

When do you stop being a citizen?



- In 1992 I first visited **Madison** it was an amazing experience.
- I am honoured and thankful to be invited back here by **In Control Wisconsin** and hope I can do some justice to everything Madison has given to me.
- I also want to honour **Terry Lynch**. Terry has taught me so much and I think we are lucky to have such a modern day saint amongst us.
- This will be an ambitious talk - combining thoughts taken from philosophy, history, economics and politics. I hope I can offer some thoughts about where next for self-directed support...
- Some of this may seem like dreaming - but we need to dream.

In memory of those who've gone before us, who loved us and whom we loved...

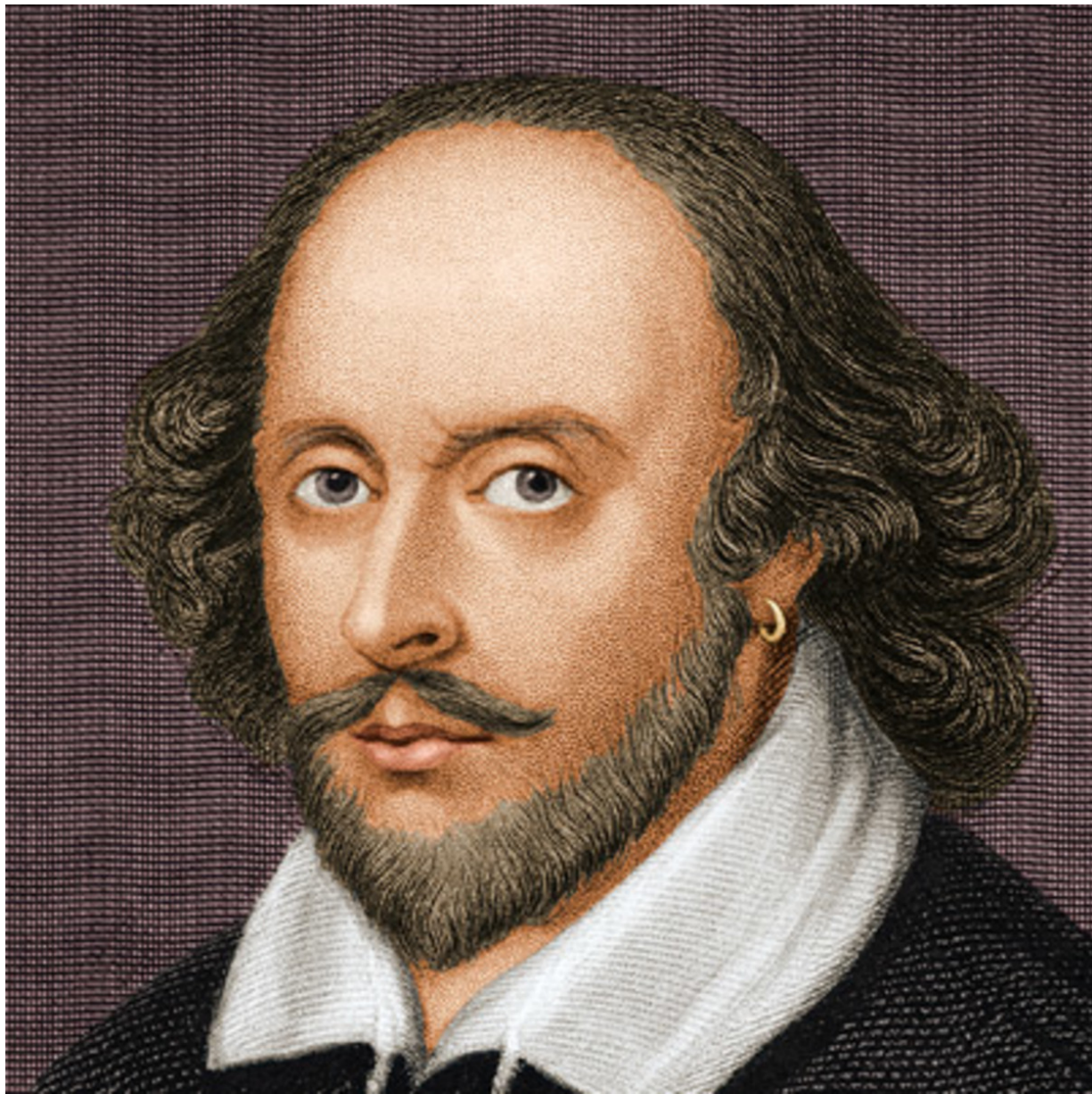




2 Esdras 2:20-23

Do right to the widow
Judge for the fatherless
Give to the poor
Defend the orphan
Clothe the naked
Heal the broken and the weak
Laugh not a lame man to scorn
Defend the maimed
Let the blind man come into the sight
of my clearness
Keep the old and young within thy walls
Wheresoever thou findest the dead
Take them and bury them, and
I will give thee the first place
in my resurrection

Shakespearean Pessimism



The sixth age shifts
Into the lean and slippered pantaloon,
With spectacles on nose and pouch
on side;
His youthful hose, well saved, a world
too wide
For his shrunk shank, and his big
manly voice,
Turning again toward childish treble,
pipes
And whistles in his sound. Last scene
of all,
That ends this strange eventful history,
Is second childishness and mere
oblivion,
Sans teeth, sans eyes, sans taste,
sans everything.

The Four Ashramas of Hinduism



Brahmacharya
learning

Grihastha
family-life

Vanaprastha
social service

Sannyasa
self-realisation



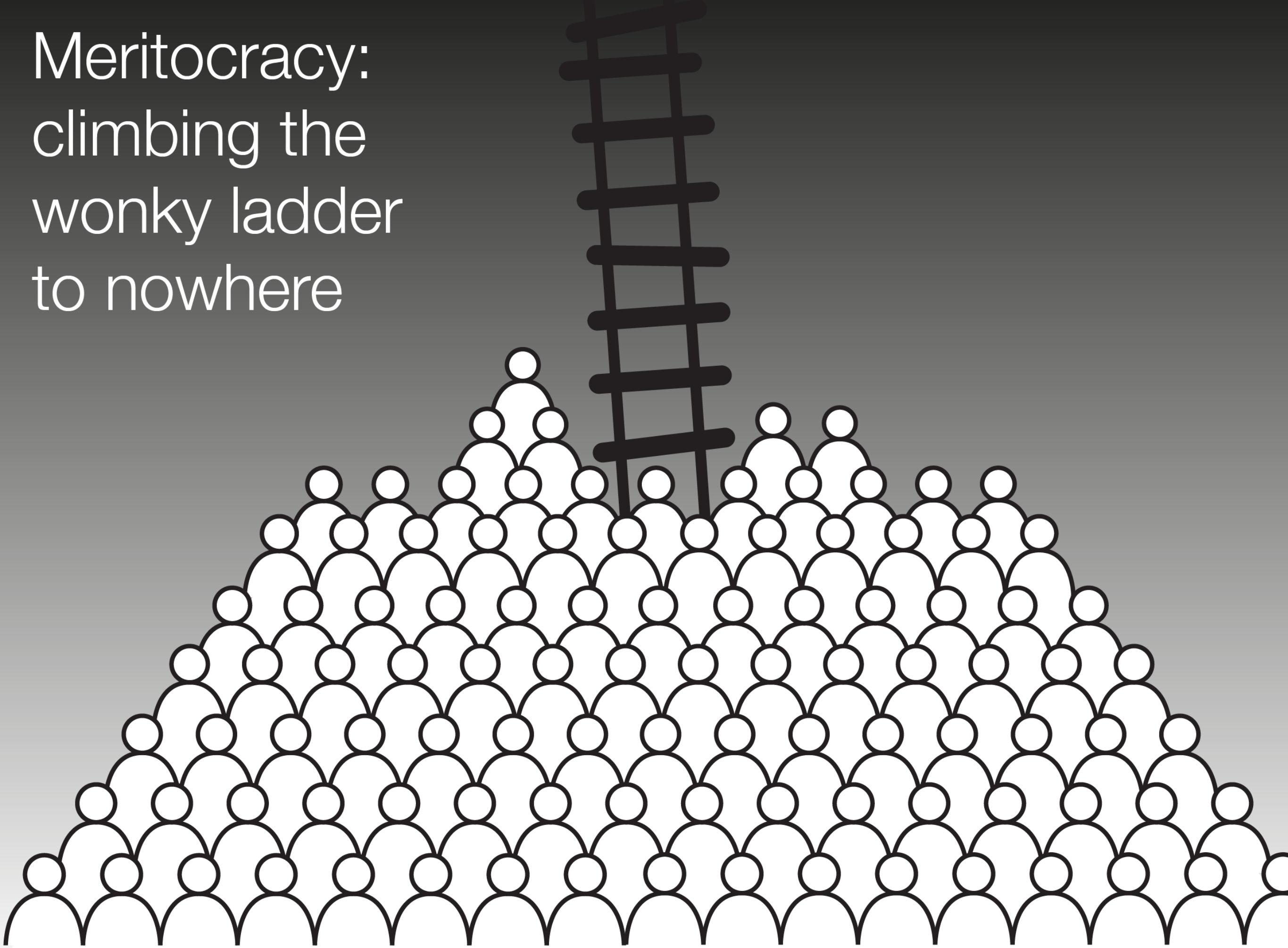
Human dignity is protected by building social systems that foster respect

- **Values** - ideals and social goals, e.g. *Ashramas*
- **Laws** - *Honour thy parents* or Roman *paterfamilias*
- **Society** - *Athenian jury system*

Today there are many forces that erode dignity

- **Values** - meritocracy, employment, income, individualism
- **Law** - increasing pressure for euthanasia and eugenics
- **Society** - inequality, segregation and insecurity

Meritocracy:
climbing the
wonky ladder
to nowhere



Eugenics and euthanasia are back on the agenda

The law's been passed and I am lying low
Hoping to hide from those who think they are
Kindly, compassionate. My step is slow.
I hurry. Will the executioner
Be watching how I go?

