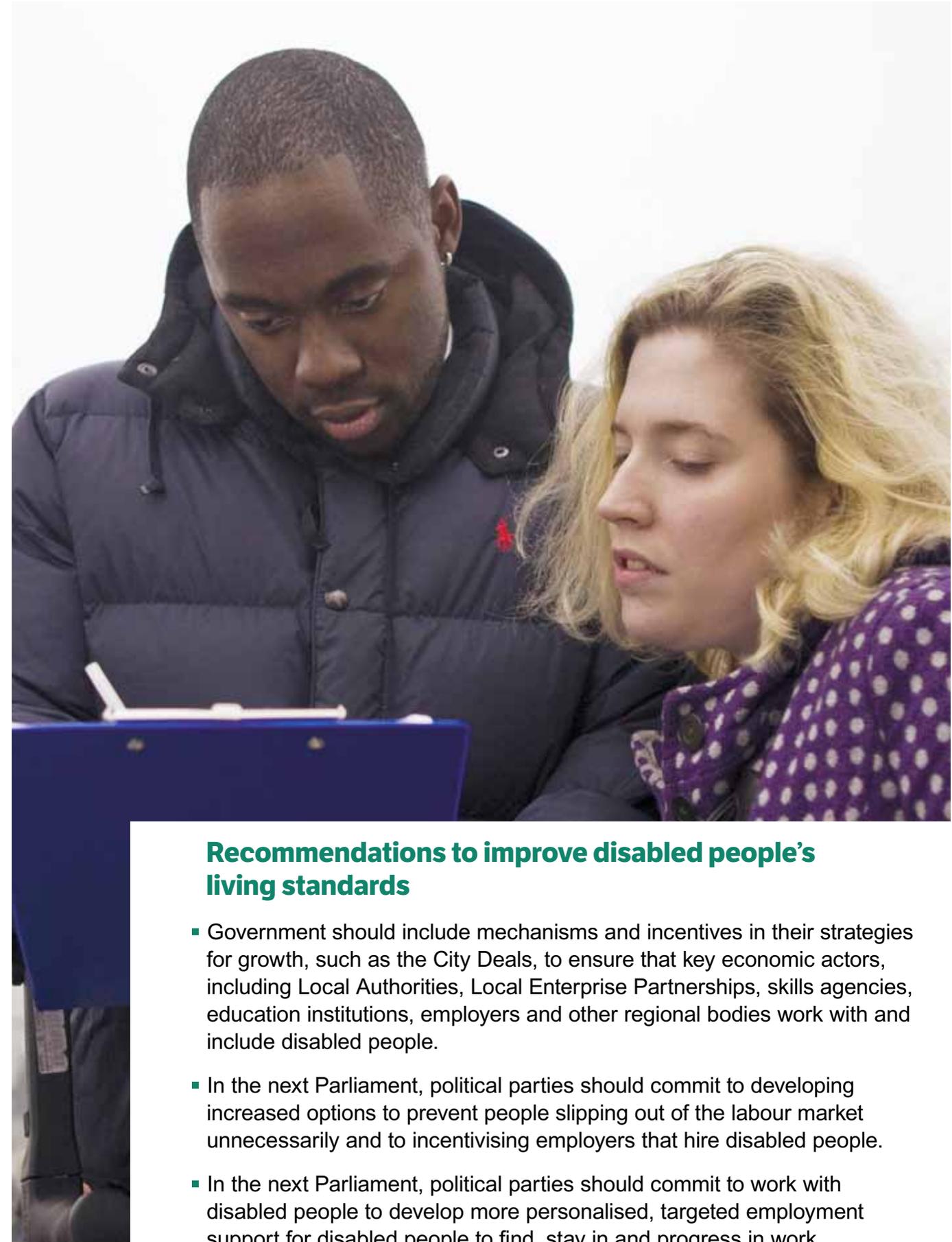
workplace such as travel costs, specially adapted equipment and support workers.

Employer attitudes are also changing for the better, with 61% of employers saying they have now made adjustments for a disabled employee, or plan to do so.^[29] These adjustments are often small, such as flexible working arrangements, with 71% of employers saying they incurred no extra costs at all.^[30] The Government's Disability Confident campaign will help employers continue to improve disabled people's opportunities in the workplace.

...but we've got a lot further to go

Disabled people need to have the support and opportunity they need to stay in work in the first place. And as the recovery kicks in, disabled people need opportunities to play their part and share in economic growth.

