

# A Fair Society and the Limits of Personalisation

A **Discussion Paper** from The Centre for Welfare Reform first presented at the Tizard Memorial Lecture, 4th March 2011.

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## Contents

Introduction . . . . .	2
1. The Challenge of Disability . . . . .	3
2. Our Institutional Heritage . . . . .	6
3. The Personalisation Response . . . . .	8
4. Our Present Predicament . . . . .	14
5. The Third Institution - the Welfare System . . . . .	19
Conclusion . . . . .	24

# Introduction

This discussion paper has been developed from the text of a speech given at the 2011 Tizard Memorial Lecture, hosted by the Tizard Centre at the University of Kent. It was an honour to be asked to give the speech and my thanks go to everyone involved. I have made some minor amendments to the text, partly to reflect questions that arose at the end of the speech.

Overall it is important to recognise that this speech only marks a beginning; it is an attempt to mark a watershed in public policy and welfare reform for disabled people. In my view we can now see more clearly than ever that those approaches which only focused on changing systems and services - that I am calling 'personalisation technologies' - are insufficient. We need to turn our attention to the law and to fundamental questions of human rights.

Although there are some specific ideas that are briefly explored here my main objective is to try and encourage people to respond to the looming crisis in disability funding by identifying a pattern of changes that will not be merely defensive. We do need to be saying to government and to the general public that the planned cuts to income, support and housing are unfair - but we also don't want to return to the old paternalistic culture. The depth of the government's cuts finally demonstrates that there is no safety in clinging to the past nor in falling back on institutional or paternalistic responses. We need a radical, rights-based approach.

It's important to note that the Tizard Centre is an organisation that is particularly focused on improving conditions for people with learning difficulties or learning disabilities. This has also been the main focus of my work. In this talk I have avoided trying to distinguish different disability communities from each other. This is partly because I think this is a time when we need to draw together not to separate; but I understand that this can obscure important distinctions and different historical routes. I hope the reader can forgive any undue simplification.

# 1. The Challenge of Disability

I'd like to begin with a gentle warning. Over the past few years I have found myself becoming identified as an advocate of personalisation and I have often argued the case for some aspect of personalisation such as person-centred planning, individual budgets, self-directed support, personalised support, community brokerage and so on. However today I will be arguing that the limits of personalisation are now apparent.

This does not mean personalisation has no value. But it is time to move our thinking forward. It is time to think much more deeply about the welfare state as a whole - and 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 people managing long term health conditions. It was designed when disabled people were either institutionalised or hidden away at home. 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 okay as it is - but we just to need to add a few new bits to it like building a conservatory on the back of a house - my contention is that the welfare state is good, but deeply flawed throughout and that the experience of disabled people reveals many of these flaws.

**The philosopher and disability activist Judith Snow says:** *The gift of disability is the fact that the disabled person really 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 these needs place demands 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 need for connection, for contribution, for dignity and respect. We might say that we are increasingly clear that we have a need for citizenship (Figure 1).

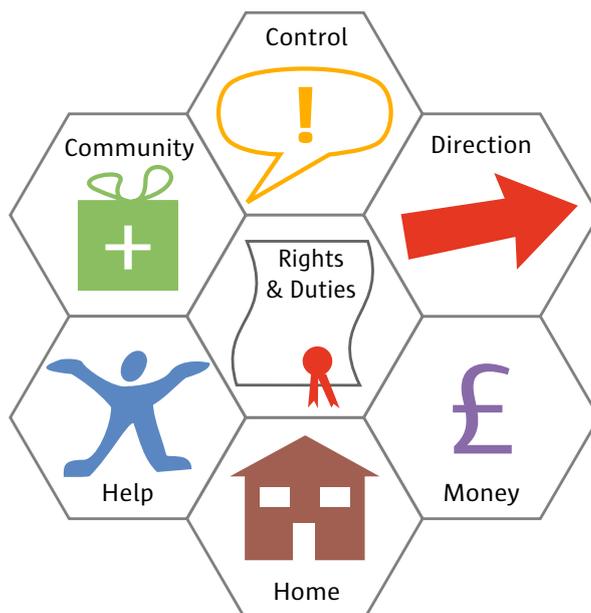


Figure 1. Keys to Citizenship

Citizenship is not just political; the citizenship that is at stake for us is a kind of 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 our diversity - welcoming our differences.

