

Interview with Dr Simon Duffy

Sheffield, December 2009



Free to Live volunteer Rob (right) shows Simon the new Free to Live website

Simon, what made you want to enter the world of social care and welfare reform?

A mixture of accidents and epiphany, I think. I was a very keen philosopher at university, I loved philosophy and I was tempted to be an academic. But I had the sense that, if you're in your early 20s and you spend the rest of your life in academia then what do you really learn about the world? And it was then that I came across the NHS management training scheme.

During the training scheme in 1988 I visited an institution where people with learning difficulties were incarcerated, and I suppose I had this dual epiphany – firstly, a strong sense of injustice in terms of what we were doing to these people, and secondly, a real sense of wonder at meeting all these great people whom I'd never met before. I realised that I had managed to get to 23 without meeting anyone with a significant disability, let alone anyone with a severe cognitive disability – this didn't seem right. I suppose that experience, and my reaction to it, has given a lot of meaning to my life ever since.

You have a doctorate in philosophy – do you think that helps you take a broader view of the role social care plays in human society?

I'm always interested in how, as a society, we can support each other with more dignity. How can we work together in a way that gives people full and equal rights? Those are philosophical concerns driven by a picture of social justice – and that's

certainly been very much influenced by my reading and thinking about moral and political philosophy.

Your thesis drew on Kant. At its heart, would you say your work to help empower people to have more control and liberty in their lives is influenced by Kant's theory of moral obligation*?

** Kant believed that we should act according to our sense of moral duty; that we should choose our actions based on whether or not we believe they should be a universal moral law.*

I'm not interested in perspectives that say 'everything's OK'. No, some things are wrong.

Well, I'm not exactly a Kantian, but I'm definitely what would be called in philosophy a deontologist, that is, I believe there's a difference between right and wrong. I'm not very interested in perspectives that just say, 'Oh well, everything's OK, it's just different points of view'.

No. Some things are wrong. It doesn't mean we automatically know what exactly is right. But we can identify what is wrong, and we can identify what is better, and we can work towards that.

So yes, without a doubt, Kant helped frame my particular moral theory but I think, to be honest, it's also the fact that I'm a Christian. I believe in God, and I think there are strong arguments for moral truth. These beliefs have certainly helped me a lot through the challenges of the last few years.

How does the term 'banality of evil'*, coined by political theorist Hannah Arendt, (which you have also written about) relate to the traditional 'professional gift' model of social care?

** The phrase 'banality of evil' is used by Arendt to describe the thesis that the great evils in history were executed by ordinary people who accepted the premises of their state and therefore participated with the view that their actions were normal.*

Hannah Arendt is probably the philosopher that has inspired me the most. She was very interesting; she was a German; a Jew; she fled Europe just before the Holocaust; she lost friends and family to the Holocaust. And she reflected very deeply on the Holocaust in a book called the Origins of Totalitarianism. And that book, which I read as an undergraduate, really helped me think about a lot of things very differently.

If you're studying political theory at university – I'm not sure how it is now, but certainly in the 1980s – thinking was still broadly dominated by a kind of simplistic left-right conflict. And I think one of the things Hannah Arendt had to say was: there are other evils in the world besides capitalist exploitation...

Often there are systems of power and control in organisations that people become used to and find acceptable even when they know they're not really working. I don't think we should bandy the word 'evil' around in this context, but I do think the sense in which unhelpful things become normal, accepted as part of the system – I think that's the kind of banality that she meant – not thinking things through.

Good thinking isn't just about logic, it's more about creatively challenging and looking at things from different perspectives. I'm very interested in the way patterns of thought and practice can be set up that are not helpful, and how they take on their own momentum.

You are one of the chief originators of the model of self-directed support in the UK. Can you summarise for us what you think the main benefits are, compared to the traditional model of social care delivery?

Self-directed support is a different system for organising support for people who need extra help in life; who are in danger of being unduly dependent on the love and concern of others or the 'gifts' of the state. It's a complex system with many parts.

On the one hand it's about trying to clarify entitlement. For me that's what a personal budget is: helping people know what they're entitled to and giving them control over that.

If people know what they're entitled to up front, then actually they can be a lot more creative. If you don't know what you're entitled to, then in a sense you've always got to ask for things in the language of the system that's already providing them. So, you know, if the system pays for residential care then you can ask for residential care, but ask for something that's 'off menu' and you won't get it.

If people know what they're entitled to up front, they can be a lot more creative with their social care package.