Positive attitudes amongst employers and work colleagues will go a long way to making this happen but modern, flexible work places that disabled people can access and where employers are confident employing disabled people are also essential.



Recommendations to improve disabled people's living standards

- Government should include mechanisms and incentives in their strategies for growth, such as the City Deals, to ensure that key economic actors, including Local Authorities, Local Enterprise Partnerships, skills agencies, education institutions, employers and other regional bodies work with and include disabled people.
- In the next Parliament, political parties should commit to developing increased options to prevent people slipping out of the labour market unnecessarily and to incentivising employers that hire disabled people.
- In the next Parliament, political parties should commit to work with disabled people to develop more personalised, targeted employment support for disabled people to find, stay in and progress in work.

3. Let's make sure all disabled people get the support they need to live as independently as possible



We should have a society:

- that includes everyone
- where more disabled people have the opportunity to live independently in the communities they choose
- in which more working age disabled people can afford the care and support they need to live an independent life.

The importance of support to live independently

Living independently in the community is about leading a life of your own choosing, being supported to build relationships with other people, and having freedom and choice over the accommodation and area in which you live. Independent living is not about living alone without support, but it is about being part of the local community and developing relationships between people, places and making choices about the things that are important to you.

Challenges for disabled people in living independently as possible

Too many working age disabled people cannot afford the care and support they need to live independently. It should not be a privilege to decide when you eat, when you sleep or who you live with – that's about basic independence. And there is a danger that this independence is being rolled back. People's support needs around communication and social interaction are often aspects of life which are neglected by social care assessments^[31] which limit what people are able to do with their care package.

In a Scope survey, nearly half the disabled adults we spoke to said services they receive do not enable them to take part in community life.^[32]

It matters for all of us

There is value in everyone being involved in their local community. A strong social network built up of family, friends, acquaintances and wider social contacts can provide emotional support during both good and bad times. It can open up opportunities to work or learn, to make use of services and to be part of other people's lives too.

A weak social network can result in limited economic opportunities, a lack of contact with others, and eventually, feelings of isolation. Socially isolated individuals face difficulties connecting with society as a contributing member and fulfilling personal aspirations.^[33]

We've come a long way...

There has been a drive towards greater personalisation of public services in health, social care and beyond. More people have access to personal budgets and direct payments, giving them greater control over the support they receive. The Care Bill is due to be implemented in 2015 and for the first time, there will be a national minimum threshold for social care.



Furthermore, the 2013 Spending Review injected additional funds into social care, which pooled with money from the health budget earmarked to improve integration, amounts to £3.8 billion.

...but we've got a lot further to go

Levels of unmet need within social care are high with 97,000 fewer disabled people who would have received social care five years ago, now receiving no support. When demographic change is taken into account this

number increases to 120,000 disabled people.^[34] Significant reductions in central government funding to councils^[35] mean social care budgets are under pressure and although NHS money is ring-fenced, almost all social care funding is not.

In this resource limited environment, personal care is prioritised over people's social and communication needs.^[36] Disabled people want to be active members of their communities and their families, but support to do so is under threat.



Recommendations to improve disabled people's living standards

- The Government should set the minimum threshold for care introduced through the Care Bill at the equivalent to the current 'moderate' level so that more people who need care and support are eligible to receive it.
- The Government should agree a new financial settlement in the next Comprehensive Spending Review that allows those eligible for social care to receive all the support they need to live independently in the community.
- In the next Parliament, political parties should commit to introducing incentives for local authorities and other local actors to improve quality of care and support mechanisms, including through the integration of strategies on employment, health and social care to keep people in work, living in their own homes and preventing crisis.

