A Fair Society and the Limits of Personalisation

This is an easy-read summary of a talk given by Simon Duffy at the 2011 Tizard Memorial Lecture at the University of Kent.

1. The welfare state is good but it is not perfect.

Over 65 years ago, in the United Kingdom, we decided to change our society. We built something we call the welfare state. This is a really good thing, it means:

- Healthcare for everyone
- Education for everyone
- Pensions and benefits for everyone

When the welfare state was built we forgot to do some other important things:

- Many disabled people were left in hospitals and institutions
- Many families of disabled people and older people got no help
- If you did get help you got no control over it
So the welfare state is a good thing - it is not perfect - it can be improved.

2. Disabled people have improved the welfare state

Disabled people, their families and their supporters have had to work hard to try and improve things:

1. the institutions had to be closed down - this has taken many years - but we have finally achieved it.

2. people have had to take back control of their lives in community - this is what is happening now.

Disabled people and families are:

• using direct payments and individual budgets to control their own help

• trying to get paid work in their communities
They also:
• want the right to go to ordinary schools
• want the right to buy or choose their homes and live like anyone else

Disabled people don’t want to live:
• in institutions with no control
• in poverty waiting for handouts

Disabled people want to be citizens - with full and equal rights

3. Personalisation is good

Over the last 20 years we have seen some big, good changes that have made lives of some disabled people better.

Examples of the changes are:

• Direct payments and individual budgets have improved people’s lives
• Person centred planning has helped people take back control
• Supported living has helped people get their own homes with the support they need
• Supported employment has helped people get work
• Inclusive education has helped some people go to mainstream schools
• Advocacy and self advocacy groups have helped people stand up for themselves

Politicians are now talking about these ideas and calling them ‘Personalisation’.

But it is important to remember that these ideas and approaches were not created by government - they were created by disabled people, families and their supporters. These are our ideas.

4. But personalisation is not the answer

Personalisation is good; but it is not good enough.
There are many big problems. Many people:

- Can’t get **any support** - even when they are in desperate need
- Can’t get **enough support** to have a decent life
- Can’t get **real control** over their lives

People don’t have the **right to get support** and there is **no right to control that support**.

Too much depends on whether you are lucky enough to meet a good professional or live in a good local area.

5. The cuts show how unfair the current system is

Between 2011 and 2015 the government will be making the biggest cuts to public services we have ever seen.

But at the same time government has said it will **protect some things**:

- healthcare - the NHS
- education and schools
• pensions

Each year we give the government £500 billion through our taxes. The above services cost £350 billion pounds a year.

It also important to notice that what is not protected is support for disabled people and we will see big cuts in

• disability benefits - money to live
• social care - support to be in the community
• social housing – houses in the community
• advocacy and legal aid - support to stand up for our rights

6. Why the cuts target disabled people

I think most people don’t realise how unfair the cuts are and how badly they will affect disabled people.

It is hard to understand why the United Kingdom
is making disabled people pay the cost for a financial crisis. The crisis was created by rich and powerful people. They still have money and power. The United Kingdom is one of the richest countries in the world.

But there are many reasons why the cuts target disabled people:

- Disabled people are quite a small group - many people just don’t think about them
- We don’t have good laws - this makes it easy to cut funding for support
  Systems are confusing - some systems - like disability benefits - are so complicated that it is easy to make cuts and call it reform
- Some people have a bad attitude towards disabled people
- Some people just imagine everything is okay - they know that the government spends more than half of all our money and they just hope that they spend it well

So what can we do about this?

7. Join the Campaign for a Fair Society

The Campaign for a Fair Society has been
launched to try and bring people together to fight the unfair cuts - but also to fight for positive and real change.

The Campaign believes:

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

We think these seven ideas could 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 things to offer.
3. **Community** - support and services should be based in local communities.
4. **Control** - we have the help we need to be in control of our own life and support.
5. **Capacity** - we are helped to achieve what we are capable of.
6. **Connection** - we all get chances to make friends and build relationships.
7. **Equality** - we all share the same basic rights. We are all entitled to
the same things.

We have learned a lot over the last 60 years about what makes for a fair society.

We know that people need to be **citizens with real rights** and the ability to live good and fulfilling lives.

We know that this means **full inclusion in society**, with support where necessary.

We know that this does not just benefit disabled people. It benefits families and communities. It makes **society fairer for everyone**. It helps build a decent society where everyone is treated with dignity and respect.

But we cannot take the things that have got better for granted. There is a real risk of things going back to the bad old days. **So we need to work together** to make sure that cannot happen.