However when Judith Snow says that disability is a gift, she does not mean that the gift of disability is always recognised by society and she 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 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
- dehumanised way in which people were treated
- shocking awareness - that, aged 23 - I had never met a disabled person before
- joy to be had from spending time with people with severe learning difficulties

But what also 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
- live in bad conditions - we might think they deserve it
- lack power - we might think that we better get power ourselves
- 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 here draws upon these ideas:**

- disability is a gift - but one that a society can fail to recognise and fail to welcome
- bad systems, rules and social structures undermine decent behaviour
- good systems encourage decent behaviour

I am going to argue that if we think about the needs of disabled people and the nature of good opportunities and support, then we may begin to understand what it takes to create a decent society. In my view social justice theory (a subject of both 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 weakness of the 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 that not every society has been able to recognise. But the awareness that the treatment of the most vulnerable, including disabled people, is at the heart of social justice is not new and it is found 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 illuminates 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 and 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 revulsion at the institution I was also lucky enough to begin my work in one of the better community services set up as they began to be closed. I began work at Southwark Consortium - the predecessor of Choice Support - and here 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 in Edinburgh. 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 very different picture of life and human values than offered by:**

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

**The ideal of inclusion seemed capable of both bringing us together - without diminishing our individuality and our freedom.**

However the very excitement generated by the ideal of inclusion also tended to sharpen the sense of disconnection 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 2).

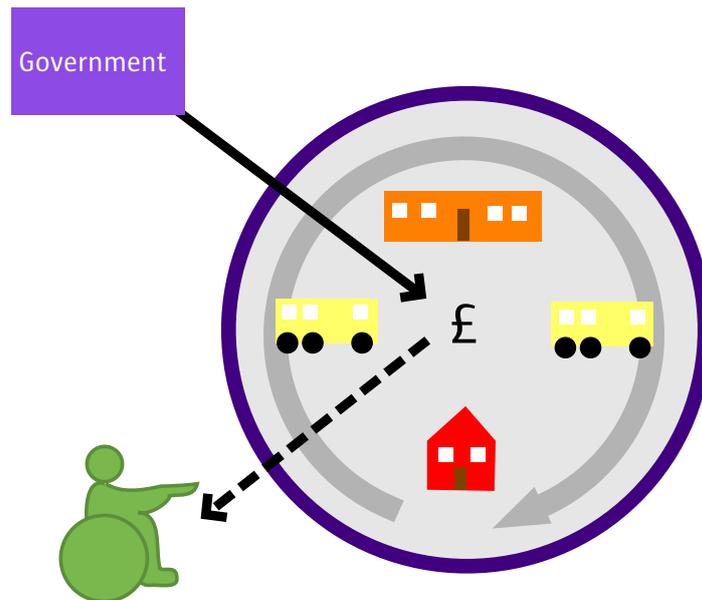


Figure 2. Community Care

**For instance we found that too often:**

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

## 3. The Personalisation Response

So, before the institutions were fully closed, we began the second phase of de-institutionalisation - the effort to de-institutionalise community services. In the first phase we focused on the building - the institution; in the second phase we concentrated on overcoming services and helping people achieve different aspects of citizenship - different aspects of ordinary life:

### The effort to get people:

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

In fact I think one of the best ways of understanding personalisation is to see it as a series of technologies - practical ways of doing things - technologies that were developed in order to try and overcome the institutionalisation that seemed to have been designed into community services themselves.

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 (Figure 3). A good life is not something you can just give to someone else. A good life is built from combining our connections, our capacities, our community resources and our personal control - and financial resources are just one part of being able to exercise personal control (although an important part in the modern world).

We might say that this is the **essence of personalisation** - helping people to achieve everyday citizenship, helping people to use and develop their own real wealth and often working to overcome the obstacles created by a welfare system that frustrates these goals.



Figure 3. Real Wealth

In our current system this also means that professionals must change how they work in order to support people to take back control - often professionals need to cede some of their own control in order that individuals and families can gain more control. But too often personalisation has become critically dependent upon professional good will and understanding, and without the support of professionals we quickly slide backwards to institutional solutions. Personalisation is about achieving rights, but it is not itself grounded in any enforceable rights.

