

A Fair Society

Putting disability at the heart of radical welfare reform

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IN CONFIDENCE

1. The challenge of disability

To begin with I'd just like to issue a gentle warning.

Over the past few years I have found myself giving many talks as an advocate of personalisation - often setting out the case some aspect of personalisation like person-centred planning, individual budgets, self-directed support, personalised support, community brokerage or whatever

But - either to your relief or disappointment - I won't be doing this today.

In fact I am not here to praise personalisation,

Instead - in a way - I am here to bury it.

This does not mean that I've changed my mind about the value of personalisation. But - I will argue - the limits of personalisation on its own are now very apparent and it is time to move our thinking forward. It is time to think much more deeply about the welfare state as a whole - in particular to explore what kind of welfare state will really support the legitimate rights of disabled people.

The welfare state was not designed with disabled people in mind.

Nor does it reflect the needs of the elderly or people with mental health problems or long term health conditions - it was designed when disabled people were either institutionalised or hidden away - it was designed at a time when most older people hardly lived long enough to enjoy a pension.

Proud as we rightly are of the post-war construction of the welfare state we must recognise that the welfare state was designed for a different era:

with different problems,

and different assumptions

and without any reference to what we've learned over the last 60 years about disability rights and the conditions that make for a good life for all

My contention is not that the welfare state is fine - but we just need to add a few new bits to it - like building an annex - my contention is that the welfare state is good - but flawed throughout - and that the experience of disabled people reveals these flaws.

The philosopher and disability activist Judith Snow says

the gift of disability is the fact that the disabled person needs help from another human

The reality of disability cuts through the myths we weave around ourselves.

It shows us that life is not about

consumption, wealth or power

we are confronted by the needs of another human being

and the demand these needs place upon us

and at the same time - if we are prepared to really look and listen -

we are also confronted by the real *meaning* of our needs

our needs for connection, for contribution, for dignity and respect

what I would to call citizenship

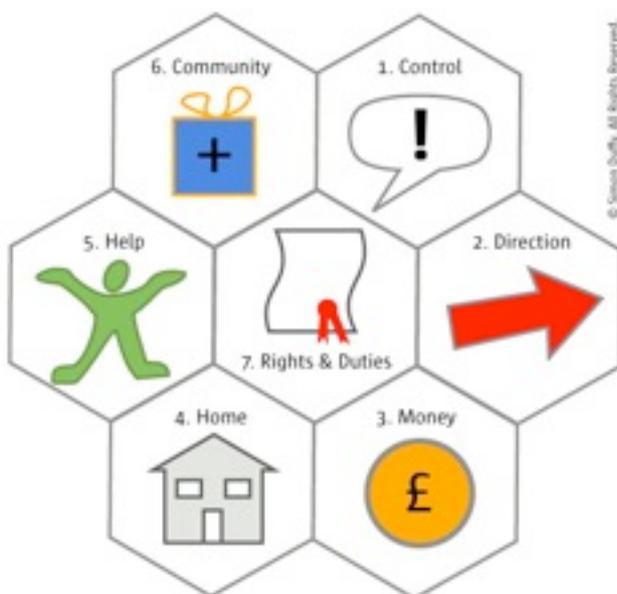


Figure Keys to Citizenship

For me citizenship is not primarily political - the citizenship at stake here is an everyday citizenship - where we have freedom and control over our own lives - yet are actively

involved in contributing and getting support from others - citizenship is about living together as equals, and living together in all diversity with all our differences

However when Judith Snow says that disability is a gift

This does not mean that the gift of disability is always recognised by society

This does not mean that the gift of disability is always welcomed by society

We see all too often that the social response to disability is to either ignore its gift or to respond to it in a mean-spirited way - not to see it as a gift - but as a problem to be eradicated

But disability does present each of us individually, and society as a whole, with an opportunity to respond to another person's needs with *decency*.

Like many people who work with people with learning difficulties my own calling only began after visiting an institution - where - like many before me - I was struck by:

- the dreadful physical surroundings
- the dehumanised way in which people were treated
- the shocking awareness - that, aged 23 - I had never met a disabled person before
- the joy to be had from spending time with people with severe learning difficulties

But what strikes me now - now I'm a little older - is that I can almost understand why one group of people (the staff) treated another group of people so badly

I believe in free will - I do not believe that we ever *have to* behave badly - we are not forced to treat people badly - but sometimes behaving badly is just *easier*, we might even say more tempting, than doing the right thing.

It is not too hard to see that

- when other people look different, even strange, we might fear them
- when other people live in bad conditions, we might think they deserve it
- when other people lack power, we might think that we need power ourselves
- when other people have to obey, we might think we'd better be giving the orders

So in this way we must recognise that the institutions did not *make* people behave badly - but they did create some of the most tempting *conditions* for bad behaviour.

What I want to talk about today draws upon these ideas:

1. Disability is a gift - but one that a society can fail to recognise or welcome
2. Bad systems, rules and social structures undermine decent behaviour
3. Good systems will encourage decent behaviour

I am going to argue that if we think about the needs of disabled people and the nature of good support then we will understand what it takes to create a decent society. In my view social justice theory (a subject of social science and philosophy) has paid insufficient attention to the experiences of disabled people and this failure has reinforced the poverty of contemporary policy-making and the structural weaknesses of our current welfare settlement.

We might say that disabled people present each society with the opportunity to learn what it takes to live together, to support each other, with decency - but this is a gift not every society has been able to recognise

The awareness that the treatment of the most vulnerable, including disabled people, is at the heart of social justice is reflected in our oldest human writings

For example - over two and half thousand years ago we hear - in Leviticus:

Do not curse the deaf or put a stumbling-block in front of the blind, but fear your God.

