

The

EU debate



SPECTRUM NEWS

April 2016

**Why we believe Disabled
People are better off if
the UK stays in the EU**

Edited By Lesley Long-Price

Think you know
Disabled People...
Think Again

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Iain Duncan Smith

From his resignation letter:



“ I have for some time and rather reluctantly come to believe that the latest changes to benefits to the disabled [*sic*] and the context in which they've been made are, a compromise too far. While they are defensible in narrow terms, given the continuing deficit, they are not defensible in the way they were placed within a Budget that benefits higher earning taxpayers ”

From the Editor:
Lesley Long-Price



Welcome to SPECTRUM's April Newsletter!

It cannot have escaped your attention that on Thursday 23 June there will be a referendum to decide whether Britain should remain in the European Union. SPECTRUM believes that it is so important for Disabled People that we vote to stay in the EU, that **SPECTRUM has taken the unprecedented step of publicly declaring our support for the Britain Stronger In Europe campaign.** This newsletter includes our briefing paper (pages 8-11), explaining why we believe Disabled People are better off if the United Kingdom remained a member of the European Union and worse off if we left the European Union.

Where else but a SPECTRUM newsletter can you read articles about unemployed Ministers, the EU Referendum, robots, a fish and chip shop, Brussels and the Disability Discrimination Act to name but a few?

We don't let things like the 'defensible' budget cuts, continuing 'deficits', and the depressing climate of austerity and 'compromise' get us down!

We take April showers and storms in our stride by purchasing a more sturdy umbrella to shelter under, and more durable water proof clothing to weather the economic and political storm.

We know that the depression of dark clouds (national government austerity policy), the wind (local government budgets) and rain (public service cuts) will blow away come summer (which summer though is anyone's guess)?

Happy reading!

Chief Executive's update



Welcome to the first SPECTRUM Newsletter of 2016. I'd like to share with you what SPECTRUM has been doing since our last newsletter, and what our plans are for 2016 and beyond.

We are all experiencing the impact of what seems to be never ending 'austerity' cuts, and what with the Chancellor's Spring Budget, we all know that Disabled People will, once again, be hit hard - now, and for many years to come. Whilst some pundits glibly call it 'Austerity 2.0', we know that for many Disabled People it is very very difficult indeed to continue to live independently. SPECTRUM is not immune from the cost cutting, impacting us at the very time when our users need more and more support from organisations like us.

But, here at SPECTRUM, we are nothing if not resilient - we will continue to support Disabled People who need support, information or advocacy to enable them to remove the barriers that prevent them living independently:

- We will maintain existing services and develop new services as best we can
- We will seek to influence how future public services and social policy develops. 'Salami Slicing' is not a solution for anyone. Radical new approaches are needed that actually **listen and act** on what users want and value. We need to focus limited resources on the services and support that users most value. Statutory Services that have a 'bunker' mentality and decide what to cut without considering the views of users as part of the solution are doomed to fail their citizens.
- We will continue to be innovative and be entrepreneurial; continuing to plan for our own future and continuing to lead on developing creative and cost effective solutions to enable more and more Disabled People to live independently, and to ensure the future of SPECTRUM. Sadly, far too many voluntary sector organisations are resisting change and just hoping not to be a victim of cuts. That isn't the SPECTRUM way!



Chief Executive's update

continued

The future...

Maintaining services and developing new services:

Our Direct Payments service in Southampton has been extended for another year.

Our Community Navigator service goes from strength to strength and we hope to extend our work when current funding ends in September (See article on page 30)

We have just launched our new **Managed Budgets** service in Southampton, enabling people for the first time to receive support to manage the finances of their Direct Payments and Managed Budgets.

Influencing how services are developed inclusively for Disabled People:

Whilst the Fairness Commission has now completed its work, and published its report (www.spectrumcil.co.uk/news/southampton-fairness-commission-report-is-published-read-it-here/), the commission (of which I was a Commissioner) will meet later this year to review progress on its recommendations.

Our co-production expert panels work in both Southampton & Hampshire to enable service users to influence how Local Authorities work

I recently spoke at a seminar called 'Can Robots be Caregivers?' (See article on page 8). Users need to be involved in this and other important technology solutions that might improve or reduce our ability to live independently. Currently users hardly ever get a say - we need to be more vocal.

We are working with users of Audleys Day Service in Basingstoke to enable them to have more say in how the day services they receive should develop in the future.

Planning for our own future:

Our Strategic Review has now been approved by the Management Committee, and following an AwayDay in February, we now have an agreed Action Plan that will enable SPECTRUM, together with our subsidiaries Unity 12 & SCILCC to be restructured to meet the needs of our users and the expectations of funders.

As SPECTRUM's Chief Executive I have been asked to sit on the National Advisory Group for the first ever Independent Living research programme to be led by Disabled People. Proving the value of Independent Living will be a key factor in ensuring that Independent Living is not a victim of the 'austerity' cuts. (See article on page 12).

Why SPECTRUM believes Disabled People are better off staying in the EU

The **EU debate**



Briefing Paper on the Advantages and Benefits for UK Disabled People Remaining in the EU

The focus of the debate on the EU referendum until now has been mainly on the economy, trade agreements, employment, legal issues and immigration. There has been hardly any key media coverage on Disabled People and their livelihood within or without the EU, except an article by Richard Howitt MEP in the Guardian.

This briefing paper is to make clear some key issues and benefits for Disabled People by remaining in the EU.

Why Disabled People are stronger in Europe

The UK disability movement has prospered by being part of the wider international disability movement since the early 1980s when it was formed through DPI (Disabled People's International). In particular, through being actively engaged with the European disability movement we have seen a wealth of positive changes happen which have improved the quality of Disabled People's lives in the UK. We have been much stronger by working together with the European Network of Independent Living (ENIL) and the European Disability Forum (EDF) campaigning for independent living, equal rights and an accessible environment, which has enabled Disabled People to have a positive influence on the EU. Below are some examples.

The Rights for Disabled People in Employment and Freedom of Movement

Over the years we have seen many positive changes in combating discrimination and advances in strengthening equality for Disabled People and other disadvantaged groups. Working together with our European disabled colleagues we have contributed towards bringing in an important European wide non-discrimination directive, which protects the rights of disabled people in employment and enables Disabled People to work in other European countries. The EU also supports freedom of movement for Disabled People to live and work in other EU Member States. At a time that Disabled People in the UK are facing unprecedented levels of financial hardship and high rates of unemployment, we cannot afford to lose this hard won support.

