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# IMAGINING THE FUTURE: CITIZENSHIP

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## **Citizenship and Innovation:**

### An exploration of how innovation in social services can advance of citizenship for all in Scotland

#### **Introduction**

This paper was written in order to explore the future of social services in Scotland. The work was commissioned by the Institute for Research and Innovation in Social Services (IRISS) who asked for a 'think piece':

- 1 To increase awareness of the challenges and drivers likely to operate over the next decade (until 2025)
- 2 To increase awareness of the ideas and resources that can assist individuals and organisations in their planning
- 3 To encourage a willingness to respond creatively to these challenges and increase the level of practical innovation.

Change occurs when old patterns break down and new patterns begin to replace them. Change is not always good. In human affairs it is just as likely that people will react with fear, hatred or injustice to change. So the challenge is not just to change - but to change well - to innovate. If innovation means good change then this forces us to ask a further question - what is good?

This paper is not neutral about the future direction in Scotland. The future is not certain, but whatever difficulties we face, we must seek to increase social justice. Social services, at their best, are a powerful means to build a fairer society. This means a society where the unique talents and abilities of each citizen can flourish. This also means a society where there is a strong sense of mutual responsibility and where citizens, families, community and the state can each find their proper roles.

The paper begins with a moral framework - a source of inspiration for our actions. It is only with the right framework that we can usefully approach more practical questions. I will suggest that the idea of active citizenship should play a much greater part in our future thinking about social justice.

I then consider challenges and drivers that are forcing change upon us and to which we must respond. I will argue that our current problems are rooted in our failure to think about the whole of society and how to achieve sustainable change. Instead we have tended to focus only on professional services and public spending. If we take a more holistic approach then we can start to identify many more solutions for current problems.

In the light of this purpose and those challenges we face we can then identify a range of possible innovations. I have described a range of Scottish and international innovations which demonstrate why a different approach to social change will be much more positive and sustainable.

We will end by considering the political and organisational challenges ahead. Positive social change requires good leadership - at every level. When national, local or community leaders do not see the possibility of positive change then we will slip backwards. It is vital to consider the kinds of personal and relational changes that are most likely to support principled leadership.

## 1. Citizenship

Social services developed over the twentieth-century, striving to promote social justice, yet often constrained by the negative legacy of the workhouse, eugenics and institutional care and the difficulty of achieving complex change in the modern welfare system.

Today there is a growing awareness, both in Scotland and in international law, that the core purpose of social services is to support the achievement of human rights for all (Chetty, Dalrymple and Simmons, 2012). One helpful framework for defining this purpose is the achievement of citizenship for all.

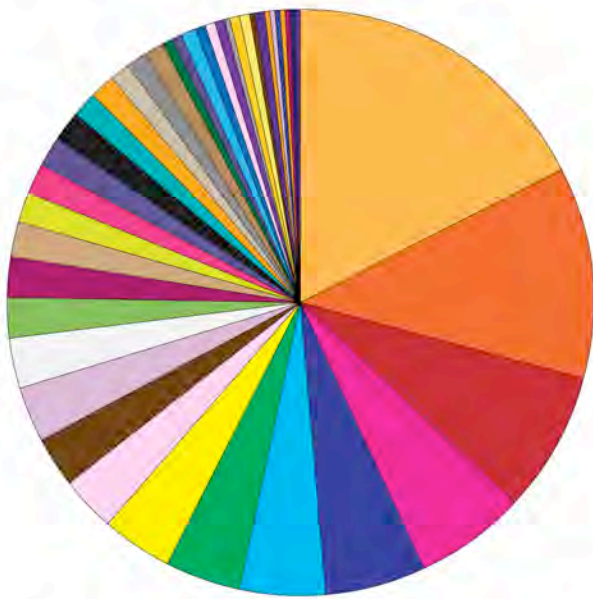
### 1.1 Identifying a shared purpose

To understand the purpose of social services we must begin with the experiences of those who depend upon them. Social services are important to all of us, to our families and to our friends, and they are particularly important to:

- Disabled children, and children with life-limiting conditions
- Families, who provide the vast majority of support
- People with learning difficulties
- People with mental health problems
- People with dementia and other long-term conditions
- People with physical or sensory impairments
- Older people, especially as they begin to need more support
- People at the end of life.

The variety of needs is important. There is a risk that social services is only understood through the perspective of one group. Figure 1 underlines the enormous variety of needs that can be captured by broader terms like disability. It sets out all the underlying conditions for those entitled to Disability Living Allowance (DLA). Although the figure does not include data for people over 65, it does vividly demonstrate the breadth and complexity of the conditions which can create a need for support.

Recipients of DLA  
by main qualifying condition or impairment



Ranked from smallest groups (blood disorders)  
to largest group (Arthritis)



Figure 1 Breakdown of recipients of DLA

It is important to respect the diverse experiences of the many groups that rely on social services (or other services like health and education). However, when we look past these differences, we can also identify important common ground. There is an enormous amount that each group has in common.

We can see this common ground when we examine the distinct government policies for each group and each service area; what stands out is a shared vision of citizenship (Scottish Executive, 2000; Scottish Government, 2007a; 2007b; 2009; 2012a; 2012b):

- Freedoms - independent, able to express your own views and build your own life
- Rights - with rights to support and protection, free from harm and discrimination
- Duties - responsible, contributing to family, community and national life.

These are the three inter-locking dimensions of citizenship as pictured in Figure 2. Citizenship is impossible without each of these dimensions. And each supports the other.

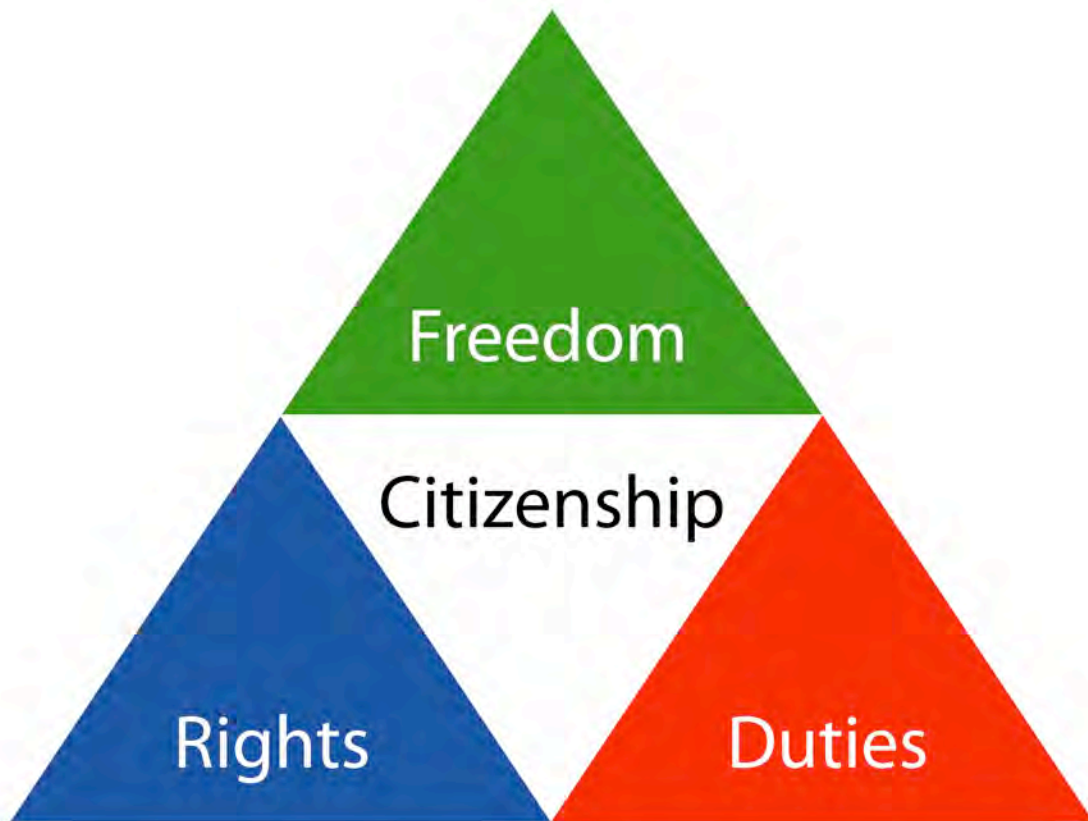


Figure 2 Three dimensions of citizenship

Every government policy seems to echo these themes; the following example is from the [Same as You Consultation](#) (Scottish Government, 2012a) where we hear:

It said that people with learning disabilities had the right to be included in, and contribute to, society, to have a voice, and to have access, with their families, to support to live the life of their choosing.

This is not just a government idea. The idea of citizenship has been used by disabled people since the 1960s to articulate its aspirations and it is still powerful today (Shapiro, 1993). For example a recent report published by Independent Living in Scotland explores the weakness of new terminology like 'personalisation' and instead states clearly:

It was clear that the shared goal of professionals and users of social care is that of citizenship and human rights. [ILiS, 2013]

The fact these aspirations are so long-standing reminds us both that they are important, but also that the challenge of making them real has been very significant. There is still a long way to go to achieve the goal.

## 1.2 Citizenship in social policy

The reality for people, when they find themselves using social services, is that the experience can make them feel like second-class citizens - or perhaps not even true citizens at all. Diminished citizenship is experienced in:

- 1 Demeaning attitudes and a failure to recognise the individuals' unique worth
- 2 Lack of basic freedoms and reduced access to the full range of human rights
- 3 Insufficient income, extra taxes (charges) and inadequate controls over that income
- 4 Homelessness, although often disguised by institutional residential provision
- 5 Inadequate care, rather than useful support that the individual controls
- 6 Exclusion or significant barriers to community, work, leisure and a full life
- 7 Fractured families, lovelessness and isolation.

All of this is unnecessary and deeply damaging to our social fabric. Nothing is to be gained by treating people who have an illness or an impairment, as if they are passive objects. It is wasteful and wrong to ignore people's gifts and capacity for contribution. Yet society has struggled to confront its own history of prejudice, fear and stigmatisation. Indeed the kind of thinking that has dominated social policy in the twentieth-century has been woefully inadequate at doing justice to the experiences of disabled people (Duffy, 2010a).

The two main approaches to social policy have either been statist or liberal. The statist approach has been to treat difference as a problem and then to enforce standardisation, to control individuals and to try and make people more alike. At its extremes this approach leads to eugenics and totalitarian thinking where all differences are erased. The liberal approach is to sacrifice justice to freedom and to accept that, while some groups can flourish, others must suffer. Both the statist and the liberal are willing to sacrifice some people to the 'greater good'. Both approaches threaten anyone who is just too different or who needs a little bit more help than other people.