Others about me clearly feel the same.
The deafest one pretends that she can hear.
The blindest hides her white stick while the lame
Attempt to stride. Life has become so dear.
Last time the doctor came,

All who could speak said they felt very well.
Did we imagine he was watching with
A new deep scrutiny? We could not tell.
Each minute now we think the stranger Death
Will take us from each cell

For that is what our little rooms now seem
To be. We are prepared to bear much pain,
Terror attacks us wakeful, every dream
Is now a nightmare. Doctor's due again.
We hold on to the gleam

Of sight, a word to hear. We act, we act,
And doing so we wear our weak selves out.
We said "We want to die" once when we lacked
The chance of it. We wait in fear and doubt.
O life, you are so packed

With possibility. Old age seems good.
The ache, the anguish - we could bear them we
Declare. The ones who pray plead with their God
To turn the murdering ministers away,
But they come softly shod.

Euthanasia (1980) by Elizabeth Jennings

Support for us when we age remains highly institutional

Institutional Exclusion



Deinstitutionalisation

Service System Ghetto



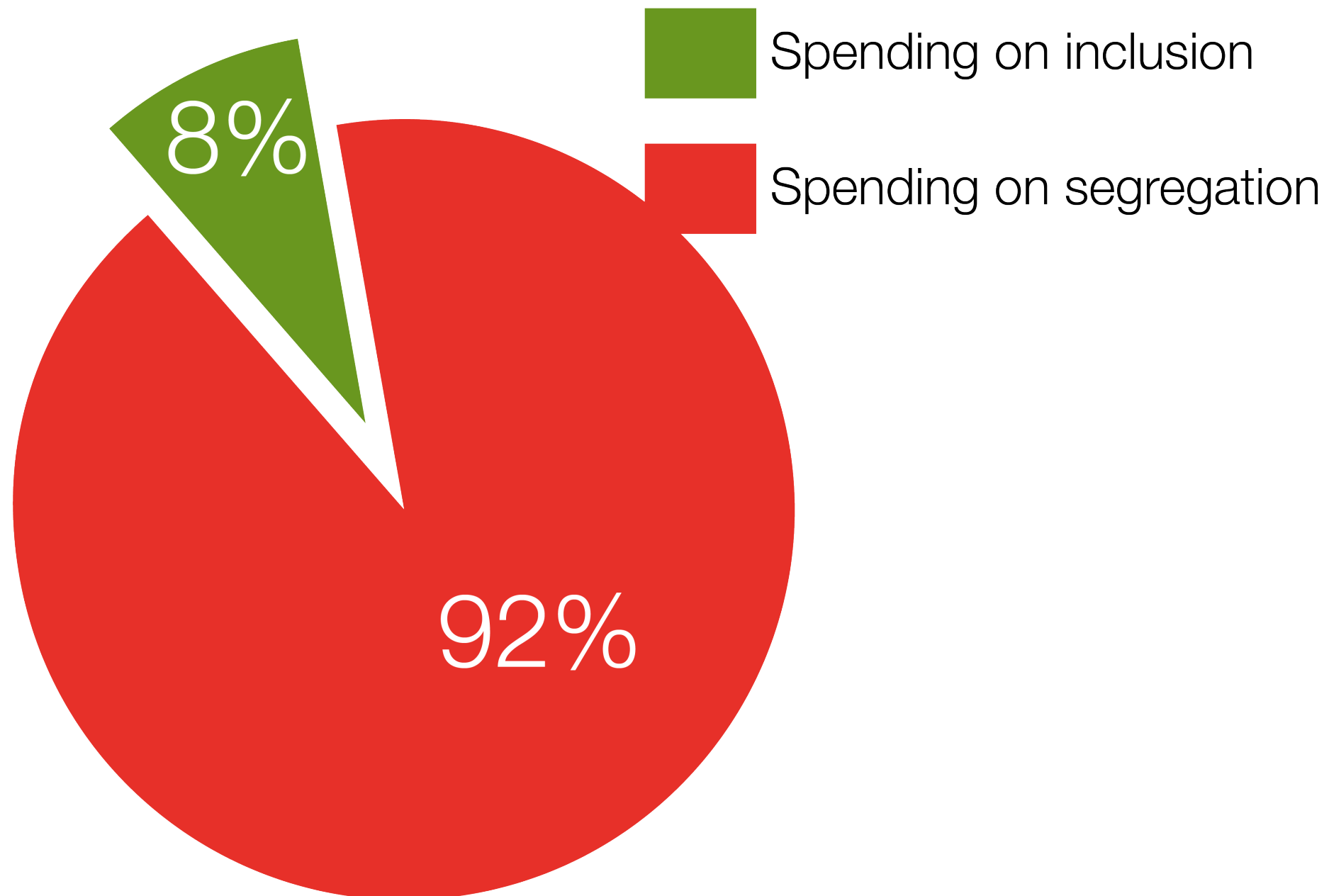
Equal Citizenship



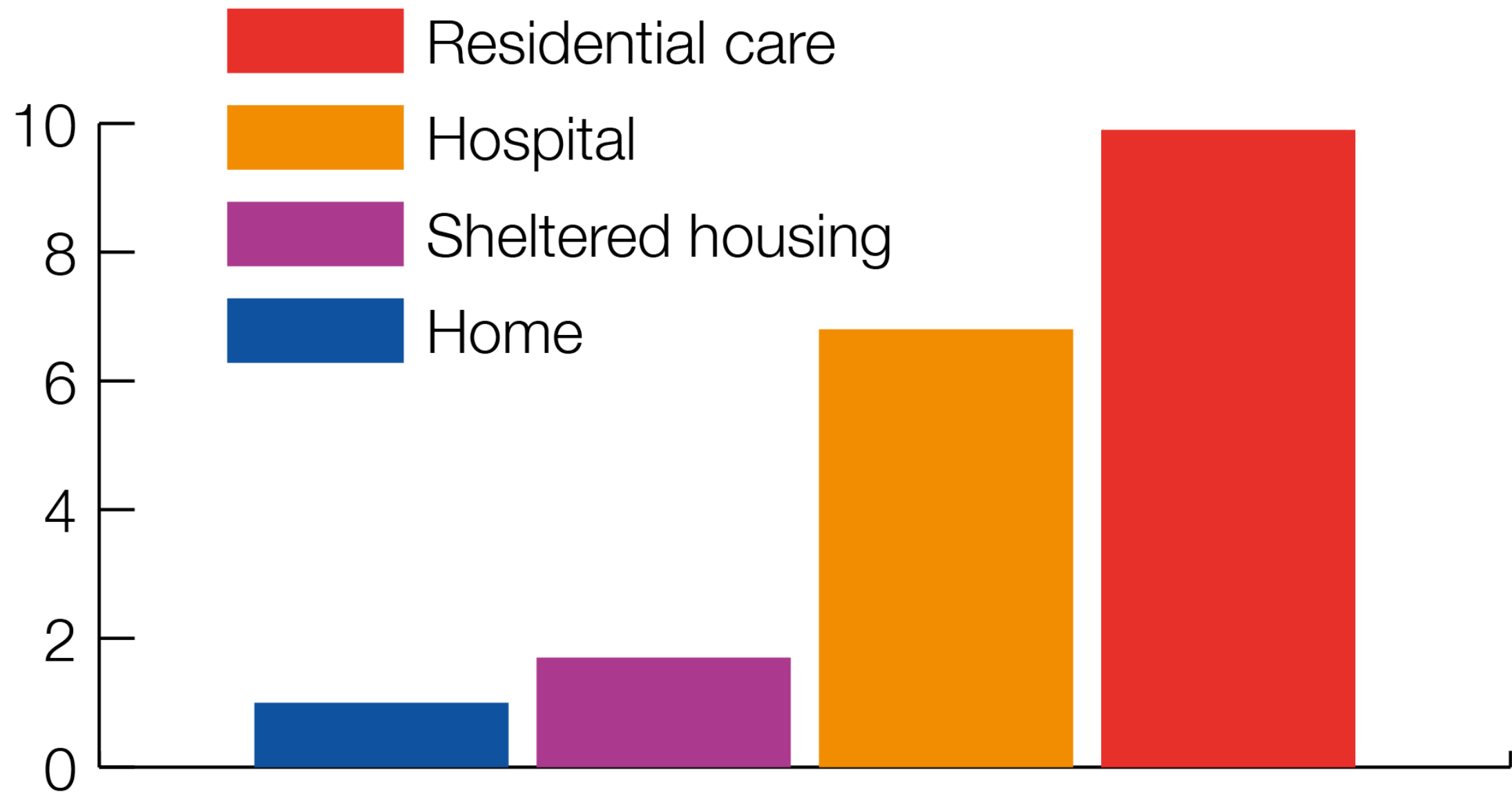
Inclusion

Spending remains locked in the wrong things

The pattern of expenditure - Lancashire early 2000s



The risk of being abused increases as you move into more institutional environments.



[Data on abuse from Action on Elder Abuse (2004) Hidden Voices: older people's experience of abuse. London: Help the Aged. Primary data combined with population data from various sources. See Duffy S (2010) Safety for Citizens.]

“But I Don’t *Want* Eldercare!”

*Helping Your Parents
Stay As Strong As They Can
As Long As They Can*

Terry Lynch

We are simply not provided with enough practical information or flexible support to help us keep ourselves or our family well, at home and to get the best out of life.

We foster our own ignorance - always putting off thinking about it.