Why SPECTRUM believes Disabled People are better off staying in the EU

The **EU debate**



Independent Living

The UK has been one of the pioneers in the development of the Independent Living movement across Europe. We have learned much from the many ideas and exchanges we have had with Disabled People in other countries and, together, have successfully influenced EU support for Disabled People having the right to control our own lives. However in the last five years we have seen some big threats to Independent Living in the UK with the closure of the ILF and the austerity measures affecting local authority budgets to support Independent Living. Our future for Independent Living would be stronger by remaining part of the EU and keeping the support of the European disability movement and the EU structures and policy.

Inclusion of Disabled People

The EU is also supporting Independent Living by the policy initiatives towards stopping European funding for renovating and building new institutions which segregate disabled people. Deinstitutionalisation is now a very positive development in encouraging the funding for more community-based services for Disabled People so they can live inclusively with others in local communities. This is an issue of vital importance for Disabled People as we have seen, for example with the terrible abuses inflicted upon People with Learning Disabilities in Winterbourne View and other care institutions.

European Social Funding

There has been much debate about how much the UK pays into the EU but little is said about the significant sums of money that the EU provides to support Disabled People and other disadvantaged groups in the UK. 87,000 British Disabled People were supported by the European Social Fund last year, helping them towards the world of work. For many years Disabled People have also been able to access EU funding to set up projects, organisations and conferences and a range of other support. In addition, the legal exemption from EU state aid rules to allow public authorities to directly contract, provides an important boost for Disabled People to set up and run their own social enterprises. As funding sources in the UK become ever tighter, this European funding will be a vital lifeline for Disabled People that we can ill afford to lose.

Why SPECTRUM believes Disabled People are better off staying in the EU

The **EU debate**



Equality and Human Rights Commission (EHRC)

The EHRC has been subject to a barrage of criticism's threatening its position, but it is protected by the requirements of being an "Independent body" laid down by the EU non-discrimination directives. Since the closure of the Disability Rights Commission the EHRC has been the main organisation supporting the protection of rights for Disabled People in the UK and this protection could well be weakened by leaving the EU.

European Accessibility Act

The forthcoming European Accessibility Act will mean there will be a duty to make sure that all services and products will be accessible regardless of impairment or age in the EU. This will include air, rail and sea passenger transport services, banking services, telephone services and audio visual media services. If the UK exited from the EU we would not benefit from this new act. We should also not forget that it was a European directive, which supported us getting accessible buses in the UK in the late 1980s onwards.



Why SPECTRUM believes Disabled People are better off staying in the EU

The **EU debate**



United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Although the UK government signed up to this UN Convention, which aims to protect our rights, it has been widely criticised for failing to properly implementing it. The EU has also signed the Convention and we would be better off having our rights protected with the support of the EU as well, due to the lack of commitment of the UK. It was the united voice of European Disabled People along with others from around the world which influenced the creation of the Convention and these are important rights that we need to protect.

Summing-up

In conclusion, these are just a few of our successes being in the EU. We want to continue to work together with our disabled colleagues throughout Europe with the support of the EU. We want to pull down barriers not erect them. We recognise discrimination does not stop at borders. We want to protect Europe's very significant achievements for disabled people, and prevent others from being taken away and provide a platform for the further improvements for our future.

In today's economy of austerity, where rationing and denial of services has become the norm, never discount the fact that the economic prosperity which comes from Britain's membership of the European Union is vital, if we are to find the public services which many Disabled People believe should be theirs of right.

Written for SPECTRUM by John Evans OBE

6 April 2016

What do you think? Get involved in the discussion:

FaceBook: www.facebook.com/Spectrum.CIL

SPECTRUM's Blog: www.SpectrumCIL.wordpress.com

Or on Twitter: [@SPECTRUMCIL](https://twitter.com/SPECTRUMCIL)

Can robots be caregivers?

By Ian Loynes

On the 9th Feb 2016, SPECTRUM was asked to be on the panel at a seminar organised by the [Winchester Science Centre](#) to consider the question: “Can robots be caregivers?”



**WINCHESTER
SCIENCE CENTRE
AND PLANETARIUM**



The panel consisted of:

- Eric Cooke from Southampton University
- Dr James Luke from IBM
- Ian Loynes from SPECTRUM CIL

The event was compared by Emily Thorpe-Smith from the Science Centre and attended by an estimated 50 people—including many school children. It is really important that children consider the complexities of ethics and other aspects of this question—simply because it will be their generation that has to make decisions on what we do, and do not do with respect to the suitability of robotics to health and social care uses.

The event started with each panellist making an opening address, stating their views on the question, followed by challenging questions from the compare and from the audience, designed to test the panellist’s viewpoints.

SPECTRUM’s FaceBook account and or YouTube channel (www.youtube.com/user/southamptoncil) Provides short videos of the event, but if you would like to read about



Can robots be caregivers?

Continued

SPECTRUM's general stance:

- We welcome any technology that enables user choice & control and Independent Living opportunities
- We are concerned that any move to robotic provision of care is likely to be driven by a cost saving agenda, rather than for quality of care or user preference
- As Disabled People, we are concerned that ethical and human rights aspects of this debate are not receiving enough consideration.
- Finally, the very care recipients (users) of this brave new world are likely to be largely excluded from the discussion

We'd like to focus on the following issues, from the perspective of Disabled People:

Pros:

- Robots don't go sick, don't need holiday cover and don't cause HR problems!
- Intimate personal care can be embarrassing and undignified – robots could improve this (by supporting toilet needs for example)
- Robots could reduce certain risks – safeguarding, abuse, theft and language barriers when compared to human support
- There are real opportunities to empower and enable the individual to support some of their impairment barriers (communication aids, memory aids, visual aids, exoskeletons)
- It will happen (and already has done more than we think – iPad, Labour saving aids, communication aids)

Cons:

- May well be Imposed on people – often the most vulnerable with least voice
- The care giver will often be the only human the user sees – social isolation is already reported as the most common 'unmet need' – robots could make this worse. This would not be good for people who are already socially isolated or people whose conditions actively benefit from interactions with other human beings; i.e. Alzheimer's.
- What is the motive?: Likely to be seen as a "cheaper option" by local authorities looking to save money. This is not the right reason to use

Can robots be caregivers?