Citizenship offers a powerful alternative approach. We can begin with an assumption of shared citizenship and then seek to build the kind of society that makes citizenship real - for everyone. Taking citizenship seriously in this way helps us build a society that is capable of achieving and balancing three distinct, but interconnected outcomes (see Figure 3):

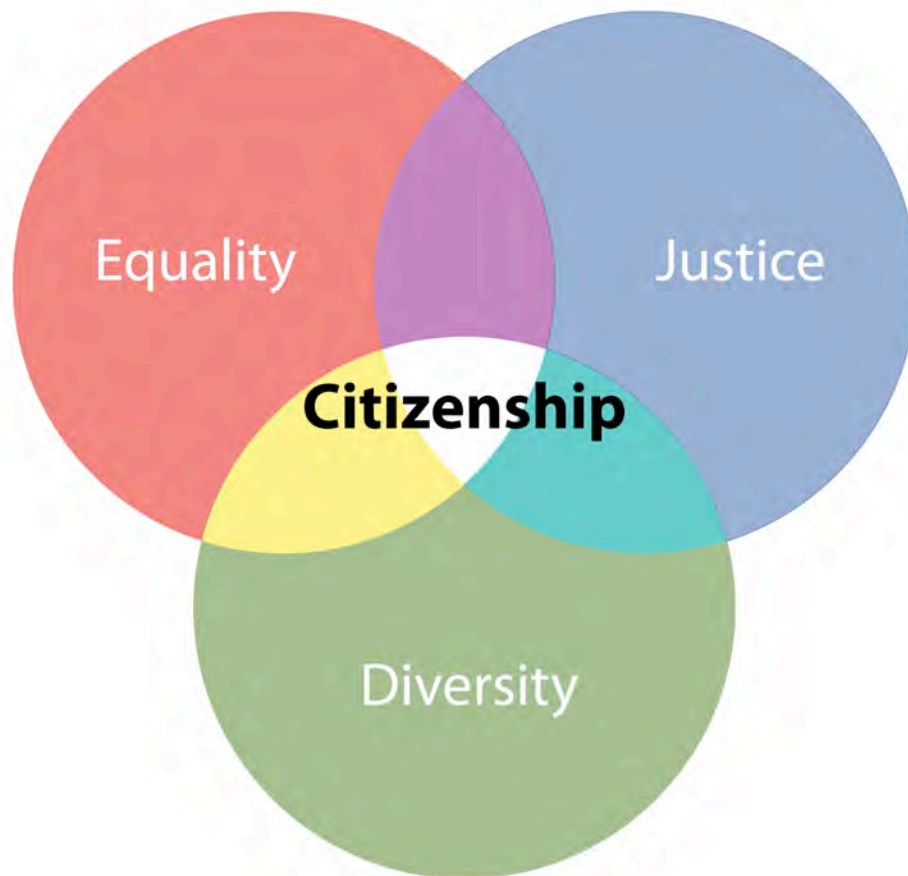


Figure 3 The outcomes of citizenship

- 1 Equality - all citizens are equal, not by being the same, but by being equal in status, equal in dignity, within the community.
- 2 Difference - citizens are different, they bring together different needs and gifts, and it is from the respectful combination of these that community is built.
- 3 Justice - citizenship is achieved by a shared commitment of community to treat each other as equals and to found its laws and institutions upon that equality.

Scotland, as it develops its own social policy for the 21st century, might set itself this challenge:

How can we be a society where everyone is supported to be an active citizen?

### 1.3 Making citizenship real

At this important crux in the history of Scotland there can be no better time to start thinking hard about what citizenship demands of us. As we do this, those who use social services will be the most important people in defining what citizenship means and whether or not it has been achieved. To begin with, one practical framework for citizenship is described in Figure 4 (Duffy, 2006).



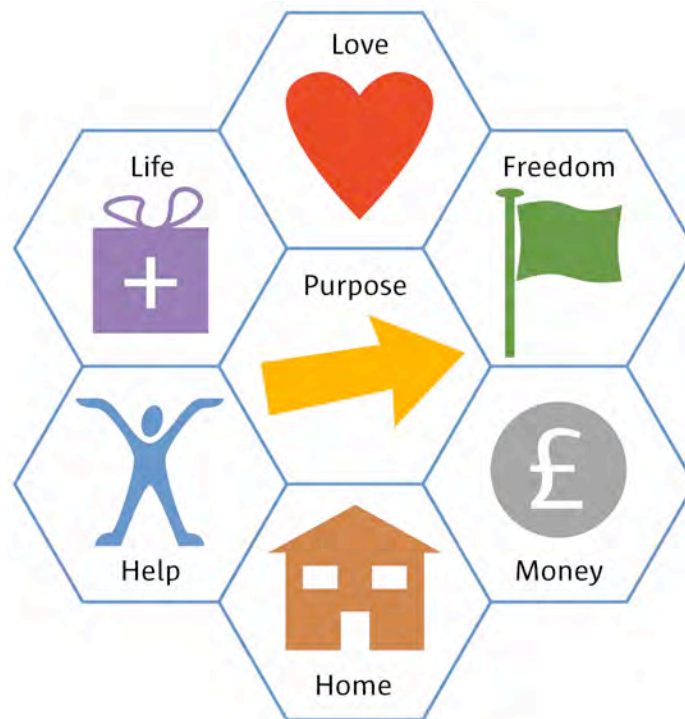


Figure 4 The keys to citizenship

Understood in this way, citizenship provides an account of how diverse individuals can come together in society in respectful and sustainable relationships that ensure:

- 1 Purpose - Citizens can live with purpose, build on their own distinct gifts and needs and set their own goals.
- 2 Freedom - Citizens can be free, can make their own choices and shape the best life that makes sense to them.
- 3 Money - Citizens have enough security of income that they are not unduly dependent on other people but can pursue their own goals.
- 4 Home - Citizens are part of the community, they have a safe and private home that they can control and use to build a life.
- 5 Help - Citizens need other people, they are not isolated, instead they give other people the chance to help and to share their gifts.
- 6 Life - Citizens join in community life, they make a difference within their community and they contribute in ways that make sense of their own gifts.
- 7 Love - Citizens are part of families, form friendships, fall in love and have their own families.

Citizenship does not give us human dignity. Our innate dignity (or worth) exists whatever our circumstances. However citizenship does help us to see that dignity - to feel respect for ourselves and for others. It is a general model of social value, not just for people using social services, and this means it can also be used as a tool for examining many social questions.



Of any social question we can ask:

Will this increase citizenship within our community?

It is also important to notice that citizenship is not a lump or a fixed quantity which can be distributed more or less equally. Extreme inequality kills citizenship for everyone. The most inclusive understanding of citizenship is the strongest form of citizenship. Citizenship, like justice, is something that a fair and decent society measures itself by, or as Ursula Le Guin puts it:

Honour can exist anywhere, love can exist anywhere, but justice can exist only among people who found their relationships upon it.

## 2. Economic realities

Scotland is a wealthy country with a vast range of personal, social and natural assets. Yet in social policy there is a tendency to only think about public services and funding through taxation. To find better solutions for the decade ahead we will need to open our eyes to Scotland's real wealth:

- Diverse population of over 5 million people
- Wide range of talents, skills and abilities
- Rich history, reflected in diverse communities and institutions
- Wonderful natural environment
- Positive values and a commitment to social justice

This will require a change in focus, away from seeing solutions that only focus on taxation and professional service delivery and towards solutions that build on all the capacities of the Scottish people.

### 2.1 Looming threat

The current economic crisis, which has afflicted Western democracies more than most, only underlines a sense of crisis that has been growing in those societies with developed welfare systems since the 1970s. Scotland is not alone in confronting three major challenges:

- 1 Growth in public expenditure, on its own, does not solve social problems (Wilkinson and Pickett, 2010).
- 2 Scotland's demography and society are changing, and the consequences of this are unclear.
- 3 Democratic politics is increasingly focused on swing voters who resist tax increases.

Behind these questions looms a significant level of fear and anxiety about the future. Sometimes policy-makers are even tempted to paint a worst case scenario like this (Hockey, 2012):

Expectations on the state grow, while the willingness of the tax payer to contribute declines. So those parts of the welfare system that don't seem relevant to the majority become increasingly narrow, targeted or even punitive.

If this is the only way in which we can confront economic realities then we will face extreme difficulties in the years ahead. Recent policy-making in Westminster certainly seems to be trapped by a dangerous mental model which is having an increasingly negative impact on the Scotland.

- Public expenditure is perceived as a 'burden' and citizens are encouraged to see existing tax levels as unreasonable and unfair.
- Universal services that are seen as valuable to 'everyone' are protected, while cuts are targeted on those that have less popular support - disabled people, benefit claimants, social services and local government (Duffy, 2013a).

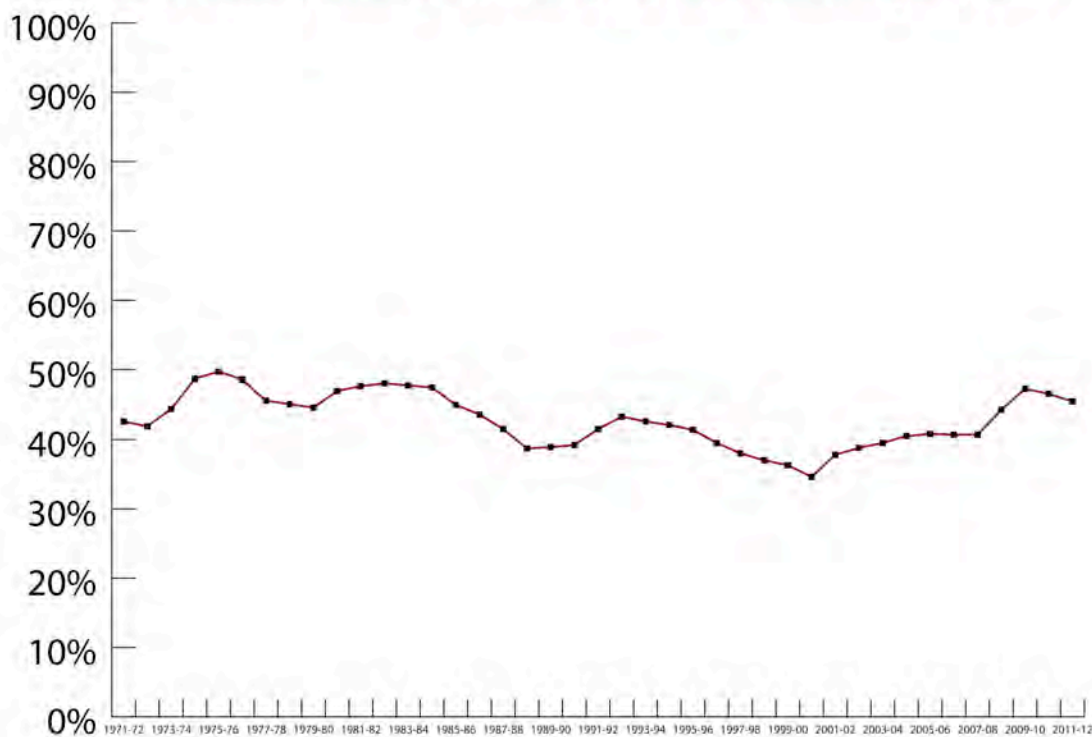
- The idea of rights and entitlements is coming under attack, politicians are tempted into the use of stigmatising language that picks out some groups as ‘undeserving’ of public support.

This pattern of behaviour has a democratic logic for it appeals to the fears and prejudices of key electoral groups. However it is not likely to be the basis of a fair society and it does not seem like the kind of path that Scotland would want to take. The current strategic objectives of the Scottish Government indicate a much healthier path for positive transformation (Scottish Government, 2007b):

- 1 Wealthier and Fairer - Enable businesses and people to increase their wealth and more people to share fairly in that wealth.
- 2 Smarter - Expand opportunities for Scots to succeed from nurture through to life long learning ensuring higher and more widely shared achievements.
- 3 Healthier - Help people to sustain and improve their health, especially in disadvantaged communities, ensuring better, local and faster access to health care.
- 4 Safer and Stronger - Help local communities to flourish, becoming stronger, safer place to live, offering improved opportunities and a better quality of life.
- 5 Greener - Improve Scotland's natural and built environment and the sustainable use and enjoyment of it.