**Self-directed support plays
a key role in building better
social systems**

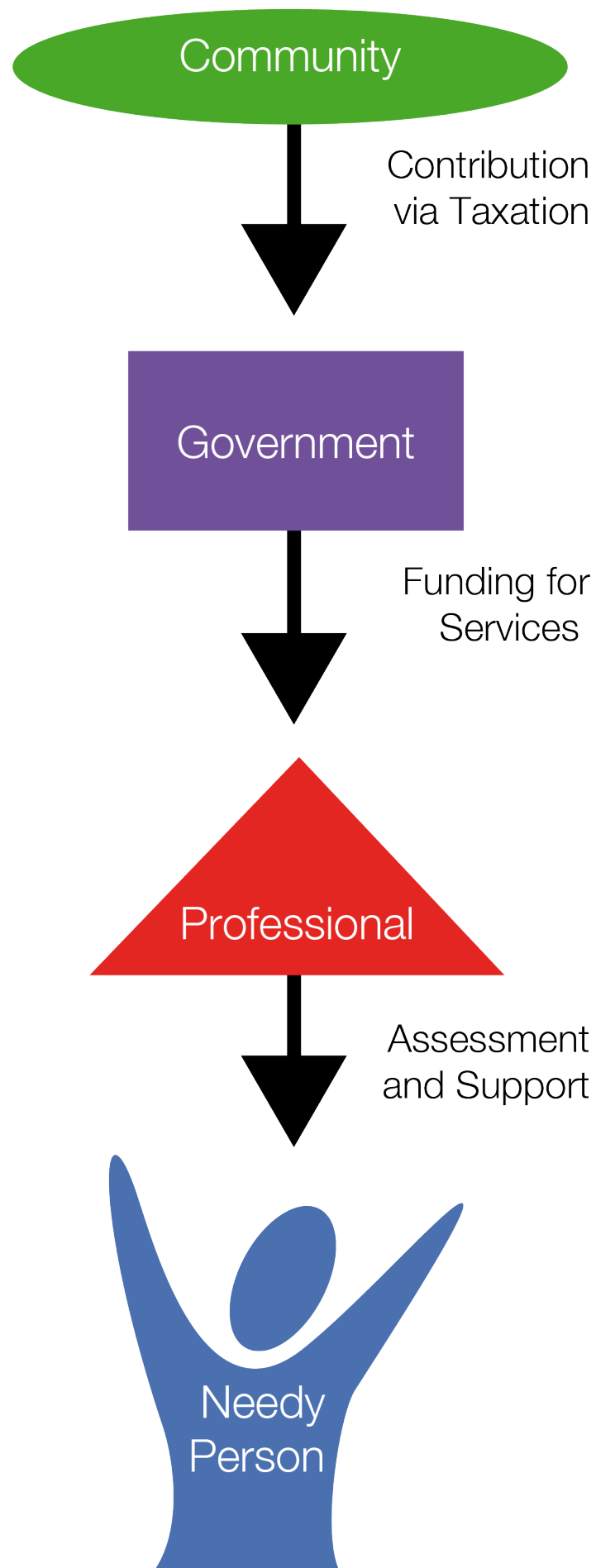
Self-Directed Support

IF IT'S SO GOOD THEN WHY IS IT SO HARD?

by Simon Duffy



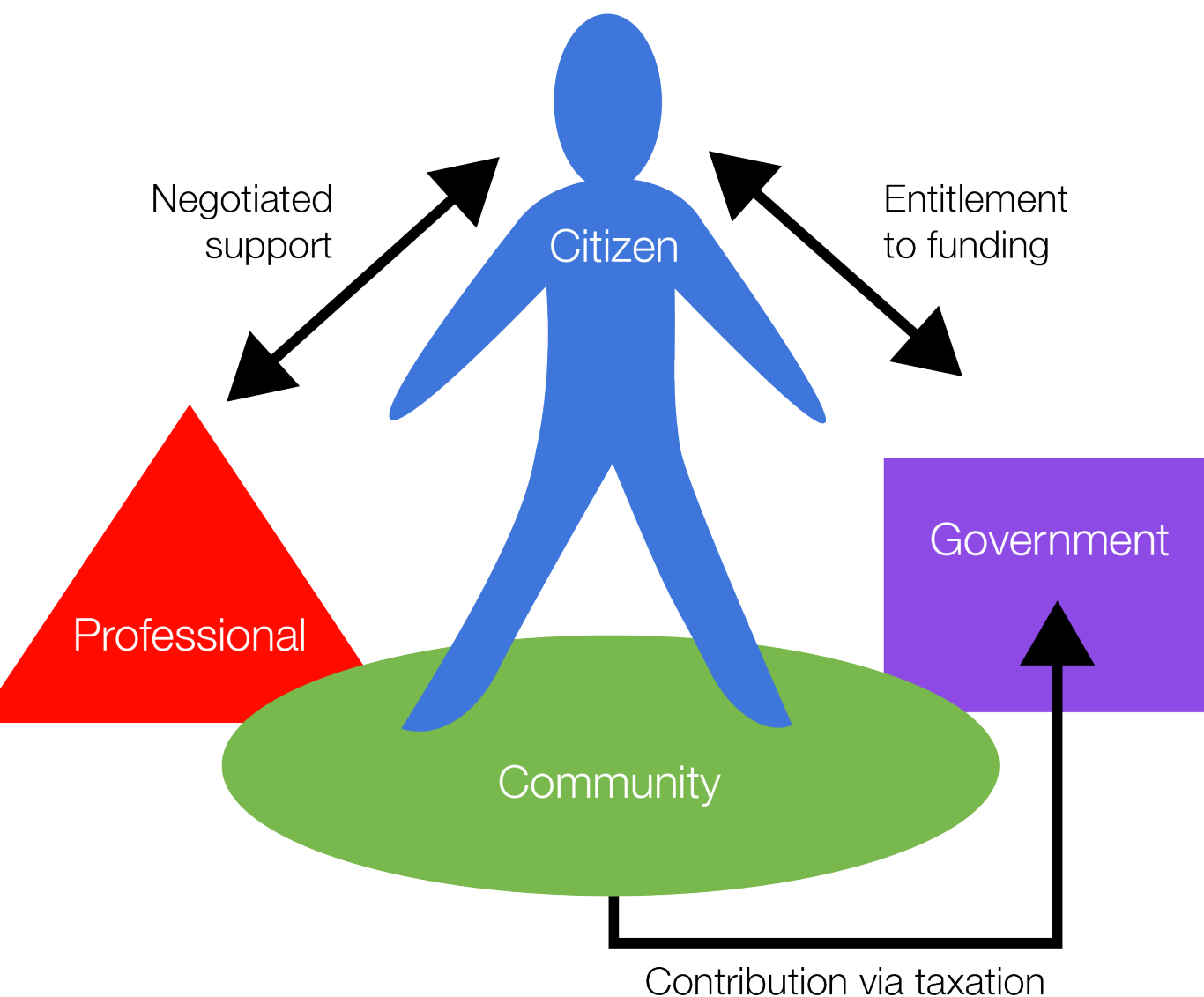
- The intellectual case for self-directed support is strong and it is emerging as the new norm everywhere.
- Increasingly people are recognising that it is an issue of basic human rights - not an option.
- The challenge is to build systems that make it an easy and natural way of doing things.



People with disabilities often find they must **sacrifice** freedom and control in order to get help.

They get help, but that help has been **defined in advance** (a priori) by the system and by the professionals who work in the system.

This is the **professional gift model** of service delivery.

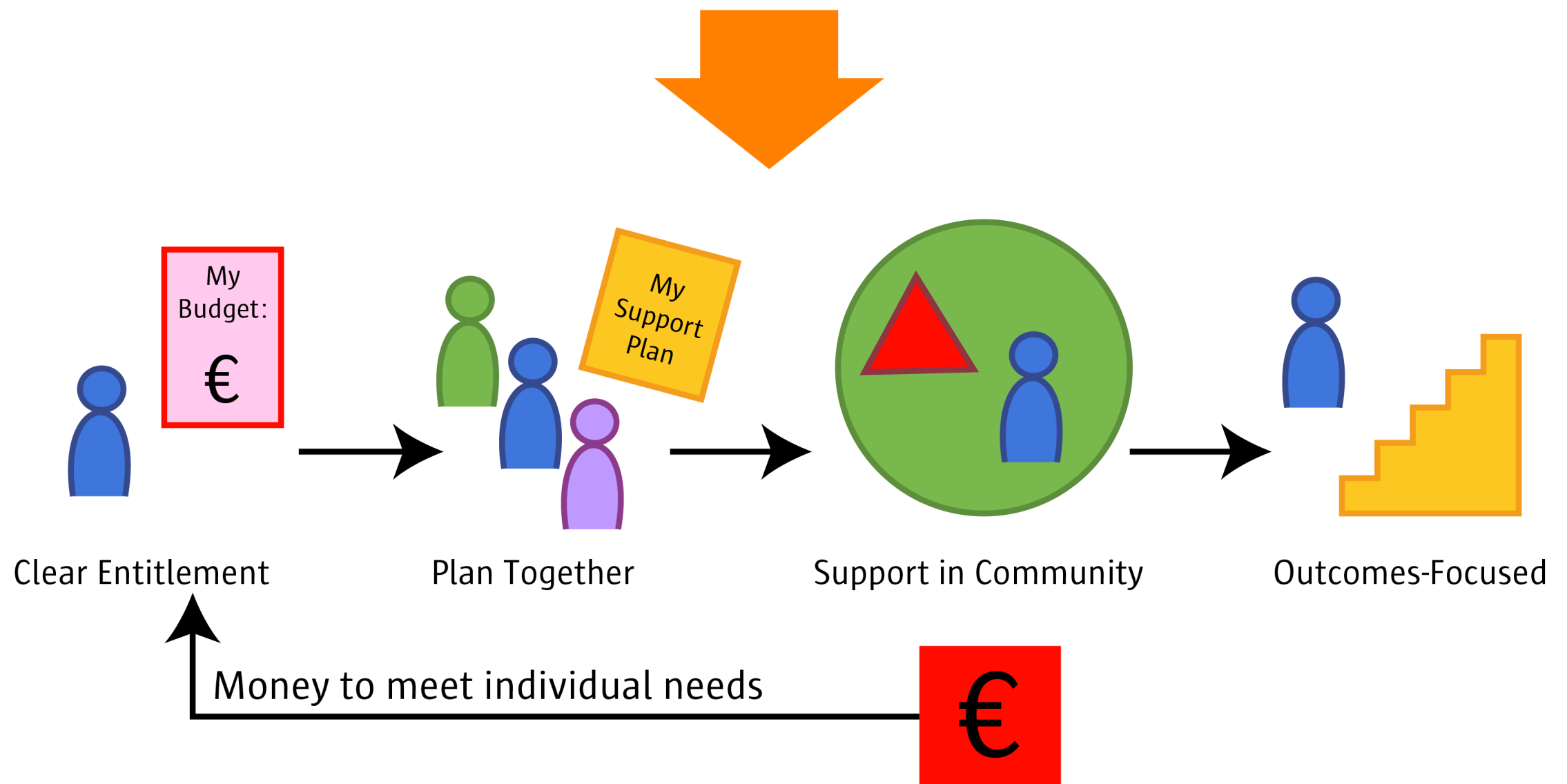
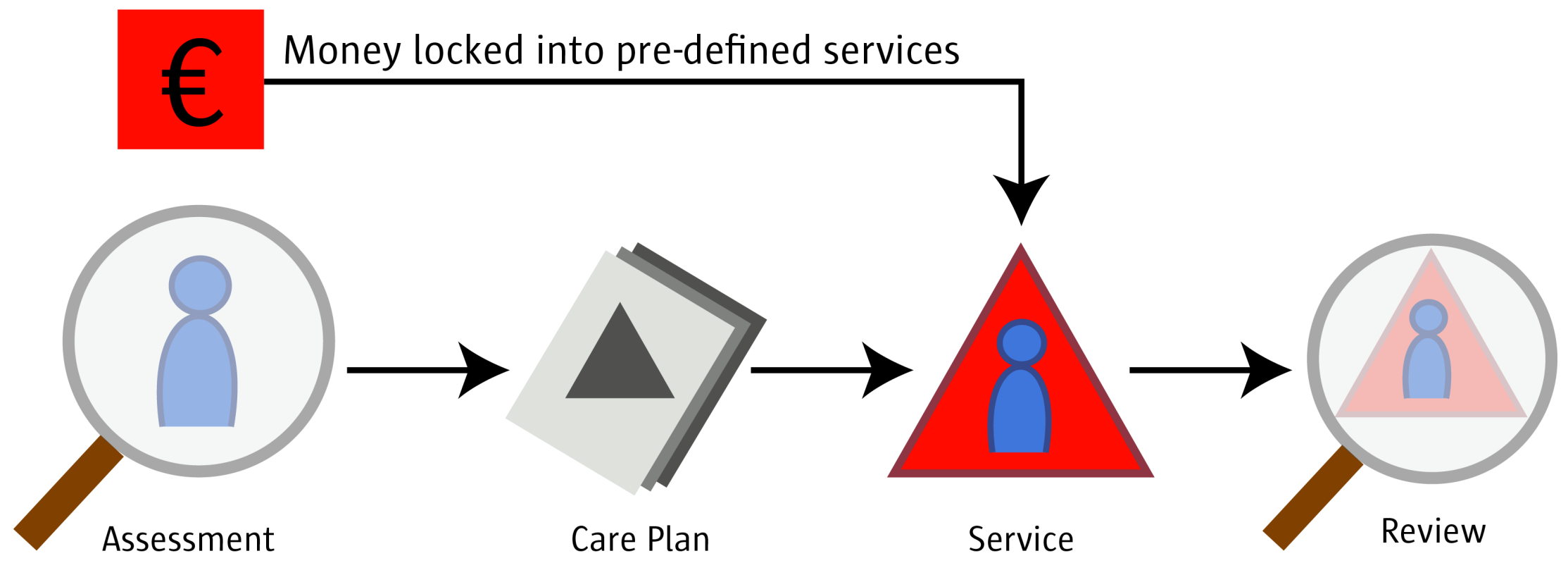