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

In 2005 myself and colleagues in Sheffield, particularly Pippa Murray, began to redesign the system of transition from secondary education for young people with severe learning difficulties (Figure 4) and we developed a model we named *Personalised Transition* (Cowen, 2010):

- Families and young people were put in charge of planning their own lives and support.
- Professional expertise was simplified and coordinated.
- The school began to support young people to plan ahead for citizenship.
- 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.

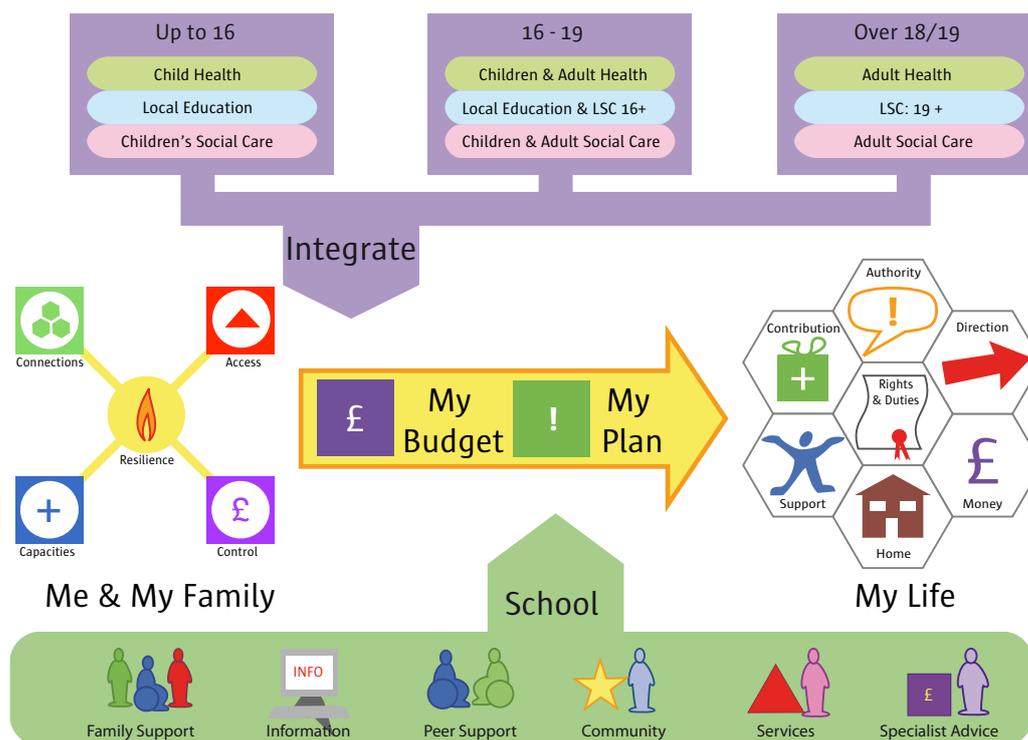


Figure 4. Personalised Transition

**Nick Clegg was so impressed that he talked about this in his 2008 conference speech:**

*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)

In fact I would suggest 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 kind of thinking in the work of the disability movement that led to the creation of personal assistance, direct payments and centres for independent living. We can also see the same themes in the recovery movement with its focus on hope, community inclusion and peer support to improve mental health.

Despite some minor differences there is a distinctive and important set of shared values here, rooted in shared experiences of disadvantage, rooted in shared aspirations for inclusion, rights and a desire for full citizenship (Figure 5). These are all visions of social justice and they have given rise to a great array of practical strategies for enhancing social justice - what I am calling here (for want of a better term) personalisation strategies.



Figure 5. Roots of Personalisation

In other words, personalisation is the fruit of the long-standing effort of disabled people, and many other excluded groups, together with their allies, to achieve social justice from within a broken welfare system. But personalisation has always faced considerable resistance and this resistance is now growing (Figure 6).