The key to avoiding an unnecessary crisis is to recognise that positive social change and increased citizenship cannot be achieved by a narrow focus on taxation and public services. The real fact is that the level of public expenditure as a share of GDP has remained broadly static since the 1970s; if anything it has been slowly reducing (see Figure 5). But while an exaggerated sense of crisis is not appropriate, neither is complacency.

## UK Public Spending (1971 to 2012) as a percentage of GDP



[Source: HM Treasury (2012) Public Expenditure: Statistical Analyses 2012]

Figure 5 UK Public Expenditure as a percentage of GDP (1971-2012)

Public services will play an important role, and sustainable levels of taxation are essential, but the key to enabling citizenship for all is to work with the whole community. In particular, we need to shift our attention to the real wealth of our communities - of which money is only a small part.

### 2.2 Real wealth

We identified citizenship for all as an appropriate goal of social services, but when it comes to policy and practice the focus of attention quickly narrows. Instead of thinking about the whole population we focus our attention on professional staff. Instead of thinking about the capacities of the whole population we focus on public expenditure. In other words, while we talk about citizenship, we only use the tools of state control.

This path is neither necessary or sensible. It relies on a one-eyed vision of society. It has lost sight of all the many other goods that are not paid for by taxes and which may not even be financial. It has confused society with services.

A useful mental exercise, which helps restore a sense of balance to the discussion, is to simply imagine that all the money in Scotland disappeared. This would not be a good thing - it would disrupt patterns of expectation and leave people fearful that they could not get what they want. But after a moment one can also recognise that all the really essential things of life would still remain in existence.

- People - with skills, time, knowledge and needs

- Relationships - family, friendships, partners
- Assets - buildings, roads, telecommunications, mountains, farms, rivers, the natural world
- Communities - clubs, groups, organisations, churches and faith groups.

This is not to recommend the destruction of money. Money is the best and most efficient system we have yet discovered for enabling certain kinds of very useful exchanges between individuals. But money simply lubricates higher forms of social value - it is not a value in itself. And, as the great Scottish economist Adam Smith noted:

*All money is a matter of belief.*

Focusing only on money - leads to the 'money illusion' - we focus on the appearance of wealth not on the reality of wealth. An alternative model of real wealth has been developed by Murray (2010). By working in partnership with families of disabled children, she explored the factors that kept a family strong and capable of creating positive solutions. Murray's model of real wealth has the following five elements:

- 1 Gifts - our needs, strengths, aspirations and skills
- 2 Assets - money, but also including free time, energy and capital
- 3 People - our network of family, friends and wider connections
- 4 Community - accessible groups, jobs, peer groups, services and places
- 5 Spirit - our inner resources, including a sense of hopefulness or resilience.



Figure 6 The Real Wealth Model

This model is not just relevant to social services, it is relevant to one of the most fundamental changes in perspective that is taking place in both political theory and social policy. During most of the twentieth century theories of social justice have tended to focus primarily on questions of tax and income redistribution. Even the most sophisticated theories have paid little attention to the details of how public expenditure is used nor the other resources essential to a good life (Rawls, 1971).

However, towards the end of the twentieth century, social policy has begun to focus on a different approach. Instead of treating money as the only social good - philosophers like Amartya Sen have observed that injustice cannot simply be treated as the relative lack of money (Sen, 2009). Instead it is more useful to focus on the resources and freedoms which people actually use to build lives of values for themselves. Putting the matter simply we can observe:

*A fair society makes sure everyone is free to contribute to that society.*

It is not enough to just give people money, services or products. People must be free and able to contribute. This is partly because freedom and the ability to contribute are essential elements of the good life and human well being - but it is also because any other approach is unsustainable.

## **2.2 Scotland's real wealth**

If we take the real wealth model and apply it to some of the problems that Scotland will have to tackle over the coming decade, it is clear that Scotland has enormous real wealth. We can see this more clearly if we examine the demography of Scotland from a real wealth perspective.

Table 1 sets out some of the basic demographic data for Scotland. If we just focus on tax and public services we may notice that about 47% of the population are working and thereby paying income tax (although it is important to remember that everyone is paying tax, the very poorest paying the most tax as a percentage of income). We may also notice that about 7% of the population is working in health and social work and so will largely be dependent on taxation and about 8% of the population have an impairment which makes them eligible for DLA or Attendance Allowance.

|                               | number    | percent | source                                |
|-------------------------------|-----------|---------|---------------------------------------|
| Scottish Population 2011      | 5,255,000 |         | National Records of Scotland          |
| Households                    | 2,368,000 |         | National Records of Scotland          |
| Average household size        | 2.2       |         |                                       |
| Aged 0 to 14                  | 1,266,455 | 24.1%   | National Records of Scotland          |
| Aged 14 to 65                 | 2,669,540 | 50.8%   | National Records of Scotland          |
| Aged 65 and over              | 1,319,005 | 25.1%   | National Records of Scotland          |
| Carers                        | 516,358   | 9.83%   | Valuing Carers                        |
| 16 to 65, but not working     | 758,000   | 14.42%  | National Statistics (Inactivity) 2012 |
| Working full time             | 1,788,000 | 34.02%  | National Statistics (Inactivity) 2012 |
| Working part-time             | 672,000   | 12.79%  | National Statistics (Inactivity) 2012 |
| Health and social work staff  | 358,000   | 6.81%   | National Statistics (Inactivity) 2012 |
| Scottish Carers Allowance     | 39,398    | 0.75%   | IFS data (8.5% of UK)                 |
| Scottish DLA Recipients       | 272,247   | 5.18%   | See Appendix                          |
| Scottish Attendance Allowance | 127,500   | 2.43%   | IFS data (8.5% of UK)                 |
| Over 65 and not needing care  | 1,191,505 | 22.67%  | Estimate, based on calculation        |

**Table 1 Demographic data for Scotland**

However there are other ways of looking at the Scottish population. Life is not all about earning money and paying taxes. Modern Western societies have developed increasingly efficient ways of meeting basic human needs, without excessive human labour. If we look at the capacities of Scottish people beyond full time employment:

- 10% of the population currently offer love and support to people who have an illness or impairment (much more if we include families and children)
- About 20% of the population are retired, but don't now need care and support
- About 26% of the working-age population are not in full time employment and so have time for other work
- 8% of the population have significant disabilities - but they too can earn, volunteer, care or contribute in other ways
- The growing population of older people is balanced by a reducing number of younger people, with a subsequent reduction in use of education and other services for children (see Appendix).

So, as Figure 7 indicates, if we think about the needs and the capacities of the whole population then a much richer and more positive picture emerges. All of us need each others support, and



some people may need more support than others, but there is nothing to suggest that we lack the human capacities to take care of each other and work together to ensure everyone can contribute to their maximum potential and in the way that makes best sense of their own gifts.

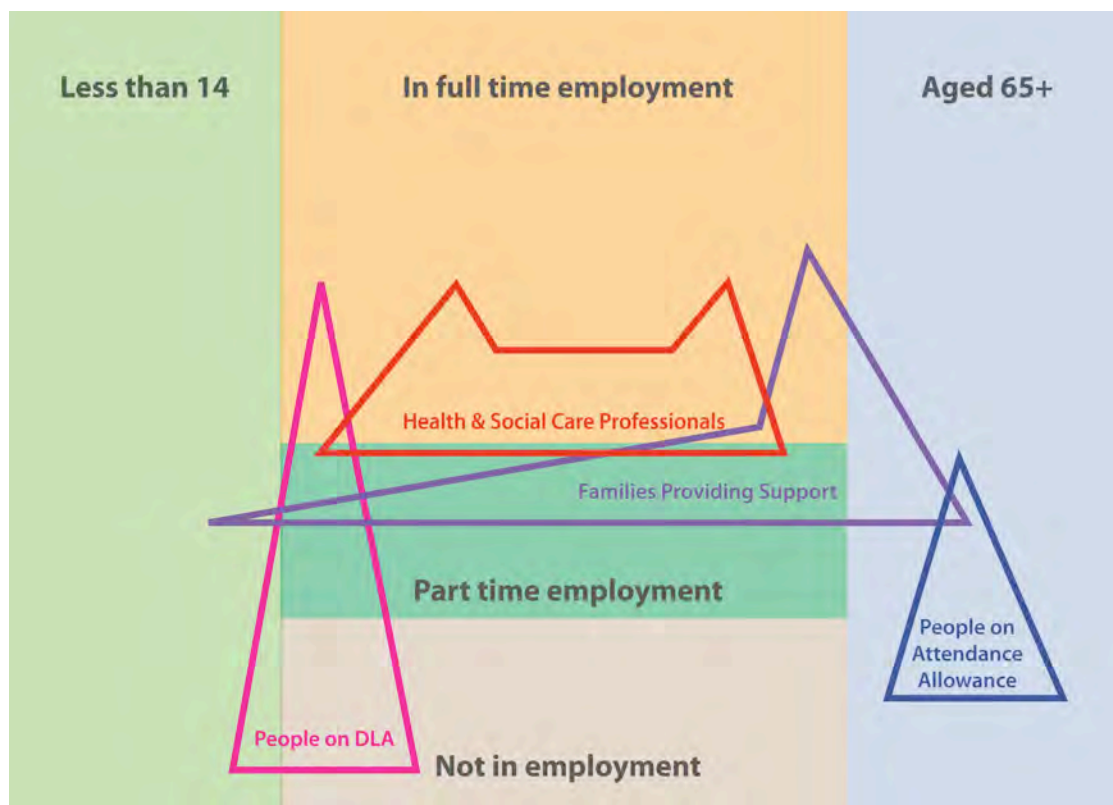


Figure 7 A graphical representation of Scottish population's capacities

This is not to suggest that everything is fine and there are no problems. There will be an important balance to be achieved between:

- Paid employment
- Taxation
- Work that is not paid
- Benefits or personal budgets

If the only solution to every social need is increased expenditure on professional services paid for by taxation then there will be real limits to how Scotland can develop. However, as we will argue, this is not the best way to think about Scotland nor is it how best to promote innovation or increased productivity.

### 3. Pathways for Innovation

The key to finding better solutions for our problems is to innovate. Innovations are not constrained by old patterns and habits; they are attempts to imagine new solutions that channel human energy into much more productive forms.

In particular, innovation tends to think differently about the available resources; it is not limited to narrow zero-sum solutions (Thurow, 2001). Innovation offers us a real alternative to increased rationing, burden-shifting, consumerism or managerialism, the solutions that have tended to dominate recent social policy.

Instead innovations focus on a wider set of resources - and social innovations often focus on our real wealth. Social innovations tend to:

- 1 Make the best use of our gifts, aspirations and skills
- 2 Increase our assets, our money, our free time and our savings
- 3 Develop vibrant and accessible communities
- 4 Encourage stronger relationships between people
- 5 Sustain the human spirit

In fact increased innovation is not just a useful method for achieving citizenship for all, it is actually a strong indication that greater citizenship is being achieved. Human beings are naturally innovative and when they can act freely, with both rights and duties, they will innovate.

In the following sections I will explore the shape of some of these emerging innovations. This will in no way be a comprehensive survey of social innovations. However I hope to indicate the kinds of innovations that one might expect if Scotland used increased social innovation as the means for increasing citizenship for all across the next decade.