Citizens live their lives in **community** (family, friends, peers, colleagues, neighbours etc.)

The **right** to get support should not determine how we are supported.

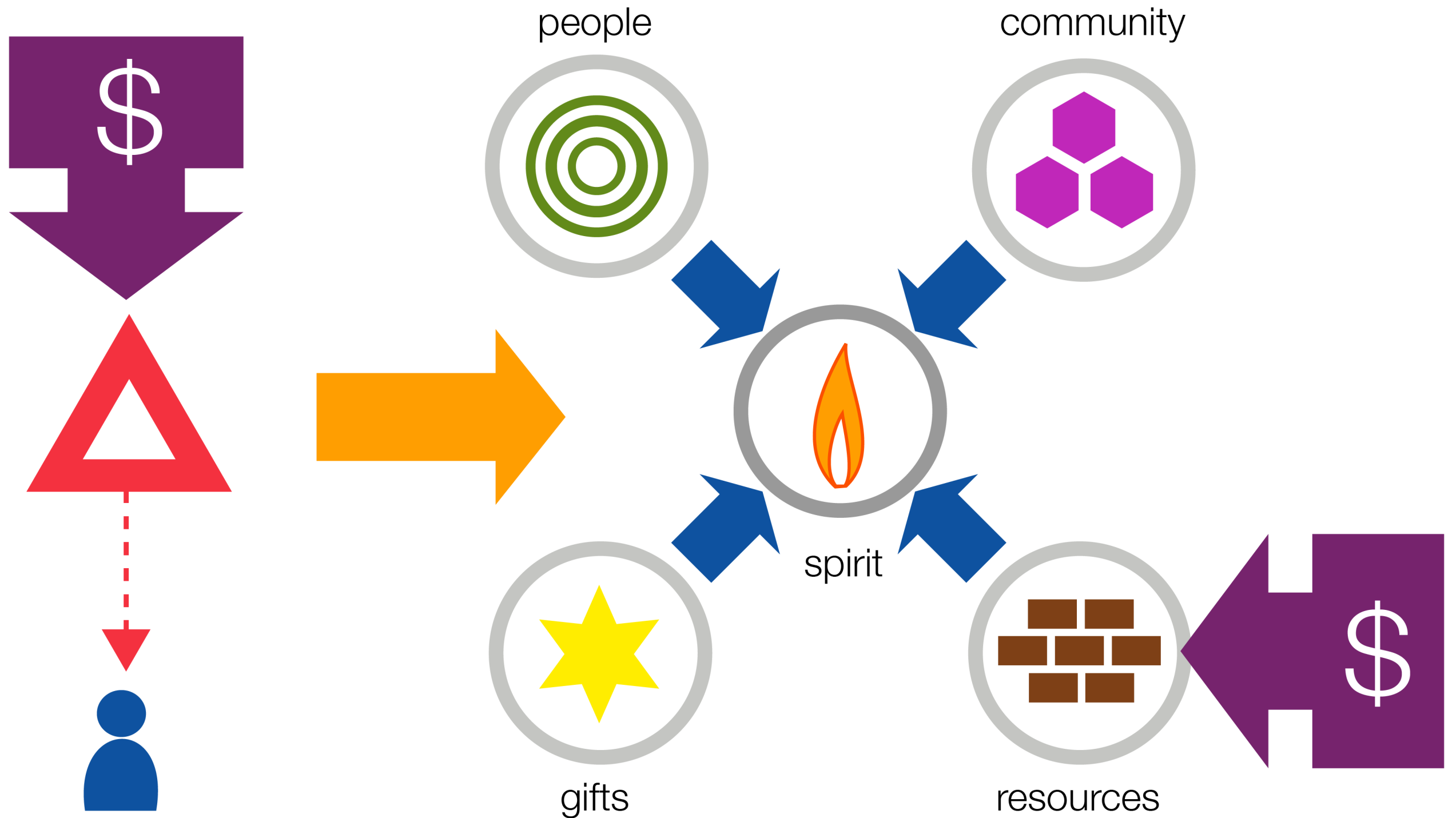
Support should be organised to **respect**, not replace community life.

This is the **citizenship model** of service delivery.

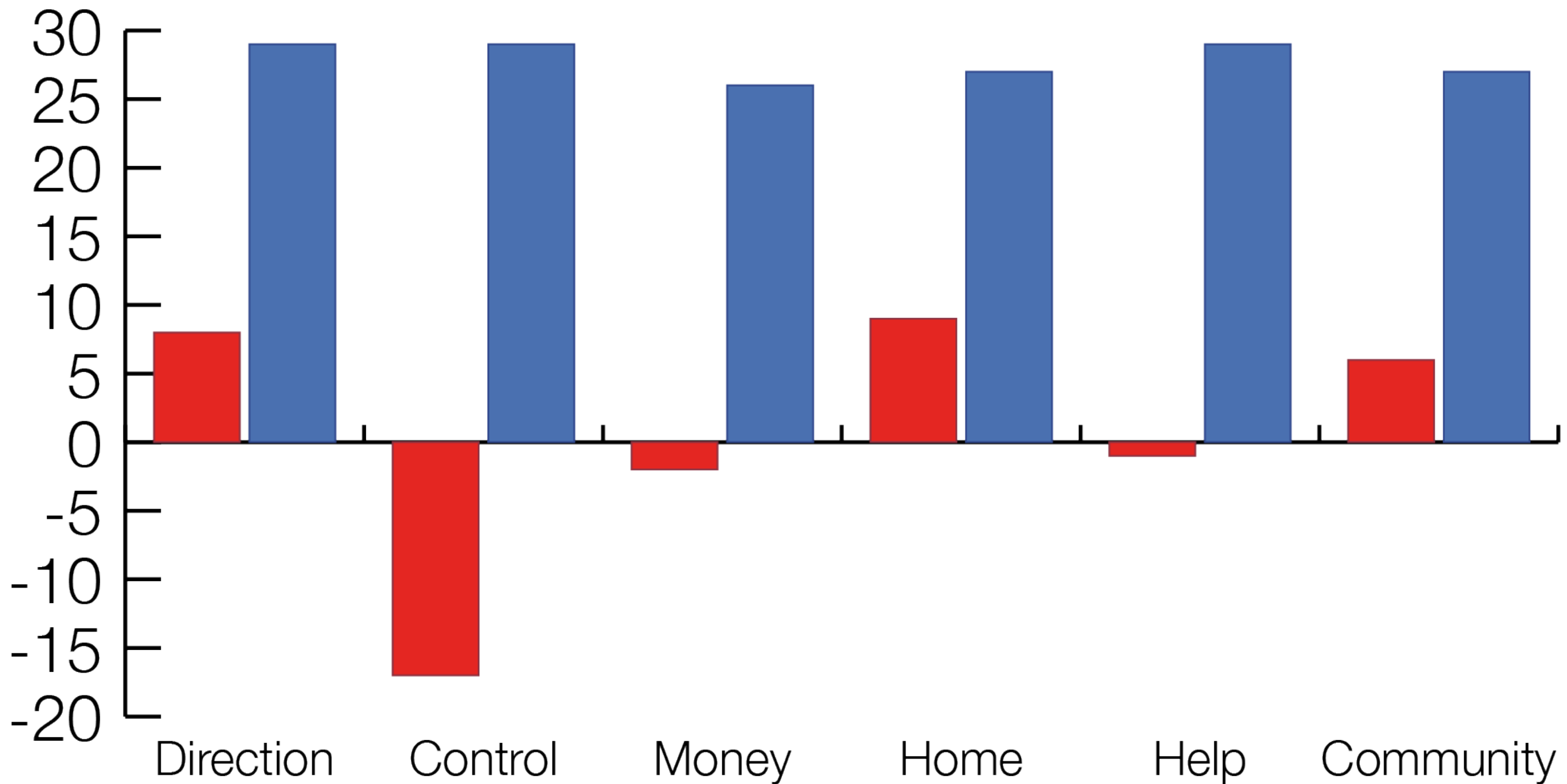



From Push Economics...


to Pull Economics



Sources: Push vs. Pull Economics is an idea developed in Hagel J and Seely Brown J (2005) *The Only Sustainable Edge*. Boston, Harvard Business Press; Real Wealth was first defined in Murray P (2010) *A Fair Start*. Sheffield, The Centre for Welfare Reform.