It took tremendous effort to push the strategies of personalisation into the centre of policy making and we might mark the publication of *Putting People First* as a kind of high water mark of political interest in personalisation. But the system has now managed to adapt its own resistance to personalisation. Instead of writing personalisation off as marginal or under-evidenced the system now seeks to reduce the impact of personalisation by emeshing it within

a confused mess of competing policy initiatives or by asking local leaders to implement changes without putting in place the necessary legal frameworks that will embed and support those changes. The continuation of the policy of *Fair Access to Care Services* alongside the development of *Resource Allocation Systems* - two logically incompatible approaches to rationing - is just one example of the current confusion.

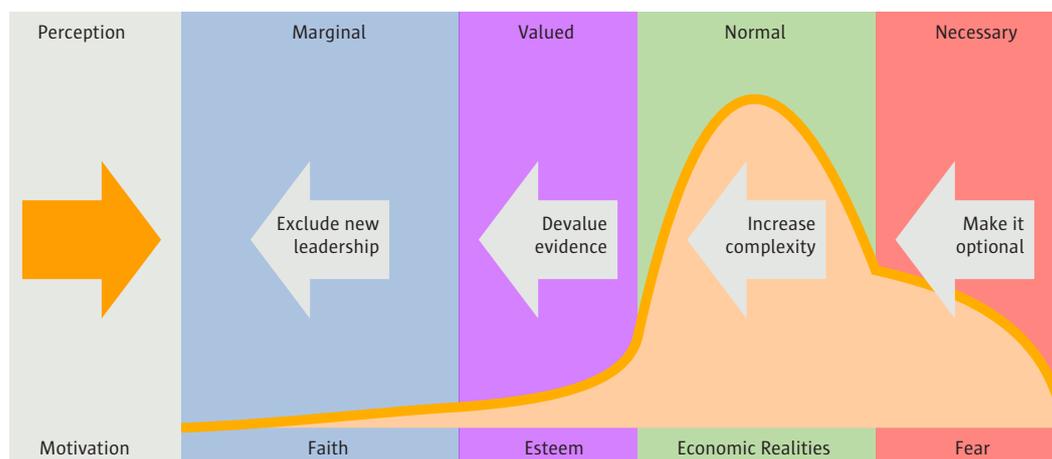


Figure 6. Technological development and resistance

Although we have made some advances in many areas we are now going backwards. Today personalisation is confronted by a set of forces which are undermining its coherence, its scope and its effectiveness.

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

**Personalisation is being undermined even as government declares its enthusiasm for personalisation. Families and disabled people tell us:**

- Individual budgets are becoming virtual budgets - and people have no meaningful influence over how they can be used.
- Even when people are given individual budgets they are then told how to use them and face burdensome rules and bureaucracy.
- 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 hard 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 and reduce public expenditure - a programme of cuts that directly targets disabled people.

## 4. Our Present Predicament

The cuts planned by central government are far worse than anything Mrs Thatcher even imagined. In fact disabled people made some significant progress during her tenure and during the following Major government: institutions finally started to close, social care funding rose significantly and disabled people won the right to control their funding in the 1996 Direct Payments Act. Yet she and her government are 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 seem to offer hope on every front. But the reality is going to be much more negative - despite brilliant public relations. The *2010 Comprehensive Spending Review* simultaneously reveals and obscures the problems we will face.

First the government has tried to protect 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 even going to be invested in reforms to the benefit system in order to create better incentives for people to work. How can government then pull off the trick of balancing its budget? The answer it seems is to target the cuts on those areas of public expenditure that the media either does not understand or where there is little general interest.

Local government will face a cut in funding of 28% from £28.5 to £22.9 billion. But what people do not seem to realise is that almost all of local government funding is money for care services for adults and children. Local government, excluding those functions over which it does not have direct control and which are protected from this cut (e.g education and housing benefit), is primarily a social care service. Social care for children and adults (in England) is currently about £21 billion. In other words, social care is approximately 73% of all local government funding over which local government has any meaningful control.

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

- cut social care by about £5.88 billion
- reduce eligibility to social care - which means about 250,000 people losing vital supports
- cut staff - so that about 250,000 people will lose their jobs
- cut the salaries of the some of the lowest paid workers

**Rather confusingly the government has talked about there now 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 this is a local government responsibility.
- The mechanisms for shifting funding from the NHS to local authorities are weak and the current reorganisation of the NHS is liable to undermine all existing local arrangements.
- 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 of radical reform and the desire to balance budgets, the government has simply just forgotten what local government does. If not, then this must simply be the most vicious intentional attack on the most vulnerable in 70 years.

