

**The “Affordable Papers”: Contributions to
an Economy That Includes Disabled
People**



Disability Rights UK

April 2016

“This is one way that the Disability Rights movement is making the larger economic system less tolerable, because it is saying, “No, this is not a fact of nature, this is not pre-ordained that disabled people should be impoverished and lonely and miserable. And they are not somehow less than fully human”. When we extend full humanity to more and more people it makes a system that constitutionally demands that some people be on the bottom less tolerable.”

Charles Eisenstein, author of Sacred Economics.

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Guest speakers at Seminar 1, “Affordable: an economy that includes disabled people 2014” (15th December 2014): Tom MacInnes (and Adam Tinson), New Policy Institute; Prof. Jacob S. Hacker, Yale University; Prof. Mark Priestley, University of Leeds; Dr Aaron Reeves, University of Oxford (now at London School of Economics and Political Science (LSE)) and Prof. Victoria Chick, University College London.

Guest speakers at Seminar 2, “How can disabled people reduce their cost of living ad risk of poverty?” (4th November 2015): Helen Dewdney, “The Complaining Cow”; Louise Woodruff, Joseph Rowntree Foundation; Teresa Perchard (and Minesh Patel), Extra Costs Commission/Scope; Charles Eisenstein (and Marie Goodwin), author of “Sacred Economics”; Kay Allen, Trading for Good / Really Useful Stuff; John Lamb, The British Assistive Technology Association (BATA); Mike Adams, The ecdp (formerly the Essex Coalition for Disabled People) and Daniel VandenBurg (and Alison Blackwood), Citizen’s Advice.

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Foreword

As disabled people we are significantly excluded from participation in society but it is our economic exclusion that arguably affects us the most. Less than half of disabled people are in work. Linked to this many disabled people lack the money to pay for services beyond those funded through Government programmes. Almost one in three (30%) of families living in poverty have a disabled child. Our exclusion stems in part from the failure of Government back-to-work programmes such as the Work Programme, but also from an economy that views disabled people as being less productive and therefore of less value than our non-disabled counterparts. This belief needs challenging but the best way to challenge the failure of the economy to provide affordable goods and services and provide jobs, is to build a different economy.

Economics dictates politics and politics shapes lives, disabled people's lives more than most. So why aren't more disabled people's representative organisations going beyond debates about the nature of our politics and looking instead to engage with the nature of our economic system? Disability Rights UK accepted the challenge and with the support of the Joseph Rowntree Foundation organised two seminars on how an economy that includes disabled people might be achieved. The seminars examined major questions including: is austerity necessary and is it inevitable that disabled people are the most affected and how might we reduce the living costs faced by disabled people? This report presents the contributions made to these questions.

Of course there are many possible future directions but the papers reproduced here look at two in particular. Firstly consideration is given to ways of helping disabled people's ambitions to succeed within the present economy through the co-production of new markets e.g. disabled people employed in user testing to support businesses to attract new disabled consumers. Or secondly could disabled people be in the vanguard of a new more social and sharing economy and one that builds upon their own strengths of resilience, resourcefulness and empathy? For example through exchange systems whose members trade in time credits to provide services or goods such as Fureai Kippu, a community care service for older people in Japan.

Both approaches would be massively boosted by support for measures that help disabled people to coalesce into communities. At present disabled people are largely treated as individuals with only individual problems whereas with a population of 11.9 million disabled people it is conceivable that they could crowd source from each other many answers to their own problems. The task is therefore to connect them to each other. Such a community would then have real political leverage but also be able to exercise its consumer power to drive down the costs of goods and services sold to disabled people.

The end goal for these seminars has to be more than the one of debating new possibilities, but actually creating new possibilities too. As business increasingly moves to business models that derive their value from their relationship with their consumers, so too do these consumers gain power over the producers and providers. As the power shifts so too does the possibility for disabled people to have more power. Technology such as digital fabrication gives us the potential power to manufacture locally for local markets including our own need for aids and adaptations for independent living, whilst platform business models give us the power to bring spare capacity to the market and be both consumers and providers of it. So Disability Rights UK hopes that disabled people will be inspired to want to build community and to co-produce their own economy of inclusion.

Philip Connolly, Policy and Development Manager, Disability Rights UK.

March 2016

Executive Summary

One in five people in the UK has a disability and a third of all people living in poverty have a disabled person in their household. “Disability and poverty” is therefore a mainstream issue affecting everyone and not a matter simply to be confined to the margins of society. Nonetheless, the impacts of austerity in the UK and Europe have more damaging effects on the disabled community than on mainstream society.

To tackle this specific issue of disability and poverty, Disability Rights UK hosted two seminars in London, funded by the Joseph Rowntree Foundation in 2014-15. In addition to a presentation from Disability Rights UK, the first of the two seminars in December 2014 saw guest speakers from various academic institutions present their cases for why disabled people need to be more fairly represented in the national economy. Highlighting historical trends and comparing the UK economy with that of other European nations, they expertly illustrated how the current era of austerity does little to “claw back” the national deficit, yet penalises the most vulnerable.

Having already looked at the effects of austerity on the disabled community and wider society, the second of the two seminars, in November 2015 focused on forming a disabled community and harnessing the potential of the “purple pound” to reduce their cost of living. Although welfare cuts, sanctions and insufficient supported employment schemes are issues all worth campaigning against; lowering the cost of goods is one viable solution to poverty in the disabled community, just waiting to be tapped into. With expert grassroots experience, representatives from a wide range of organisations including Disability Rights UK spoke of the reality “on the ground” - the gap between most disabled people’s financial needs and their relative income. Disabled people generally have a higher than average cost of living to meet requirements such as specialist equipment and unnecessary increased insurance premiums. Some of the presenters therefore spoke about the idea of “collective consumerism”: disabled people coming together to drive down unnecessarily high costs. They also demonstrated how it is in the interests of businesses to be more receptive and responsive to disabled consumers; the “purple pound” makes sound business sense and should not be regarded as a mere corporate social responsibility. Indeed one only needs to look to the “grey pound” - the forerunner in this movement.

Each of the chapters in this report gives more detail on the speakers' presentations – the issues raised, questions considered and most importantly, the recommendations made. Whilst a number of different themes were covered and numerous recommendations contemplated, there is a significant degree of commonality: disabled people living in poverty affects everyone. Likewise, the solutions lie in mainstream society.

In addition to a synopsis of the two seminars, Disability Rights UK has included a chapter on how disabled people can co-produce markets. Much like the theme of the second seminar, this chapter gives examples of “platform thinking” and “co-production” – concepts and business models that enable disabled people to actively shape the products and services they use, making common sense as much as good business sense. Disabled consumers should be at the forefront of user-testing as much, if not more so than anybody else, driving change and proving that they have as much to contribute as non-disabled people. Helping disabled people to thrive economically and socially is as much about embracing what they can achieve as individuals and as a collective, as it is about supporting them through the difficult times.