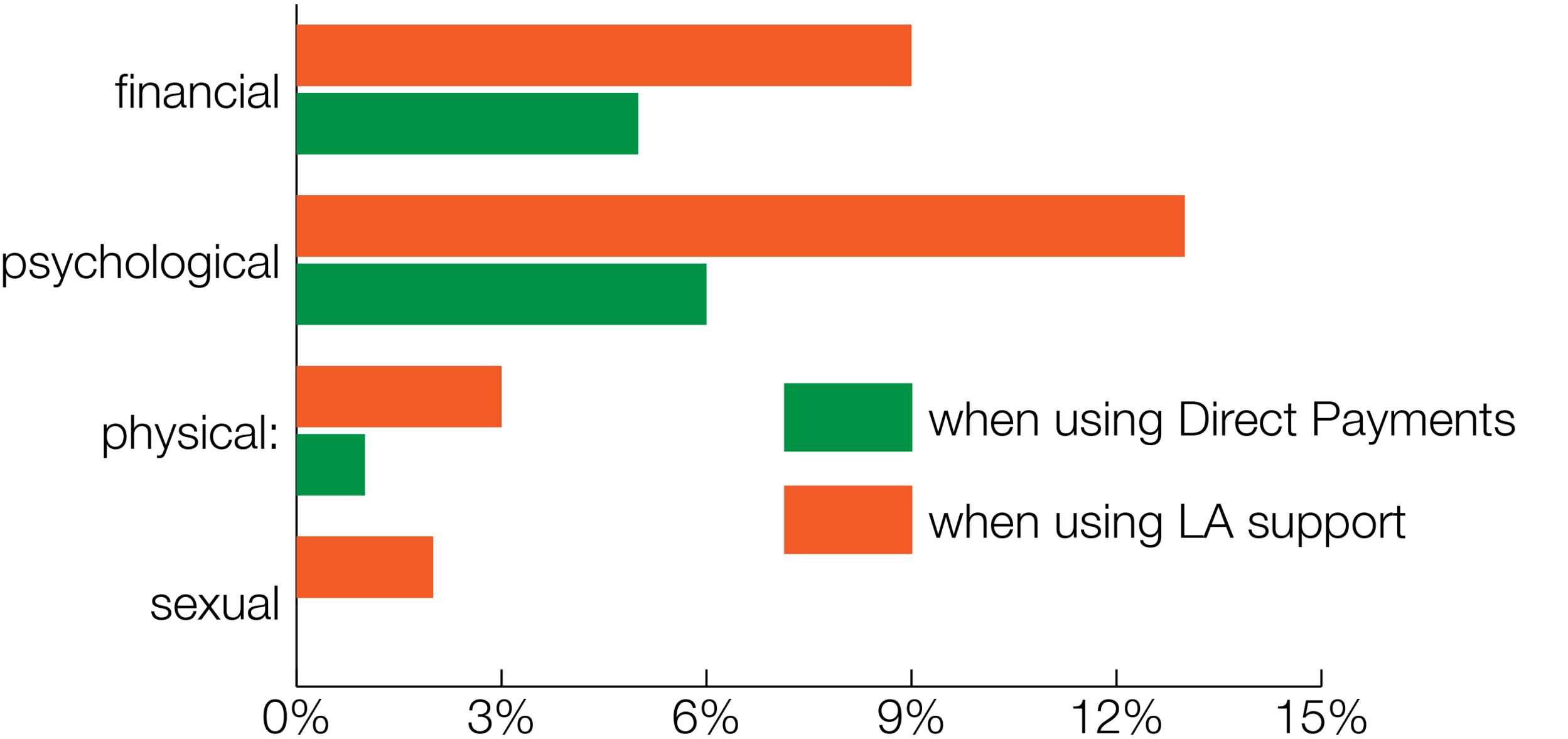


 After SDS

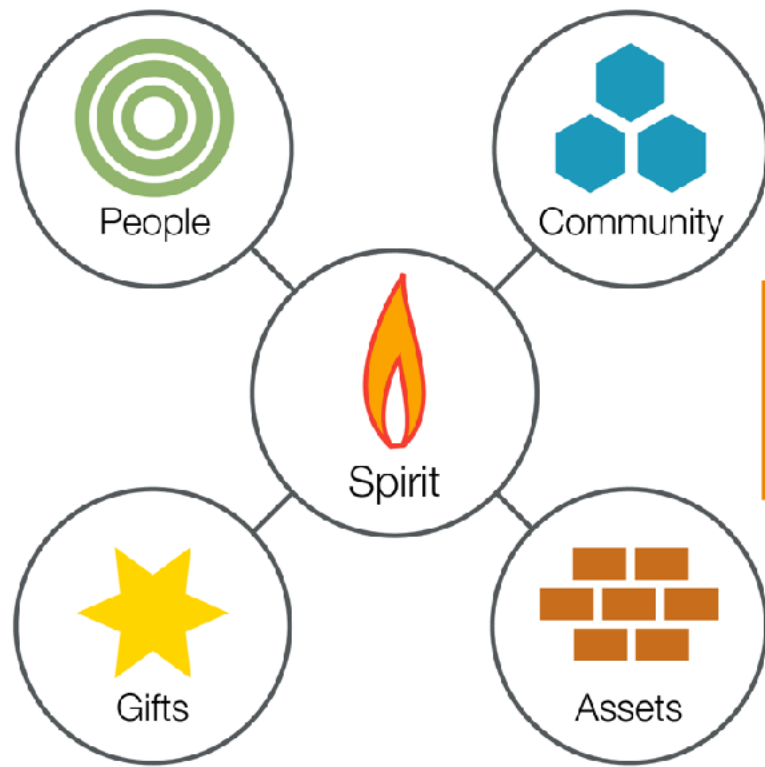
 Before SDS

Combined data from *A Report on In Control's First Phase* (2006). Minus score is combination of 'unhappy' and 'really unhappy'; plus score combines 'quite happy' and 'really happy.'

Level of abuse experienced by disabled people reduces when people have more control

