



# **From Unfair Cuts to a Fair Society**

Submission to the Joint Committee on Human Rights

and its

**Inquiry into the implementation of the right of disabled people to independent living.**

on behalf of

**The Campaign for a Fair Society**

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## Summary

The current welfare system is not designed to support the rights of older and disabled people - particularly the right to independent living. Many people find that they lack essential supports or, if they are entitled to any support, they find themselves constrained in ways that undermine independent living.

The current government has imposed spending cuts in a way that targets older and disabled people - more than 25% of the planned cuts are likely to fall on 3% of the population - those with the most significant disabilities. It is unfair that these cuts target older and disabled people; but moreover the way in which these cuts are being made will also promote dependency and institutional solutions and is further evidence of the fundamental inadequacy of the current welfare settlement.

We need to reverse the current situation. In a decent society cuts would not fall first on those with the greatest needs. As a society we are failing this critical moral test. It is time to change course, time to build a fair society that ensures citizenship for all; so the Campaign for a Fair Society proposes:

1. **A commitment to human rights:** this means embracing the European Convention on Human Rights and building the UN Convention on Rights of Disabled People into UK law. This reform will involve a fundamental redesign of the obligations of government at every level to secure citizenship for all.
2. **A commitment to make the right to support an objective right established in law:** this will remove the dependency of older and disabled people on 'gifts' from professionals. Instead our entitlement to support and the level of that support will be established as a fundamental aspect of our shared citizenship.
3. **A commitment to provide families and individuals with early support:** this will prevent crises, reduce the need for expensive interventions, and end the indignity of severe eligibility thresholds.
4. **A commitment to put people back in control of their own lives:** this will enhance personal autonomy and dignity by restoring people's right to control both their lives and any essential support that they need.
5. **A commitment to good housing:** this will give people the right to live in their own accessible homes, with a choice of the full range of different types of tenure. This will involve reform of the housing benefit and mortgage interest relief systems.
6. **A commitment to a guaranteed minimum income free from means-testing:** this will create the necessary incentives for people to work and make contributions to civic life. Older people and disabled people will be able to avoid poverty and dependency.
7. **A commitment to end the current super-tax on older and disabled people levied through local authority charges:** this will end the indignity of older people having to spend or give away all their savings just to get minimal support. The right to essential on-going support will be put on the same footing as our rights to healthcare and education.

## Information on the Campaign for a Fair Society

The Campaign for a Fair Society was launched on 8th February 2011. The Campaign has already well over 1,000 personal members and over 60 organisational members.

### 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.*

The Campaign has also identified the **seven principles** below that will help us create a fair society:

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

Organisational members of the Campaign include:

Access Dorset	ENABLE Scotland	Personalisation Plus Ltd
Action for Advocacy	Generate Opportunities Ltd	Paradigm
Advance Housing and Support	ibk initiatives	Partners in Advocacy
Altrum	Isle of Wight Carers Forum - Adults with a Learning Disability	Peaks and Dales Advocacy
Aldingbourne Trust	Enough Is Enough	People First (Scotland)
Alzheimer Scotland	The Foundation for Families	See Me As Me
Ambrey Associates	Havencare (Plymouth) Ltd	Progress Care Housing Association (member of Progress Housing Group)
Archibald Foundation	Heavy Load	Rebound Doncaster
Association for Supported Living	Housing Options	Richmond Mencap
Care Co-ops Community Service	KeyRing	United Response
Cartrefi Cymru	Learning Disability Alliance Scotland	Self Direct
The Centre for Welfare Reform	LivesthroughFriends	Sense Scotland
Choice Support	Lives Unlimited	Sheila Jones Trust
Circles Network	Long Term Conditions Alliance	Skills for People
CCPS - Coalition of Care and Support Providers in Scotland	Scotland (LTCAS)	Southdown Housing Association
Contact a Family - for families with disabled children	MCCH Society Ltd	Stay Up Late
Creative Support Ltd	North West Training and Development Team	Values Into Action Scotland
Centre for Inclusive Futures	Parkwood Extra Care	VoiceAbility
Down's Syndrome Association	Pathways Associates CIC	Jan Walmsley Associates
Down's Syndrome Scotland	Personalisation Forum Group	West Lancs Peer Support Group

More information is available at [www.campaignforafairsociety.org](http://www.campaignforafairsociety.org)

## Introduction

The United Kingdom's welfare system was designed in the 1930's and implemented after World War II. It was an important achievement that created entitlements to income security, health care and education for all. However its design was constrained by thinking that now seems out of date.