So the idea that disability helps us understand social justice is not modern.

2. Our Institutional Heritage

But I want to begin by saying something about modern history - the last 40 years or so - during which so much has been achieved

I will then make some observations about our current predicament

I will end by setting out some proposals for action and policy for the years ahead

I cannot do full justice to the trials and challenges of closing the institutions

The difficulty of challenging and then closing the institutions is reflected in how many still exist throughout the Western world

It took hard work by great men and women including

- Wolf Wolfensberger - who sadly died this very week, and
- Jack Tizard, who we remember in this lecture,
- and many others working inside and outside the system

Although my own work was inspired by the revulsion at the institution - I was also lucky enough to begin my work in one of the better community services set up in their wake.

I began work at Southwark Consortium - the predecessor of Choice Support - and I was able to benefit from meeting people who were living in much better surroundings, with much better staff support and in communities that could offer many more positive experiences.

I was also lucky enough to be inspired by many of the leaders who helped shape some of these early patterns of thinking and practice

Of particular importance to me were individuals like John O'Brien, Nan Carle and David Towell

In fact - given my previous training as a philosopher - it was particularly exciting to discover a vision of human value and of wider social responsibility that I had not found while studying social justice theory at Edinburgh University. Concepts like inclusion, community living and valued social roles, while often imperfectly realised in practice, certainly fed the mind and the spirit - they offered a different picture of life to that offered either by:

1. **Right-wing thinking** - dominated the neo-liberal idea that we were rational consumers, blindly working together for the maximisation of economic productivity, or
2. **Left-wing thinking** - where the goal of equality seemed to have collapsed into the notion that being equal just means getting the same public services

The ideals of inclusion seemed capable of both connecting us together without diminishing our individuality and freedom

However the very excitement generated by the ideals of inclusion also tended to sharpen the sense of disconnect between the values that we all *talked about* and the *reality* of the actual community services that replaced the institution

In fact what seemed obvious was that in many respects we had not left the institution behind - we'd knocked down the walls - we'd moved people into the community

But we'd taken the institution with us

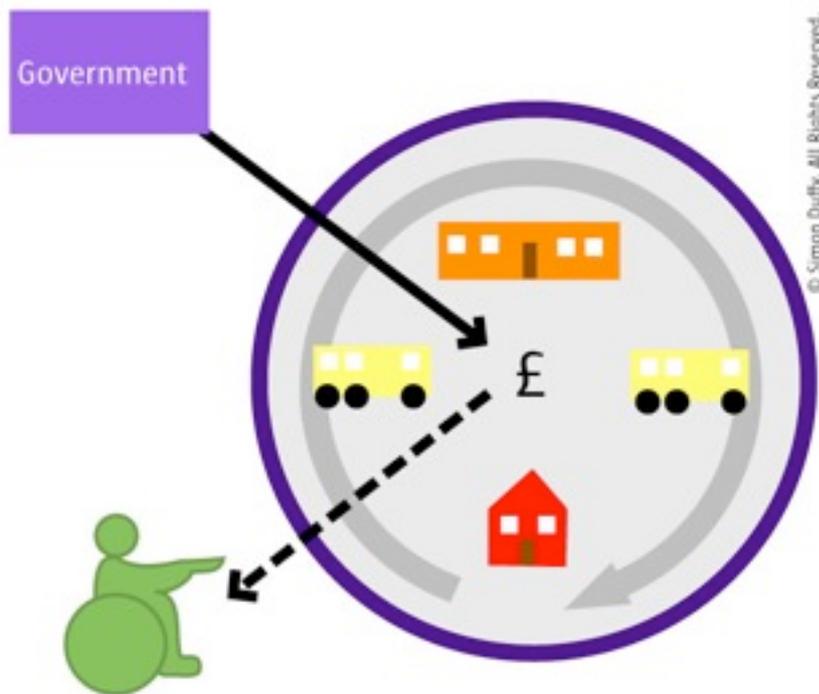


Figure Community Care

For instance we found that

- Too often - support in the community became - transport to the day centre
- Too often - support in the home became - powerlessness in residential care
- Too often - community inclusion became - social isolation

3. The Personalisation Response

So, before the institutions were fully closed, we began what seems to me the second period of de-institutionalisation - the attempt to de-institutionalise community services.

- The effort to get people proper jobs - what became known as supported employment - led by people like Anne O'Bryan
- The effort to get people real homes - what became known as supported living - led by people like Peter Kinsella
- The effort to help get full, interesting and connected lives - what became known as person-centred planning - led by people like Beth Mount
- The effort to give people control over their lives - what became known as self-directed support and individual budgets

In fact I think one of the best ways of thinking about personalisation is to see it as a series of technologies that were developed in order to try and work round the old broken welfare system,

Not only were these all attempts to promote citizenship - but they were all also rooted in working from people's own assets - in Pippa Murray's helpful words - their real wealth

A good life is not something you give someone else

A good life is built upon combining

connections, capacities, community resources and personal control - and financial resources are just one part of being able to exercise personal control

(although an *important* part in the modern world)



Figure Real Wealth

This is the essence of personalisation - helping people to achieve citizenship, despite the system. Helping people to use and develop their real wealth.

In our current system it also means that professionals change how they work in order to support people to take back control. - often professionals need to cede some of their own control

But too often personalisation is critically dependent upon professional good will and understanding - without this support we can quickly go backwards.

Just one example will demonstrate both the power and fragility of personalisation.