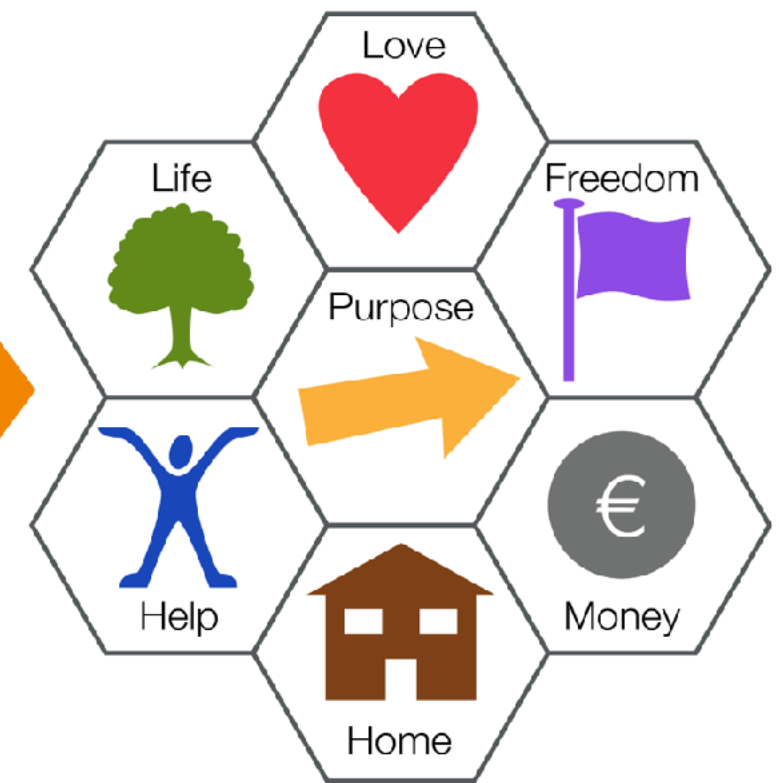


Enhancing Real Wealth



Self-Directed Support

Achieving Citizenship



Community Support



Family Life



Association



Social Enterprise



Business

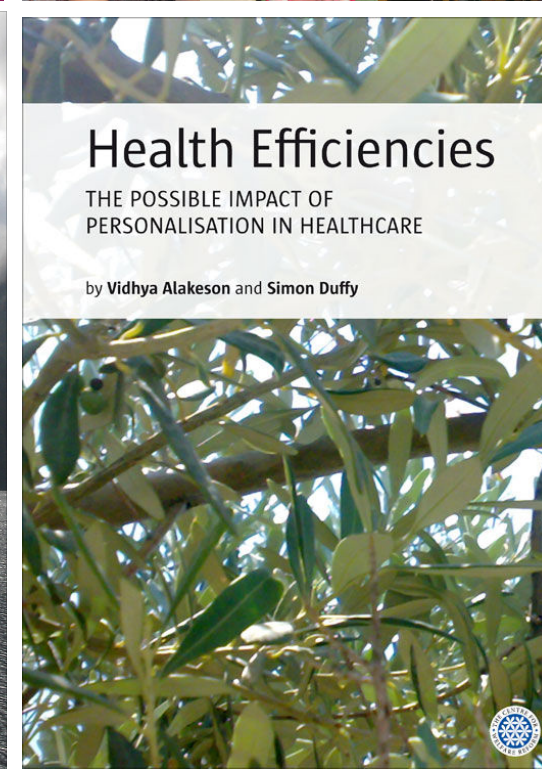
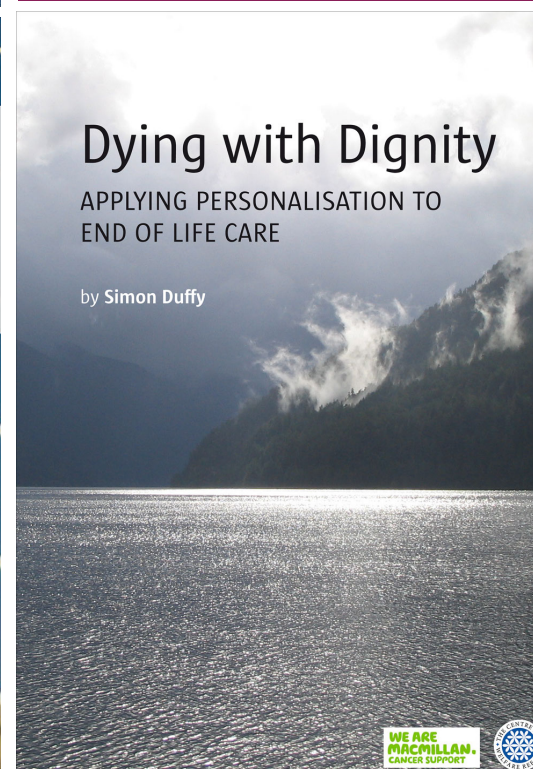
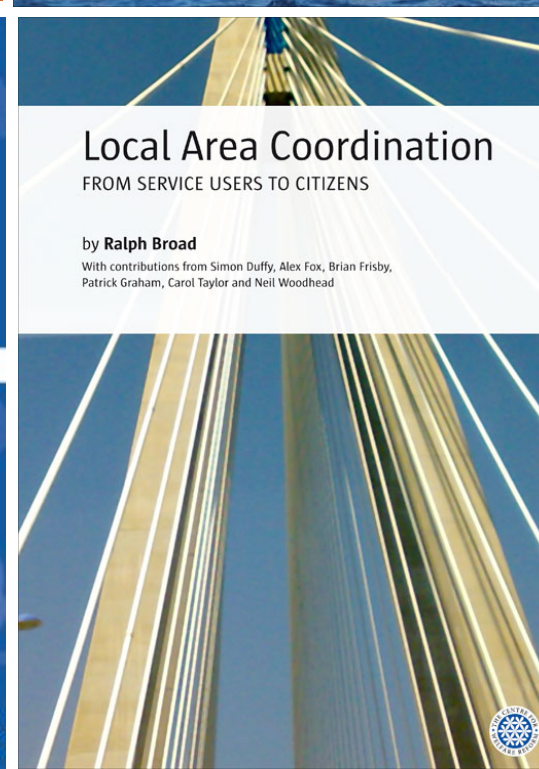
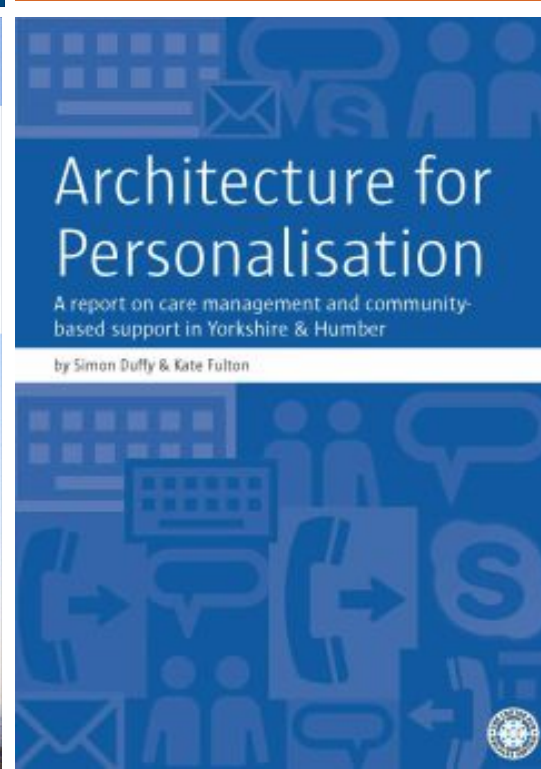
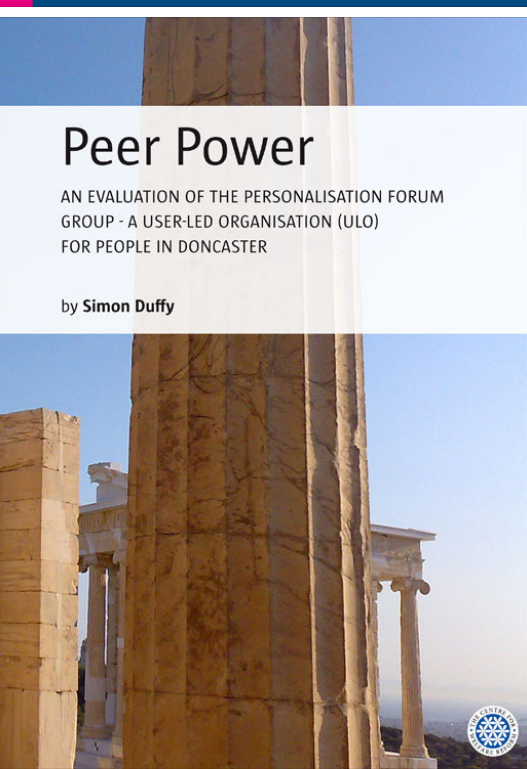
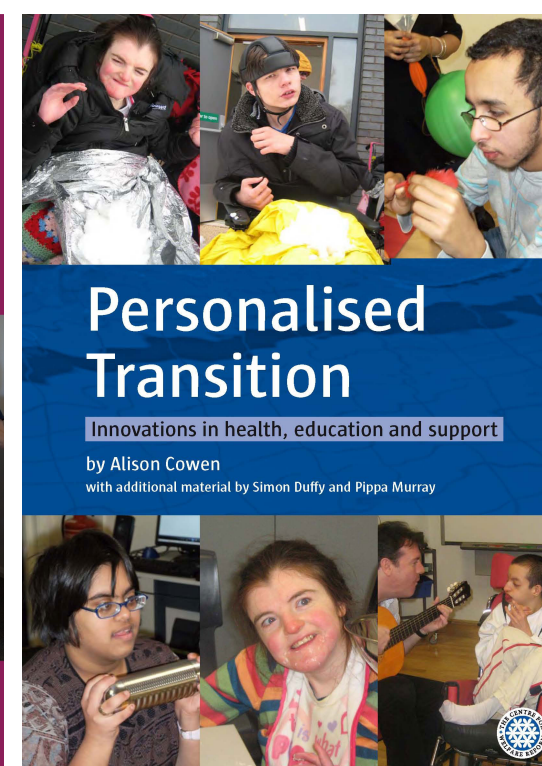
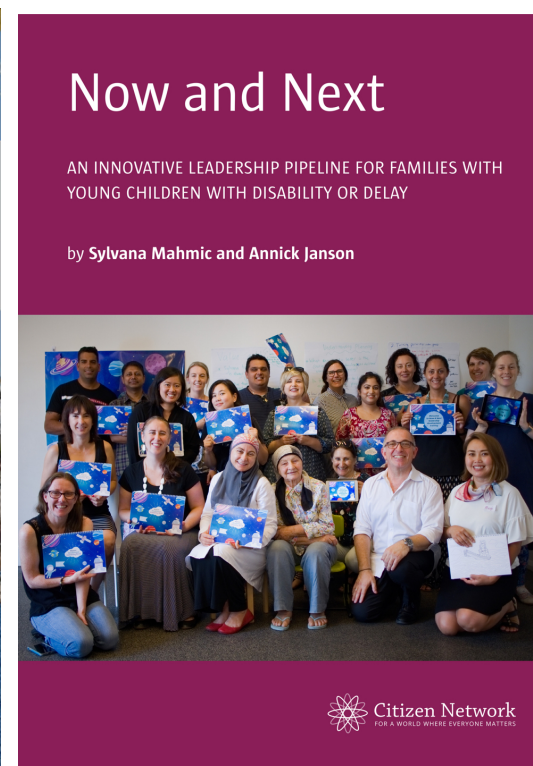
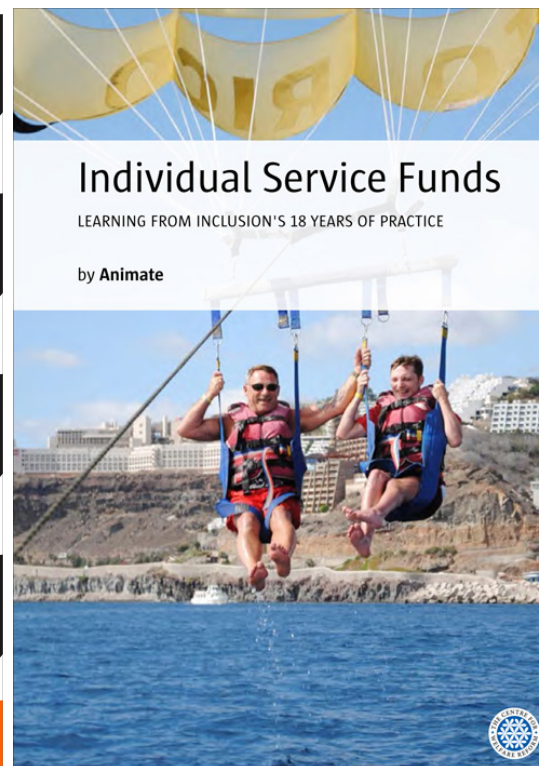
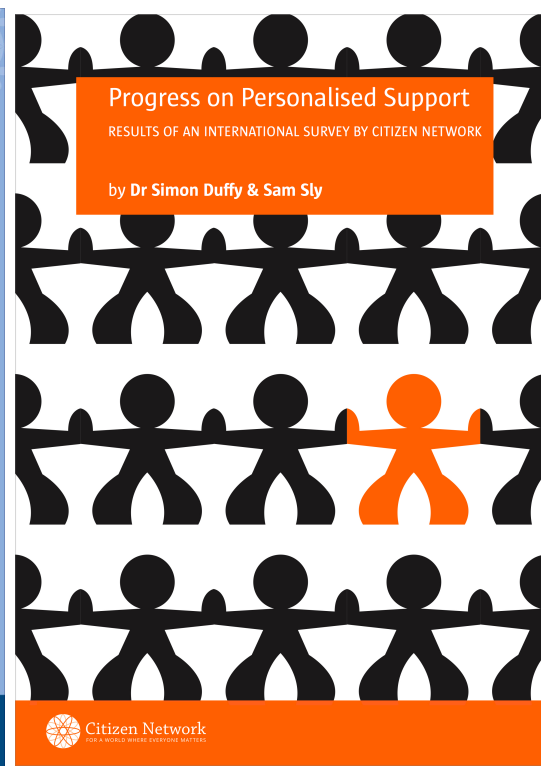
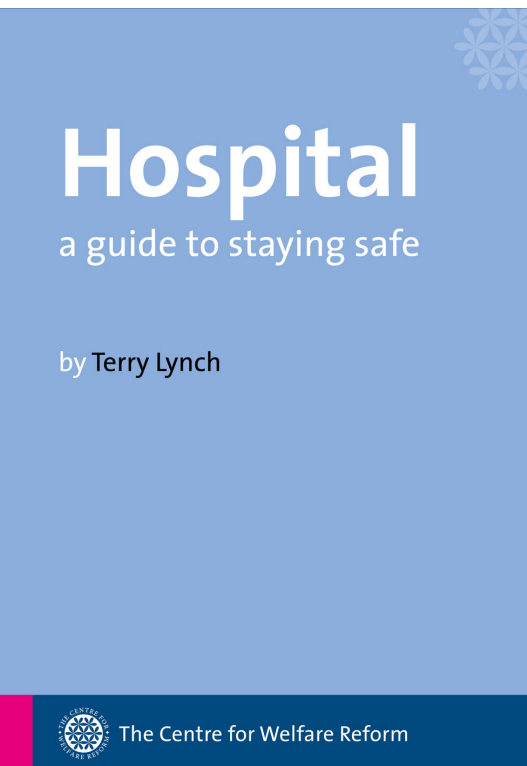