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

(Grant and Wood, 2010)

The multiple benefit reforms and the creation of a system of Universal Credit mean that the final impact of these cuts and changes will remain uncertain and in many areas the cuts will be reflected in changes in detail that may escape political scrutiny.

**However what is clear is that the government's strategy is to:**

- protect and strengthen pensions
- invest more in back-to-work programmes to reduce the tax burden on those on the verge of work - a noble, but expensive, goal

- reduce the overall cost of benefits

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

This becomes clearer when we review the major benefits. It seems that those benefits that are vulnerable to reductions, that have not been protected or which will not get extra investment are those that relate to either low income or disability (Table 1).

<b>Benefit</b>	<b>£ billions</b>	<b>status</b>	<b>recipients</b>	<b>per cap.</b>
Retirement Pension	72.392	protected	12,537,000	£5,774
Tax Credits	24	protected	7,200,00	£3,333
Housing Benefit	21.519	vulnerable	4,750,000	£4,530
Disability Living Allowance	12.467	vulnerable	3,214,000	£3,879
Attendance Allowance	5.436	vulnerable	1,635,000	£3,325
Child Benefit	11	questionable	7,200,000	£1,528
Income Support	5.763	vulnerable	1,746,000	£3,301
Pension Credit	7.673	vulnerable	2,664,000	£2,880
Council tax benefits	4.085	vulnerable	5,794,000	£705
Jobseeker's Allowance	4.841	questionable	1,402,000	£3,453
Carer's Allowance	1	vulnerable	566,000	£1,767
Employment Support Allowance + IB	6.869	questionable	2,469,000	£2,782
Independent Living Fund	0.2	terminated	21,000	£9,524
<b>TOTAL</b>	<b>177.245</b>			

**Table 1.** Major benefits in current policy context

We could add to this an analysis of the proposed changes to housing funding. We already see changes that have effectively stopped disabled people from being able to purchase their own home, and further changes to Housing Benefit are likely to reduce people's effective housing rights and promote residential care or other institutional solutions. This is a pincer attack on the rights of disabled people. An attack on income and support.

**If we just focus on the 1.5 million people with the most significant disabilities, they will lose:**

- £5.88 billion in social care support
- £1 billion in Disability Living Allowance
- £0.2 billion with the termination of the Independent Living Fund
- Supporting People funding
- housing support and other benefits

**So, more than £7 billion of the total £27 billion (more than 25%) which the government is saving from departmental budgets is to be borne by less than 3% of the population - those who are least able to bear these cuts.**

**And we also have to remember that disabled people are only one of the vulnerable groups 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?**

We need to balance a budget that is out of balance because the government chose to bail people out after the collapse of a housing and investment bubble. The political and economic priority is to protect people from the economic consequences of their own greed and to ensure that inflated house prices - which benefit the many - are sustained.

However disabled people and the poor were not the beneficiaries of these increases in housing values nor the investment profits that were made by over-lending. So we have Robin Hood in reverse - the poor are being taxed to ensure the wealthy are protected from their own poor decisions.

Perhaps the very viciousness of this attack might galvanise some deeper thinking about what we really need to be arguing for. We cannot just complain and we cannot want to simply return to the paternalism of the past.

**We can no longer rely on the crumbs of support 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*.

**The Campaign believes:**

*Everyone is equal, no matter their differences or disabilities. A fair society sees each of its members as a full citizen - a unique person with a life of their own. A fair society is organised to support everyone to live a full life, with meaning and respect.*

**We think the following seven principles could help us create a fair society:**

- **Family - we give families the support they need to look after each other.**
- **Citizenship - we are all of equal value and all have unique and positive contributions to make.**
- **Community - we root support and services in local communities.**
- **Control - we have the help we need to be in control of our own life and support.**
- **Capacity - we are helped to be the best that we can be.**
- **Connection - we all get chances to make friends and build relationships.**
- **Equality - we all share the same basic rights and entitlements.**

## 5. The Third Institution - the Welfare System

For too long we been constrained in our thinking about welfare reform. And the current crisis for disabled people demonstrates that - from the perspective of the disabled person - the whole of the welfare state itself is still highly institutional.