The other part of self-directed support is a change in relationship between the citizen and the state. The new relationship we developed is a kind of outcomes-based contract. So a person's entitlement to support is still framed by a contract with the state, where the state's saying, 'We're giving you these resources, in order that you can achieve these outcomes, but also we're going to check that you're OK and check that you've got the right kind of support to use that entitlement.'

The model is pragmatic in the sense that it takes the current legal framework as a given, and then tries to develop something innovative within those constraints.

The other important principle of self-directed support is that we should continue to be very open-minded about the kinds of support that are available to people. We should actually treat the underpinning support structure itself as an object for constant innovation. As a society, we should look for better and more efficient and more appropriate and more empowering ways of doing things, and learn from that process.

How does having a personal budget give people more control and flexibility?

You can't get away from the fact that all human services involve money at some stage. And I'm strongly opposed to the view that there's something good about wrapping services up in a huge organisational blanket and then kind of 'parcelling out' bits of it to people in a way they can't control.

The most important and powerful way of controlling services in your own life, surely, is to have the money that underpins them. I can't see any alternative to that.

I think some people are very worried by this idea because they see it as being overly individualistic; that's quite a common criticism. But the people making these criticisms usually take for granted their individual control over their life – what things they get involved in and what things they don't get involved in. That seems a naïve perspective to me.

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In order to be involved as a citizen you need enough independent control to determine how and when and with whom you're going to do that. That's what self-directed support, personal budgets, direct payments are all about trying to achieve. To recognise that people need a significant degree of independence in order to function effectively as citizens of the community.

Since *Valuing People* in 2001, what do you see as the biggest steps forward for people with learning difficulties – and the biggest challenges yet to be realised?

Valuing People was really important in getting the language of central government to change around people with learning difficulties. Before that point, the language was not the language of citizenship; it wasn't the language of ordinary life. The policy statements that were made were very paternalistic and service-oriented. So I think *Valuing People* philosophically marked a big step forward.

Self-directed support was not part of *Valuing People*. What happened was that *Valuing People* promoted person-centred planning but found that person-centred planning didn't work when it was done on its own. There was no point, at least for people in services, to *just* help people plan differently, and then say, 'Oh, actually we can't do anything about that because all the money's already spent on the home or on the day centre.'

So from my perspective, and this is a very personal perspective, the great achievement of *Valuing People* was mainly in raising impossible expectations that then led to a sense of crisis, that *then* led to people saying 'Well, I wonder what would happen if we actually did change how we organise the money?' And that's what led to self-directed support and the setting up of In Control.

In creating a positive picture of what's possible through SDS, isn't there an implication that people in social care haven't been trying hard enough in the past?

No. A lot of people get upset and feel personally attacked by the different vision self-directed support creates. I remember talking to a senior figure in Social Care, and he was saying to me, 'Simon, you've got to be careful. I know you need a burning platform for change' (that's how he put it), 'but you've got to be careful about being so negative about social care.'

And I can see that, from his point of view, somebody who's a very successful manager, fighting for change, working hard, as he has done, within the old system, that all the things that I was saying were perceived as a kind of criticism of his competence or his intelligence or his hard work. And it isn't that.

These people have worked very hard, they are very intelligent, they mean very well. I just think there's a lot wrong with the social care system that they have inherited. I don't think it's acceptable that people, say, have to go to day centres because that's where we put the funding, or they have to live in group homes because we've pre-purchased the group homes. I don't think that's an acceptable way of treating citizens in the 21st Century.

The thing about self-directed support is that it creates a different paradigm. It says to the people working in the old way, not that you weren't working hard enough; you were just striving to do the wrong thing, because that's how the system was set up. Instead we need to do the *right* thing.

How do you protect the core values that make SDS so revolutionary and liberating? How can we stop it getting swallowed up by the very institutionalism it is being set up to challenge?

The most important thing that I see is the combination of increased expectations and increased peer support and communication between individuals and families and fellow citizens. I think that is a powerful force for change, however organised.

You know, I see it here in Sheffield where I'm living and do a bit of work. When one family achieves something new, that travels through the grapevine, people find out and it changes other people's sense of what is possible.

I think if we can keep alive an active sense of what is possible and the underpinning rights – things like the right to use funding flexibly in a way that meets my needs and my outcomes – then we're in a good place.

Peer support and communication between individuals and families and fellow citizens is a powerful force for change.

Some people who criticise SDS, but don't know very much about its origins, see it as something 'foisted' on people by the government as a cost-cutting exercise. We know it originated from the leadership of disabled people, but what would you say to those who do see it in this negative light?