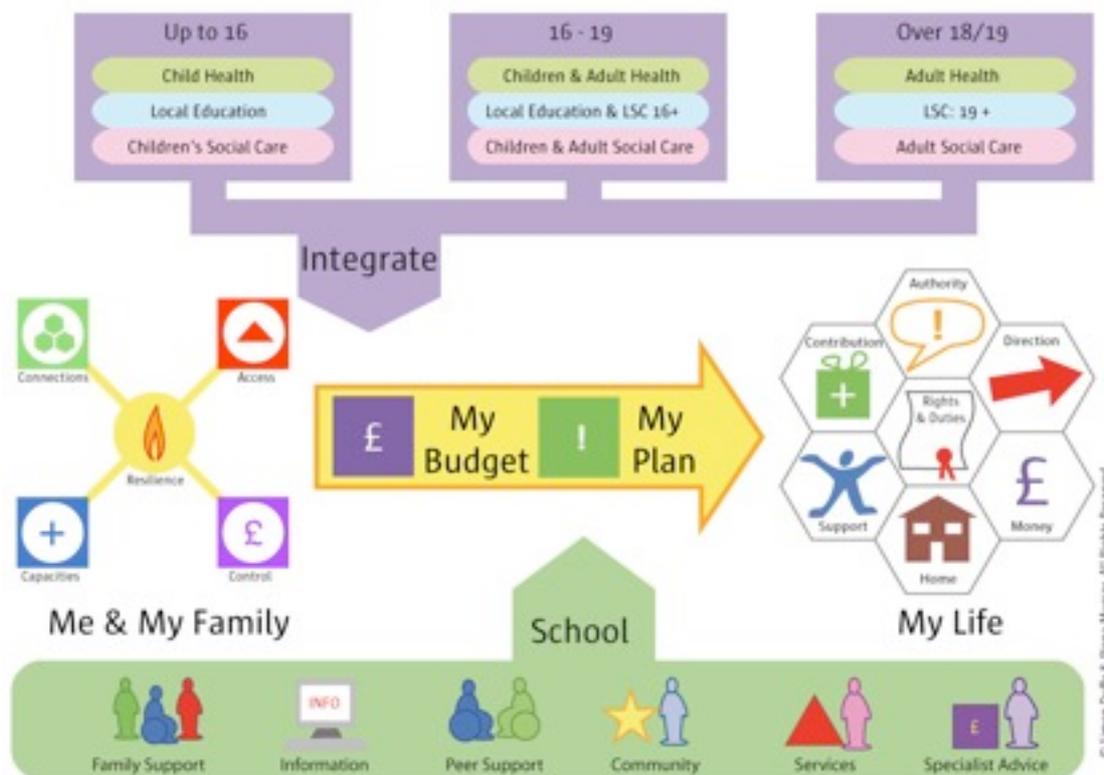


Figure Personalised Transition

In 2005 myself and colleagues in Sheffield, particularly Pippa Murray, began redesigning the system of transition for young people with severe learning difficulties:

1. Families and young people were put in charge of planning their own lives and support
2. Professional expertise was simplified and coordinated
3. The school began to support young people to plan ahead for citizenship
4. Families gained control of health, social care and education budgets.

The outcomes were very positive and the system seems to have ended a long-standing tradition of sending young people away from the city into residential colleges.

Nick Clegg was so impressed he talked about this in his 2008 conference speech - I quote:

I want patients to have far more control over the care they get. So people with long term conditions get to be part of designing the care they need. Choosing what suits them - and making it work. For mental health patients. For pensioners in need of care. For people with disabilities. It works.

A couple of weeks ago in Sheffield, I met a wonderful woman called Katrina. She's got three disabled sons. The oldest is Jonathan, a charming, warm hearted young man of 19. He can't walk or talk clearly, or feed himself alone. He's had a breathing tube in his neck since he was a toddler. Under a scheme the new Liberal Democrat council in Sheffield is extending, Jonathan's just got his own individual budget and care plan.

Now he's doing work with a local charity, attending a music group, has his own personal assistant. A child whose potential seemed so limited. Finally as a young man, engaged in life in a way he and his mother never thought possible. Katrina told me with the biggest smile I've ever seen. She said: We've gone from having nothing to having everything. I wish every child's needs would be taken this seriously. (Nick Clegg, 17 September 2008).



Figure Roots of Personalisation

In fact I would argue that the kinds of reform I've just described are just one part of a much wider response to our institutional inheritance. We can see the same kinds of thinking - in the work of the disability movement - creating direct payments and independent living centres. And the recovery movement, with its focus on hope and community inclusion. Personalisation is in fact the fruit of the long-standing effort of disabled people, many other excluded groups together with their allies - to try and achieve justice from within a broken welfare system.