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1:0 Introduction: The significance of disabled people on measures to resolve poverty

A third of people living in poverty in the United Kingdom have a disabled person living with them. The Joseph Rowntree Foundation (JRF) defines* poverty as “*when a person's resources, mainly material resources, are not sufficient to meet their minimum needs, including social participation*” (Joseph Rowntree Foundation, 2015). Considering approximately one in five people self-identify as having a disability (Scope, 2015), we can quite readily see that being disabled and poor is very much a mainstream issue and therefore not something that should be a social taboo. This report is a synopsis of the main themes that emerged from two events hosted by Disability Rights UK (DR UK) and additional research into the topic of disability and poverty. Over a twelve month period DR UK hosted two seminars, funded by the Joseph Rowntree Foundation, to address some of the key causes of disabled people living in poverty - and to seek the potential solutions that lie broadly in policy and within the organisation of our economy. The first of the two seminars, “*Affordable: an economy that includes disabled people*” welcomed a range of speakers, mostly economists (table 1), who expertly argued why our national economy needs to be more inclusive of disabled people, from an economic viewpoint as much as a social one.

Table 1: Authors of research papers presented at Seminar 1 “Affordable: an economy that includes disabled people 2014” (15th December 2014)

Speaker	Organisation	Title/Theme of Presentation
Tom MacInnes	New Policy Institute (No longer at NPI)	Disability, long term conditions and poverty
Philip J Connolly	Disability Rights UK	Research and the DRILL project
Prof. Jacob S. Hacker	Yale University	The Promise of Predistribution: Markets that Work for All
Prof. Mark Priestley	University of Leeds	Disability rights and economic inclusion in an age of austerity
Dr. Aaron Reeves	University of Oxford (Now at LSE)	Disability, austerity, and the labour market
Prof. Victoria Chick	University College London	Austerity: bad for (nearly) everybody, worse for the disabled

Disabled people generally have an income that is lower than the national average and that falls far short of meeting the higher than average living costs they typically face. Being disabled tends to require more money just to meet basic needs, so those with a disability are already at an economic disadvantage. Add to this that many disabled people struggle to find suitable, fairly paid employment, it is certainly not a level playing field for them economically speaking, let alone socially. Those that are able to work should be supported to and it must be recognised that regular employment will not always be an option. A fair benefits system and good policy would recognise that many people have fluctuating health conditions and are only able to work some of the time. A good economy would permit the adaptation of jobs, to enable people with fluctuating needs to participate.

It is estimated that there is a higher percentage of disabled working-age adults living in poverty (31%) compared with the national average (20%). However, these estimates include benefit income designed to meet extra costs but not the costs themselves. Once these benefits are removed, there are an extra 1.8 million people in families with a disabled person, in poverty (New Policy Institute, 2015). Benefits aimed at meeting the extra costs of disability are clearly not bridging the gap.

The second of the seminars therefore moved on to address the question *“How can disabled people reduce their cost of living and risk of poverty?”* This seminar saw a host of speakers (table 2) largely from the third sector, who gave their experienced and honest perspectives from “on the ground” and made viable recommendations of how we might seek to redress the balance, particularly through collective consumer power. With a combined spending power of £212 billion in the UK (The Extra Cost Commission, 2015), disabled people have considerable potential to be powerful consumers – to flex the “purple pound”.

Table 2: Speakers at Seminar 2 “How can disabled people reduce their cost of living ad risk of poverty?” (4th November 2015)

Speaker	Organisation	Title/Theme of Presentation
Helen Dewdney (Chair)	The Complaining Cow	How to Complain
Louise Woodruff	Joseph Rowntree Foundation	Anti-poverty strategy in the UK; poverty and disability
Teresa Perchard	Extra Costs Commission	Findings from the Extra Costs Commission
Philip Connolly	Disability Rights UK	Coalescing a community
Charles Eisenstein	Published author	Sacred Economics
Kay Allen OBE	Trading for Good / Really Useful Stuff	Aggregating the disability market
John Lamb	The British Assistive Technology Association (BATA)	Developing a competitive market for disabled consumers
Mike Adams	ecdpc (formerly The Essex Coalition for Disabled People)	The “disabled consumer’s” perspective
Daniel VandenBurg	Citizens Advice	Know your new rights

This seminar looked at how disabled people can come together to drive down market prices and speak up for their rights as consumers. Disabled people have as much right as anyone to work, should they be able to. Even if employment prospects for disabled people improve, it is only right that their living costs are not unfairly augmented, for example by insurance companies or taxi firms - being “different” shouldn’t mean unnecessary increases to premiums or fares.

The two chapters that follow provide a summary of each of the speakers’ topics. Each chapter gives an overview of their most salient points, the questions they raised and perhaps most importantly, their recommendations based on sound evidence and professional knowledge. Each speaker has their own merit, yet unanimously they argue that change is needed. We need new policies, a change in attitudes and an inclusive economy that will enable disabled people to participate as equal members of society. Disabled people and their support networks need to work together as a collective, to move disabled people out of poverty and the rest of society must be ready to respond. Following these two chapters is an additional chapter explaining how disabled people can co-produce markets - that is ensuring involvement at all stages of the design and marketing of products and services aimed at the disabled sector of the market. The information from this chapter has

come from research carried out by Disability Rights UK into the concepts of “platform thinking” and user-testing by disabled people.

*The standard, widely-accepted measurement of poverty is: having a household income below 60% of the median, after housing costs are adjusted for household size (New Policy Institute 2016).

2.0 Affordable: An economy that includes disabled people

2.1 Why austerity blocks participation – Professor Victoria Chick

Professor of Economics Victoria Chick clearly explained that the UK's current deficit is financed by borrowing and the cumulative effect of deficit is a rise in debt. The debt figure is usually deflated by GDP to discount for overall price changes. The debt/GDP graph (figure 1) for the period 1909-2009 shows dramatically higher debt ratios caused by the two world wars. At the peak of this debt, former Prime Minister Attlee established both the National Health Service (NHS) and the welfare state; the size of the debt was clearly no obstacle. What the current government claims to be concerned with is – by comparison - the very small rise, just at the end of the graph. When looked at in an historical context, it is barely significant.