I find it so ironic when people talk about this being 'foisted' on people. I mean, in 1990 when I first started working in community services, I, like many other people before me, was struck by the fact that most disabled people receiving services didn't have control over the funding, and that seemed wrong. So I, as have many people in the disabled people's movement, as have many other people, tried to do something about it.

And this has been a long campaign. It goes back at least to the 1960s and the beginning of the independent living movement.

So to have these efforts portrayed as a sort of government plot is bizarre. The reality is that these ideas threaten existing vested interests and old paternalistic assumptions – it is for these reasons that it has taken so long to get central government to accept just some of these ideas – and we still have a long way to go.

It is sad to me that many people, even some of the disability movement itself, want to portray this work as part of some government plot. But in the end it will be the real-life experiences of disabled people which will determine the meaning of these reforms.

Around 25,000 people in the UK now have a personal budget – how long do you think it will take before this becomes the national ‘norm’?

We’re going to come to a fork in the road and there are various scenarios, depending on things that are hard to predict.

Looking at the trend, and if you put personal budgets and direct payments figures together, there are probably 70 or 80,000 people who now have a significant degree of individual control over their money, and that’s roughly 7–8% of the social care population.

So one interesting question is, what’s the tipping point? What is the point at which that goes from feeling abnormal to normal? We haven’t yet reached it. But it doesn’t have to be 50% for that to change.

I don’t think it’s going to change evenly between the local authorities. There are probably now 5–6 local authorities where it’s 30, 40, 50%, and it is normal business. And the question is, will other local authorities reach that way of working, or will they be diverted by the economic crisis, political changes, and the backlash that is likely to happen once the ‘new money’ has gone and people look and see how little real progress has been made against the expectations of *Putting People First*?

It’s so ironic to hear people describing self-directed support as some sort of government ‘plot’ after all our efforts campaigning for it.

Central government has done what it tends to do. I mean, it took a long time for them to even accept that this was a good idea, and when they did, they immediately turned around to local government and said, ‘Right, now this is the thing you’ve got to do,’ and started pointing the finger at local government. But it didn’t put in place any of the policies, economic arrangements, legal arrangements that really support it. So I think the most likely scenario is that we are going to be in a fractured environment where some local authorities are going to have made significant progress but they will be in the minority.

And then you’ve got to add into the frame the fact that we’ll have a different government, we don’t exactly know what the complexion of that will be. I think we’re going to be in very interesting times.

But – and this is a positive thing – I think we’ll find that the ‘virus’ of self-directed support has infected other bits of the system. So we will find examples in children’s services, in education, in health care of people starting to look at similar innovations. At a policy level that creates the possibility of a better, broader framework.

What is the *greatest* barrier we need to overcome in achieving self-directed support?

The greatest barrier is that it's difficult. That might sound really stupid, but it's hard to change complex systems that have been built around a bad paradigm, but to which people have lots of commitment, for all sorts of reasons. And it's particularly difficult to achieve those changes in a policy environment that isn't as helpful as it could be.

When you tested out self-directed support did you find that overall it saved money, or cost more?

In my experience, SDS brings better outcomes for the same money – it doesn't save money, but it has a positive economic logic

In my experience we got better outcomes for the same money; it wasn't saving money. If you really, really want to save money then you just end up warehousing people.

I mean, the idea that people are being driven by a desire to cut funding is completely mistaken. Most local authorities are frightened of this approach because they think it will lead to *increased* cost. However, if resources are more tailored to the individual, if they can be used in ways that are more connected to community, then this has a positive economic logic.

A personal budget gives people more control. But what if people don't want to take on the responsibility, say, of using their personal budget to manage a team of personal assistants?

As a society we start where we start, don't we? There's no panacea. You could say with a personal budget, well I don't want to micro-manage my staff, and then you could ask somebody to do that – but you'd have to pay them to do it. That's not unreasonable, is it?

At Inclusion Glasgow we were supporting people with very significant cognitive disabilities and so what we did was, we created kind of managed personal assistants, so your team were recruited for you, *by* you, but you didn't manage them in the same way – and that model works very well.

So far, very few providers have offered disabled people that kind of flexibility. They're still in that mode of, either, 'We're completely in control' or 'OK, you take over complete control' – and I think there are a lot of other solutions that would offer disabled people a more balanced approach, where they can choose the things that are important to them but don't have to manage everything.

If you do need that kind of extra support in managing your budget, or in guidance and advice and planning and assessment, somebody is paying for it, if it's part of a formal system. If it's provided through local community connections then, in a sense, we can build it ourselves from scratch. Those are our choices, and at the end of the day, given that there's only ever going to be so much tax money in the system, the rest of it is going to come through the smartness by which we collaborate, work together and strengthen our communities.