In particular:

**Key groups were excluded:** disabled people, older people, people with mental health problems, people with long-term conditions were not considered in the fundamental design of the system.

**Paternalistic solutions were accepted:** schools, hospitals, institutions and centres were accepted as good practice, community alternatives went unrecognised, the idea of independent living not considered and the negative impact of provider interests went unrecognised.

**Communities and families were taken for granted:** little thought was given to the impact of welfare systems on family life or upon the fabric of existing community structures.

At the most general level this has meant that welfare solutions for everyone often discourage citizenship, can undermine family structures and weaken community involvement. However, for older and disabled people and all those who need longer-term support, the impact of the current system has been much more negative: any support has been largely mean-spirited and institutional in character.

Since the 1960's, there have been efforts to amend this post-war settlement and to ensure that older and disabled people are included in ways that better reflect their true needs. But the impact of these changes has been limited and incoherent. Today it is still the case that:

- Older people who need support and disabled people are much more likely to live in poverty
- People who want to work cannot access work (7% of people with learning disabilities work - 65% want to work)
- People often lose their homes or cannot access real homes of their own
- People are subject to hate crimes and abuse - older people are more than 10 times likely to be abused in residential care than in their own home (*Duffy, 2010a*)
- Discrimination is still very real (92% of unborn children with Downs Syndrome are aborted in the UK.)

But perhaps one of the most striking instances of the underlying systemic weakness of the welfare state is that, during the current financial crisis, it is the services, income and support for older and disabled people that are being subject to the most severe cuts. The current round of unfair cuts demonstrates that these supports have not been established as universal rights - instead they are being treated as marginal and optional 'gifts'.

## 1. Unfair cuts

The current cuts in public spending target older and disabled people. Our current estimate is that **at least 25% of the government's cuts will fall on 3% of the population**, those with the most significant disabilities.

Our fullest analysis to date is set out on the Campaign's website and two papers drawn from the website have been enclosed with our submission - *Unfair Cuts* and *Unfair Cuts in Detail*.

If we just focus on the 3% of the population with the most significant disabilities - those entitled to some level of social care - cuts will come in the following areas:

- **Social care funding** - cumulative cuts of £4.6 billion, 20% of the CSR Target (*Comprehensive Spending Review, 2010*).
- **Disability benefits** - cumulative cuts of £4 billion, 17% of CSR target.
- **Social housing** - cuts to social housing will also fall particularly on those older and disabled people who are not in residential care.

However this is to understate the level of unfairness. Additional cuts target other groups with important needs that just happen to fall outside the mainstream public services that have been largely protected, for example: older and disabled people who are not eligible for social care, people with mental health problems, women and families experiencing domestic violence, refugees and many other minority disadvantaged groups.

## 2. Weak entitlements

As well as noting the severity and unfairness of these cuts it is important to note the reasons why the cuts target older and disabled people.

To begin with it is easier to target cuts on older and disabled people because the infrastructure for meeting the rights of disabled people is so fragile, complex and incoherent.

There are multiple disability benefits - but there is no clear logic to their organisation and no clear principle defining either:

- sufficient personal income for a disabled person or
- extra income necessary to meet the costs of disability

The benefit system has developed incrementally and it needs fundamental reform. However the lack of any underlying framework of rights, and the lack of any public principles that can be used to define levels of entitlement, means that the reforms planned by the current government can be made without any reference to principles of fairness or sufficiency.

Additionally social care has been made the responsibility of local government and local government is subject to a set of complex and overlapping legislative

instruments that do not provide a strong guarantee of any right to support. As the Law Commission has noted, social care law is a “a confused patchwork” of measures.