Public Services

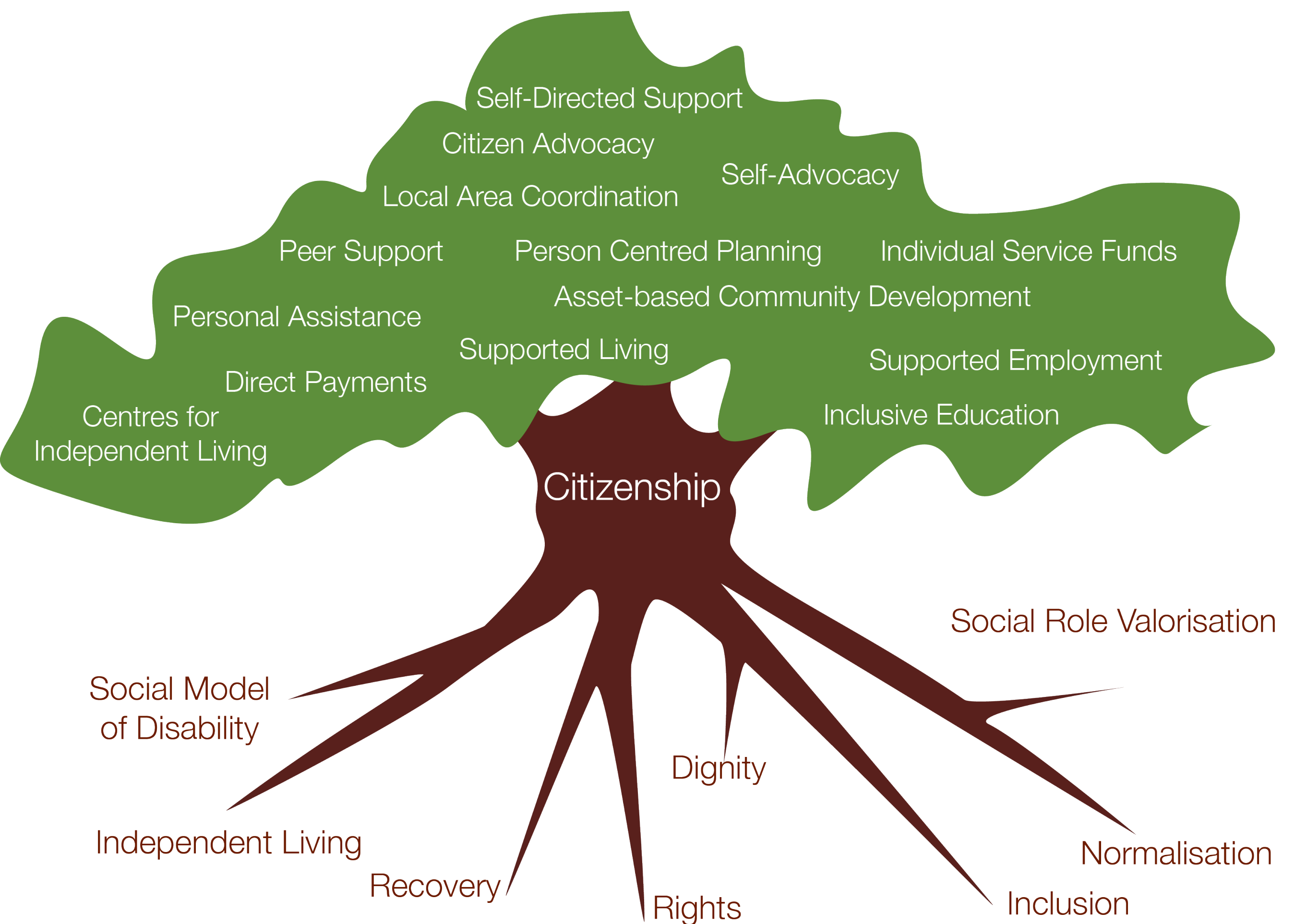


Law

Self-directed support is extending into different areas



**But self-directed support
can be corrupted by
the wrong values**

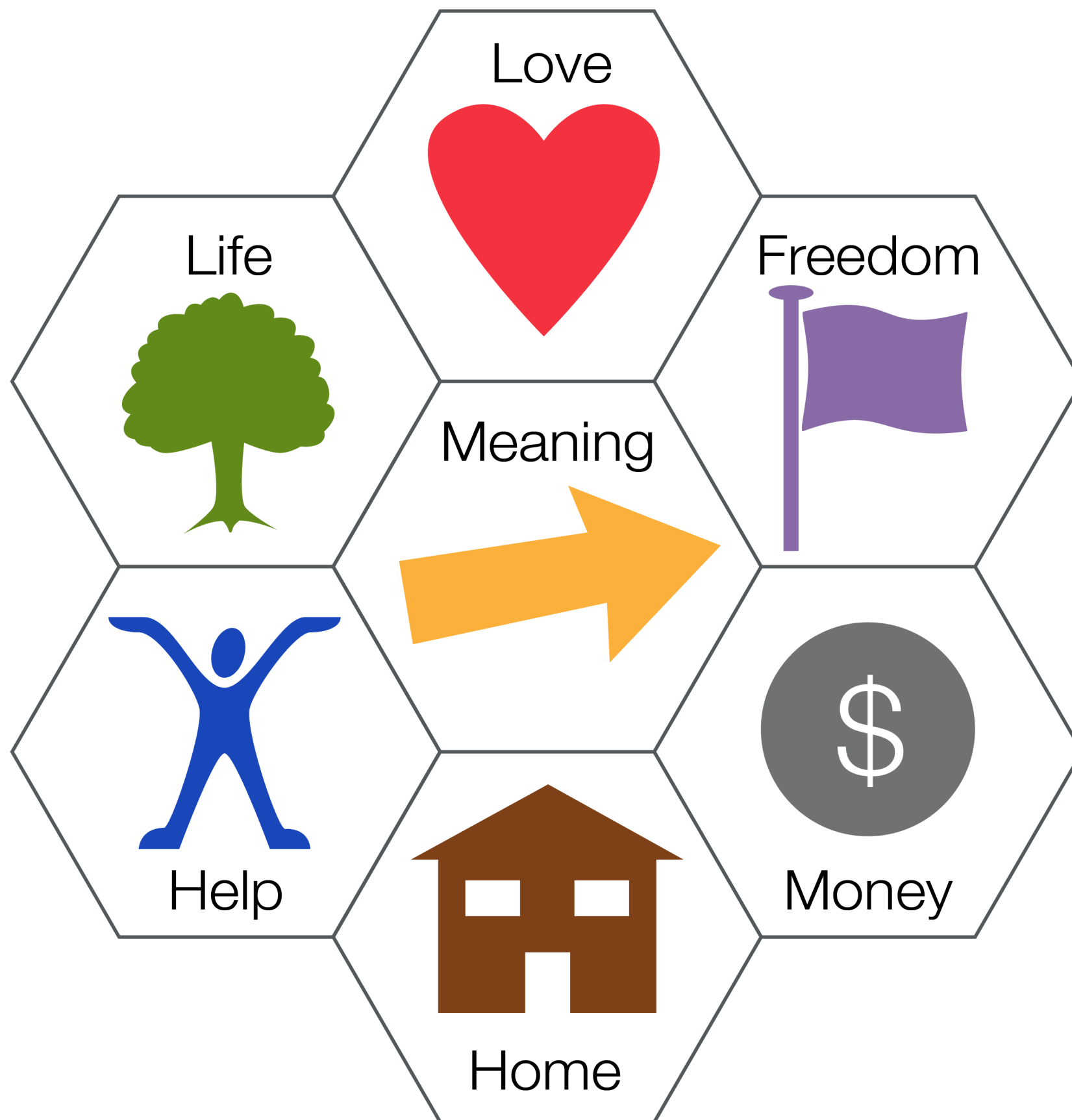
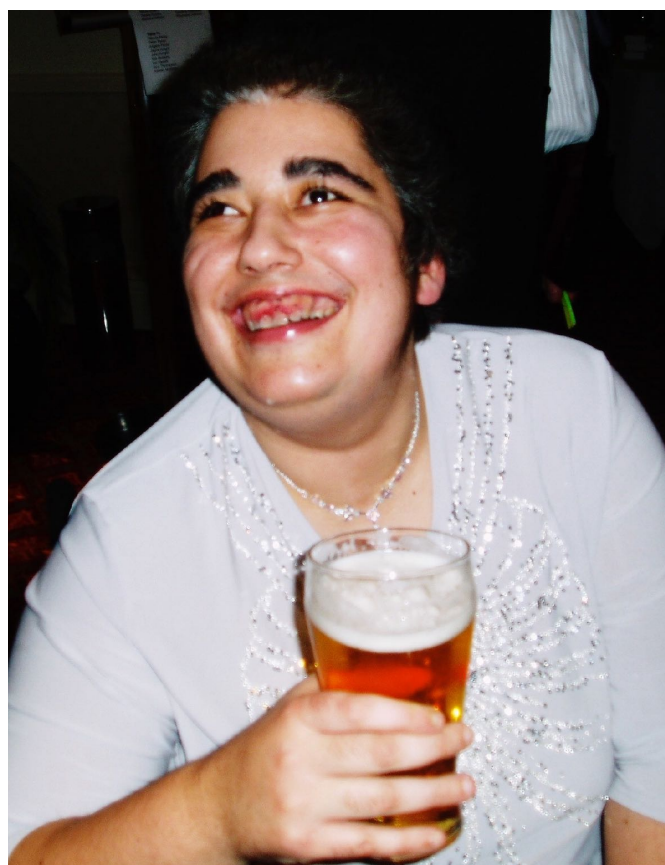