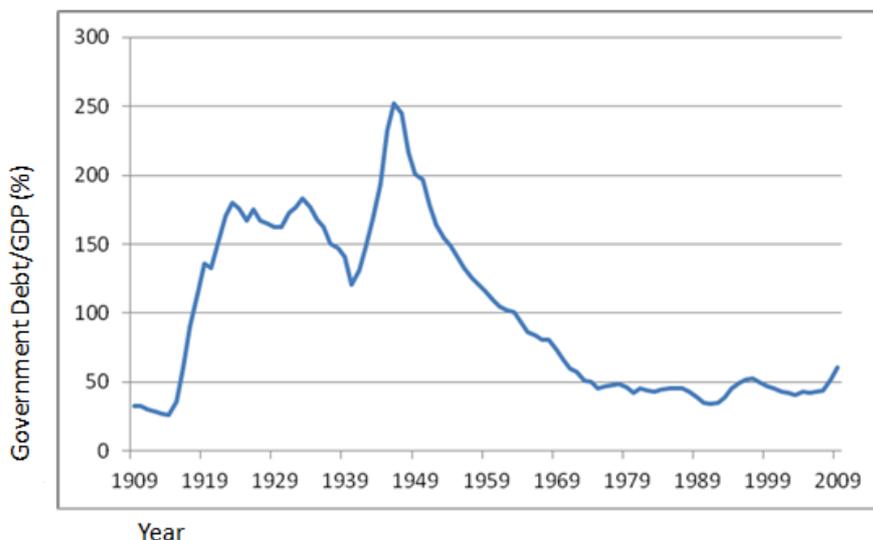


Figure 1: Debt/GDP, 1909-2009

Source: Chick, Pettifor and Tily, 2014

Professor Chick questioned if there could therefore be another reason for 'austerity in perpetuity'. She suggested that the focus on the deficit and 'necessary' cuts deflects attention from this government's true objective: to end the welfare state. Evidence for this includes: privatization of the NHS; redistribution to upper incomes (for example reduction of upper tax bracket from 50 to 45%); reduction of benefits; harsher terms for unemployment and disability benefits and housing support and

subsidies to businesses that pay low wages. There is a general policy of supporting capital at the expense of labour - and the rich at the expense of the poor. Most shameful of all is a reduction of benefits to people with disabilities to the same level as that of able-bodied job-seekers, despite the additional expenses and difficulties they face.

Professor Chick stressed that any political views expressed during her presentation were her own; UCL was not implicated in any way.

2.2 The effects of austerity and sanctions on disabled people – Dr. Aaron Reeves

Often missing from debates about the financial crisis are the negative consequences on people's health and wellbeing. Evidence from Dr. Aaron Reeves from the University of Oxford (now at the London School of Economics and Political Science) highlighted the shocking effects austerity measures have had on the European population:

- Approximately 8,000 excess suicides ¹
- 7.3 million with unmet medical needs ²
- 10 million are food insecure ³

The 8,000 excess suicides are higher than we would have expected since the start of the great recession in Europe (¹Reeves, McKee and Stuckler 2014). There are 7.3 million more people with unmet medical needs since the recession, largely because they are now unable to afford the cost of accessing healthcare (²Reeves, McKee and Stuckler, 2015). An additional 10 million people are now experiencing food hardship and are unable to afford to eat meat regularly (³Loopstra, Reeves and Stuckler 2015). These data represent the population of Europe, yet we need to consider that a significant proportion of those affected are likely to be people with a disability (including mental health) and who would have already been at a significant disadvantage, before austerity plunged them further into poverty. Furthermore many of the damaging effects from certain medical conditions and of course suicide are irreversible, causing long-term effects to individuals and the wider community.

¹Reeves, A., M. McKee, and D. Stuckler. 2014. "Economic suicides in the Great Recession in Europe and North America." *British Journal of Psychiatry* 204(6):1-2.

²Reeves, A., M. McKee, and D. Stuckler. 2015. "The attack on Universal Health Coverage in Europe: recession, austerity, and unmet needs." *European Journal of Public Health*.

³Loopstra R., A. Reeves and D. Stuckler. 2015 "Rising food insecurity in Europe". *The Lancet*.

2.3 The value of disabled peoples' rights as protection – Professor Mark Priestley

Professor Mark Priestley from the University of Leeds reminded the audience of the UK government's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2009. This raised the bar of expectation for the full participation and equality of disabled people in all aspects of society. However, it conversely coincided with the onset of fiscal consolidation and austerity measures as a response to the economic crisis:

"If we are to achieve European policy targets for high employment, high participation in education and reduced risk of poverty and social exclusion then disabled people need to become part of the solution rather than the 'problem'."

Professor Priestley went on to describe a number of important points regarding disabled people in four main areas: employment; economic activity; education and training; poverty and social exclusion. With regard to employment, he explained that there is a significant disability employment gap across the EU, of about 26 percentage points and it is higher in the UK at 30+ percentage points (figure 2):

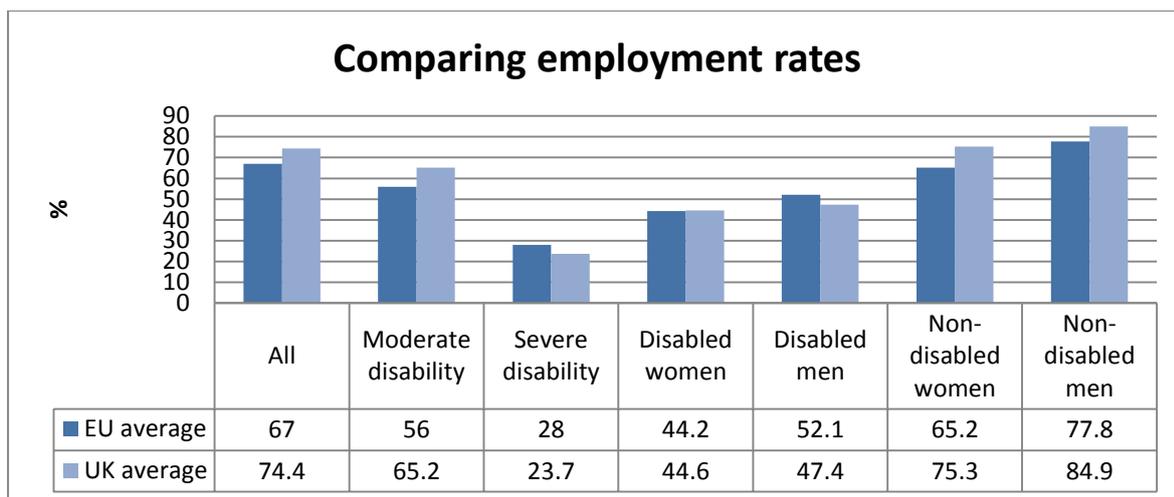


Figure 2: Comparative employment data for UK and EU for persons aged 20-64 years.

Source: EUSILC UDB 2012 – version 2 of August 2014

He highlighted the following important points regarding disability and employment:

- The employment rate of disabled people remains well below the 75% target. (Can this target be achieved for the general population without their participation?)
- Countries with similar employment rates for non-disabled people present large differences for disabled people. This suggests that national regimes and policies **do** make a difference and that there is potential to act.
- There remains some difficulty in monitoring employment rates for disabled people using national statistical sources.