Continued

Ethical considerations:

In SPECTRUM's experience (i.e. The telecare debate) ethical and human rights issues often receive scant attention.

For instance:

- Who is responsible if the robot or software goes wrong or breaks or causes damage/death? – these events will happen.
- Who is in control? The care recipient, the local authority or the manufacturer?
- The main challenge in creating robotic care givers is the problem of programming a machine with a reliable set of ethics.
- A robot will have to make complicated decisions regarding its users on a daily basis (particularly for nursing care). Since its function will involve giving advice that will determine the health/welfare of human beings, it will need to have an ethical system that will allow it to properly carry out functions while treating users with respect.
 - For example, if a robot is programmed to remind its users to take their medicine, it needs to know what to do if the user refuses. On one hand, refusing the medicine will harm the user. On the other hand, the user may be refusing for a number of legitimate reasons that the robot may not be aware of. For instance, if the user feels ill after taking the medicine, then insisting on administering the medicine may turn out to be harmful.
- These scenarios are everyday situations that humans navigate with ease. The human brain can assess a situation not only based on data that it directly receives through its senses, but it can also logically process other signs, such as the look of a person or the intonation of a response. If there is not enough data to make a decision, a human can figure out which questions to ask in order to receive more information.
- A key point for SPECTRUM is that many of the remote technologies in use or in development today rely on being able to track people's movement and behaviours; in practice, that can - and does - very easily lead to some serious breaches to people's rights to a private life as well as putting dignity and autonomy at serious risk. We are alarmed at how little attention providers seem to pay to these issues - in fact I'd go as far as to say in telecare they were mostly oblivious to these risks.

Can robots be caregivers?

Continued

- The Health Select Committee also raises concerns about this issue. They emphasised that while technology can facilitate things like robotics and telecare, this has to be balanced against people's right to privacy. They recommended that privacy and confidentiality policies and protocols should be developed, implemented and audited when new technologies are introduced.
 - They said that: “It is essential that a balance between the use of technology and the continuation of human contact is an important element in any such judgement. Furthermore, evaluation needs to take account of the qualitative benefits for users and carers over time”.
- We don't want to rain on robotic's parade – we really don't. Anything that can play a positive role should be welcomed.
- But, we do have to be realistic about what it can achieve and, more important still, we need to recognise that there are no quick fixes to the challenge of building a social care system capable of addressing the needs of an ageing population.
- Rather, we need a serious debate about the value we place on social care and the willingness – on the part of both government and the public - to invest in social care as a positive public policy resource.
- And we must do this in an environment where we know that the reality of social care at the moment is that, if anything, overall provision is in decline and local authorities are deserting families who require their support.

What do you think?

Watch videos of the event on our FaceBook Page, or on our YouTube Channel:

www.youtube.com/user/southamptoncil/videos

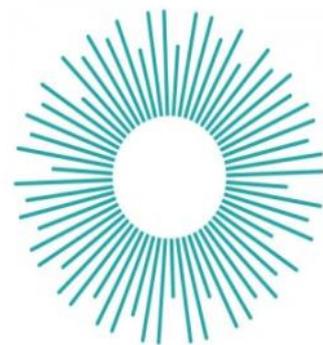
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Disability Rights UK, DRILL Project: Disability Research on Independent Living & Learning



The DRILL (Disability Research on Independent Living and Learning) is a new innovative 5 year UK wide programme, funded by the Big Lottery, which will deliver the world's first major research programme led by Disabled People.

The four nation programme is funded by the Big Lottery Fund and delivered by Disability Action in partnership with Disability Rights UK (DRUK), Disability Wales and Inclusion Scotland.

Our partnership brings together the major pan-disability organisations in each UK nation, working together with powerful groups of academics with diverse expertise to create a new and innovative research agenda in each nation and UK-wide. We will engage policy makers and senior practitioners from the outset and use dissemination and influencing strategies to build an appetite for the findings and ensure that findings inform positive policy and practice solutions, to fit future economic and social trends.

The research programme which will be delivered over five years will involve a number of significant research projects specifically engaging Disabled People looking at areas contributing to Independent Living and learning. The findings will lead to a number of pilot projects aimed at enhancing the lives of Disabled People.

DRILL aims to work in partnership with Disabled People, academics and policy makers to build a better evidence base about approaches that enable people to live independently, which will be used to inform future policy and service provision, as well as giving greater voice to Disabled People in the issues that impact them.

For more information on DRILL:

Contact: Sophie Walsh - DRILL Programme Officer

Telephone: 020 7250 8197

Email: sophie.walsh@disabilityrightsuk.org

Website: www.drilluk.org.uk



LOTTERY FUNDED

Pensions & Auto Enrolment

By Becky Clegg & Berni Vincent, SPECTRUM's Independent Living Team

The SPECTRUM Independent Living Team exists to support Disabled People in Southampton with managing their Direct Payments support needs. If you employ staff using Direct Payments or other means, pension automatic enrolment could apply to you. The following provides you with some basic information. It also makes suggestions about where to begin if you want to start the ball rolling.

The law on workplace pensions has changed. Under the Pensions Act 2008, every employer in the UK must put certain staff into a pension scheme and contribute towards it. This is called pensions 'automatic enrolment'.

The basics:

- When do you have to start paying pensions for your staff? The Pension Regulator will let you know your start date for auto enrolment. If you use a payroll company to pay your staff you can ask them to act as your nominated contact to deal with the Pension Regulator on your behalf.
- Anyone employing staff who are between 22 and state pension age and using Pay as You Earn (PAYE) will be affected.
- Auto enrolment does not affect you if you use an agency or if your staff are self employed.

What can you do now:

- Based on your staffs' earnings you can calculate what your minimum contributions will be.
- Once you know the gross earnings for individual staff, an online contributions calculator can be found at: <http://www.thepensionsregulator.gov.uk/en/employers/employer-contributions/>
- You can talk to eligible staff to inform them they are entitled to a pension and when this will begin.