#### 3.1 Making the best of our gifts

Perhaps one of the most straightforward approaches to strengthening our real wealth is to improve our skills or abilities. In fact, in one sense, this has been the primary method of engagement offered by the NHS and other professional services: to make people well or to reduce impairment. However, for many disabled people this approach has become oppressive:

- Therapies - not adaptations or aids
- Hospitals - but limited personal assistance
- Medicine - rather than work, peer support or community networks

At a theoretical level this experience has also been conceptualised as the dominance of the 'medical model' over the 'social model' of disability - the system treats problems as if they are 'in the body' of the person rather than in the person's experience of society. This tendency to treat the person as the problem is dangerous and in blatant contradiction to basic human rights.

However, people with rights may also seek to change their abilities. Not just by means of medical science, but also by education, technology or practice. In fact, while it may be true that in some situations disabled people experience medical systems as oppressive in other situations a failure to engage, challenge or stretch someone can also be oppressive (Curran, 2011).

- Many people with learning difficulties and mental health problems want to work but don't get the right support or opportunities. The Office of Disability Issues states, 'In 2012, 46.3 per cent of working-age disabled people are in employment compared to 76.4 per cent of working-age non-disabled people' (ODI, 2013).
- Many people can, with the right support, be much more independent - including older people who can quickly become unduly depressed or dependent in hospital (Lynch, 2008).
- Many people with severe disabilities, with the right adaptations, equipment or technology can communicate, engage and control their own lives (Clarke, 2013).

Education should play a critical role in bringing about the necessary changes. Instead of keeping disabled people segregated in schools and special places, increased inclusion would make disability seem less mysterious and more positive. It would be easier for people to accept impairments as a fundamental fact of the human condition and a reality that will eventually touch all of us.

One obvious area to start would be the whole delivery of training and education. Instead of focusing our education efforts only on professionals, professionals should see the education of citizens as part of their primary role - equipping people with the skills they need to tackle the everyday problems caused by ill health, problems in learning or mental disturbance. In fact this seems to be one of the primary strategies successfully used in developing countries to tackle health problems and it has often been highly successful (Crisp, 2010).

Moreover, attention to the real skills and knowledge that people need will probably lead to the discovery that many of the best educators will be families, disabled people or other citizens outside the existing professional system. If more education and training were provided by people themselves, not by professionals, then efforts to teach and educate would be more universal and community-focused.

It is encouraging to see a new range of books that look at the issue of ageing - not as a professional issue - but as a human life issue - for all of us. These books are particularly focused on helping families plan ahead or deal with the practical, financial and emotional issues that will come with old age (Lynch, 2008; Moon-Willems, 2012).

Overall Scotland may be wise to rethink the whole of the professional education for social services and beyond, with a focus on citizenship development:

[It is time for a radical review of all professional education in social services with a focus on citizens learning for citizenship.](#)

This is not all just about self-improvement. It is also interesting to note some of the innovations in the delivery of medical services that we find in the developing world. In some areas it seems that a different focus and organisation really helps. For example, the Aravind Eye Care Hospital has achieved astonishing outcomes in improving eye sight - by every means, from glasses to surgery - by a sustained and focused outreach strategy. As Vinesh Kumar writes:

Aravind performs roughly 50 percent of the entire NHS's ophthalmic surgical volume, while spending less than 1 percent of the £1.6 billion expended annually by the United Kingdom for eye care delivery. (In 2008-2009, the NHS performed 567,629 eye surgeries. Aravind performed 269,577 surgeries in the same period) (Kumar, 2012).

At a more modest level the recent focus on ensuring people are supported at home after a visit to hospital, to ensure people regain old skills and environments are adapted it likely to be an area of continuing importance (Francis, Fisher and Rutter, 2010). In the same way there are many recovery strategies in mental health which appear to offer helpful improvements and which can often be delivered through peer support (Duffy, 2012b)

### 3.2 Increasing our assets

One of the most important innovations in social services is to give people budgets in place of fixed services. This approach to social services has a long international history, going back at least to the 1960s (O'Brien and Duffy, 2009). Although disabled people have been demanding this approach for some time there has been significant disagreement about:

- Scope - Is it only useful for a narrow group of disabled people who will use it to employ their own personal assistants or does it have much wider application?
- Purpose - Is it an alternative system for delivering social services or is it an entitlement that enables the disabled person to adjust any aspect of their life?

Direct Payments for social care, as it was originally implemented, was usually conceptualised as both narrow in scope and narrow in purpose. However the [Social Care \(Self-directed Support\) \(Scotland\) Act 2013](#) marks an important stage in the further development of these ideas. Furthermore Scotland has played a particularly important role in the international development of these ideas.

One of the most important Scottish innovations has been the 'Individual Service Fund' which is a system for managing personal budgets within an organisation (Scottish Executive, 2000; Fitzpatrick 2010). This innovation opens up the control of budgets to a much wider group - in the early work this was people with learning disabilities and people with severe mental health problems. It also enables service providers to take on a new and more creative role - designing bespoke services around people and making the best use of limited resources. It means taking a budget and holding it safe within an organisation; management costs are controlled and the budget must be treated as restricted funding - only to be spent for the person's benefit (see Figure 8).

## Individual Service Fund

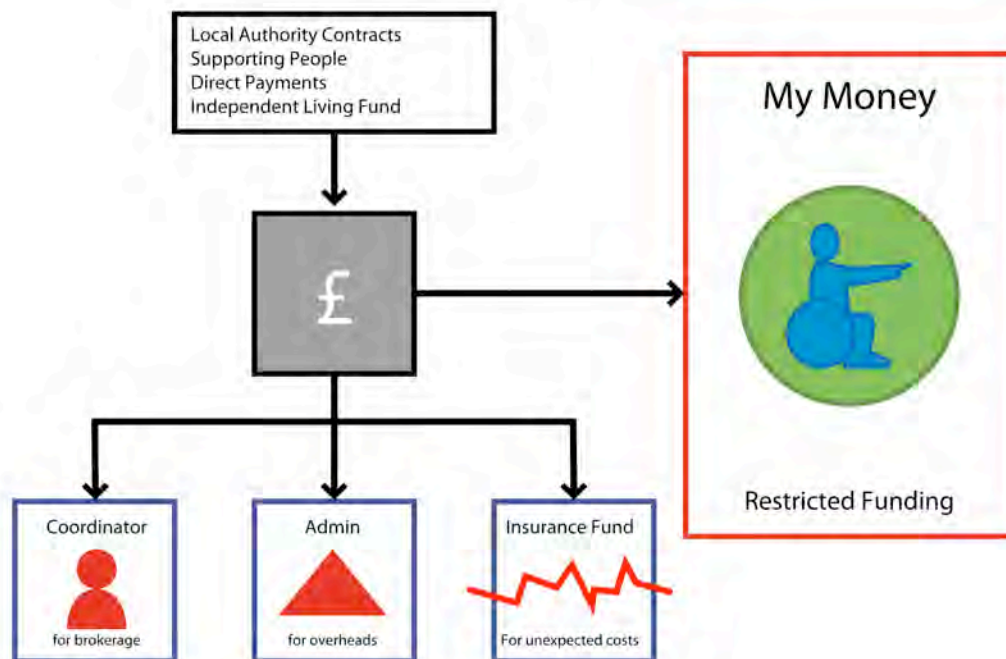


Figure 8 Individual Service Fund

Lynn was a woman with severe physical and intellectual impairments. Her family wanted her to live at home full time but work and the physical limitations of their home made this impossible. For lack of support she left her family home and was moved into Lennox Castle Hospital. The normal model for institutional closures has been to move people, especially with significant disabilities, into group homes. However Lynn was supported by Inclusion Glasgow, the organisation that invented Individual Service Funds. Lynn's budget was used flexibly to fund:

- Professional support and advice
- Personal assistance
- A new family home
- Suitable adaptations

This may sound expensive, but it in fact cost 50% of the average service for someone leaving Lennox Castle Hospital. It was efficient and it was effective because it fitted Lynn's needs, her desires and it was developed as a partnership with Lynn's family.

Innovations like Individual Service Funds demonstrate that people who do not want to directly manage a cash budget or employ staff can still benefit from a system that enables more control and flexibility. This may include:

- People with mental health problems
- People with chronic health conditions

- Older people needing assistance, but unwilling to become an employer
- People with dementia
- People at the end of life
- And many other groups

Self-directed support is not only an innovation in itself, it is also the source of further innovations. When people know what they are entitled to and can use the funding flexibly then they will often spend that money in ways which are more creative and appropriate than the old system which was locked into funding fixed services (Duffy and Etherington, 2012). For instance, as the data in Figure 9 demonstrates, people with flexible budgets often move away from using traditional services altogether. Instead many will focus on getting more personal support, accessing the community or supporting themselves, each other or their families. In other words - using and developing their real wealth.

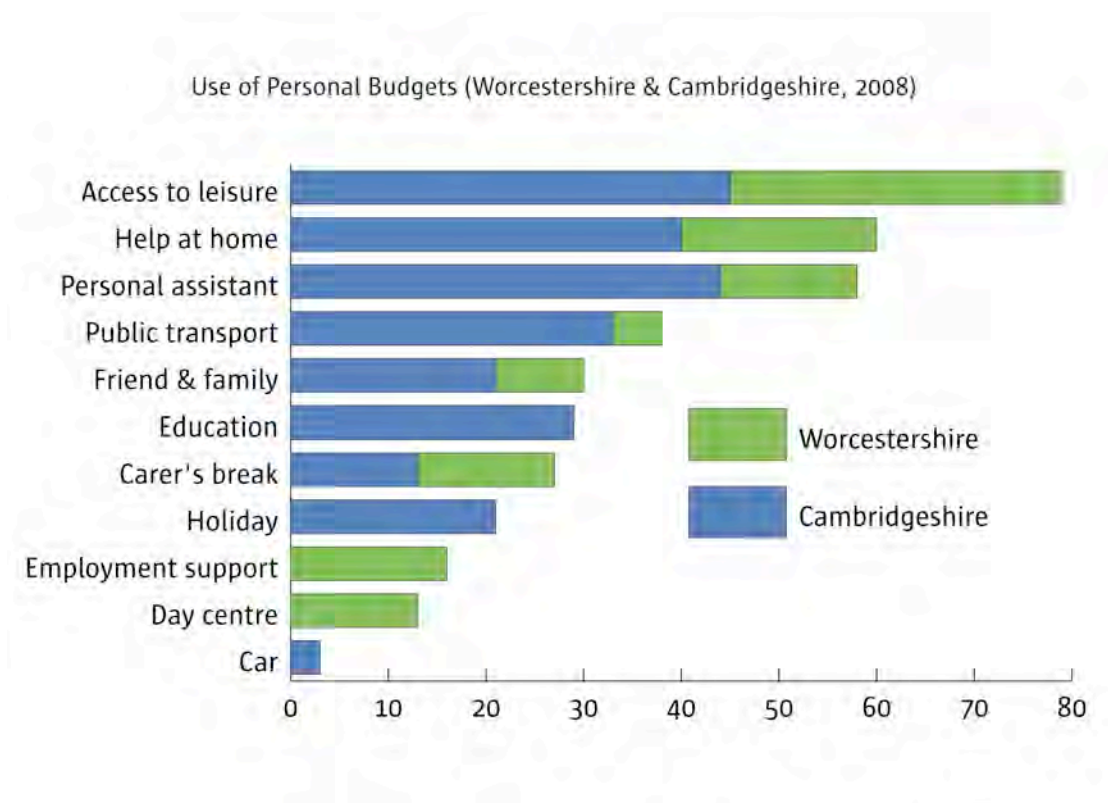


Figure 9 How people can use personal budgets

However it is very important to note that the details of how self-directed support is introduced are vitally important - poor implementation will lead to increased waste and no improvement in outcomes (Duffy, 2011a, 2012a, 2013b).