But I am not here to praise personalisation - but to bury it

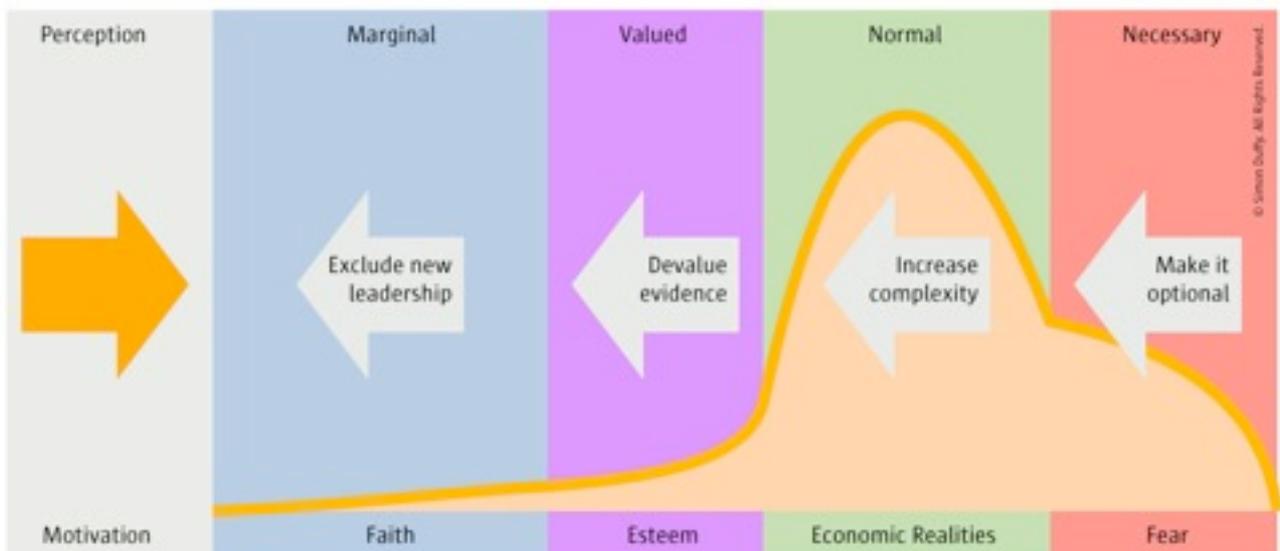


Figure Technological development and resistance

Although we have made some advances we still face considerable resistance and in many areas we are now going backwards

Today personalisation is confronted by a set of forces which are undermining its coherence, scope and effectiveness.

Today in Sheffield - 3 years after Nick Clegg's conference speech - families have lost the ability to directly control their education budgets; health care funding is in disarray and local government colleagues are left trying to make the whole system make sense in the face of centrally imposed cuts and central government policy confusion.

The personalisation is being undermined even as government declares its broad commitment to personalisation. We hear families and disabled people tell us:

- Individual budgets are becoming virtual budgets - and people have no meaningful influence of how they are used
- Even when people are given individual budgets they are then told how to use them
- Many local authorities are reducing the number of providers they commission, reducing choice and weakening local markets
- Advocacy services and legal aid are being slashed

So - individual budgets - like direct payments before them - are being mired within a broken and paternalistic system. Individual budgets, on their own haven't transformed the social care system and - on their own - they won't.

Many of these difficulties were rooted in the unwillingness of central government to do the necessary thinking and policy-making to ensure that personalisation would work.

But today these difficulties are further exaggerated by the assault on disability rights that has been unleashed by the current government's attempt to balance the budget

4. Our Present Predicament

The cuts planned by central government are far worse than anything Mrs Thatcher did. In fact disabled people made some significant progress during her tenure and during the following Major government.

- Institutions finally started to close,
- community care funding rose significantly
- disabled people won the right to control that funding in the 1996 Direct Payments Act.

Yet she and her government are still pictured as wicked and mean.

Today we have a government of smiling young men, we have a Prime Minister whose own son had a very significant disability. We have a government whose rhetorical commitments to personalisation, localism and the Big Society offer hope on every front.

But the reality seems to be much more negative - despite brilliant public relations.

The *Comprehensive Spending Review* at the end of 2010 simultaneously reveals and obscures the problems we will face.

First the government protects the big-ticket, media-sensitive items. The NHS is to be protected. Education is to be protected. Pensions are to be improved. More money is to be put into 'back to work' benefits. How can government then pull off the trick of balancing its budget?

by focusing on areas that the media either does not understand or where there is little general interest

Local government will face (excluding police and fire) a cut in funding of 28% from 28.5 to 22.9 billion - in real terms - what people do not seem to realise is that almost all of local government funding (excluding protected funds over which local authorities have no real control) is money for care services for adults and children. Local government - now that most other functions have been stripped away from it - is primarily a social care service.

So in order to deliver these cuts local government will be forced to:

- Cut social care by about £5.6 billion
- Reduce eligibility - which means about 250,000 people losing vital supports
- Cut staff - so that about 250,000 people will lose their jobs and
- Cut the salaries of the some of the lowest paid workers

Rather confusingly the government has talked about there being some extra money for social care from within the NHS:

- But we all know that the NHS cannot and does not deliver social care - that's a local responsibility.

- The mechanisms for shifting funding from the NHS to local authorities are weak and the current reorganisation of the NHS will undermine all existing local arrangements.
- And if this is a real transfer of funding out of the NHS then the loudly proclaimed protection of the NHS and cuts to local government are an even more confusing public relations stunt.

I don't know whether - in all the confusion or radical reform and balancing budgets - the government has genuinely just forgotten what local government does - or whether this is simply an intentional attack on the most vulnerable.

When we come to the benefit system there is also confusion.

A recent report from DEMOS captured some of the government's intentions:

Benefits cuts will include:

a change in indexation of uprating benefits from the higher Retail Price Index (RPI) or Rossi to the lower Consumer Price Index (CPI), said to save £6 billion a year by 2015

the reassessment of claimants of Disability Living Allowance (DLA) to drive a 20 per cent reduction in costs [c. £2.4 billion]

and the reassessment of Incapacity Benefit (IB) claimants to move more onto JSA – a plan first proposed by the previous government and intended to save £1.5 billion, and which the current government believes will see 23 per cent of IB claimants moved to JSA

(Demos, Destination Unknown, 2010)

The multiple benefit reforms and the creation of a system of Universal Credit mean the final impact is uncertain in many areas. However government strategy has been:

- to protect and strengthen pensions
- to invest more in back to work programmes to reduce the tax burden on those on the verge of work
- to reduce the overall cost of benefits

The only way of squaring this circle is to reduce spending on disabled people, families and carers.