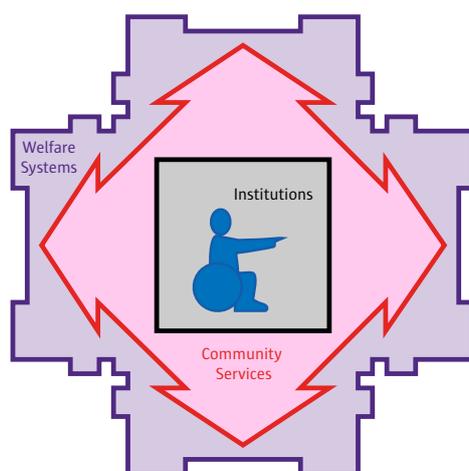


Figure 7. Three Institutional Walls

The first institution was the obvious one - buildings standing high on hills, away from towns, often walled and remote - exclusion *from* community. The second institution was community services - group homes, day centres, special buses - leading to exclusion, segregation and social isolation *within* communities. The third institution is the welfare system itself - the framework of funding, entitlements and power that shaped support and opportunity within society. The current welfare system creates a series of systemic obstacles that undermine citizenship and frustrate people's natural desire to connect to others and to build good lives for themselves.

**What are these obstacles? I would offer this list of third generation problems.**

1. **Weak entitlements** - the law is a mess - in the words of the Law Commission - social care is "a confused patchwork" - and the spirit of the law is mean. For example if a local authority has set the eligibility to 'critical' then this means you will **NOT** be entitled to care even if **ANY** or all of the following were true:
  - you only have partial choice and control over your immediate environment

- you have been abused or neglected, or you will be abused or neglected
  - you cannot carry out the majority of your personal care or domestic routines
  - you cannot sustain involvement in work, education or learning
  - you cannot sustain the majority of your social supports and relationships
  - you cannot fulfil the majority of your family roles or other social roles
2. **Super-taxation for disabled people** - What other group pays taxes all their lives and yet, when they need help, are faced with crippling extra taxes (called charges or means-tests) that ensure people will have to be in poverty before they are entitled to essential supports?
  3. **Deep 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** - 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 difficulty - and 7,000 have an IQ of less than 70.

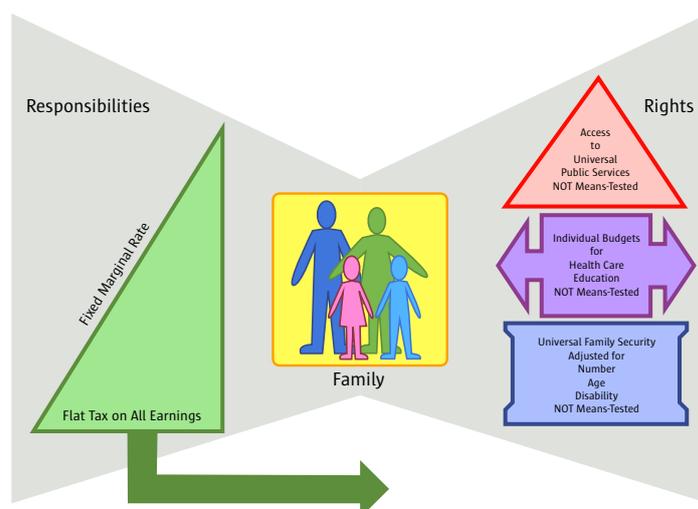


Figure 8. Tax-Benefit Reform

### **How is this fair? How is this even acceptable in the 21st Century?**

We may even begin to feel that all these problems are inevitable. But surely the people who first tried to close the institutions must have often felt the same. Some things in life are inevitable - but this pattern of deep, structural injustice is not inevitable - it is just difficult to challenge, and difficult to change.

### **And solutions are possible, for example we could:**

- Integrate the tax-benefit system - cut out the stigma and complexity of the current system and reduce the inherent poverty traps (Figure 8).
- Take means-testing out of benefits and social care - we've already paid our taxes, why do those in need have to pay a second set of taxes?
- Guarantee a minimum level of income including income for support - to create a clear and open process for defining what is enough money for each of us to operate as an active citizen.
- Create a constitutional right to support and control - a right that can be protected by the courts.
- Create a robust constitutional framework for delivery of these rights - end the repeated interference by central government with local government, the NHS and every other local 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: our problems are inequality, dependency, over-consumption and greed - these are the problems of wealth not the problems of poverty.