In addition to employment (and economic activity and education and training), Professor Priestley also highlighted some very salient points about poverty risk factors and social exclusion and how the UK compares with the EU overall (figure 3):

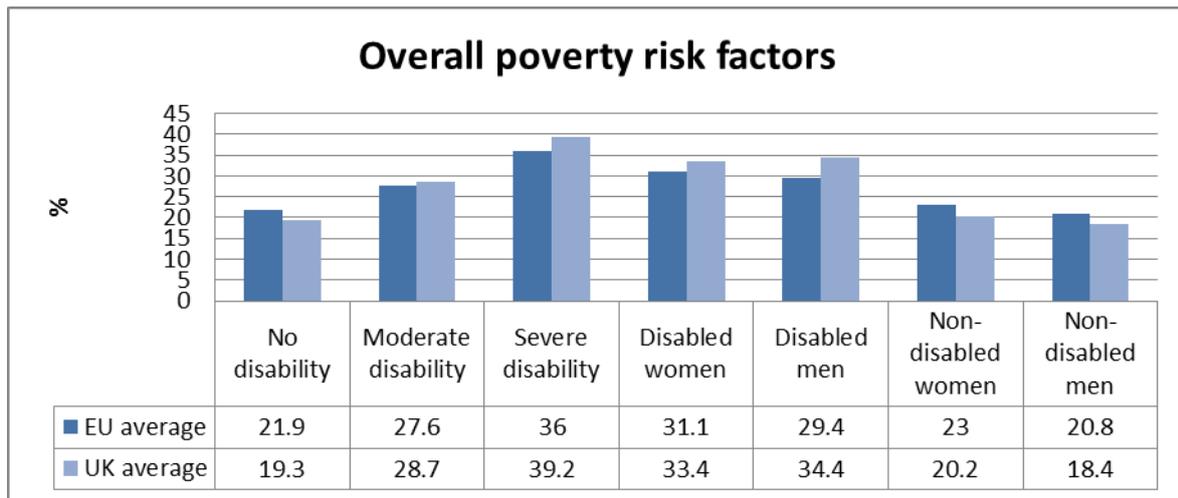


Figure 3: People living in household poverty and exclusion by gender and severity (aged 16+)

Source: EUSILC UDB 2012 – version 2 of August 2014

- There are very different rates of relative household poverty for disabled people in different European countries, and gaps between households in different European countries and gaps in the UK are wide – especially for people of working age.
- Poverty risk for non-disabled households in the UK is better than the average yet for disabled households it is **worse** (and would be far worse if we corrected for additional cost of living benefits, as the Joseph Rowntree Foundation have shown).
- Higher median levels of household income (in richer countries) do not correspond with risks of relative poverty for disabled families, or with poverty gaps between disabled and non-disabled people.
- Irrespective of employment markets and national wealth creation, **social policies make a difference** (e.g. policies for employment and social protection).

As a result of these gaps, Professor Priestley concluded that employment protections are failing to keep disabled people and chronically ill people in work and that sanctioning ultimately results in moving (disabled) people off unemployment benefit. He also noted that the public generally supports welfare for vulnerable groups. Based upon his findings he made the following recommendations:

1. Target and mainstream disability equality as a concern in all policy development;

2. Involve disabled people and their organisations in policy process at all levels;
3. Invest in accessible infrastructure for inclusive education and labour markets;
4. Provide active and personalised support for disabled people in those markets;
5. Ensure adequate and flexible disability benefits that protect people unable to find secure and economically viable jobs.

2.4 “Predistribution” – Professor Jacob Hacker

Professor Hacker from Yale University spoke at the seminar about his concept of “predistribution”; that is the idea that the state should try to prevent inequalities in the first instance, as opposed to trying to even them out through welfare once they have occurred (known as redistribution). The benefit of “predistribution” is that prosperity is shared and therefore leads to improved social health. He gave a sound explanation of why it also makes economic sense for society to facilitate the full participation of disabled people:

“We often conceive of efforts to end discrimination and promote equality of opportunity as all about social justice. But they are also measures to better utilize the dispersed talent of diverse societies. A society that fails to promote the skills and opportunities of all its members is leaving money on the table [...]The central pillar of successful societies is fulfilling and socially valuable work for as many citizens as possible.”

With this in mind, austerity measures – leading in cutbacks to education and health - will ultimately create an undereducated and unhealthy society, therefore preventing “predistribution” from being realised. Disabled people in particular, who are likely to need support and adjustments to enable them to work, are the most likely to be affected:

“Of course we should create opportunities for the permanently disabled to move back into the workforce — laws requiring accommodation are a major “predistribution” strategy. But these opportunities will not be seized unless

governments invest in technology, training, and targeted inclusion that allows disabled people to cultivate and use their distinctive skills.”

Cutting the benefits that enable disabled people to work will therefore ultimately cost, not save money and lead to greater inequality and an “unhealthy” society.

2.5 Research and the DRILL project – Philip Connolly

Philip Connolly, Policy and Development Manager at Disability Rights UK (DR UK), presented at both seminars, the first of which he focused on research priorities. He explained where the gaps in policy research, with regards to moving disabled people out of poverty, are:

- Research allied to parliamentary cycles;
- Research on how to prevent the economic exclusion of disabled people rather than cure it;
- Focus on strengths: resilience, problem solving, empathy, etc;
- Research on how disabled people can be agents of change – not simply what we have done for disabled people;
- Research on how to go beyond an economy based upon shortages e.g. the £360 million budget for specialist employment support;
- Research on assisting disabled people to become networked to the satellite centres of research and in turn directly involved in research.

The research presented by the economists at the December 2014 seminar goes some way to addressing this research gap, particularly the issue around economic exclusion. One of Philip’s key points is that there is too much discourse around *barriers* to participation and about what disabled people cannot do. Instead we should focus on what they *can* do, support them to do it and in doing so empower them to be agents of change. The Disability Research on Independent Living and Learning (DRILL) Programme is a new innovative five year UK-wide programme, funded by the Big Lottery and led by Disability Rights UK. It will deliver the world’s first major research programme led by disabled people. The second of the two

seminars, encapsulated in the following chapter, very much focused on this idea of disabled people leading change.

3.0 How can disabled people reduce their cost of living and the risk of poverty?

3.1 The significance of disabled people forming community - Philip Connolly

At the second seminar, Philip explained how he was inspired to organise the event for one very important reason:

“I was struck by the fact that if you are a disabled person and you are seeking support in this country at the moment, you are treated very much as an individual. If you qualify for social care and you meet the financial threshold, you will get an individual care plan. If you qualify for back to work support, and mostly it is not effective, you will get an individual back-to-work support plan. If you qualify for membership of a travel concessionary scheme, you are an individual holder of a permit or pass to use that scheme. What never happens is a conversation like this: “Well, would you like to meet your peers? Would you like to meet people who have had that learning, faced the challenges you have had in the situations you encounter and have learned to find adaptational coping? Would you like to be part of a learning network? Would you like to pass on your skills and your knowledge, your attributes to other people with newly acquired disabilities? Would you like to be part of a community?” It simply doesn’t happen.”