Furthermore the relationship between local and central government in the UK has declined to the point that local government has progressively lost control and influence over most local services - whilst funding for centralised services like the NHS or local services with central funding, like schools, continues to strengthen (even in the current difficult economic climate). Despite the rhetoric of localism (from the current and previous government) the real power of local communities has weakened. This only serves to further weaken the rights of older and disabled people who rely upon locally funded and locally organised services.

### **3. Public confusion**

In addition this pattern of underfunding and inadequate legal protection is part of a long-term pattern where funding for education and healthcare has been prioritised by successive governments. Education and healthcare are perceived as universal services that benefit all of us. Whilst social care and disability benefits are treated as marginal services benefiting minority groups. This perception of marginal status thereby helps to undermine the political will to treat older and disabled people fairly.

This perception marks a fundamental weakness in the current welfare settlement. Moreover this perception is also an illusion - on-going support, the kind of essential support necessary for independent living, is a fundamental and universal right and it is relevant to all of us:

- If we are born with a disability
- If we grow frail in later life
- If we acquire a disability through illness or accident
- If this happens to our family, friends or neighbours
- Or even if we just fear we might experience such an impairment

There is nothing marginal about the right to on-going support. In fact many of the public are quite surprised to find that the right to such support is as weak and fragile as it is. The public often imagine that such support is an essential part of the welfare settlement and are rightly upset and concerned when they find that there is in fact no significant right to such support.

In fact the creation of the concept of social care (as distinct from healthcare) may have played an important part in adding to public confusion. As Nigel Crisp - ex-CEO of the NHS - rightly says, the principles of independent living should be at the heart of all future healthcare provision: “in health the goal for people is independence and the freedom to live a life that they have reason to value” (*Crisp, 2009*).

Moreover, as personalisation and individual budgets are progressively extended into healthcare, including mental health services, many citizens and professionals begin to understand that the idea of a health-social care divide is incoherent and will need to be fundamentally reviewed (*Duffy, 2010b*).

This suggests that ultimately the NHS itself will need to fully embrace the principles of independent living and enable us to end the nonsense of generously funding healthcare while tightly rationing social care. Revisiting the health and social care divide would be one sensible strategy for radically rethinking the current welfare settlement.

## 4. Lack of objective entitlements

One of the other reasons that entitlements to support have been weak is that in the past public responses to disability have been in the form of concrete services - not financial entitlements. However the development of personalisation and the use of individual budgets to meet successfully meet needs has demonstrated that support can often be more usefully framed in terms of money - and that defining a fair budget can be clarified according to public principles - that is, **as a matter of right**.

Of course the notion that an impairment, and any disability it causes, gives rise to an entitlement has been long been recognised in Tort law where calculating the 'cost of a disability' is normal practice. And, although the duty to meet this cost in Tort law lies with anyone who is appropriately culpable, the size of the 'award' is defined only by the level of disability in accordance with principles of natural justice (rather than by the level of blame).

**However the UK welfare system does not currently operate according to principles of natural justice, and this is wrong and incoherent.**

In fact the recent shift to personalisation in social care has not been supported by any coherent account of the principles that should underpin the allocation of budgets and there is some reason to fear that new ideas like 'resource allocation systems' are now being used as a smokescreen behind which significant cuts can be made without adequate legal protection (Naysmith, 2011).

The principle that should underpin the right to support is that any such support should be **sufficient to enable the individual to achieve full and active citizenship**. In addition we need to identify a model of citizenship that should include:

1. The right to be in **control** of one's life and to have the necessary support to make this possible.
2. The right to **direction** and a life of meaning, to be able to set personal goals and the freedom to try and achieve those goals.
3. The right to sufficient **money** so as to avoid undue dependence on others and to enable independent living.

4. The right to a **home** where one can have privacy, safety and live with those you have chosen to live with.
5. The right to decent **help** which enables and supports independence and the pursuit of personal goals.
6. The right to active involvement in the life of the **community**, including access to work and volunteering, the opportunity to form relationships and the chance to have a family.

This model of citizenship could be built in to UK law (with full allowance for the differing legal structures of the four home countries). Although it may seem ambitious it is in fact the minimum requirement of a decent society.