Finally it is also worth reflecting on how much further the idea of self-directed support could go. For instance, there are good reasons to think that it could play an increasing role in both education and healthcare. Much of the early work on self-directed support was carried out in the USA with people in the mental health system (Alakeson, 2010). It has been further argued that there is



considerable potential for reducing waste within the healthcare system by applying self-directed support (Alakeson and Duffy, 2011).

The value of self-directed support in education is far from clear, but some early pioneering work does seem interesting. One of the most radical innovations so far has been in Sheffield, where local families and professionals reformed the transition process for disabled children (Cowen, 2010). In this model, the school acted as a hub both for both a citizenship-focused curriculum and family peer support (Murray, 2011). Families were given budgets for social care, healthcare and education and the chance to make flexible use of these resources (see Figure 10). This model not only improved outcomes but it helped families manage their expectations and avoided the pressure for out of area placements, which often coincides with the transition process.

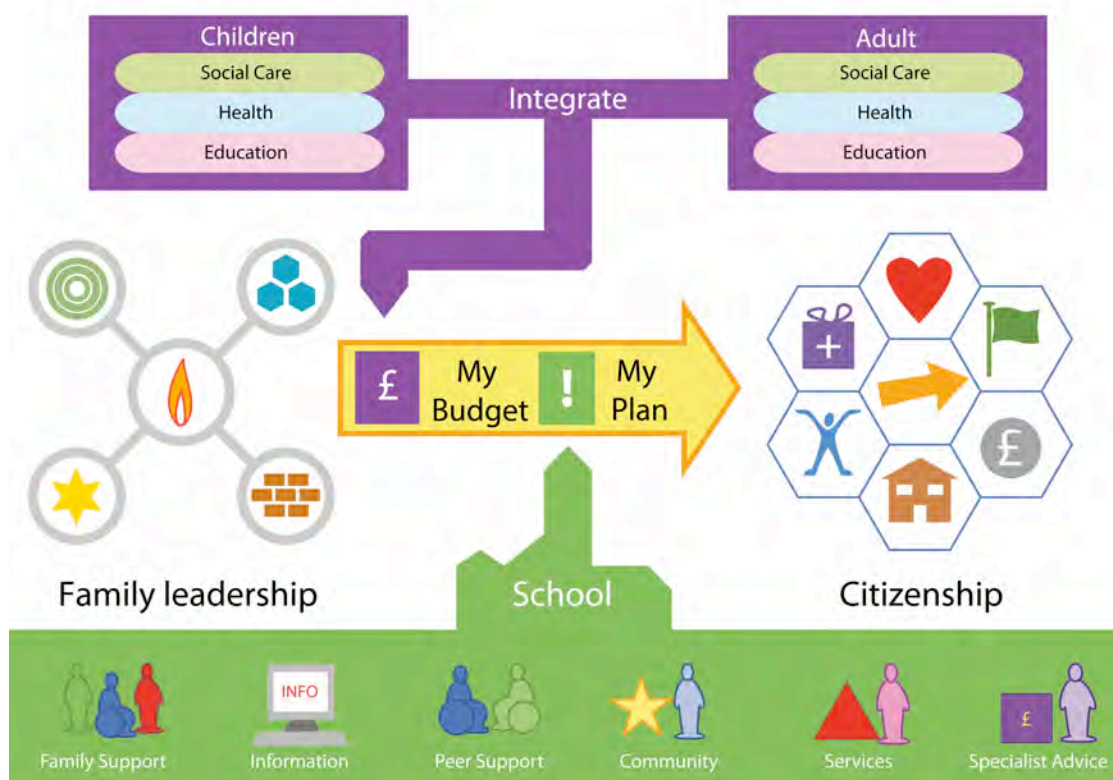


Figure 10 Personalised transition in Sheffield

Again, these innovations are far from easy. In particular they raise significant questions about the purpose of social services and the degree of trust in the system. If there is no assumption that citizens have the right to make decisions for themselves, nor any systems to support decision-making or offer appropriate representation then these arrangements will breakdown. Although the data strongly suggests people make the best decisions about their own lives there is a natural resistance in existing services to see power transferred to citizens.

### 3.3 Improving our communities

One of the criticisms of systems, like self-directed support, that focus on individual rights and individual control, is that they might undermine collective systems of support or social security. This is a legitimate worry, but it is interesting to note that our notion of the 'collective' is often confused. There is tension between three kinds of collectivity:



- 1 State-based - System organised and funded by the state to which citizens contribute by taxation and which can be influenced by political processes.
- 2 Commerce-based - Collective solutions which citizens can choose to purchase or can choose to become employed within.
- 3 Community-based - Activities that bring citizens together and to which citizens willingly contribute time, money and good will.

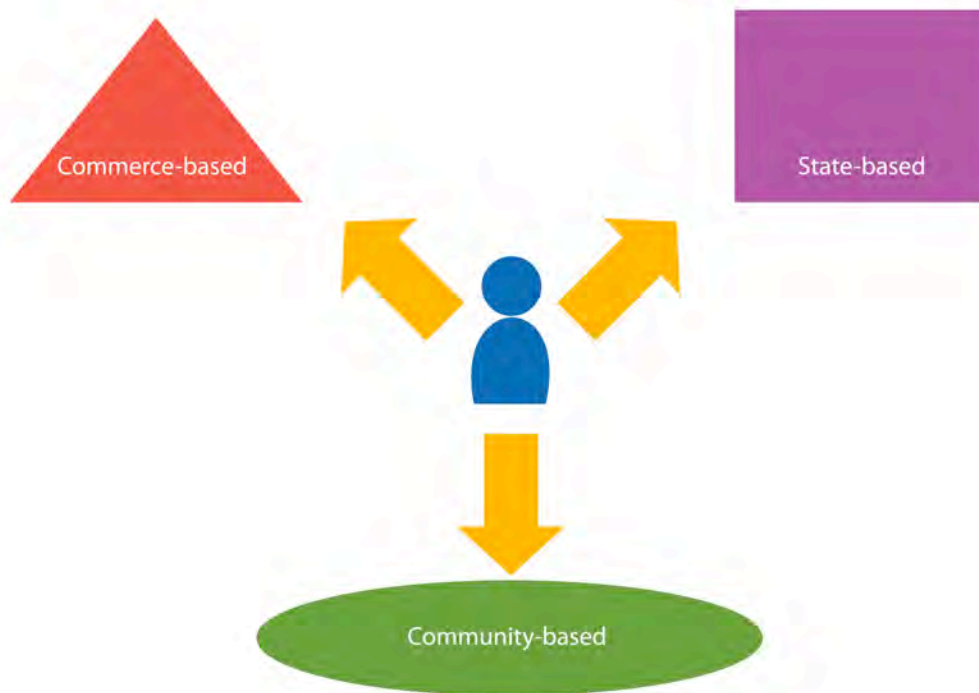


Figure 11 Three kinds of collective effort

All three approaches are necessary. There are some things which, on balance, we prefer to have organised 'for us' by the state or by commerce, but there are other things which might be better organised by ourselves. And this question is not static. Sometimes things which start as citizen-based initiatives become, in time, established as a state-based systems. Sometimes a state-based initiative is re-established as a citizen-based initiative. As society changes it is likely that these patterns will also need to change.

In fact it has been cogently argued that much that we take for granted in the welfare state was first established by a combination of citizen action or municipal initiative (Yapp, 2011). It may well be that the current economic crisis and the end of the 'growing welfare state' will require a similar focus on citizen-based initiatives - both to supplement and replace welfare solutions that no longer seem effective.

Scotland has a long history of effective collective action and self help in its communities. A contemporary example of this approach is found in Neighbourhood Networks, an organisation that supports people with learning disabilities to be active citizens in their local communities. The model ensures that people living in their own homes are connected into a self help community within a small geographical neighbourhood. Limited on-going support is not focused on care, but

on facilitating self help and advocacy between the group members. It is a highly effective and efficient alternative to institutional residential care or providing professional support to people who live in their own home. It taps into the power of collective action. Group members do not just have rights - they also have responsibilities to each other - and the exercise of these responsibilities strengthens their own confidence and community. Similarly Scotland's housing association and co-operative movement is a solid example of social change, innovation and social enterprise started by collective action and community self help and leadership.

One of the most powerful sources of support and of collective political action is peer support. For example the Personalisation Forum Group from Doncaster has in a very short period of time, and without any statutory support:

- Created a system of mutual support with an annual value of £250,000
- Pressured their local authority and NHS provider to provide personal budgets for people with mental health problems
- Developed a wide range of new community activities in partnership with civil society organisations - private and voluntary
- Created new networks of peer support organisations locally and nationally

Rather than just demanding changes within the mental health system the group are creating those changes and working with other local leaders to bring about those changes (Duffy, 2012b). As Figure 12 indicates these changes rely not just on the existence of a group, but the ability of that group to find a way of working which has integrity. Often this requires skilled facilitation.

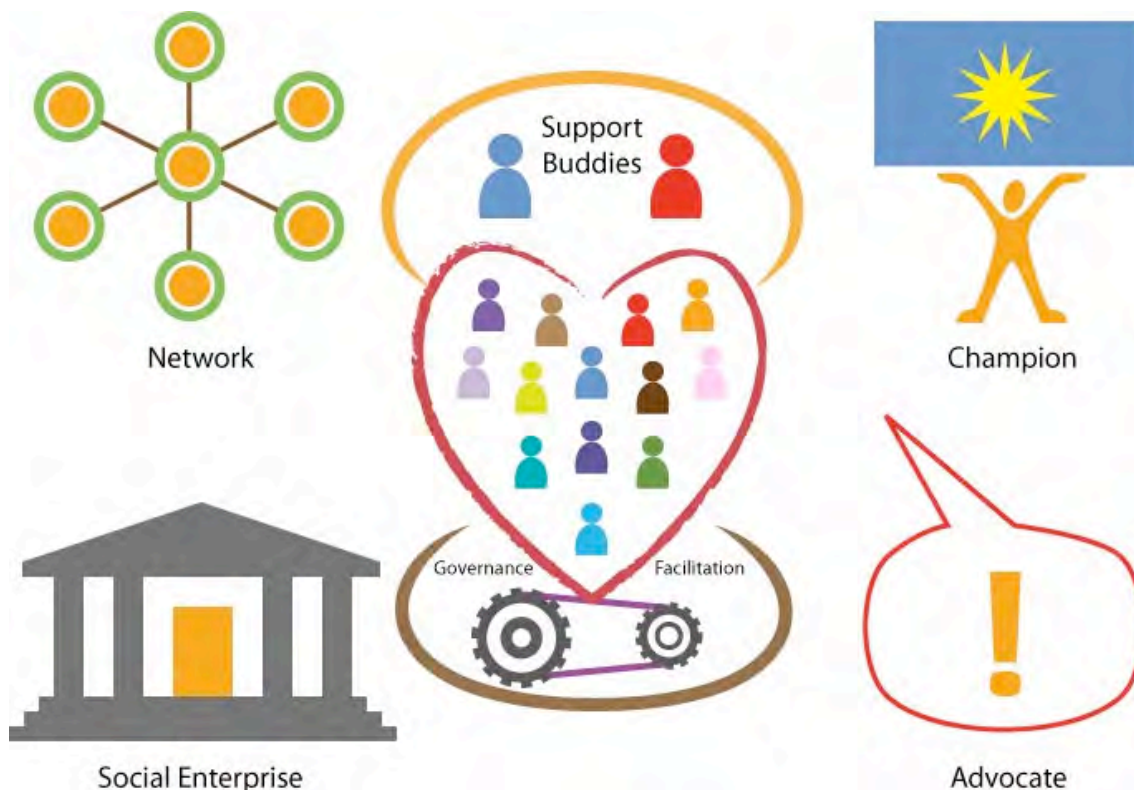


Figure 12 The work of the Personalisation Forum Group in Doncaster

It is particularly important to note that there is no direct conflict here between community-based approaches and the role of the state - quite the opposite. To the extent that the state helps clarify entitlements and shift resources towards citizens and communities more of these genuinely local initiatives can develop. When entitlements are eroded collective action becomes harder - not easier.