There are an estimated 11.9 million disabled people in the UK (Family Resource Survey 2011/12) and a further 6 million carers, therefore great potential for forming a “disabled community”. Yet despite these numbers, approximately only one in four declare their disability – perhaps for fear of stigma, or a reluctance to receive “charity” - and only 50% are likely to be in employment. A significant proportion of disabled people are therefore likely to have either little or no income. This needs to be addressed, alongside looking at how we can empower disabled people to come together to drive down their cost of living.

3.2 How can disabled people be in the vanguard of a new economy? – Charles Eisenstein

Author of Sacred Economics and other published books, Charles Eisenstein, spoke at the seminar about the concept of creating a “compassionate society” - where community members look out for each other and put their talents to good use to help others. This has the advantage of humanising members of marginalised groups, giving them a voice:

“This isn’t just about disability rights, it is part of a larger shift towards maybe you could say a compassionate society which is very different from the mentality of charity, which is based on pity. Compassion is much different from pity. Compassion starts with the question: What is it like to be you? [...] From that viewpoint different policies emerge... one of the more subtly political things that you can do is to make the disabled visible as full human beings, and to tell your story. What is it like to be disabled? Because that is actually very inconvenient if you are a policy-maker and you can’t just write off the disabled through some set of statistics.”

Charles spoke specifically about the alternative economy of “time banking”, a practice known widely in Japan as “Fureai Kippu”, where people use *time* rather than money as a currency to buy and sell services. If for example you spend one hour doing chores for an elderly or disabled neighbour, you “bank” that hour and in exchange someone can offer an hour of their time to help either you, or a family member who perhaps lives too far away for you to be able to help. This avoids the need for money – especially important for those who have insufficient funds - and creates a more *compassionate* society. The result is increased social inclusion for those who would ordinarily be on the margins, enabling them to access “services” without having to pay and - most importantly - in a more personal and dignified manner. Referring back to the Joseph Rowntree Foundation’s definition of poverty, social isolation and an inability to participate are measures of poverty as much as a lack of finance.

3.3 Collective consumer power - Teresa Perchard

Teresa Perchard represented the Extra Costs Commission (ECC), a year-long independent inquiry into the extra costs faced by disabled people, to which Scope provided the secretariat. The Commission was set up in July 2014, in response to disability charity Scope's 2014 report *Priced Out: Ending the Financial Penalty of Disability by 2020*, which highlighted a lack of evidence and ideas about how to drive down the cost of products and services for which disabled people typically pay more:

- The disability charity Scope has worked out that disabled people spend, on average, £550 a month on extra costs related to their disability. The welfare benefits which are supposed to help cover these costs – Disability Living Allowance and Personal Independence Payment - amount to an average of only £360 a month.
- There are 12 million disabled people in the UK. One in every five people is disabled. Altogether disabled people spend £212 billion a year, known as the “purple pound”. Collectively we could have a lot of power to get much better value for disabled people's money.

The ECC's findings concentrated on addressing extra costs in five particular areas particular:

1. The cost of energy (especially electricity and gas)
2. The cost of clothing and bedding
3. The cost of specialised disability equipment
4. The cost of taxis and private hire vehicles
5. The cost of insurance

Please see <http://www.scope.org.uk/Get-Involved/Campaigns/Extra-costs/Extra-costs-commission/Full-Report> for a link to the full report online.

Some key statistics and points to consider emerged from the research:

- Three quarters of disabled people and their family have left a shop or ceased to do business because of poor customer service and disability awareness; businesses could be missing out on a share of £420 million of revenue a week by failing to meet the needs of disabled consumers.
- Six in ten businesses said that they would find information about disabled people’s consumer habits and preferences useful in understanding how to serve this group more effectively.
- There are 11.9 million disabled people in the UK with a combined spending power of £212 billion. That group of consumers should have a lot of more power in the marketplace as a whole than at present.
- More than 90 per cent of those surveyed by the Commission favoured the idea of a card for disabled people to access discounts and offers on goods and services.

The Commission has called on four different groups to help drive down additional costs for disabled people:

1. **Disabled people** and their families should be ‘bold and loud’ and build power behind the “purple pound”.
2. **Disability Organisations** should improve information to disabled people and businesses to allow them to drive down the extra costs of disability.
3. **Businesses** should improve the customer experience of disabled people and recognise the power of the “purple pound”.
4. **The Government** and **regulators** should intervene where features of markets result in unfair extra costs for disabled people.

Since the launch of the final report Scope has developed its information resources to have a greater focus on disabled people’s needs as consumers. The ECC hopes resources like this will encourage disabled people to be more confident as consumers. The charity has also had successes in encouraging businesses to drive down extra costs for disabled people. This has included work with Marks and Spencer to introduce a new sleepwear range for older disabled children that is cheaper than similar existing items. Another example is Uber, who have responded

to the work of the Extra Costs Commission to provide a service offering additional assistance to disabled passengers, as well as wheelchair accessible vehicles in London. Furthermore, through Scope's engagement with the Financial Conduct Authority (the regulator for the insurance industry) they will be looking in more detail at the experiences of disabled people when purchasing insurance.

The Commission will reconvene in June 2016 to review the progress made in delivering its recommendations.

3.4 The size of the market in goods and services for disabled people - John Lamb

John Lamb from the British Assistive Technology Association (BATA) explained some of the work that the Association is currently focusing on:

1. An area they are very much involved with at present is Value Added Tax (VAT). Assistive technology products designed for disabled people are presently VAT free. However, HM Revenue & Customs (HMRC) is currently reviewing this, so there is a risk that people may have to pay twenty per cent more for much of the technology they need.
2. There is a growing demand for access to assistive technology that is driven by greater numbers of disabled people, who increasingly expect to conduct their lives online. Over half of all consumers have a connection to disability (figure 4), so there is an evident need to bring the assistive technology market into the mainstream:

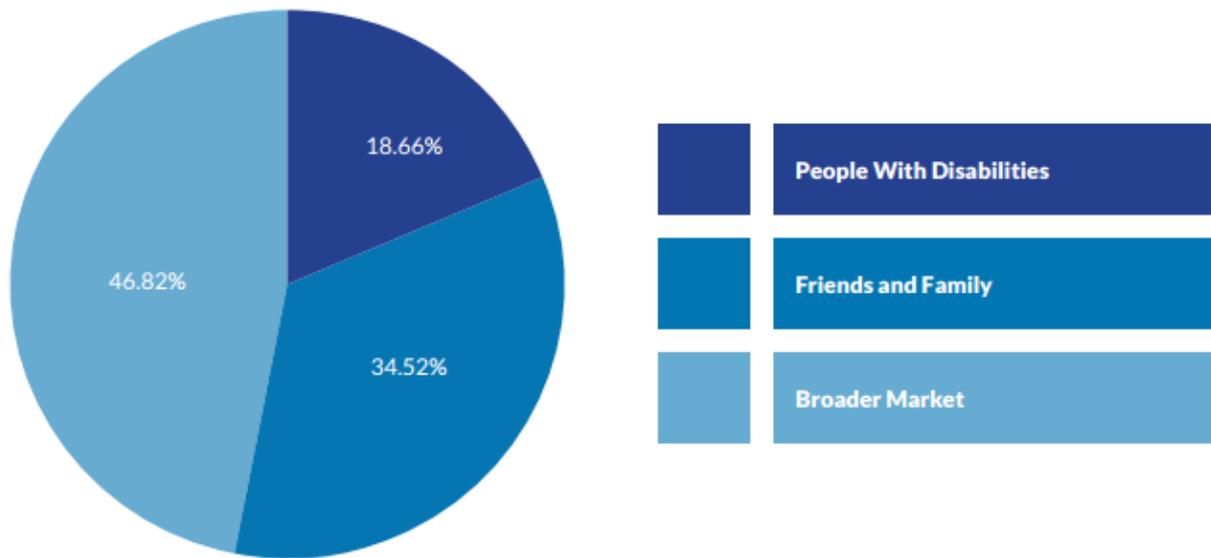


Figure 4: Consumers with either a disability or a connection to disability outnumber the rest of the UK market.

Source: Fifth Quadrant Analytics.

3. However, over a quarter of disabled people have never used the internet. Many of them could do so with the help of assistive software products such as voice recognition, screen readers and literacy aids and hardware such as switches, adapted keyboards and mouse alternatives. Disabled people already often pay a premium for the products they use, in part because they are produced in very small production runs and tend to be highly customisable which adds to the cost. It is estimated that 29 million (57%) of 18 to 64 year olds could benefit from using assistive technology.

4. Household names such as Boots, Barclays and B&Q, many of them members of the Business Disability Forum (BDF), are increasingly embracing assistive technology to help them to deliver products and services for disabled people:

“Research by the Business Disability Forum has found that over a third of disabled people said that good disability service was the primary reason for choosing a provider or product. Two thirds chose businesses where they

have received good customer service related to their disability [...] Being disability friendly is likely to boost the employment prospects of disabled people... companies could focus first on gaining more disabled customers and use this as a bridge to employing more disabled people.”

John summarised the benefits of the industry working together to make assistive technology more mainstream:

- Significant additional revenues;
- Disabled people are increasingly consumer-minded;
- Changes to benefits systems give disabled people more choice;
- Ripple effect among friends and family;
- Early mover advantage;
- Meets legal and social obligations.

3.5 Aggregating the market – Kay Allen OBE

Echoing John Lamb’s suggestions for how the industry can act together, Kay Allen founder of “Trading for Good” and the online shop “Really Useful Stuff, spoke about the “Amazon” model; bringing lots of suppliers together in a very simple portal so that as an online customer, all you need do is visit one website:

“You go to one place so as a consumer, you now have an easy shopping service. What that does is allow Amazon to negotiate hard with its suppliers. Disability doesn’t have that...The suppliers will give you a better deal if they sell more. They are not selling more because you know what, disabled people, you are a tough lot to market to. If you have a visual impairment, you have a different marketing method to someone who has a hearing loss. You have different products. So actually, you are not 11 million disabled people, you are a fragmented bunch of folk who have different needs, who read different magazines, go to different sources.”

Even more significantly Kay spoke of how the disabled community need to act together to put pressure on the industry, to increase their power as a consumer group:

“I don’t know any big corporate that is saying to its suppliers, if you want us to spend money with you, we need you to do the following things on disability. So I think the disability movement as a whole is kind of missing a trick if you are not bringing enough pressure within that procurement to leverage that spend to deliver change. It is a movement. You talk about the disability coalescing 11 million disabled people into a powerful movement, you need to get some way of looking at that [...] The dial has not really moved [in twenty years] so if you want to make real change about the extra cost of disablement, about coalescing the voice of 11.9 million, you will have to do something radically different you have not done in the last twenty years.”

Kay was one of several speakers at the seminar to highlight the potential power of the “purple pound”.

3.6 The perspective of disabled people as consumers - Mike Adams OBE, ecdp (formerly Essex Coalition of Disabled People)

ecdp is an organisation run by disabled people, for disabled people. CEO Mike Adams also addressed the audience about how the power of disabled people as consumers is hugely underestimated and underutilised. Linked to this however, is the reluctance or the nervousness around people approaching disability for fear of inappropriate language and etiquette:

“If you look at the perspective of disabled consumers, traditionally they have been viewed by business as a corporate social responsibility...if you are going out to market, you need to be confident about the people you are selling to ...there is an issue around a lack of disability confidence...There is a danger that if you don't move out of that kind of corporate social responsibility

mentality, then you view the commercial opportunities through the wrong prism and as a business there is money to be made with disabled people. If you are providing high quality services that disabled people want and need, then there is a market opportunity.”

Mike also talked about the lack of choice and control available to disabled people as consumers, something his organisation is seeking to address. Traditionally there has been a view that disabled people should be grateful for whatever adjustments are made to accommodate them. This is now beginning to change. Disabled consumers are quite justifiably beginning to demand better, more personalised service, and businesses should not necessarily view this as their corporate social responsibility, but as a good business opportunity.

3.7 Know your new rights – Daniel VandenBurg

Rather fittingly, the November 2015 seminar took place during National Consumer Week, the theme of which was Know Your New Rights. The aim of the 2015-16 campaign is to raise awareness and to promote the use of the new consumer rights that were brought into force through the Consumer Rights Act legislation on 1st October. Because of the Act the law will be easier to understand, which should support all consumers to buy with greater confidence. Daniel VandenBurg from Citizens Advice, reminded the attendees of the importance of disabled people in particular, knowing their rights. Citizens Advice runs the Consumer Service – a service that provides advice to consumers in England, Scotland and Wales by telephone and e-mail. Any member of the public can contact the service in relation to: pre-shopping advice; information on consumer rights; advice on specific problems and referral or signposting to other organisations. Daniel highlighted that 38% of Citizens Advice clients have a disability, in comparison with the national figure of people with a disability at 21%, one example of this being the number of calls to the Consumer Service in relation to disability aids and adaptations (figure 5). Daniel suggested that with new legislation in place, now might be the ideal time for disabled consumers to come together to use their rights to enable better deals and to call businesses into account.