When we review the major benefits it seems that those that vulnerable - that have not been protected or which will not get extra investment are those that relate to either low income or disability.

Benefit	(£ billions)		10/11 (mn)	pc pa
Retirement Pension	72.392	protected	12.537	£5,774

Tax Credits	24	protected	7.2	£3,333
Housing Benefit	21.519	vulnerable	4.75	£4,530
Disability Living Allowance	12.467	vulnerable	3.214	£3,879
Attendance Allowance	5.436	vulnerable	1.635	£3,325
Child Benefit	11	questionable	7.2	£1,528
Income Support	5.763	vulnerable	1.746	£3,301
Pension Credit	7.673	vulnerable	2.664	£2,880
Council tax benefits	4.085	vulnerable	5.794	£705
Jobseeker's Allowance	4.841	vulnerable	1.402	£3,453
Carer's Allowance	1	vulnerable	0.566	£1,767
Employment Support Allowance + IB	6.869	questionable	2.469	£2,782
Independent Living Fund	0.2	terminated	0.021	£9,524
TOTAL	177.245			

This is a pincer attack on the rights of disabled people. If we just focus on the 1 million people with the most significant disabilities will lose:

- £5.6 billion in social care support
- £0.7 billion in disability living allowance
- Termination of ILF
- Cuts to Supporting People
- Many further cuts in housing support and other benefits

So, more than £7 billion of the total £27 billion (more than 25%) which government is saving from departmental budgets is being born by less than 2% of the population - those who are least able to bear these cuts.

And we also have to remember that disabled people are only one vulnerable group who will suffer. Other key groups will include:

- People with mental health problems
- Women suffering domestic violence
- People out of work

- Refugees and asylum seekers

Is this *fair*?

And what *caused* these cuts?

The desire to balance a budget that was only unbalanced because we had to bail out the wealthy from financial gambles from which only the wealthy benefited

But perhaps the very viciousness of this attack might galvanise some deeper thinking about what we really need to be arguing for

We can no longer rely on the kind of state handouts for disability that characterised New Labour:

- one pound extra for the most vulnerable
- two pounds extra for services that benefit swing voters
- three pounds extra for bureaucracy and big government

It is time to be more radical

It is time to think harder about why we are in our current predicament

It is time to set out a vision for the years ahead

It is for this reason that many of us came together to form *the Campaign for a Fair Society*

5. Challenging the third institution - the welfare system

I think we have for too long been constrained in our thinking about welfare reform

And the current crisis for disabled people shows us that

In fact - from the perspective of the disabled person - the whole of the welfare state itself is still highly institutional

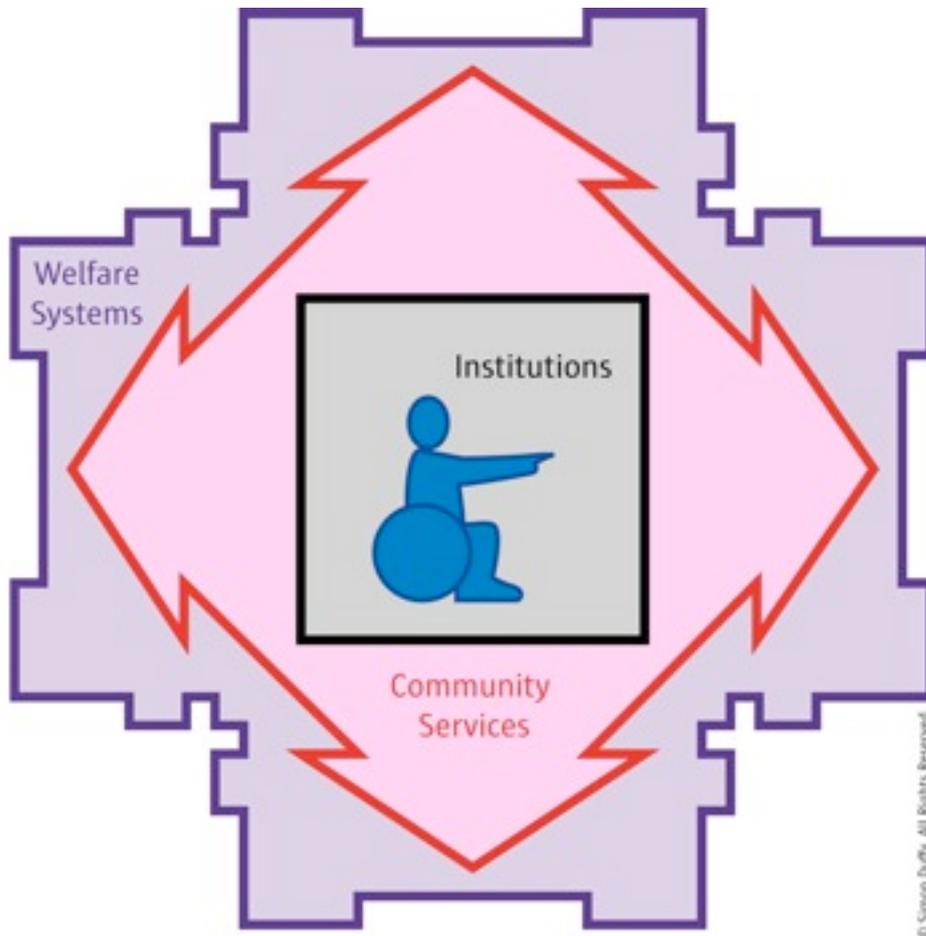


Figure Three Institutional Walls

The first institution was the obvious one - buildings standing high on hills, away from towns, often walled and remote