If the prospect of navigating pensions auto-enrolment sounds daunting, SPECTRUM Independent Living team are here to help.

For more information on Pensions & Auto Enrolment:

Contract Becky or Berni on 023 8020 2931 or email: help@spectrumcil.co.uk

20 years of the Disability Discrimination Act

By Gerry Zarb

2015 marked the 20 year anniversary since the Disability Discrimination Act (DDA) became law in Britain. To mark the event we canvassed opinions about the DDA - good and bad - from SPECTRUM's members and staff. This article reflects our collective views and reflections on what the DDA has achieved for Disabled People - and, just as important, where we still have work to do to achieve full inclusion.

First the good news!

Several of our staff and members gave concrete examples of how life for Disabled People has improved over the past 20 years, and how the DDA has helped them to challenge discrimination and exclusion in a way that simply wasn't really possible before we had any anti-discrimination laws for Disabled People:

"Back then, travel on trains was almost unthinkable – I'd be in the guard's van with bikes and animals – if I was lucky! (Of course for such luxury travel I'd have still had to pay a full fare). Now, in 2015, travel on the train to London is FANTASTIC, I have a reserved space as a wheelchair user, I have almost perfect accessible support and ramp provision and I can usually get a discount if I need to take a Personal Assistant with me."

"I was 15 when the DDA came into force, so I'm only aware of the outcome now. I'd say the DDA forced the mainstream college I attended to provide accessible learning areas, this allowed me to thrive and go onto higher education. The DDA also helped me feel more socially inclusive with better access to the wider community."

"On a trip through Reading Station in early 2005 I call in for a coffee and was turned away because of my Guide Dog. I did take this issue up with the company and received a payment of £1,000 and their commitment to DDA training for their staff, which we provided."

"... when I left college in 1982, in the first job I got – my boss said I'd have to go self-employed because he didn't want to be 'lumbered' with paying me if I was off sick. He was quite open about it! Never mind that in 30 odd years of employment I have in fact had a minute amount of sick leave – In 1982 I could only get a job if I took all the risks and of course as a result, I had no employment rights at all! This practice in 1982 would be unthinkable today."

20 years of the Disability Discrimination Act

Continued

For me, as a person with a Mental Health condition the DDA also meant that, for the first time, it felt like the numerous forms of mostly invisible discrimination I experienced were acknowledged and recognised. That was very empowering. Sure, that's a long way from stopping the discrimination happening in the first place - a battle that still goes on today - but it did mean we at least had some sort of tools to start to challenge it.

And, like many people it's a tool that I have used several times since 1995 - sometimes successfully and sometimes less so. It's a big shame however that many Disabled People do not exercise their rights, either because they don't have the support to do so, or even because they don't even know that they have them:

“There have been some good things coming out of the DDA, it's just a shame not enough people make use of their rights.”

"I have no knowledge of what is in the DDA."

We are in this together

Probably one of the biggest reasons for celebrating the DDA is that it represents what the collective strength of what Disabled People can achieve in bringing about real social and political change. While we might now take some of the rights it gave us for granted, it's important to remember how the DDA came about - and how things were before we had any anti-discrimination laws at all. As Berni Vincent explains:

"The DDA did not just happen - it came about as a result of years of lobbying and sheer hard work by Disabled People and their allies. During this time there was a real sense of collective identity. We were supporting each other, sharing our stories of struggling to exist in a world that presented many barriers. At this time Disabled People were not involved in society, we were set apart in segregated services, schools and day centres. We did not have meaningful employment or the support to participate. The lead up to DDA put rights for Disabled People on the agenda, we were voicing our anger, finally we were being listened to and there was a real sense that together we might just be able to change things for the better."

20 years of the Disability Discrimination Act

Continued

SPECTRUM's Chief Executive, Ian Loynes, has a similar tale to tell:

"For me, still green behind the Disability Rights ears in 1995 – it defined who I am today. I've gone from a passive, 'grateful for what I was given' Disabled Person prior to 1995, to a full blooded Disability Rights evangelist from 1995 onwards. I remember the power I felt when I went on my first Direct Action Network (DAN) 'Action' in London. I was one of dozens of Disabled People in a pen, surrounded by police who obviously had no real idea what to do with us – after all not even the police arrest vans were accessible in those days!! I also remember it was the first time I felt truly PROUD to be a Disabled Person. For me, the DDA was a defining moment for Disabled People."

And, as Robert Droy says, this collective action by Disabled People also meant that the rest of the world had to sit up and take notice:

"The DDA was a crucial part of getting the wider society in the UK to consider the needs of Disabled People from an equality and human rights perspective rather than from a charitable perspective. The private sector particularly had to address their policies around employment and reasonable adjustments and in the retail sector, there have been some effort to ensure premises are more accessible to people with physical impairments. The transport sector were given much longer time to implement some aspects within the DDA, up to 25 years in some cases. However it did provide an impetus to transport providers to start considering vehicle design and how they delivered customer service to Disabled People."

And now the not so good news!

Several staff and members commented on the concept of 'Reasonable Adjustments' that employers and service providers now have to make to deal with any unfair barriers we face in employment or accessing services. The concept was in many ways ground-breaking and there was nothing like it in any of the other equality and anti-discrimination laws (like the Race Discrimination Act) that existed before the DDA. All the same, it has always been something of a moveable feast - which can be frustrating at times:

20 years of the Disability Discrimination Act

Continued

"There's no teeth in it. 'Reasonable Adjustments' is a get out clause. Lots of public buildings including Law Court rooms are still not accessible - you still have to check if places are accessible when it should be a given."

"At some stage in the DDA journey I joined other Disabled People at a meeting with William Hague in the Houses of Parliament. I found the tea and biscuits provided interesting and wondered if he thought this was what he needed to do to pacify us. But he seemed genuinely interested in hearing what we had to say. I remember questioning William Hague on the term 'reasonable' – "what does it mean in the context of the DDA because what may be reasonable to the government may not be reasonable to Disabled People". His response was that the term reasonable was standard language used in law".

In other words, it's all 'in the small print' - and we all know that small print usually spells bad news for Disabled People!