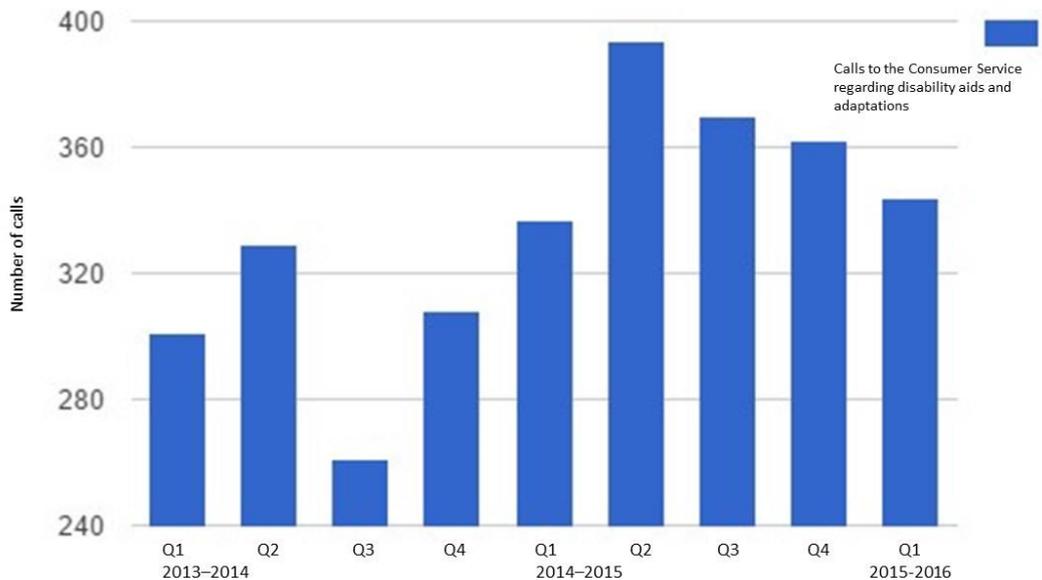


Figure 5: People and consumer issues at Citizens Advice: number of calls to the Consumer Service in relation to disability aids and adaptations.
Source: Citizens Advice Consumer Service 2015

3.8 How to Complain - Helen Dewdney

Helen Dewdney, The Complaining Cow consumer rights blogger and author of *How to Complain: The Essential Consumer Guide to Getting Refund, Redress and Results!* chaired the seminar, in addition to sharing her guidelines for writing the perfect letter/e-mail of complaint. She reminded the audience that writing the perfect letter or e-mail makes it much easier for the reader to understand what you are asking for and results in a swifter response. In summary her top ten tips for the perfect letter were:

1. **Be clear** – make sure your letter reads well. Ask someone to check if necessary;
2. **Be assertive** – but stay objective, keep to the facts and do not write in capital letters;
3. Keep events in **chronological order** (if more than one event/correspondence to refer to);
4. Write to **customer services** in the first instance;

5. If the matter is more serious (or you are unhappy with the response from customer services) **go to the CEO** (see <http://ceoemail.com/>)
6. Provide **all** the **evidence** that you can – correspondence, photos as necessary;
7. Provide a **summary at the end** in bullet points, particularly if it's a long letter;
8. **Exercise your legal rights** – quote the relevant law. (For goods purchased prior to October 1st 2015 quote the Sale and Supply of Goods Act 1994. For services prior to October 1st 2015 quote the Supply of Goods and Services Act 1982. After the 1st October 2015 quote the Consumer Rights Act 2015.);
9. **State what you want.** Be clear about what you expect: an apology; explanation for mistakes/misinformation/poor service etc; refund; repair or replacement; redress for inconvenience caused;
10. **Inform them of next steps if not satisfied.** Give them a deadline by which you expect a response (usually seven days) and state what you will do if you don't hear by then. (Only mention the media if it is a big story and something a bit different, no company is going to care about your threat to take your story about a broken kettle to the papers!)

In her role as chair, Helen also very succinctly summarised the ethos of this second seminar: disabled people have considerable power as consumers, but to harness this power and to influence the market they need to create a coherent community. The disabled community can learn from examples of other consumer groups that were once overlooked but are now targeted as customers. Older people are one key example - many companies now target the “grey pound”. There are approximately 12 million disabled people in the UK making them one of the largest consumer groups, however they currently largely list as individuals with little sense of an overarching community identity and it was this issue that the second seminar – for the most part – sought to redress.

4.0 How do disabled people co-produce markets?

In addition to the guest speakers at the two seminars, Disability Rights UK is keen to champion the ideas and concepts of further individuals and businesses, whose ideas - by design - add momentum to the moving disabled people out of poverty campaign. Their business models and ideas essentially promote “co-production” - involving (disabled) people at all stages of product/service design through to dissemination. For further information on a particular idea or company, please see the website address listed at the end of the relevant section. These websites are the source of much of the information presented here.

4.1 “Platform Thinking” - Sangeet Paul Choudary

Generally speaking there are two broad business models: “pipes” and “platforms”. Pipes are the traditionally dominant model. Businesses create a product, push it out and sell it to customers. Value is produced upstream and consumed downstream. It is a linear flow, much like water flowing through a pipe. Platform business models on the other hand, enable creation and exchange of value *between* users, with the firm (startup) acting as an infrastructure, *enabling* users to interact. The value in the business is its relationship with its consumers – not the brand. The rise of “platforms” is being driven by three transformative technologies: cloud, social, and mobile. The result is a globally accessible network of entrepreneurs, workers, and consumers who are available to create businesses, contribute content, and purchase goods and services. Television channels work on a pipe model but YouTube works on a platform model. Encyclopedia Britannica worked on a pipe model but Wikipedia has flipped it and built value on a platform model; the site enables creators to create a knowledge base and consumers to consume that information. Airbnb enables hosts and travellers to interact and engage in commerce. Instagram enables photo creators to show off and discuss their creations with photo viewers. These are all examples of platform business models connecting producer and consumer and allowing them to interact with each other. The use of platform thinking however, extends beyond the tech sector. Retailers are shifting from distribution channels selling products, to engagement platforms co-creating value, in much the same way that Kay Allen advocated in the second seminar. Online retailers such as eBay, Etsy

and Amazon led the way and traditional retailers are now following. Businesses that provide products and services for disabled people could also follow suit if they are to produce products and services of *value* to their customers. Businesses that adopt a platform model and engage disabled users can also enable disabled people to create value for the wider market. This would enable disabled people to “give back” and challenge the common misconception that disabled people are only worthy of charity.

For more information: <http://platformed.info/wp-content/uploads/2013/09/Platform-Power-Sangeet-Paul-Choudary.pdf>

4.2 “The Lean Startup” – Erik Ries

Erik Ries’s business model can - by design – help disabled people in much the same way as “platform thinking”. His methodology includes inviting a selection of end users of products to contribute at the very beginning of a product’s evolution (i.e. the design phase) and involving them throughout. There is co-production with selected end users at all stages and consumers therefore ultimately become the co-producers of the products. Too many startups begin with an idea for a product that they *think* people want. They then spend months, sometimes years, perfecting that product without ever showing the product, even in a very rudimentary form, to the prospective customer. When they fail to reach broad uptake from customers, it is often because they did not consult prospective customers. When customers ultimately communicate - through their indifference - that they don’t care about the idea, the startup fails. Disabled consumers in particular, need to be at the forefront of user testing - informing designers of what they expect from their products and why, and testing proto-types.