### **3.4 Strengthening our relationships**

In the twenty-first century we will need to start becoming much more mindful of our relationships with other people. It is certainly not the case that people are simply becoming inevitably more isolated, lonely and disconnected. The fact that a vast section of the population of Scotland are providing support to their children, their family or friends demonstrates that love, duty and relationships still matter.

However it is true to observe that social services are often not sensitive to the damage done to relationships in their work (Rhodes, 2010). Here are just a few of the problems that are created by systems that don't always focus on the value of relationships:

- Families often experience limited support, until they reach crisis point, then family support is completely replaced with residential care.
- Women go to prison for minor crimes, rather offering appropriate support the system funds both their stay in prison and the cost of putting the children into care.
- Rather than linking people into community associations, clubs or friendship groups the system has invested in day centres.
- People are not supported into work and miss the chance to make new friends and experience new responsibilities.
- Some people, especially people with learning disabilities are not given the education or the opportunity to enter into loving sexual relationships.

Of course the kinds of peer support organisations described above are also about building relationships of friendship. Other important initiatives seek to support and protect families who are on the edge of fracture. One inspiring example is WomenCentre - an organisation run by local women in Halifax for local women. Its work has won international attention for its commitment to support those women whose lives are in the greatest difficulties. It often ends up serving people who have been failed by public services, who have many needs and seem too complex for mainstream services or those who are in danger of going into prison or losing their children. Its work is practical, highly effective and costs a fraction of statutory services (Duffy and Hyde, 2011).

The WomenCentre's model is described in Figure 13. At its heart is the relationship with women which works hopefully and positively to overcome practical and emotional problems. Many women who work through their problems come back to work as volunteers or staff.

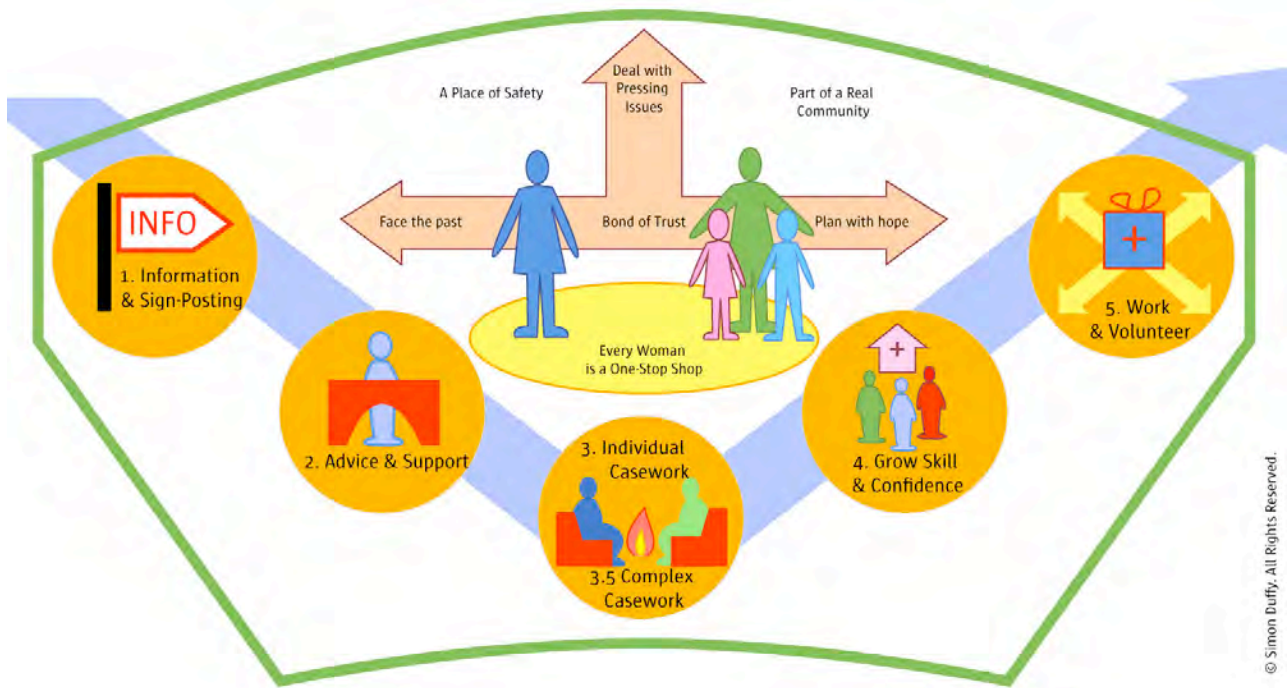


Figure 13 WomenCentre

This is not just a problem of social services ‘substituting for’ or damaging existing relationships. Often social services have developed in ways that seem to undermine the possibility of relationship between the professional and the citizen. The development of more transactional approaches, like care management, may have contributed to a loss of capacity for social workers and others to form the kind of relationship that can be genuinely transformative.

### 3.5 Igniting the human spirit

What is at the heart of many of these innovations is a willingness to pay much more attention to the inner dimension of human change. Exciting systems, models, initiatives or organisations fail because the people implementing them have lost sight of what they were really trying to do. With failure comes new funding, regulations, bureaucracy and management - all of which repeat the same failing pattern.

Increasingly social innovators are looking inward. They are seeking to both ensure that their own work has more integrity and that they listen more closely to the dreams, aspirations and real needs of those they support. At its best concepts like Recovery and Person-Centredness help us avoid damaging professional definitions of need. Instead people’s own journeys, dreams and aspirations are validated. We see this same approach in an important innovation imported from Australia to Scotland - Local Area Co-ordination. This can help people define solutions on their own terms, building on their own real wealth (Broad, 2012).

Perhaps one of the most striking international examples of this focus on the inner dimension of change also comes from India. Manavodaya helped train facilitators to support self help groups in India (Vidyarthi and Wilson, 2008). Their impact has been tremendous. Hundreds of thousands of villagers, usually women, have worked together to:

- free themselves from debt-slavery
- start businesses

- tackle domestic violence and alcoholism
- challenge powerful vested interests
- and much else beside

These groups live in a kind of poverty which it is difficult for Westerners to understand. Yet they are not powerless, if they are able to recognise within themselves that capacity to bring about change with integrity.

As I have described, Scotland already has a powerful and positive tradition of social innovation to build on. Many of the best innovations in social services today can be seen in Scotland. But the challenge is to go further. This is both about increasing the capacity to innovate and the commitment to move away from institutional models of care and disempowering systems. In the final section of this paper I will outline some of the main systemic strategies that Scotland might want to consider.

## 4. Making it real

The future for social services in Scotland is in our hands. It will be defined by the actions of Scottish people, within local and community groups, professional associations, organisations and Scottish government. It is possible that there will be no progress. If we remain attached to an unsustainable model where every social problem requires more funding from the tax-payer then progress will cease.

Equally if we fall into the opposite trap of seeing the welfare state or taxation as the problem we are likely to make things even worse. The way forward depends upon stepping out of a simplistic less-or-more paradigm and instead asking some different questions. In particular:

- We need to clarify our purpose. If we see citizenship and the realisation of people's human rights as the goal this makes our task both more feasible and more respectful of the experiences of disabled people.
- We need to rethink our resources. The 5.2 million people of Scotland are our greatest resource - with all their gifts, skills, knowledge, time and energy. We need sustainable approaches for getting the best from ourselves and each other.
- We need to innovate. When there is no more new money the only way of improving value is to do things differently, design things better and to embrace fresh thinking. Scotland will not develop by sticking to solutions and structures that were defined in the 1940s.

But how do we make any of this real. In this final section I am going to address the issues of social policy that Scotland will need to consider if innovation is going to be more than a buzz word.

### 4.1 The process of innovation

Innovations cannot be produced on demand, they cannot simply be purchased and they cannot be simply implemented by the command of central government. Innovations have their own life-cycle as described in Figure 14 (Duffy, 2013c). This is important to understand because one of the classic mistakes of government when it decides to promote innovation is to believe that government itself is likely to know how to discover and deliver innovations. Nothing could be further from the truth.



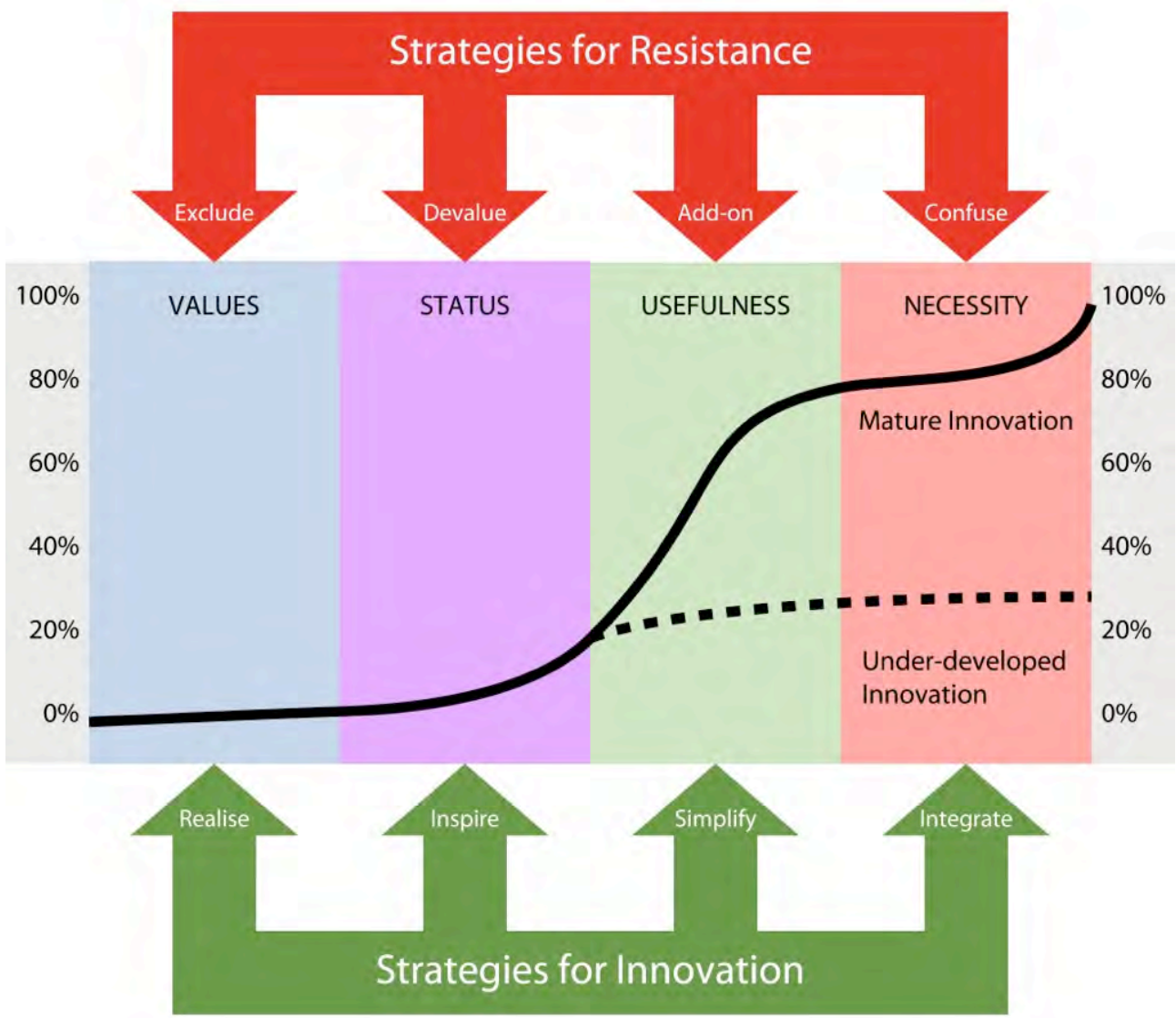


Figure 14 The diffusion and corruption of innovations

In fact any important innovation is almost always perceived as a threat to the status quo, vested interests and the normal pattern of good practice. In the same way innovators are typically seen as mavericks or trouble-makers. The way in which all systems tend to treat innovation is to resist it by marginalising the innovator and the innovation - often by simply ignoring them.