The solutions proposed will ensure everybody, absolutely everybody, is a more active citizen: contributing, connecting and saving. This will increase, not reduce, overall productivity. It is the current system that leaves one third of households in benefit dependency and millions of people operating at reduced levels of productivity.

The real problem is not economics. The real problem is *politics*. All the political parties have become conditioned to fight each other to try and achieve what they believe will be incremental improvements - even when the combined impact of their changes often combines to negate or reverse any real progress. And all political parties chase votes based upon lazy, unfounded and unempirical assumptions:

- **Money improves quality** - putting more money into the NHS improves health, putting more money in education improves education.
- **Regulation improves quality** - more regulation of care, education or health drives up standards.

- **Reorganising (again) improves efficiency** - the perfect structural reorganisation of the NHS, local government, schools or whatever is just around the corner.
- **Toughness and targetting is the answer** - lets better target benefits, get tougher on 'benefit thieves', get tougher on criminals.

We might notice that all of these false assumptions have a share in one deeper illusion: *the more power we give to government the better government will be at solving our problems.*

These illusions 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 the swing voters who determine which group of politicians gets to take control over us.

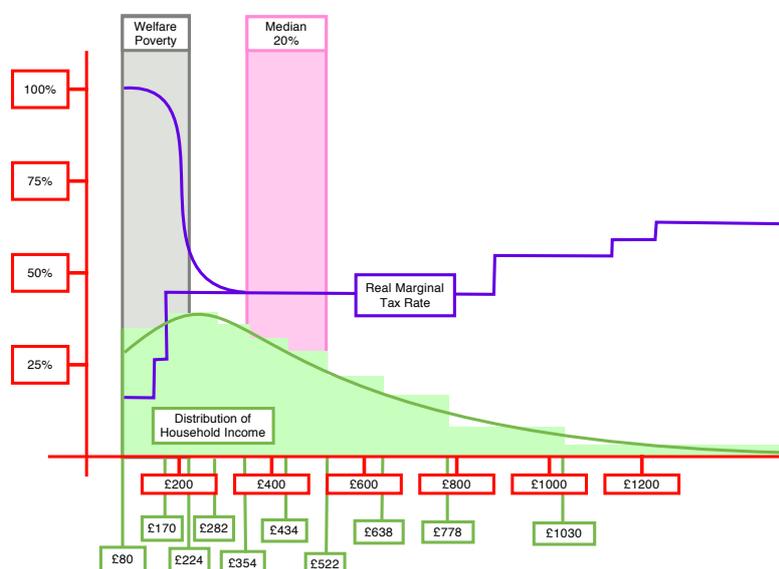


Figure 9. Marginal Tax Rates

For example, if we track the combined marginal tax rates by income (not just the marginal tax rate for income tax) we find that the lowest marginal tax rates are those paid by swing voters - i.e. median voters. The highest marginal taxes are paid by the poor, and then the rich - but not the middle. This is where the important votes sit.

In addition I think there is also a deep problem that is 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 now left in control of next to nothing.