And, rather than being costly, it is in fact the most economically sustainable model - for it ensures the **full use of the whole community's talents**.

## 5. 'Charging' - the disability super-tax

It has also become widely accepted that social care must be subsidised by charging. However the word 'charge' is misleading. Charging is actually a super-tax that targets older and disabled people. Its impact is to lock disabled people into poverty and to encourage older people with modest savings to transfer property to their families far earlier than necessary - further promoting dependency and poverty.

There is no moral case for this super-tax on those in greatest need. The only reason for levying this tax on this group is that social care was not built into the initial welfare settlement and older and disabled people have never exercised sufficient political influence to resist this hidden tax.

In fact our approach to taxation or means-testing for services is entirely incoherent: people with substantially similar needs can find themselves in very different situations simply because of how their need was generated:

- Someone born with Down's Syndrome will be super-taxed
- Someone who has worked through all their life but who then becomes frail in their old age will be super-taxed
- But, someone who acquires a long-term health condition or experiences mental illness may not be super-taxed

The substantial need - the need to live with dignity and to be able to make an active contribution to community life - is identical in every case.

Charging, or super-taxing, disabled people is not only unfair it is expensive. Each local authority sets up its own distinct means-testing system (not one integrated into the tax or benefit systems) and the cost of collecting the relatively modest charges (less than 10% of social care funding) is high. Often disabled people or older people find themselves first assessed for a service, they are then means-tested and finally they can then be told that the cost of



their putative service is equal to the charges they have to pay. This process can take months to complete.

Recent reviews of social care funding have encouraged the idea that we cannot afford to provide sufficient support. This is despite the fact that almost all paid social care is already publicly funded (about 2% of GDP and 4% of government spending) yet most care and support is provided by families - not funded by the taxpayer.

Proposals to encourage private saving or insurance for social care in old age seem particularly unrealistic given the fact that social care for older people is usually only received by a minority of people for a very short period. Currently most people seem unwilling to make proper provision for their own pension - something that will be of benefit to most people for a significant period of their life. So, it seems highly implausible that we can also be persuaded to take out social care insurance. Moreover creating government subsidies in this field is fraught with moral hazards and is likely to further encourage unattractive institutional solutions which are easier for insurance providers to cost control. Such arrangements are most likely to lead to a repeat of the disastrous public policy of the 1980s which saw massive growth in residential care - funded by central government through Board & Lodgings payments to service providers.

The pressure to introduce new insurance funding for social care has been fuelled by a fear of demographic change. But the fear of some 'demographic time-bomb' seems highly exaggerated. Any increase in the population of older people will be relative to a reduction in the population of younger people. And, as a society, we spend significantly more on younger people than we do on older people. Taking a broader view there is no reason to fear that a shift in the demographic profile of the UK demands some new private-insurance model of funding for on-going support.

The real threat emerges if we continue to fail to focus on how to strengthen and support the much more significant network of care and support that already exists in our community. It is by better supporting families, enabling citizenship and strengthening local communities that we will build a society where people will be protected from isolation, abuse, institutionalisation and dependency.

It would be fairer, more efficient and more realistic to abandon this incoherent model of super-taxation for older people and disabled people and to return to the principles that have been successfully enshrined in our health and education systems: support according to need, taxation according to means.

## **6. Prevention and eligibility**

Current government policy demonstrates a deep confusion about prevention and eligibility. On the one hand local authorities are exhorted to prevent need, to provide rehabilitation services and to build community capacity. These are good and sensible measures.

However, and at the same time, local authorities are also told that their responsibility to local citizens can be terminated if people are not eligible for support. This policy - paradoxically named *Fair Access to Care Services* - allows at its most extreme local authorities to only provide support to people who are in critical need and this explicitly **excludes** people in **any** or **all** of the following circumstances:

- you have only partial choice and control over your immediate environment
- you have been abused or neglected, or 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

This level of entitlement is inconsistent with the UN Convention. But it is also inconsistent and incoherent with a policy that promotes prevention. In fact *Fair Access to Care Services* promotes personal and family crises, creates additional needs for support and discourages early intervention.