It's a combination of what the financial stuff will buy you and then what you bring, what the community brings, what you can create through what you do.

It's part of life, as a Spanish writer and thinker, Baltasar Gracian, said (to paraphrase): 'Life is like a sword – you can either grab it by the blade or by the hilt. It's up to you'. In other words, we're all faced by constraints and difficulties and opportunities and problems, but it's about attitude, about how you take those things forward. Nobody can do that for you. That's part of the human condition, it's not about disability.

I think we have to have a bit more faith in ourselves and in our own communities, and we have to accept that things are imperfect but in that is the opportunity to make things better. It's a bit like the change process for self-directed support.

I have faith in the ability of good leaders in local and national systems, that they will latch on to these ideas and they will, over time, bring about improvements. And with a little bit of luck, that can then bring about bigger improvements. But I think it's more an organic, developmental process than it is a kind of magical, 'Let's flick a switch and it will all fall into place'.

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What would you say to social workers who feel that SDS will just create more work for them or make life difficult – what are the positives for someone working as a social worker now?

The nicest thing is that social workers can answer that for themselves. Because when we've asked social workers who've actually done it, *not* who are theorising about it before they've done it, they have very positive things to say about how it leads to better outcomes. And also how it's more empowering and creates a better relationship, because they feel they're genuinely getting a better opportunity to work alongside people.

In terms of workload there are two important things to remember. One is that if local systems and local leaders don't reduce some of the burdens in other parts of the social work job then this *will* feel like more work. There are some choices that local leaders need to make in order to make the job more manageable.

The second thing is, if you expect social workers to be running around actually doing detailed support plans for most people, well, you've got it wrong. You know, most people can do their own support plans. The people they need help from most are other disabled people, their family and service providers.

When I first tested out the model of self-directed support in Scotland, I practically had to hold the hands of the social worker and say, 'Tell this family their budget, tell them what you need from the support plan, and then let them figure it out. And they will surprise you by what they come back with.' And every time they did. They worked out a plan, it was within budget and it was a really good plan.

You've just set up the Centre for Welfare Reform – how would you describe its function and aims?

The purpose of the centre for welfare reform is to help radically reform the welfare state. Which sounds a little ambitious, but I do think the whole welfare system is deeply dysfunctional, and needs a radical overhaul.

That won't be easy to achieve, but I think what we do know is the current system is bad for people in some powerful ways. It's bad for citizenship, it doesn't encourage people to take control, it doesn't encourage people to grow, it doesn't encourage people to develop their skills and their gifts, it creates massive poverty traps. This goes far beyond social care.

As a society we could do so much better if we actually organised the way we helped people, the whole welfare state, in a way that really enhanced citizenship, family and community.

So I want the centre to do two things. 80% of what it should do is what I've been doing for 20 years, which is find or create innovations, help them happen and freely share them so people can do them better. The other 20% is about trying to create consensus at a political level that it's time for a bigger set of changes.

Peer support is very important – you've got to link people up. I don't think we've even begun to tap into its power yet.

What we need is a kind of constitutional set of rights as citizens that is built around a proper understanding of what it takes for human beings to flourish.

The welfare state was designed around a paternalistic, state-led model; it's done a good job within the confines of what it can do. But it can't do any more than it's doing now.

Rob and Alison are part of the Leeds Personal Budget Peer Support Network, Free to Live. How important do you think peer support is, in helping people feel more comfortable with the concept of directing their own support?

I think peer support is what disabled people themselves say is the most important form of support, so we'd better listen to that, hadn't we?

I remember that one of the things that inspired me most was a comment by a professor of general practice in the US called Bill Schwab. I went to a speech he gave in Wisconsin in the nineties and he said:

'If a family has a child with a disability the most important thing you can do, bar none, is refer them to another family with a child with a disability'.

In other words, paradoxically, peer support is *the* most important professional intervention. You've got to link people up.

I don't think we're anywhere near getting that sense of its value into our systems. I don't think we've even begun to tap into the power of it yet.

Finally – we’re based in Leeds – do you have any thoughts about the different challenges we face in the North?

I think part of the reason why northern authorities have been more enthusiastic about these ideas is because they recognise that it’s all about improving social justice, and in the North we know that families and communities matter.

For me, self-directed support is a northern revolution!

I think in the South there is a rather more individualistic approach. And that’s why a lot of people in the North resisted direct payments at first, because it was perceived to be driven by a more individualistic paradigm, a kind of opt-out from the welfare state.

Self-directed support started in the North, and it is based on principles of social justice. For me it is a ‘Northern revolution’!