Other people pointed out that, even with the DDA, we still don't always have even basic access - especially when it comes to buildings and the environment - and some employers and businesses are still dragging their feet when it comes to making the workplace and services fully accessible:

"It is still hard for people to be accepted with access into some buildings. Also we do still get discriminated against."

"Changes are slow, but some are happening."

"We need to have more than the minimum."

"Lip service is not enough."

"Overall, it's good but more support is needed for small and medium sized companies to meet their obligations. I always hoped the Federation of Small Businesses would be more supportive to their members in meeting their obligations."

20 years of the Disability Discrimination Act

Continued

Any laws are only as good as the enforcement available to people who want or need to use them. Some parts of the DDA have always been quite hard to enforce consistently, or without costly legal support, but the recent cuts in public finances have certainly made it much harder than it used to be (especially changes to Legal Aid and the cuts to funding for advocacy and advice organisations).

As our resident Marxist put it in one of his more sombre and reflective moments:

"... in my opinion we are moving away from inclusiveness in our society despite the legislation as any legislation is only as good as its ability to access it. The current financial restraints and barriers that have been created to minimise cost and maximise resources have created division and marginalised groups that are already excluded disadvantaged. The hidden cost of the Governments Policy, in my personal opinion."

A related theme in the views expressed by our members and staff is that, whatever the merits of the DDA, this offers little protection against the severe restrictions to Disabled People's basic rights and freedoms that have come in the wake of austerity and welfare reform.

"I feel that the DDA is something that should be celebrated; however, in light of the cuts currently affecting Disabled People, a valid question is "Does it go far enough?" DDA is a good starting point; however, it does not seem to protect people from the cuts. It seems to me that we need something that goes further to protect people's ability to live normal lives."

And, there is plenty of evidence to back up this view as Disabled People's status is lower than ever. For example, the Equality and Human Rights Commission's review of the state of equality in 2015 shows that, on every single measure of equality Disabled People feature in the negative side of the account but fail to feature in any of the areas of progress.

- Unemployment rates for Disabled People increased since 2010.
- Poverty for Disabled People increased at a faster rate than non-disabled people.
- The education gap between Disabled People and non disabled people widened.
- Health inequalities have increased.
- Harassment, hostility and bullying has also increased.

There is more - but this is depressing enough!! It really does feel like we are going backwards at the moment.

20 years of the Disability Discrimination Act

Continued

So, was it all worth it then?

A lot has been said about the DDA at 20. William Hague MP, who was the Government Minister who pushed the legislation through Parliament said in a recent interview that it was the achievement he is most proud of in his political career.

From the perspective of Disabled People themselves, Baroness Jane Campbell - who was very much involved in the 'Rights Now' campaign at the time the DDA was drafted - is similarly positive:

"We became full citizens. What can be better than that. The DDA has given Disabled People confidence, self-belief and a greater sense of equality."

All of that is true, but is it enough?

At the time the DDA came into being the Disability Movement was absolutely clear that it was not a substitute for the full civil rights we had been campaigning for. As Ian Loynes has said, "... it was not really comprehensive anti-discrimination legislation (commentators at the time said it had more holes than a colander!)"

For SPECTRUM at least, that remains our position - and it is unequivocal. The lack of protection against the impact of cuts in services and welfare in recent years only serves to underline how badly we need meaningful civil rights legislation - probably now more than ever.

It's understandable - and right - that Jane Campbell and others want to 'accentuate the positive' and celebrate what was achieved. We are better off with the DDA than without any rights at all - but that doesn't alter the fact that we still a long way off achieving full inclusion. A more realistic tone was perhaps set by Chris Holmes, the Disability Commissioner at the Equality and Human Rights Commission, who says that, while there has been progress over the last 20 years:

"In the next 20 years what we need to see is everybody moving to that next level of understanding what it means to have a truly inclusive society."

20 years of the Disability Discrimination Act

Continued

The journey continues

For any equality legislation to be effective you need to have three things. First, the legislation itself needs to be comprehensive and clearly drafted, with unequivocal rights and obligations. Second, you need to have effective enforcement. Third, people need to know their rights and have the confidence and capacity to exercise them. Weaknesses in any of these three areas can critically damage the effectiveness of any legislation, however well intentioned, and the DDA has certainly not been water tight by any stretch of the imagination.

So, the search for the keys to unlock a fully inclusive society for Disabled People goes on and we need to look to the future. As Robert Droy says:

"The DDA can't be judged in isolation. Whatever its limitations, it is part of a journey that all minority groups have to go on to hopefully eventually achieve full equality and human rights. Legislation doesn't change people's attitudes overnight, however over time as people consider the issues and change their working practices, then slowly their attitudes do change. It is a drip drip effect and although it feels painfully slow to those of us most directly affected by it, Disabled People in the future will look back on the DDA and see it as an important stepping stone on the journey to equality."

Beyond all the many individual victories that the DDA has made possible, probably the most important of all is that securing these rights brought Disabled People closer together and made our movement even stronger. As the following description, from Berni Vincent, of what it was like on the front line 20 years ago shows, this was genuinely empowering and is something worth celebrating:

"My small contribution to campaign work started when volunteering for an emerging User Led Organisation in Sutton, London. The organisation had an office not much bigger than a broom cupboard, situated in a side room in a local day centre for Older People. The office was stacked high with piles of paper, two desks, a word processor and phone. There was no email or internet and very little money as usual. What the organisation did have was passionate people and a management committee made up of Disabled People who wanted things to change.

20 years of the Disability Discrimination Act

Continued

On one occasion I was helping to plan a demo in central London, when we got a call from a local residential home who were ringing to say "they had heard about the rally and would like to come along", I can't remember much about the rally, but do remember taking that call and thinking how amazing it was that they wanted to join us. I think that was a defining moment for me, I realised what we could achieve together."

And a final word from Ian Loynes:

"... for all its shortcomings, it recognised for the first time in the UK that Disabled People WERE discriminated against. Disabled People became visible and could seek redress for at least some of the instances of discrimination we experienced. But despite all of these barriers I still experience after 20 years of the introduction of the DDA, the simple fact is that I believe that the DDA has directly, or indirectly, resulted in the world I live in being far more equitable, far more accessible and far more welcoming than it was prior to 1995."

Together we have come so far but we still have a long way to go. The journey towards full inclusion is far from over.