It is useful to look at some of the innovations described above or some of the other important innovations in social services developed over the past fifty years. Some of these innovations include:

- Centres for Independent Living - hubs of peer support for disabled people
- Recovery practices - therapies and support for people with mental health problems



- Personal assistance - personalised support, often an employee of the disabled person
- Supported living - real housing rights and flexible support for people with learning disabilities
- Self-directed support - giving control of funding and support to the citizen

None of these innovations was invented by government. Each of these innovations was developed by individuals or by small groups. Progress in making these innovations real and then developing and extending the innovations has varied and is often very patchy. There are four main stages to the process of innovation and the challenges change at each stage:

- 1 **Realise** - The first hurdle is to find a way of making the innovation real - at any stage. At this stage it is inevitable that the innovator is working from faith not evidence, as innovations inevitably lack evidence - that's what makes them an innovation. The fewer people who need to be convinced at the beginning the greater the chance of doing an initial experiment. Any ideas that demand whole system change are especially hard to introduce.
- 2 **Inspire** - Once an innovation becomes real then it is easier to inspire people, to get interest, status and further support for the idea. Of course this will require evidence. If it is easy to show satisfaction, share positive testimony, produce data or prove savings then the innovation may develop. Of course many innovations will fail here because the evidence is lacking - the innovation was not good enough. However systems will often resist the innovation further by demanding unachievable levels of evidence.
- 3 **Simplify** - The third stage of innovation development is design improvement and simplification. It is rare that any innovation is perfect. Usually early innovations are too complex and too demanding of their users. It takes time and a focus on the 'average' user in order to improve an innovation. Sometimes in systems this process of development doesn't happen, instead resistance is turned into grudging acceptance and the innovation is imposed on the system 'warts and all.' This seems to be a particular risk in public systems where government can impose an innovation without citizens being able to pick, choose or reject the innovation.
- 4 **Integrate** - The final stage of development of an innovation is to be integrated into the wider system so that it becomes necessary for everyone. At this stage the innovation can almost disappear into the background.

The welfare state of the 1940s was not designed for on-going innovation. Although it was a powerful innovation in its own right, its actual design has made further innovation difficult, for several reasons:

- too many details are locked in legislation
- there is too much conformity and too much pressure for conformity
- it is insufficiently sensitive to citizen preferences
- it is insufficiently sensitive to economic incentives

The welfare state has certainly grown, with new funding and new services. However the result of that growth is often complexity, confusion and wastefulness. And innovation, transformation and more radical change is very difficult to achieve within our current framework.

The reality is that society has changed. It is impossible for the welfare state to develop simply by spending more money. There is even a danger things will go backwards if society's support for the welfare state declines. It is time to redesign the welfare state infrastructure so that it supports innovation:

- More opportunities to make changes
- Increased transparency and easier process for research and evaluation
- Greater scope for effective leadership and development
- Self-discipline and protection for people's human rights

Creating the right environment for innovation should be the primary goal for policy-makers and researchers. Innovations start at the margins and they need positive attention and resource flexibility in order to thrive. Bodies like IRISS and other academic bodies have a valuable role to play in supporting innovation at a much earlier point in the innovation cycle - and in a manner that is proportionate.

#### **4.2 Innovation values**

While innovation is challenging it has been achieved, to some degree, and in some place. When we examine the factors that enabled this innovation to begin it turns out not to be money, systems or influence but values.

As Figure 14 describes, if we explore what lies at the roots of any of the powerful innovations that have had some success it is a commitment to equal and active citizenship, a rejection of stigma, segregation and isolation. It is the moral fabric of Scottish society that will determine the success of innovation in Scotland.

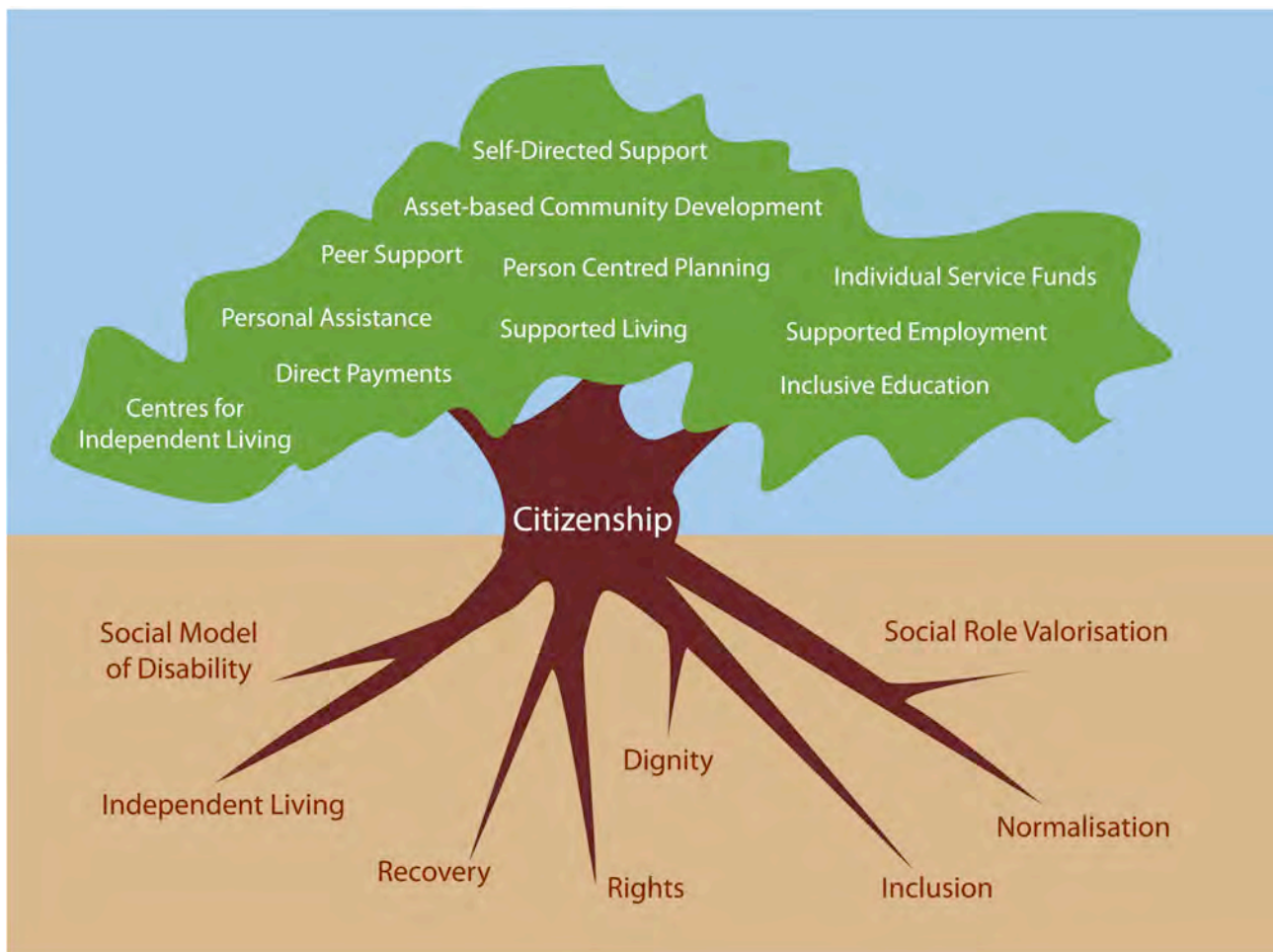


Figure 15 Innovation and values

Perhaps even more fundamental than values themselves are the people who hold them. For innovations to come to life there needs to be communication and points of understanding and trust between different individuals and groups:

- Different disability groups
- Charities and advocacy organisations
- Service providers
- Local government

The paradox is that innovation and the necessary opportunities to realise those innovations depend on trust within and between these groups. However often the relationships within and between these groups have been damaged and fear closes down opportunities for innovation. Partly this may have been caused by the very process of competing for funding. When central government is the primary source of funding then it is natural that each group will seek to push itself forward ahead of other groups.

A culture of innovation demands that people think about citizenship not just as an end - but as a means. We will need to take personal responsibility for:

- Supporting fellow citizens with their ideas - but also constructively challenging those ideas
- Sharing information, learning - both successes and failures
- Building new partnerships and overcoming mistrust
- Participating in the democratic processes

It is positive to see the emergence of initiatives like the Scottish Campaign for a Fair Society, which is trying to establish a wider alliance for positive change in Scotland - finding the common ground between different groups and trying to insert new solutions into the political process.

### **4.3 Diversity and innovation**

One of the biggest challenges for innovation is to accept the possibility of diversity. Without diversity innovation dies. This issue is going to be particularly important as Scotland sets about rethinking the role of local government and its relationship to the NHS. It is also relevant to the question of how Scotland might develop its own constitutional arrangements.

From an international perspective the UK is possibly the most centralised welfare state in the world. Scotland has a choice of maintaining this model or of shifting to a model where local communities have a much greater level of local control.

Innovation and development requires diversity because making something better can never be achieved immediately. It begins in one place, in one service or in one system and then it spreads over time - if the conditions are right. Logically this also means that there will be an uneven distribution of the innovation.