The Lean Startup methodology has as a premise that every startup is an experiment that attempts to answer a question. The question is not "Can this product be built?" Instead, the questions are "Should this product be built?" and "Can we build a sustainable business around this set of products and services?" The experiment is therefore more than just theoretical inquiry; it is a first product. If it is successful, it allows a manager to start his or her campaign: enlisting early adopters, adding

employees to each further experiment or iteration and eventually starting to build a product. By the time that product is ready to be distributed widely it will already have established customers. It will have solved real problems and offer detailed specifications for what needs to be built. Further to offering opportunities for disabled people to shape the products that they need at an affordable price, this methodology undoubtedly makes good business sense as it is more likely to result in a sustainable business venture. When a business's value resides in its customer relationship, it is the customers that have the power. This power includes leverage over accessibility, availability, cost etc., and is therefore important to help disabled people to act as a consumer group in addition to knowing and exercising their power as consumers.

Erik serves on the advisory board of a number of technology startups, and has consulted to new and established companies as well as venture capital firms. In 2010, he was named entrepreneur-in-residence at Harvard Business School and is currently an IDEO Fellow. (IDEO is an award-winning global design firm that takes a human-centered, design-based approach to helping organisations in the public and private sectors innovate and grow.)

For more information: <http://theleanstartup.com/principles> and <http://theleanstartup.com/>

4.3 AbilityNet - Robin Christopherson

An example of disabled people forming user groups to advise businesses on how to adapt or design products for disabled people, and hence widen their consumer market is produced by Robin Christopherson of AbilityNet. Robin is Head of Digital Inclusion and part of the globally-acclaimed accessibility and tech team of AbilityNet. The company has a team of consultants and testers who help businesses, charities and public bodies to design and maintain accessible websites, apps and other digital tools, advocating the user-testing methodology. Such an example is AppleVis, a community-powered website for blind and low-vision users of Apple's range of: Mac computers; the iPhone; iPad; iPod Touch; Apple TV and Apple Watch. AbilityNet also provides a range of high quality paid for and free services that help people

regardless of their disability and age, to succeed at work, at home and in education. Their services have helped to change the lives of disabled people, enabling them to use digital technology.

Despite being blind, Robin uses technology very effectively - using speech output to access computers, the internet, his iPhone and many other technologies to assist him in his work. More importantly he has a first-hand appreciation of the importance of good web and mobile design and its impact on both accessibility and usability for every customer. He furthers his mission to raise awareness and advocates for digital inclusion through projects including blogging on AbilityNet's website, numerous guest posts and articles elsewhere and publishing AbilityNet's State of the eNation Reports. Robin is also an active member of leading professional organisations such as the Guild of Accessible Web Designers, the International Association of Accessibility Professionals and the Cabinet Office Digital Inclusion, and in 2015 was runner up Digital Leader Public Figure of the Year.

For more information:

<https://www.abilitynet.org.uk/homepage> and
<https://www.abilitynet.org.uk/robinchristopherson>

Guide to contributors

Affordable: An economy that includes disabled people (Seminar of 15th December 2014)

The significance of disabled people on measures to resolve poverty

Speaker: Louise Woodruff

Policy and Research Manager, Joseph Rowntree Foundation

Contact: louise.woodruff@jrf.org.uk

Why austerity blocks participation

Speaker: Victoria Chick

Emeritus Professor, University College London, Dept. of Economics

Contact: v.chick@ucl.ac.uk

The effects of austerity and sanctions on disabled people

Speaker: Aaron Reeves

(Former) Research Fellow, University of Oxford, Dept. of Sociology

Currently: Associate Professorial Research Fellow at the London School of Economics and Political Science (LSE)

Contact: aaron.reeves@sociology.ox.ac.uk

The value of disabled peoples' rights as protection

Speaker: Mark Priestley

Professor of Disability Policy, University of Leeds and

Scientific Director of the European Commission's Academic Network of European Disability experts (ANED)

Contact: m.a.priestly@leeds.ac.uk

“Predistribution”

Speaker: Jacob S. Hacker

Director of the Institution for Social and Policy Studies and

Stanley B. Resor Professor of Political Science, Yale University

Contact: Jacob.hacker@yale.edu

Research and the DRILL project – Philip Connolly

Speaker: Philip Connolly

Policy and Development Manager, Disability Rights UK

Contact: philip.connolly@disabilityrightsuk.org

How can disabled people reduce their cost of living and the risk of poverty? (Seminar of 5th November 2015)

The significance of disabled people on measures to resolve poverty

Speaker: Tom MacInnes

(Former) Research Director, New Policy Institute

Please address any queries to **Adam Tinson**, Senior Researcher

Contact: adam.tinson@npi.org.uk

The significance of disabled people Forming Community

Speaker: Philip Connolly

Policy and Development Manager, Disability Rights UK

Contact: philip.connolly@disabilityrightsuk.org

How can disabled people be in the vanguard of a new economy?

Speaker: Charles Eisenstein

Author of Sacred Economics

Contact (Marie Goodwin): marie.goodwin@sacred-economics.com

Collective consumer power

Speaker: Teresa Perchard

Extra Costs Commission Commissioner

Scope

Contact (Minesh Patel): minesh.patel@scope.org.uk

The size of the market in goods and services for disabled people

Speaker: John Lamb

British Assistive Technology Association (BATA)

Contact: john.lamb@bataonline.org

Aggregating the market

Speaker: Kay Allen, OBE

Founding Director, Really Useful Stuff and Trading for Good

Contact: kay.allen@diverseadvice.com

The perspective of disabled people as consumers

Speaker: Mike Adams

ecdpc (formerly The Essex Coalition for Disabled People)

Contact: info@ecdpc.org.uk

New consumer rights and opportunities

Speaker: Daniel Vandenburg

Consumer Intelligence Analyst

Citizens Advice

Contact: daniel.vandenburg@citizensadvice.org

Chair / How to Complain

Speaker: Helen Dewdney

Consumer Rights blogger and author of How to Complain: The Essential Consumer Guide to Getting Refunds, Redress and Results!

The Complaining Cow

Contact: info@thecomplainingcow.co.uk

Additional contributions

Robin Christopherson

Head of Digital Inclusion, AbilityNet

Contact: Robin.Christopherson@abilitynet.org.uk

For more information (and contact details) regarding Sangeet Paul Choudary, author of “Platform Power”; Erik Ries, founder of “The Lean Startup” please see the website addresses listed at the end of the relevant chapters.