We need to shift to a model of support where anyone who is at risk of failing to achieve active citizenship may be entitled to support. But where support is proportionate to need and focused on strengthening:

- individual capacity
- social networks
- community opportunities, and
- income - where necessary

This approach is capability-focused and acknowledges that building a good and decent life for a citizen is only partly about having sufficient income. **Real wealth** is not just financial - it also has internal and social dimensions (*Murray, 2011*)

## 7. Personalisation

This government, just like the previous government, has placed considerable emphasis upon what what can be achieved through increased personalisation of health and social care. Personalisation is a broad term but might be thought to include:

- The use of direct payments
- Individual budgets and self-directed support
- Peer support
- Personal assistance

All of these ideas were first developed by disabled people and their allies and were first tested and developed in local communities without the support of central government. Over time, as central government was slowly persuaded of the benefits these ideas, they have been appropriated by policy-makers. However, there has often been a failure to fully consider the real meaning and consequence of these ideas and this is then reflected in poorly thought-through implementation strategies from central government:

The focus of central government effort has been to spend money on consultancy, provide extra funding, offer its own guidance (rarely rooted in good practice) and to set targets for others to achieve. All of these measures are better achieved by communities themselves.

Instead central government has failed to do the very things that only central government can do. It has not created the right legal and economic conditions to promote success nor has it helped define the central rights that personalisation is supposed to realise.

The thinking behind personalisation, like the thinking behind independent living, is that mostly people and local agencies are the best agents for positive change in their own lives and the lives of others. These values have not been reflected in recent change efforts.

The results of this incoherent policy initiative are therefore patchy and inconclusive. In some areas:

- People have budgets on paper, but often have no meaningful control or influence over how those budgets are spent
- People have some control, but are then told - often in retrospect - that they cannot spend that money as they see fit
- People are told that they must live in groups, with people they do not know or like because there is insufficient money to meet ordinary human rights
- People have some money, but not enough, and the individual budget has been used a crude means for cutting funding.

Personalisation offers hope. But it is not a solution for the underlying problems that were created by the old welfare system; personalisation and technologies such as individual budgets were adaptations - designed to bring about positive change within a poorly functioning system. But, in the long-run, it will be necessary to create the right legal and economic changes to properly embed personalised practices.

## **Key Recommendations**

The promotion of independent living within the older welfare system has been piecemeal and often incoherent. The Campaign for a Fair Society believes that the time has come for a much more fundamental review of the rights of older

and disabled people and for a much more radical redesign of the whole welfare state.

Progressive governments have failed to respond to this challenge. However the the implementation of the right to independent living for disabled people, as guaranteed by Article 19, UN Convention on the Rights of Persons with Disabilities creates an ideal opportunity to develop a more wide-ranging and radical approach to establishing independent living for all.

The Campaign for a Fair Society is currently working with its members across the UK to develop a set of practical policy proposals which will transform the experiences of older and disabled people. In summary the current seven proposals seem to offer a strong basis for positive reform:

1. **A commitment to human rights:** this means fully embracing the European Convention on Human Rights and building the UN Convention on Rights of Disabled people into UK law in order to safeguard the full citizenship of older and disabled people.
2. **A commitment to make the right to support an objective right defined in law:** this will remove the dependency of older and disabled people on “gifts” from professionals.
3. **A commitment to provide families and individuals with early support:** this will prevent crises, reduce the need for expensive interventions, and end the indignity of eligibility thresholds.
4. **A commitment to put people back in control of their own lives:** this will enhance personal autonomy and dignity by restoring people’s right to control their lives and any support they need.
5. **A commitment to good housing:** this will give people the right to go on living in their own accessible homes, with a choice of the full range of different types of tenure.
6. **A commitment to a guaranteed minimum income free from means-testing:** this will create the necessary incentives for people to work and make contributions to civic life.
7. **A commitment to end the current super-tax on older and disabled people levied through local authority charges:** this will end the indignity of older people having to spend or give away all their savings just to get minimal support.

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### **Published documents - to be provided**

Unfair Cuts.

Unfair Cuts in Detail.

Fair Society and the Limits of Personalisation.