At some point standardising any such innovation may be necessary; what began as a marginal innovation can reach a point when it is best treated as a standardised part of the framework. However there are severe dangers when:

- Standardisation leaves no room for innovation
- Immature innovations are standardised too early
- Local government or peak bodies reduce the capacity for innovation by demanding national guidance or targets

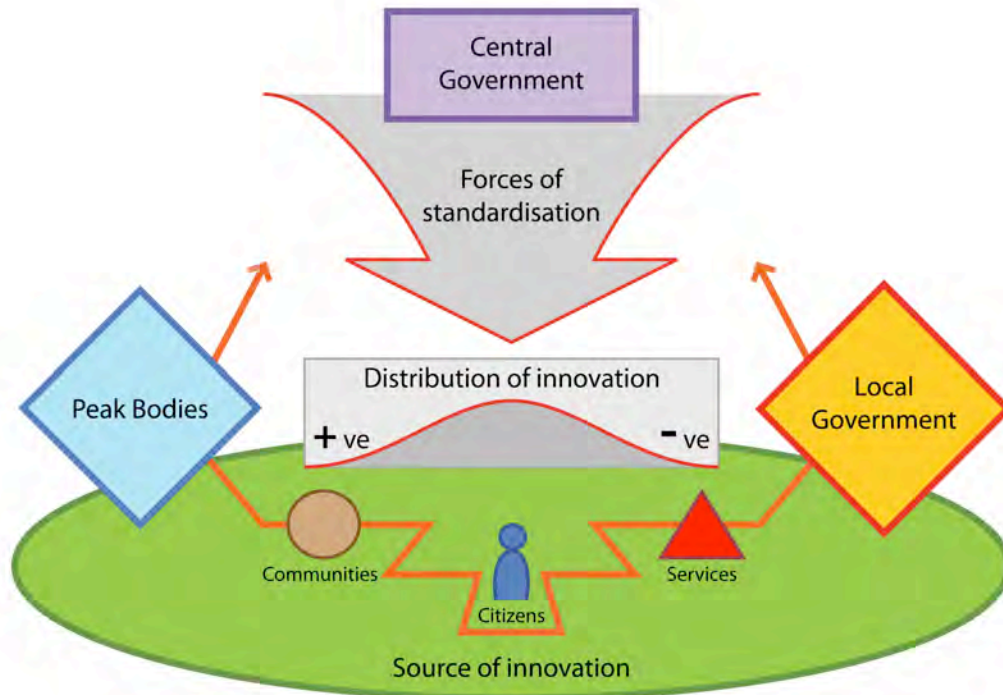


Figure 16 Innovation and diversity

Rethinking the health and social care divide presents a particularly interesting example of this problem. The health-social care distinction was defined by the Thatcher government and has now been institutionalised across the UK in a divide between local government (managing modest, highly means-tested resources) and a centrally-managed NHS (managing significant, non-means-tested resources).

Arguably the divide has been unhelpful in many areas, and it seems particularly out of place in mental health services. There is wide recognition that better mental health will not be achieved by further spending on institutional placements, care homes, day centres and hospital beds. Instead the focus should be on employment, inclusion, peer support and talking therapies. However the current balance of spending has largely remained in place - high spending on professional or institutional services, low spending on community and peer support options.

Furthermore, the development of self-directed support suggests there may be better fault-lines in the system. Perhaps it would be more helpful to abandon the distinction between health and social care but to seek to distinguish those services that are best commissioned for people and services that people are better at commissioning for themselves. This may also be the time to abandon means-testing altogether.

Innovation is possible in almost any structure, but Scotland would be advised to explore developing structures that are more open to innovation and diversity.

#### 4.4 Funding innovation

Paradoxically funding innovation may not be the best focus for developing innovation. The danger in new funding for new projects is that the process repeats the old pattern of welfare service

delivery and pushes money into the wrong projects. When the new money runs out it is hoped that commissioners will then disinvest from older systems and start to invest in new systems. In practice this often does not happen and it will be even harder to achieve in an economic environment where such new money will be even harder to identify.

Instead it may be more useful to focus on sustainability and the 'recycling' of resources. Innovators and leaders will need to focus on entrepreneurship:

The entrepreneur shifts resources out of an area of lower and into an area of higher productivity and greater yield (J B Say).

From the very beginning the innovator should be focused on the process of shifting resources out of the old system. The system can do many things to make this kind of entrepreneurship possible:

- Make current investment patterns much more transparent
- Increase the flexibility of contracts and statutory funding
- Avoid 'creaming' off funding from contracts or personal budgets
- Individualise funding, rather than locking it into big blocks
- Encourage transparency of pricing
- Use open source standards for developments
- Limit the use of regulations and bureaucratic measures to exclude competition
- Work with the grain of existing organisations or professions

An example of how innovations can be undermined by the system's tendency to protect itself from innovation was in the direct payment system. It has been quite typical for someone to take a direct payment only to find that they receive only a fraction of what someone without a direct payment receives. Salary levels are presumed to be lower and management costs are excluded - naturally this undermines the development of the innovation and continues to lock up resources wastefully within the statutory system.

Innovations do not flourish when they are seen as an expensive addition to current practice; they flourish when they are designed to be a more efficient alternative to current practice.

#### **4.5 Innovation and a constitution for welfare**

Even if Scotland does not become an independent state there is great value in considering the value of a constitutional approach to welfare. Constitutions can help create the right disciplines that allow for a combination of local freedoms within a framework of shared rights.

The development of the nation state was combined with a great increase in centralised power during the fifteenth and sixteenth centuries. There was then a further period of constitutional challenge as people tried to make the state more accountable to the people. Possibly there is an analogy today between that situation and our own. In the twentieth-century the state has taken on even greater powers and responsibilities - the nation state has become the welfare state. But

it is not clear that the balance of responsibilities between the welfare state and the citizen is correct.

Constitutional settlements create rights and duties, and they also create structures within which entitlements can be defined, fine judgements can be made and debates and challenges can be heard. Arguably the current democratic structures have not really been designed to support the development of the welfare state.

The [UN Declaration of Human Rights](#) and the [UN Convention on the Rights of Person with Disabilities](#) provide us with strong intellectual foundations for our thinking. But these ideas are not well reflected in the current welfare system and our attempts to use them as leverage for change are piecemeal and tactical.

A logical approach to Scotland's future, and one that builds on its Enlightenment heritage and its commitment to social justice, is to begin to distinguish:

- 1 **Core human rights** - these would be protected by law that was difficult to change
- 2 **National Entitlements** - within the framework of rights it would be possible to define specific measures that would be fixed nationally, by some transparent process (e.g. a minimum income guarantee for Scotland).
- 3 **National Insurance or a system of hypothecation** - financial self-discipline would be increased if entitlements were defined in relationship to a share of national income
- 4 **Independent National Systems of evaluation** - helping clarify outcomes achieved, costs, patterns of innovation
- 5 **Local entitlements** - local democratic bodies could set local levels of entitlement (e.g. person budget levels)
- 6 **Clear local leadership** - democratic structures at the local level to guarantee local strategic oversight
- 7 **Judicial or quasi-judicial review** - allowing local systems to be challenged if they did not seem to be delivering within the national framework

This kind of constitutional approach to innovation and the welfare state might better promote rights and innovation.



## Conclusion

The aim of this paper is not to predict but to define an attractive and feasible pathway which opens the imagination up to possibilities. In brief the main points have been:

- The need to make the advancement of citizenship central to the purpose of the modern welfare state
- The need to look at capacities, not just funding, and to recognise Scotland's real wealth
- The existence of multiple opportunities for radical innovation
- The possibility of building systems that promote more effective and rapid innovation

If Scotland were to follow this route to innovation in social services it could break out of the damaging approaches which are currently dominant in Westminster. It could define a more positive and Scottish direction, based on its commitment to social justice and faith in the qualities of the Scottish people to develop fairer and more effective solutions.

If this is the direction of travel that Scotland determines for itself then I would suggest that these are four things we could expect to see:

- 1 Citizens and families will have more clarity and more control, they will be reshaping their experience of social services both individually, with peers and in partnership with local government.
- 2 Local leaders will be working with greater freedom to innovate and build different partnerships to promote positive social change.
- 3 Policy-makers and civil society leaders will be focusing on how to create the right framework of rights and entitlements for all Scots.
- 4 Internationally Scotland will be known as a champion to innovation, social justice and human rights.

This is a possible pathway, and it is the only pathway that ensures the development of an effective and sustainable social services system.

## Appendix

### Disability

This breakdown of the use of DLA presents a good overview of the complexity and breadth of the category of disability and the diversity of experiences of physical illness, impairment or mental illness (although it excludes Attendance Allowance and so does not reflect the full experiences of people over 65). Figures for Scotland are estimates, based solely on relative population size (8.5% of UK).

|                                 | UK     | Scotland |                                  | UK     | Scotland |
|---------------------------------|--------|----------|----------------------------------|--------|----------|
| Arthritis                       | 562390 | 47803    | Parkinsons Disease               | 18,310 | 1,556    |
| Learning Difficulties           | 380250 | 32321    | Severely Mentally Impaired       | 17,080 | 1,452    |
| Psychosis                       | 245030 | 20828    | Renal Disorders                  | 16,640 | 1,414    |
| Muscles, Bone or Joints Disease | 197440 | 16782    | Bowel and Stomach Disease        | 15,900 | 1,352    |
| Psychoneurosis                  | 177940 | 15125    | Skin Disease                     | 15,880 | 1,350    |
| Back Pain                       | 150960 | 12832    | Personality Disorder             | 15,180 | 1,290    |
| Neurological Diseases           | 127920 | 10873    | Dementia                         | 14,850 | 1,262    |
| Heart Disease                   | 125070 | 10631    | Multi System Disorders           | 10,840 | 921      |
| Cerebrovascular Disease         | 102920 | 8748     | Metabolic Disease                | 10,270 | 873      |
| Chest Disease                   | 91250  | 7756     | Traumatic Paraplegia/Tetraplegia | 9,380  | 797      |
| Spondylosis                     | 91060  | 7740     | Inflammatory Bowel Disease       | 8,740  | 743      |
| Unknown                         | 88520  | 7524     | AIDS                             | 8,000  | 680      |
| Epilepsy                        | 72350  | 6150     | Cystic Fibrosis                  | 7,160  | 609      |
| Blindness                       | 69630  | 5919     | Blood Disorders                  | 5,610  | 477      |
| Multiple Sclerosis              | 63680  | 5413     | Frailty                          | 1,990  | 169      |
| Diabetes Mellitus               | 58790  | 4997     | Motor Neurone Disease            | 1,820  | 155      |
| Trauma to Limbs                 | 53,300 | 4,531    | Haemophilia                      | 1,600  | 136      |
| Malignant Disease               | 51,540 | 4,381    | Cognitive Disorder               | 1,390  | 118      |
| Hyperkinetic Syndrome           | 51,510 | 4,378    | Multiple Allergy Syndrome        | 1,170  | 99       |
| Behavioral Disorder             | 45,900 | 3,902    | Double Amputee                   | 1,100  | 94       |
| Deafness                        | 42,950 | 3,651    | Haemodialysis                    | 580    | 49       |
| Chronic Fatigue Syndromes       | 38,190 | 3,246    | Deaf/Blind                       | 570    | 48       |

|                             | UK     | Scotland |                            | UK        | Scotland |
|-----------------------------|--------|----------|----------------------------|-----------|----------|
| Terminally Ill              | 34,890 | 2,966    | Infectious disease         | 450       | 38       |
| Asthma                      | 31,780 | 2,701    | Tuberculosis               | 330       | 28       |
| Alcohol and Drug Abuse      | 21,340 | 1,814    | Total Parenteral Nutrition | 320       | 27       |
| Peripheral vascular Disease | 20,850 | 1,772    | Bacterial disease          | 70        | 6        |
| Major Trauma                | 20,220 | 1,719    | TOTAL                      | 3,202,900 | 272,247  |

Of course these numbers will significantly understate the true incidence of each illness or impairment. DLA is an under-claimed benefit with high eligibility criteria. The incidence of each illness or disability will be much higher; however it does provide a certain profile of the experiences of those people with the most severe disabilities.

## Acknowledgements

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## Organisations

The Institute for Research and Innovation in Social Services (IRISS) [www.iriss.org.uk](http://www.iriss.org.uk)

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