A Case Study: Our Chief Executive takes action...

My local fish and chip shop is not accessible! They have a 8cm high step, which I cannot climb in my wheelchair. For years I have put up with being served out on the pavement. Asking the server to ask their manager to put in a ramp (as I have many times) has not achieved anything.

Recently however, another customer said to me "this is illegal isn't it?".

Well - yes it is, a small ramp is all I need, and would be a 'reasonable adjustment' as it would be cheap to provide.

So finally I have acted, I have written to the owner, and formally requested a reasonable adjustment. If I do not receive a satisfactory outcome I will take further action.

20 years on from the DDA, there are still far too many 'small steps' in the world! This is 'one small step' for me!



Independent Living Team

By Teresa Burnage



Direct Payments support service in Southampton

Every time a newsletter is published, you, the lucky reader will be reading about our latest exploits and what we have been up to.

The Independent Living Team of staff and volunteers work on the Direct Payments Support Service in Southampton.

The Independent Living Team exists to support Disabled People to live the lifestyle of their choice, and realise the same opportunities and control that non-Disabled People take for granted. We work closely with our partner organisations.

Our team offers volunteering opportunities for Disabled People and Carers in Southampton. Volunteers in the team work towards identified personal development goals and support people with managing their Direct Payments and with accessing community facilities.

We currently have ten volunteers, eight of whom come in regularly. Volunteers are able to access training and task based mentoring.

The tasks our volunteers are currently working on include:

- Designing and working on spreadsheets, to assist Disabled People with their Direct Payments budgeting / record keeping.
- Designing and writing job adverts, along with recruitment support.
- Volunteers also contribute to newsletters and factsheets. (Please see article pensions & auto enrolment on page 13)
- Researching and attending community activities to promote SPECTRUM and Direct Payments.
- Volunteers also work on our reception and many of the volunteers work with the Student Advocacy and Mentoring team on the skills labs at Solent and Portsmouth Universities.
- Website design.

Independent Living Team: Continued

- Last month the first 'Time for Tea' event was held, in conjunction with one of our partner organisations, Solent Mind. 'Time for Tea' is a peer support group for people with mental health impairments. It is a time to meet people, as well as receiving support with living with a mental health impairment. You can share ideas and meet new friends. Basic benefits and housing advice is available, provided by the Solent Mind team as well as tea and coffee. 'Time for Tea' is held every third Thursday of the month.
- Berni has been working together with Carers in Southampton on a joint project to deliver Direct Payments training to mental health teams.
- With assistance from Samia Stubbs (one of our Community Navigators) Teresa will be attending GP cluster group consultation meetings to promote Direct Payments to frontline services. We are also looking at how the Community Navigators can link with the volunteers in the Independent Living Team.
- In the past month Michael and Teresa have carried out around 25 hours of face to face meetings with Disabled People and Personal Assistants.
- Employer job postings and Personal Assistant registrations are on the up on the PA Noticeboard. Kerry one of our volunteers is supporting Michael with administration and recruitment support following training.
- A one day Introduction to Direct Payments training session was attended by a variety of professionals across the city and was facilitated by the Independent Living Team.
- We are running Direct Payments questions 'drop ins', from 11:30 until 13:30 on the first Monday of every month. Disabled People do not need an appointment, just come and discuss any Direct Payments query you have. Tea and biscuits are provided.

For more information, contact us:

Helpline: 023 8020 2931

Email: Help@spectrumcil.co.uk

Website: directpaymentssouthampton.co.uk

Journey to Employment

By Ross Smith

Ross has just got back from the big smoke where he attended The Work Foundation Event, on the benefits of peer support, the Minister for Disabled People Justin Tomlinson MP was in attendance. Ross had the honour of being one of four key note speakers.

We are now approaching the end of the pilot scheme having seen in the region of sixty people and we are happy to report that customers are telling us they feel their confidence has been increased by 70% since the start of the programme. The peer support provided by Journey to Employment (J2E) also has wider benefits in terms of improving health and well-being, increased activity levels and social interaction, and reduced dependency on services.

Department of Work and Pensions have calculated that achieving 4 per cent job outcomes - which was the target they set for J2E - would equate to spend per job entry of £10,375. This is cheaper than both the Work Choice Work Programmes. In fact we have achieved more than double that number of job outcomes so the cost per job entry is more like £4,500 - which is extremely cost effective.

Over time, there has been a significant change in knowledge and understanding of the Job Centre Plus staff we work with and they have now a much greater knowledge of J2E and what it can offer in terms of a more tailored and person centred approach. As a result staff are more enthusiastic to see a better result and outcome for each and every customer. Although, the introduction of Universal Credit has added a new level of complexity, whereby Job Coaches are being asked to learn and advise customers on a much wider range of benefits, the result of this has yet to be seen.

DWP are also pleased with how the pilots have been going and the Minister has recently announced that they are going to put funding into a second phase of J2E. SPECTRUM intend to bid for that work so that we can, hopefully, continue with providing this valuable support to local job seekers.

Postscript: Unfortunately SPECTRUM were unsuccessful in their bid to continue on Phase 2 with the DWP but hope to use what we have learnt creating this pilot, to reproduce a similar model and pursue other avenues of funding.



User-Led Organisation Team

By Jennie Musson



The Hampshire User-Led Organisation (ULO) team have been busy during the last few months producing their own blockbuster training package comprising of a written resource on how ULO can get access to funding in these cash-strapped times and a video on how to start up a User-Led Organisation, starring no less than three User-Led groups, Greenbuttercup, Disabled People's Voice Hampshire (DPVH) and Capable Creatures. SPECTRUM's Chief Executive, Ian, Berni Vincent from the Independent Living Team, Gerry Zarb and Jennie Musson also got in on the act either as presenters or in supporting roles (see how easily I slip into the film lingo!) The film itself looks very impressive, once you get over the shock of seeing yourself on film and is due to be released along with the written resource on funding shortly.

We have also been concentrating on our Hampshire ULO Network Group (HULON) and working out how this will go forward after the life of the ULO project. The aim of HULON is to give ULO a chance to work collaboratively with statutory bodies, giving them a stronger and more representative voice across Hampshire and ultimately building a more sustainable ULO network by doing this. The group want to use the ULO mentor programme to help them gain some funding to enable the group to become sustainable for the future and also to help them write their own constitution. Areas which HULON is interested in are access issues and how to influence decision-makers in statutory bodies. A Facebook page has also been set up by two HULON members. It can be found under Hampshire ULO Network Forum.