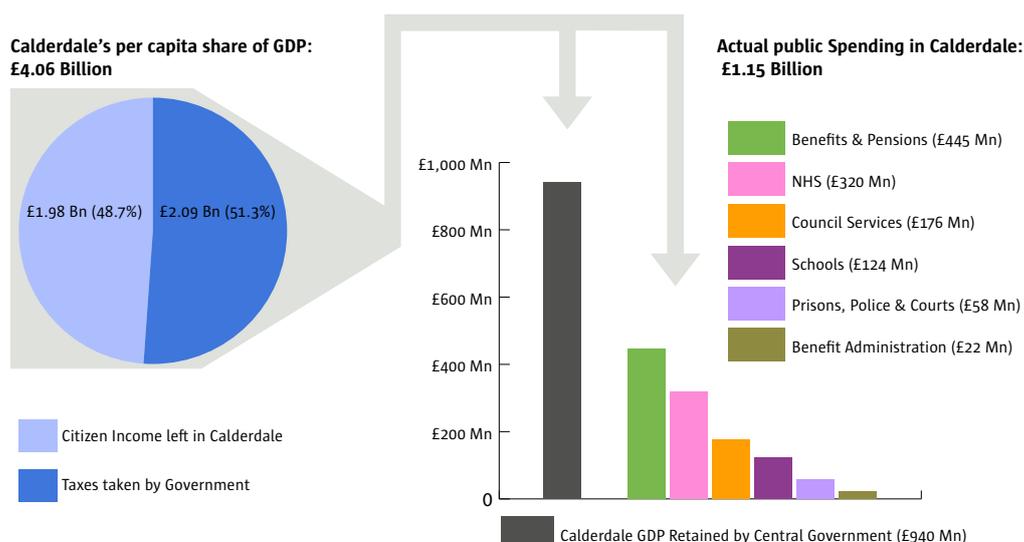


Figure 9. Calderdale Spend

In Figure 9 I have described, using publicly available data, how taxes are returned to the local community of Calderdale (Halifax and the surrounding valleys in West Yorkshire). If we divide national GDP by the population of Calderdale we find that Calderdale's share of GDP is about £4 billion. Of this over £2 billion is taken by central government (Duffy and Hyde, 2011).

**However, if we look at what funding is returned from central government to local government then we find:**

- Only £1.1 billion returns to Calderdale, £0.9 billion remains in London or in centrally run initiatives elsewhere.
- Of the £1.1 billion the largest element is benefits, run from the DWP in Whitehall; the second largest is health care, run from the Department of Health in Whitehall. Calderdale council ranks only third in importance once schools have been extracted - as they will be.
- Local government controls only really controls 15% of local public funding and has even less control of Calderdale's share of taxed income (9%)

To talk about localism in this context is extraordinary. Local government is increasingly like an occupied country - there is an illusion of local control, real power is increasingly centralised in Whitehall.

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 (Duffy, 1996).

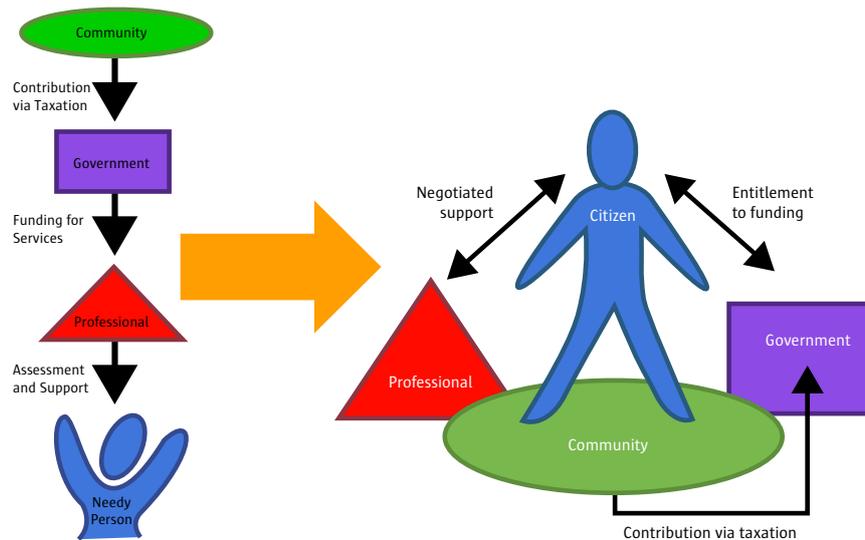


Figure 10. Citizenship Model

I still think this is a helpful way of characterising the challenge we face. Personalisation has shown us that this shift could be more than a pipe dream - when power has been shifted then we see lives improved and communities strengthened. But I am not here to praise personalisation.

The reality is that personalisation, with all the hope it offers, is never going to deliver either a decent or a fair society - unless we put in place a constitutional framework to protect the rights and entitlements of disabled people:

- Our current systems are too paternalistic
- Our rights are too 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.**

It's time to make the case for real and meaningful welfare reform; welfare reform designed with disabled people at the centre. If we do then we may also

find that we can rethink many other aspects of the welfare system - perhaps we can all achieve stronger entitlements and securities - while achieving more control over our lives.

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.

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