The second institution was community services - group homes, day centres, special buses - exclusion and segregation and social isolation within our communities

The third institution is the current welfare system itself - which brings with it a series of systemic obstacles that undermine citizenship and frustrate people's ability to connect and build good lives for themselves

What are these obstacles

Well if today you are a disabled person in the UK what problems do you face:

I would offer this list of third generation problems

1. **Weak entitlements** - the law is a mess - in the words of the Law Commission “a confused patchwork” - and the spirit of the law is mean - in some areas FACS at least helps us articulate that meanness. In an authority that accepts only critical needs as the basis of eligibility this means:

If you live in an area where eligibility is set at critical then this means you will NOT be entitled to care even if *all of the following were true*:

1. you have only partial choice and control over your immediate environment
2. you have been abused or neglected, or you will be abused or neglected
3. you cannot carry out the majority of your personal care or domestic routines
4. you cannot sustain involvement in work, education or learning
5. you cannot sustain the majority of your social supports and relationships
6. you cannot fulfil the majority of your family roles or other social roles

How can this be an acceptable state of affairs in the 21st Century?

2. **Super taxation for disabled people** - what other group can pay taxes all their lives and yet when they need help are faced with crippling extra taxes (called charges or means-tests) which ensure people will have to be in poverty before they are entitled to essential supports?

3. **Poverty traps** - even if you are not entitled to social care and just rely on benefits you will find that many of these benefits bring with them severe poverty traps - if you earn, or save then your income and your housing rights will be undermined.

4. **Weakened families** - the whole system is biased against families. If you have family support then you will have to wait until that support breaks down before you will get any significant level of support - if you choose to form a family you will lose income and support.

5. **Imprisonment for many** - far too many people with learning difficulties - and people with mental illness - are imprisoned. It is hard not to think that the prison system has quietly consumed the lives of many people with learning difficulties. Possibly 20,000 prisoners have a learning disability - with 7,000 having an IQ of less than 70.

We probably feel that all these problems are inevitable. But the people who first tried to close the institutions must have often felt the same.

Some things are unavoidable - but this pattern of deep, structural injustice is not inevitable - its just difficult to challenge.

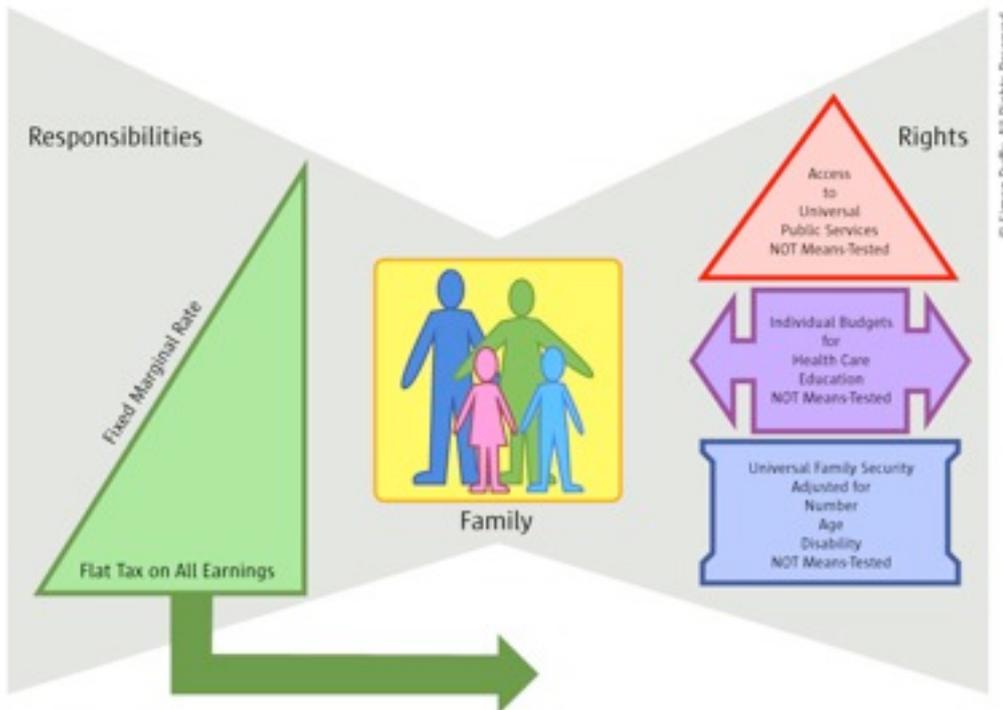


Figure Tax-Benefit Reform

But solutions are possible, for example we can:

1. Integrate the tax-benefit system - cut out the stigma and complexity of the current system
2. Take means-testing out of benefits - we've already paid our taxes, why pay a second set?
3. Guarantee a minimum level of income including income for support - create a clear and open process for defining what is enough money for each of us to operate as an active citizen
4. Create a constitutional right to support and control - a right that can be protected by the courts
5. Create a robust constitutional framework for delivery of these rights - end the process of central government fiddling with local government, the NHS and every other delivery system

It will be said we cannot afford these ideas. But we live in a country that has never been wealthier and where our problems are not the problems of dearth: they are the problems of inequality, consumption and greed - the problems of wealth not the problems of poverty

It is also not clear to me why solutions that will ensure everybody, absolutely everybody, is more active, contributing, connecting and saving will take anything away from the whole. It is the current system that leaves one third of households in benefit dependency and millions operating at lower levels of productivity.