We are also continuing with our work with Hampshire County Council's User Engagement Project Board and are currently working on recommendations for measuring the effectiveness of the Council's user engagement and user involvement activity.

In addition to all this, the ULO mentoring service is taking off too. We have three experienced ULO mentors who support smaller and new ULOs with their development. They are currently mentoring two smaller organisations in HULON and are assisting them with their structural development for the whole network to become sustainable. This free mentoring support is vital for the sustainability of ULOs in these difficult times, and HULON would like to continue this service beyond the life of the project. HULON also aims to continue to be a peer support network, share information and ideas and organise events for wider community awareness.

Consult & Challenge - Being a critical friend

By Will Rosie

Running a Focus Group

Being a critical friend can be quite daunting at times, and Consult & Challenge's (C&C) experience of this is no different. Last year, people may remember the controversial decision made by the Southampton Clinical Commissioning Group (CCG), to close the Bitterne Walk-In Service.

Well, as part of the overall consultation, the CCG asked C&C if we would be prepared to run an independent focus group. The idea of the focus group was to engage with a small group of local people and look at all the facts and statistics around the Walk-In Service and discuss whether keeping it open was value for money.

This was something that we could have declined, as we knew that it was a political hot potato, and a valued resource for the east side of the city. Any involvement could easily be seen as C&C simply siding with the 'Powers that Be'! However, we felt it was

exactly the kind of thing that we should be doing, and it was a great opportunity to show that we were happy to get our hands dirty, and still remain impartial.

Running the focus group was not simply a matter of just inviting people to come along and air their views in the room. We needed to be more organised than that. We needed to be, well, err...focussed. In order to run the group well, we needed to be well prepared. So several C&C members and myself met with staff from the CCG to talk to them about the proposal, and look at all the facts and figures around the Walk-In Service. Once we felt like we had a good grasp on the situation, we eagerly looked forward to the day.

The focus group was run at SPECTRUM and we had advertised in the Bitterne Library and Health Centre (the building where the Walk-In Service ran from). We also used our extensive networks and the CCG's website to contact local people.



Consult & Challenge - Being a critical friend

Continued

On the day, we had a good selection of people in attendance, and were able to engage in a lively, frank and honest discussion.

The group was split into two parts. The first part was just for residents to be shown a PowerPoint presentation, by us, which highlighted the use/misuse of the Walk-In Service and the kind of money that was being spent on it. It also explained where the money would be redirected in the event of its closure.

The second half of the meeting was attended by staff from the CCG, including the Chief Executive Officer and Vice-Chair. During this section, questions raised in the first half were posed to the CCG representatives, allowing residents to get answers to their queries.

Feedback, from both the residents and the CCG was, in the main, very positive, and our findings were included in the CCG's final report.

One very positive outcome from the focus group, was that the CCG were able to arrange for interested attendees to visit the NHS 111 centre. This was a service that had been discussed at length, and group participants wanted to find out more about it. Some of our members went on the 111 visit, and in turn were able to write a report for the Care Quality Commission about their observations.

The biggest challenge, we found, in running this focus group, was in remaining impartial. It is very easy when facilitating this kind of group, to either fall towards siding with the CCG, by taking things they have said as the absolute truth, or simply siding with the potentially emotional voice of the public. C&C really enjoyed this task, and are confident about running more focus groups in the future.

Postscript

The Bitterne Walk In Centre closed on 31st October 2015.

Community Navigation

By Samia Stubbs



What is a Community Navigator?

A Community Navigator supports people in Southampton to access local activities or services. Focusing on improving your health and wellbeing.

How can you help me?

We can connect you to local community groups, organisations and services in your area to maximize your choices and your control. We aim to get you actively involved in your community and we can support you along the way.

SPECTRUM CIL is working in partnership with Southampton City Council, Southampton City Clinical Commissioning Group, local organisations and community groups to improve health and wellbeing in Southampton. We aim to:

- Empower people to take control/action of their health & wellbeing
- Challenge services to become more person centered
- Build & maximize community opportunities
- Help those that need us most

This Pilot initially supports residents in Shirley/Freemantle and Woolston/ Weston areas of Southampton

Why do I need a Community Navigator?

- Community Navigators respond to local residents' needs and address issues including isolation and loneliness.
- Raise awareness of community groups and increase capacity of communities to support local residents
- Listen to and work closely with people to solve problems and enjoy a better quality of life.

'Empowering you to take control of your health and wellbeing'

Community Navigation

Continued

We can help you to access local activities & services including:

- Leisure
 - Employment
 - Education
 - Welfare rights
 - Housing
 - Friendship schemes
 - Timebanking schemes
- ...And more!

A Case Study of Community Navigation:

A GP referred a Polish man with minimal English language ability who had multiple issues such as housing and welfare benefits which were causing anxiety and exacerbating health issues.

The Community Navigator Service established contact and after discussing the individual's needs, and assessing those against the range of available services in the area, we signposted the service user to a community service called: 'EU Welcome' who has since been working with the individual to resolve their needs and issues.

We accept referrals from Health & Social Care professionals, from voluntary & not-for-profit organisations. **We also accept self-referrals.**

Our preferred method to receive referrals is by email, but we also will accept referrals via phone.

For more information, or to make a referral, please contact:

Samia Stubbs: Acting Community Navigator Team Leader

Email: Samia.Stubbs@SpectrumCIL.co.uk

Telephone: 023 8020 2930

ENIL Freedom Drive 2015 - Brussels

By John Evans OBE, ENIL Advisory Board Member



ENIL (European Network for Independent Living) held their biannual Freedom Drive in Brussels from the 29th September to the 1st October 2015. This was the seventh time that ENIL has held the Freedom Drive, but it was the first time it took place in Brussels. This year's theme was "Independent Living: The Next Generation," with its focus on younger Disabled People. Since the first Freedom Drive in 2003, they have all previously been in Strasbourg, the second home of the European Parliament and Commission along with the locations of the Council of Europe and the European Court for Human Rights. The move to Brussels was to test the impact the Freedom Drive would have on both the European Parliament and the Commission.