References

- [1] Runswick-Cole K. Goodley D. and Lawthom R. (2014) Resilience in the lives of disabled people across the life course, Manchester Metropolitan University.
- [2] A recent survey of over 1000 members of the general public found that about a quarter of people think of disabled people with awkwardness or discomfort. Opinium (forthcoming) Attitudes and Understanding of disability. Funded by Scope.
- [3] ComRes poll (2011) of 676 disabled adults.
- [4] Coleman N. Sykes W. and Walker A. (2013) Crime and disabled people. Baseline statistical analysis of measures from the formal legal inquiry into disability-related harassment, Equality and Human Rights Commission Research report 90.
- [5] Scope (2013) Changing Society. Our strategic direction from 2013.
- [6] Office of Disability Issues, Disability Equality Indicators.
- [7] Grant E. and Wood C. (2010) Destination Unknown, Demos.
- [8] Office of Disability Issues (2013) Fulfilling Potential – Making it happen: Technical annex.
- [9] Devins, D. et. al. (2011) The Role of Skills from Worklessness to Sustainable Employment with Progression, UKCES.
- [10] Fernandez J. L and Tom Snell T. (2013) Changes in the patterns of social care provision in England: 2005/6 to 2012/13, London: PSSRU, London School of Economics.
- [11] Fernández J.L. et al. (2013) Implications of setting eligibility criteria for adult social care services in England at the moderate needs level. London: PSSRU, London School of Economics and Political Science.
- [12] Pillai R. et al (2007) Disability 2020: Opportunities for the full and equal citizenship of disabled people in Britain in 2020, IPPR.
- [13] Jewell S. and Atkin R. (2013) Enabling technology, A BT and Scope report.

[14] Scope (2013) Changing Society. Our strategic direction from 2013.

[15] Scope calculation based on Demos (2010) survey data underlying Wood C. and Grant E. (2010) Counting the cost, Demos.

[16] McKnight A. (forthcoming) Disabled People's Financial Histories: uncovering the disability wealth-penalty, CASE paper funded by Scope.

[17] Grant E. and Wood C. (2010) Destination Unknown, Demos.

[18] 'More than mobility' website, accessed 26/02/2014 http://www.morethanmobility.com/8-mph-Road-Legal-Scooters/View-all-products.html#mobility_products

[19] Papworth Trust (2011) Changes to Disability Living Allowance Survey Results.

[20] Grant E. and Wood C. (2010) Destination Unknown, Demos.

[21] Office of Disability Issues, Equality indicator B5.

[22] Office of Disability Issues Disability, Department of Work and Pensions, Equality indicator B1, <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php>

[23] Papworth Trust (2012) Disability in the United Kingdom 2012.

[24] Scope (2013) Living Standards Survey. 639 disabled adults responded to our survey which asked about different aspects of living standards.

[25] Rigg, J. A. (2005) Labour market disadvantage amongst disabled people: a longitudinal perspective. CASE paper,103. Centre for Analysis of Social Exclusion, London School of Economics and Political Science, London, UK.

[26] Scope analysis of ESA Outcomes of Work Capability assessments January 2014 statistics.

[27] Office for National Statistics (2013) What does the 2011 Census tell us about older people?

[28] Office of Disability Issues (2013), Fulfilling Potential: Building Understanding, Main Slide Deck.

[29] Dewson, S., Williams, C., Aston, J., Carta, E., Willison, R. and Martin, R. (2009) Organisations' responses to the Disability Discrimination Act: 2009 study, Department for Work and Pensions Research Report No 685. London: DWP.

[30] Dewson S., Ritchie H. and Meager N., (2005) New deal for disabled people: survey of employers, Leeds: HMSO.

[31] Brady R. (2014) Facilitating the voice of disabled people and carers in the design of new eligibility systems proposed under the Care Bill: Feedback from carers and social care users on the draft eligibility criteria DH Engagement events with local authorities on the draft eligibility regulations, Scope.

[32] Scope (2012) Social Care survey of 619 disabled adults.

[33] Runswick-Cole K. Goodley D. and Lawthorn R. (2014) Resilience in the lives of disabled people across the life course, Manchester Metropolitan University.

[34] Fernandez J. L and Snell T. Personal Social Services Research Unit (2013) Changes in the patterns of social care provision in England: 2005/6 to 2012/13, London: PSSRU, London School of Economics.

[35] Over the last 3 years, England's councils have experienced a 20% reduction in funding from government: Tough Times (2013) Councils' Responses to Financial Challenges from 2010/11 to 2013/14, Audit Commission.

[36] Brady R. (2014) Facilitating the voice of disabled people and carers in the design of new eligibility systems proposed under the Care Bill: Feedback from carers and social care users on the draft eligibility criteria Department of Health Engagement events with local authorities on the draft eligibility regulations, Scope.

Scope exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

We provide support, information and advice to more than a quarter of a million disabled people and their families every year. We raise awareness of the issues that matter.

And with your support, we'll keep driving change across society until this country is great for everyone.

Look out for our future work and have a conversation on Twitter about disabled people's #livingstandards

www.scope.org.uk

Call 0808 800 3333 to let us know if you'd like this information in a format that's accessible for you.