The real problem is not economics.

The real problems is politics. All the political parties have become conditioned to accept incremental improvements - even when these incremental changes often combine to negate or reverse progress.

All political parties chase votes based upon lazy and non-empirical assumptions:

- Money improves quality - just putting more money into the NHS improves health, more money in education improves education
- Regulation improves quality - more more regulation of schools will drive up standards
- If we reorganise the NHS (again) - we'll drive up efficiency
- If we are tougher on 'benefit thieves' - this was the last government's term - we'll eradicate poverty
- If we are tougher on criminals - we'll eliminate crime
- The more power we give government the more problems will be solved

These concepts drive social and political debate - despite the fact that they are all false

Partly this intellectual weakness is caused by chasing the critical votes of swing voters.

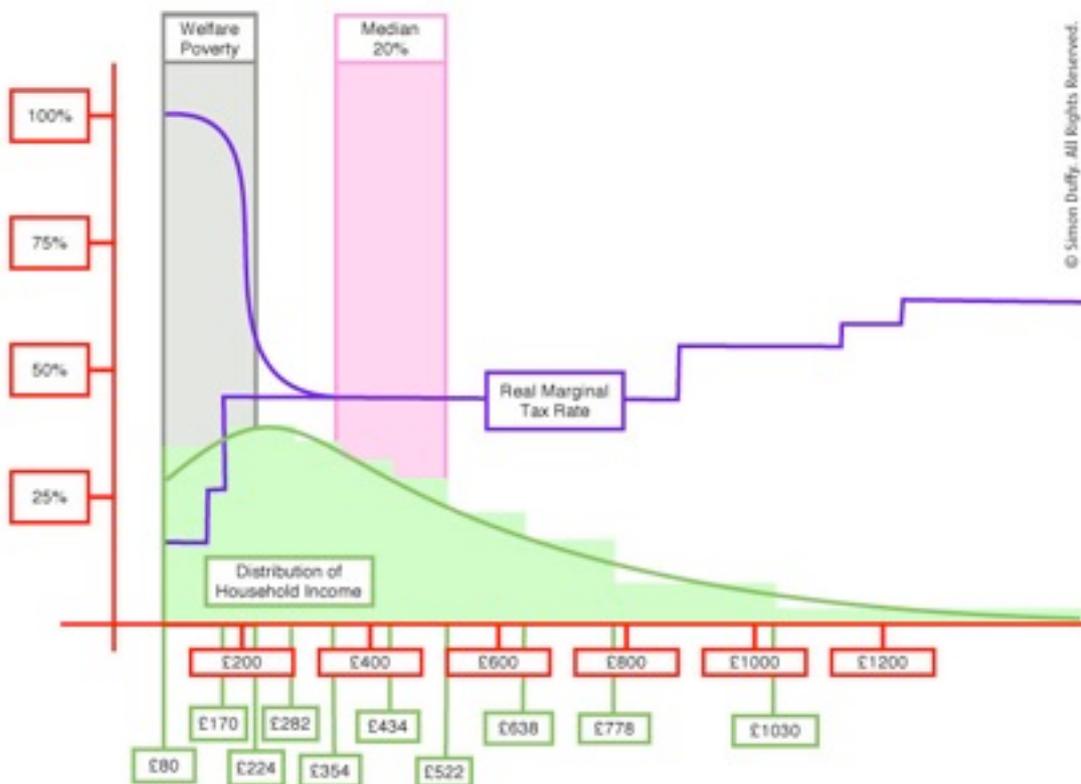


Figure Marginal Tax Rates

For example, if we track the marginal tax rate by income we find that the lowest marginal tax rates are those paid by the swing voters - i.e. median voters.

The highest marginal taxes are paid by the poor and then the rich - but not the middle.

But I think there are also deep problems caused by the highly centralised nature of power in the UK.

We have reached a kind of *reductio ad absurdum* where central government increasingly talks about localism and local power and yet local government is left in control of next to nothing.