The purpose of the Freedom Drives has always been to try and continually maintain the importance of Independent Living and Personal Assistance issues at a high level on the EU agenda. The Freedom Drives have consistently had a reputation of being uplifting and exciting occasions generating passion and bringing together activists and their supporters of the Independent Living Movement from all corners of Europe. It is also a time to celebrate our achievements in Independent Living.

The first ENIL Freedom Drive in Brussels did not lack the energy, zeal and activism of previous occasions. Despite the high cost of accommodation in Brussels and difficulties in access, there was still a tremendous turnout of over 300 Disabled People, their Personal Assistants, friends and supporters on the Freedom Drive March to the Parliament on Wednesday, the 30th September. This rally has always been the highlight of the Freedom Drive, and so it was this year. It is a very colourful and vocal occasion when Disabled People from over 20 European countries come together and chant their slogans, "Independent Living, not Institutions", "Institution – no Solution", "Rights not Charity" and many more.

ENIL Freedom Drive 2015 - Brussels

Continued

Reflections of the Different Countries

This time as the Freedom Drive was held in Brussels it did bring together a strong participation of Belgian Disabled People more than previous years. In past Freedom Drives the Irish, along with the Norwegians, Swedes and Germans tended to have the largest representation as they always seem to find more funding to support people to attend. Sadly this year saw the numbers of Irish and Germans dropped considerably. I think this was partly due to the impact the austerity measures were having in different countries.

It was sad not seeing so many lively and energetic Irish Disabled People present as they have often been the life and soul of previous Freedom Drives! Another interesting observation this year was the significant number of Greek Disabled People and their supporters who managed to make it to Brussels. This was even more remarkable due to the difficulties the Greek economy has been going through over the last years and due to the fact that the Greek Independent Living movement is only in the very beginning of its development. It was embarrassing seeing their delegation being more visible and supported than even our own UK minimal representation which unfortunately has been the case in other years. Other countries present were Austria, Italy, Spain, Poland, Slovenia, France and Finland to mention a few.

Meetings with MEP's

The Freedom Drive kicked off the day prior to the Freedom Drive March. This first day was occupied by Independent Living Activists having meetings with their national MEPs. Each country organised a room in the Parliament to meet up with as many MEPs as they could. The aim of those meetings is to promote Independent Living and try and get the main issues across to the MEPs, especially as many of the MEPs are quite ignorant about the Independent Living issues.

However, there are quite a few MEPs who are active in the Disability Intergroup of the EP. We in the UK probably have one of the longest serving MEPs in the Parliament Richard Howitt who has supported disability issues strongly for over 20 years. He is always very keen to contribute and participate in the Freedom Drive.

Other countries also have some MEP allies who are ready to support the Independent Living cause. We managed to meet seven UK MEPs and their Assistants and most of the responses were positive. Unfortunately the meeting date coincided with annual National Labour Party conference otherwise we would have had more!

ENIL Freedom Drive 2015 - Brussels Continued

Session in the European Parliament, organised by the Disability Intergroup

This year the main meeting in the European Parliament building was organised and sponsored by a Polish Disabled MEP. This made a

welcoming change. A deaf Belgian MEP was also on the plenary panel. There must have been about 200 Freedom Drivers and their supporters attending the meeting. We usually cause havoc in the Parliament building with all their security regulations! However this year entrance into the Parliament building ran quite smoothly compared to other years. The plenary room was jam-packed and even more colourful and interesting with so many different wheelchair users and people with other impairments. There was a lively discussion following the presentations which activated the atmosphere. The session ended with a Polish Disability Film Festival and a Polish buffet which offered good additional opportunities to network.



Conference

Each Freedom Drive dedicates one day for a conference debating the main issues facing the Independent Living Movement. It wasn't surprising that this year, one of the main issues was the impact the austerity measures have been having on Independent Living throughout Europe. The ENIL Youth Network was the other main focus on trying to strengthen and develop the network for the future. Other workshop sessions looked at strategies for challenging the cuts, advocating for legislation for Independent Living and Personal Assistance.

Party Time

It has always been a tradition to have at least one night devoted to a party where all the Freedom Drivers can let their hair down and enjoy a celebratory atmosphere. These occasions are often a highlight of the Freedom Drive as there is usually some entertainment arranged for the occasion. It is also a perfect time to network and to meet old and new colleagues and Independent Living activists from other countries.

ENIL Freedom Drive 2015 - Brussels Continued

Conclusions

Personally, I felt the Freedom Drive 2015 was a great success. The turnout on the streets of Brussels for the rally to the European Parliament was very impressive. The march generated a lot of media interest and there was a



main news item on Euronews that day and evening along with other coverage from film crews from different countries. This was an advantage of being in Brussels. Previously Strasbourg had also generated a lot of media publicity but this was by far the best yet. The meetings with the MEPs were also successful and many pledged their support for the Independent Living cause and further actions and some agreed to ask Parliamentary questions. Last but not least meeting other Disabled People from other countries was very inspiring and the exchange of ideas and learning from each other is, and has always been a very valuable part of the development of the European Independent Living Movement. It is to be hoped activists then leave the Freedom Drive re-energised to return to their countries to fight for more Independent Living developments and possibilities.

Future Freedom Drives

The next Freedom Drive will be in 2017. You can keep posted about this on the ENIL website and Facebook pages. I encourage you to go and experience the energy and enthusiasm to get inspired and to return to your country galvanised to keep your activism going until we do get the right to Independent Living. The main issue for all of us, from whatever country we come from, is to find funding and sponsorship in order to be able to attend the Freedom Drive. Good luck! - it will certainly be worth it.



Think you know
Disabled People...
Think Again

April 2016: Feedback received concerning our Student Social Worker Placement programme

I want to pass on my thoughts on the placements in which I have been covering for *[named person]*.

The above placements in my professional view were Outstanding in their commitment to social work students learning and development ,and this was reflected in the midway reports. Each placement had Values and Ethics at the forefront and time was given for reflection, challenge and change, and most importantly the service users right to self determination.

It has been a refreshing experience to see Social Work at it's best.

I hope these placements are used *[by these students]* to the full.



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