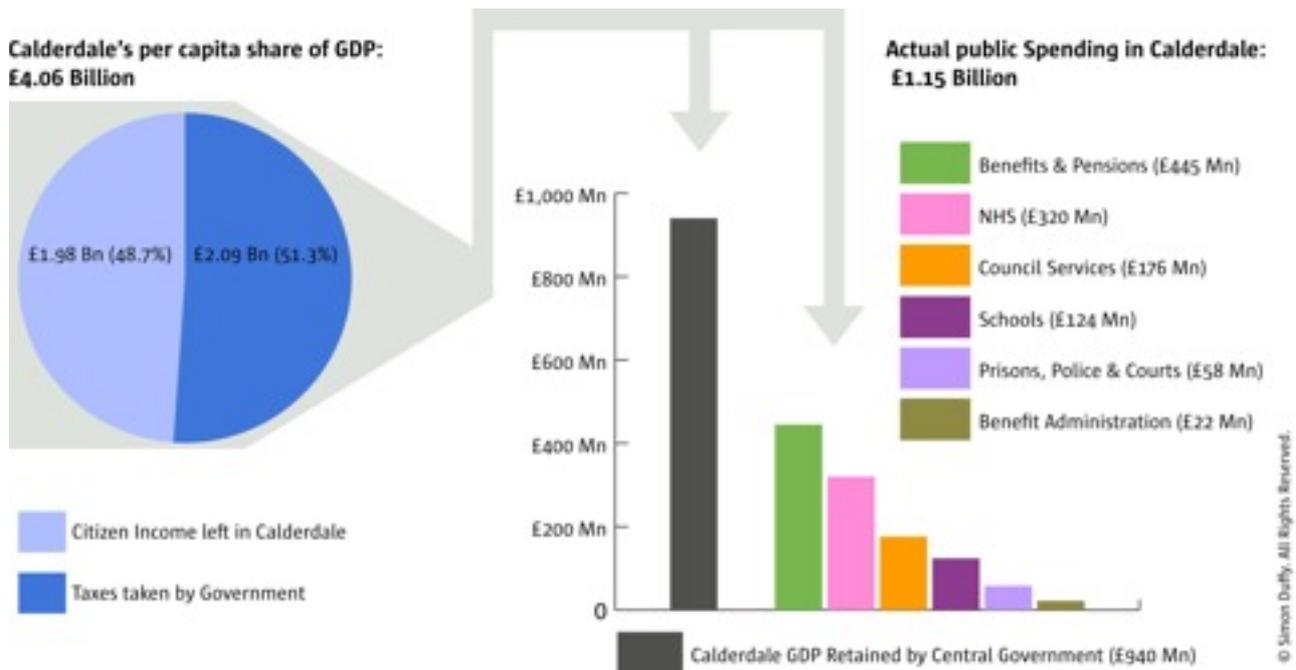


Figure Calderdale Spend

These figures from Calderdale show that - for Calderdale's share of GDP much is lost and is spent elsewhere - and what does return is in centrally controlled services. local government is treated like a native power under colonial rule.

This is not sensible. And disabled people suffer because their entitlements are pinned on the most fragile structure in the whole system.

I suspect that in order to challenge the current system we will need to make common cause with many local leaders rather than blame them for central policy decisions they cannot control.

Conclusion

Back in the early 1990's I argued that we could think about the kind of change we need as a shift from a Professional Gift Model to a Citizenship Model.

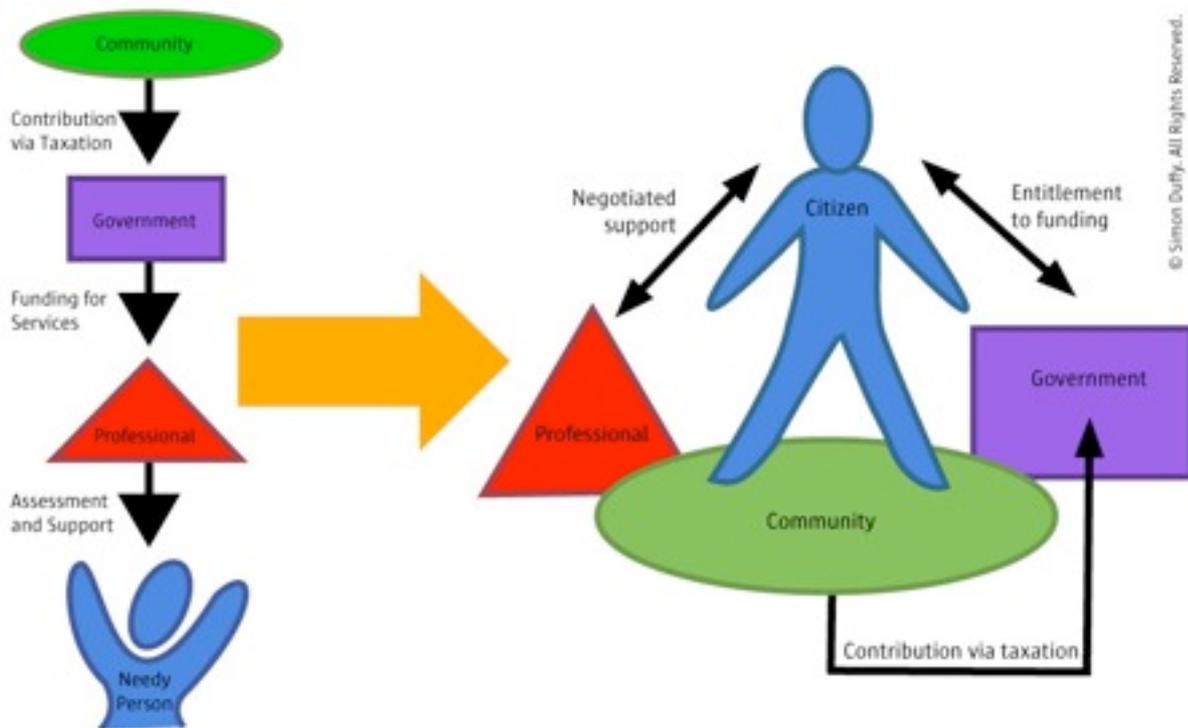


Figure Citizenship Model

I still think this is a helpful way of characterising the challenge we face.

Personalisation showed that this shift could be more than a pipe dream

But as I said

I came here to bury personalisation - not to praise it

The reality is that personalisation - with all the hope it offers - is never going to deliver either a decent or a fair society - so long as we cannot put in place a decent constitutional framework to protect the rights and entitlements of disabled people

Our current systems are deeply paternalistic

Rights are fragile or non-existent

We can no longer afford to simply put our heads down and get on with the good work of creating decent services or liberating handfuls of people from institutional arrangements in the community

Its time to make the case for real and meaningful welfare reform

Welfare reform designed with disabled people at the centre

If we do we may also find that we can rethink many other aspects of the welfare system - perhaps giving all of us back more control over our lives - while ensuring that people have adequate rights and supports

We want to live in a decent society - one where people treat each with respect, where we recognise our innate dignity as human beings - whatever our differences

But behaving decently is more difficult in an unfair society

So we need to build a fair society in order to safeguard decency

Otherwise we risk returning to the indignities and horrors of the past