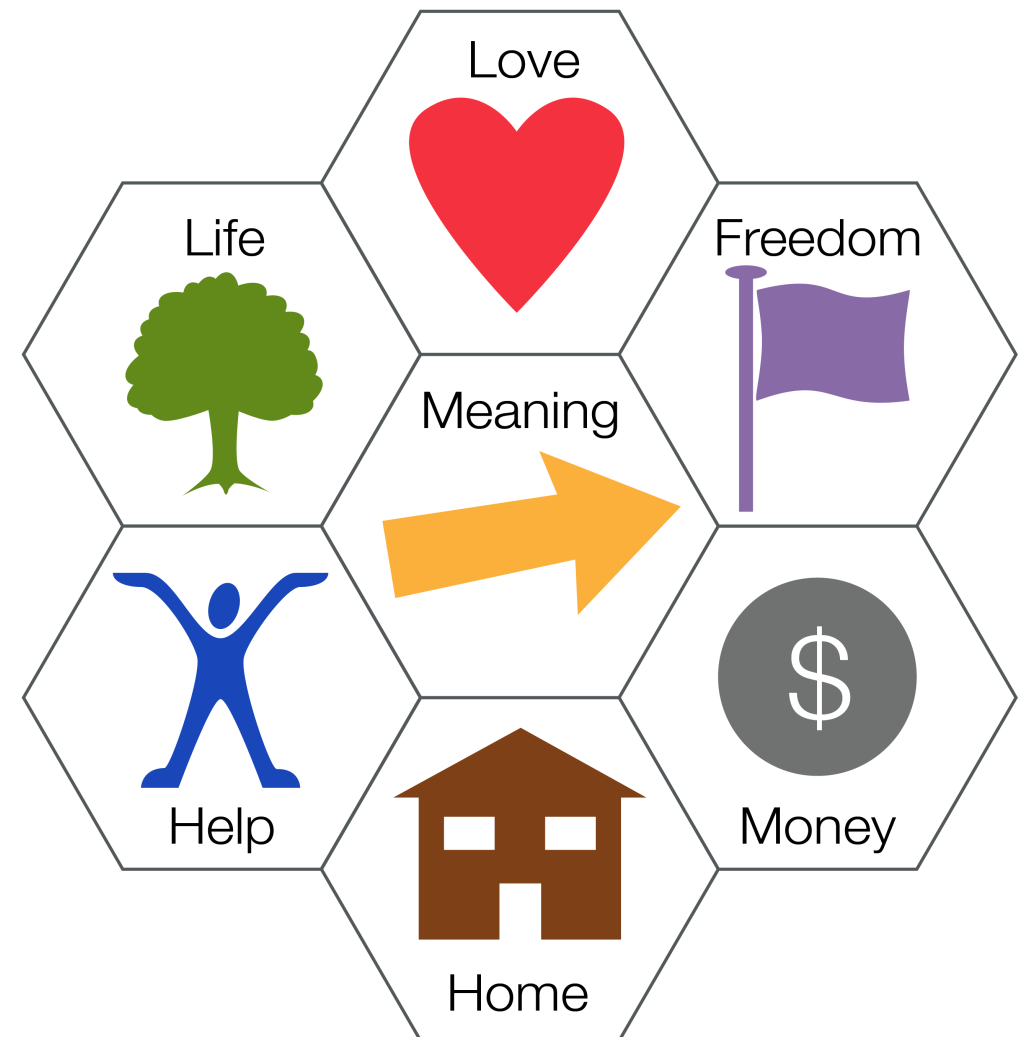
Keys to Citizenship

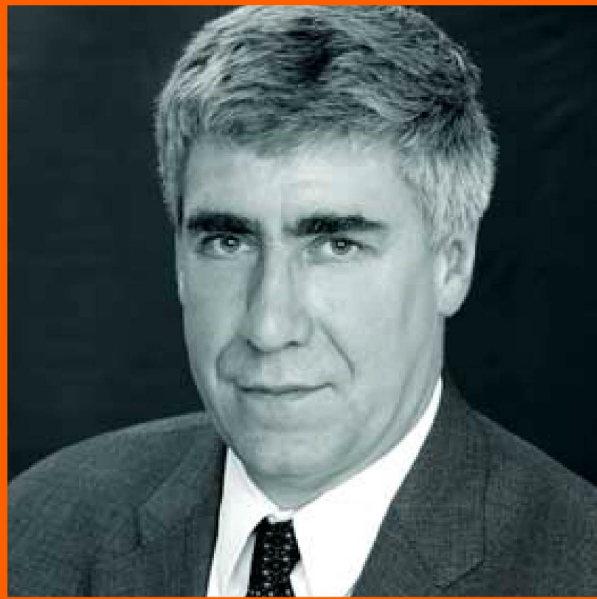
A guide to getting good support
for people with learning disabilities

by **Simon Duffy**



1. Finding lives of **meaning**
2. Having the **freedom** to pursue it
3. Having enough **money** to be free
4. Having a **home** where we belong
5. Getting **help** from other people
6. Making **life** in community
7. Finding, sharing and giving **love**





Jeremy Waldron

“Above all, I think the idea of citizenship should remain at the centre of modern political debates about social and economic arrangements.

The concept of a citizen is that of a person who can hold [their] head high and participate fully and with dignity in the life of society.”

Citizenship is not about passports

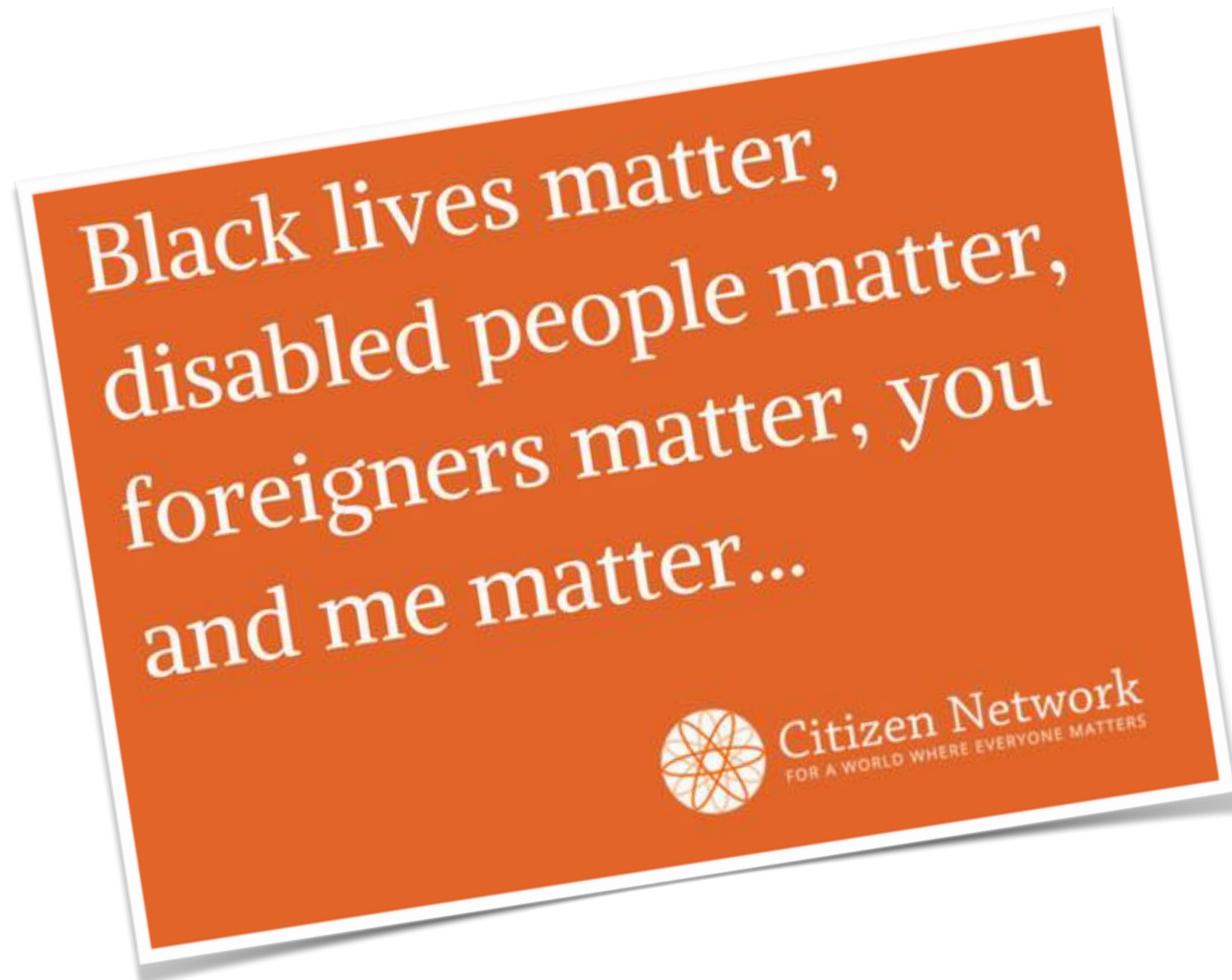
The wrong kind of citizenship - We're special because they are members of a special community (like a country) - we want to keep it special and keep the outsiders out

The right kind of citizenship - Everybody's equal and we all need to belong to many different communities - we want to welcome and include everybody

We give each other the gift of
citizenship when we treat each
other as equals



**That's why we're building a global movement for
equal citizenship and inclusion**



Who understands the meaning of citizenship?



“The time will come when our nation will honour the memory of all the sons, the daughters, the mothers, the fathers, the youth and the children who, by their thoughts and deeds, gave us the right to assert with pride that we are South Africans, that we are Africans, and that we are citizens of the world.” **Nelson Mandela**

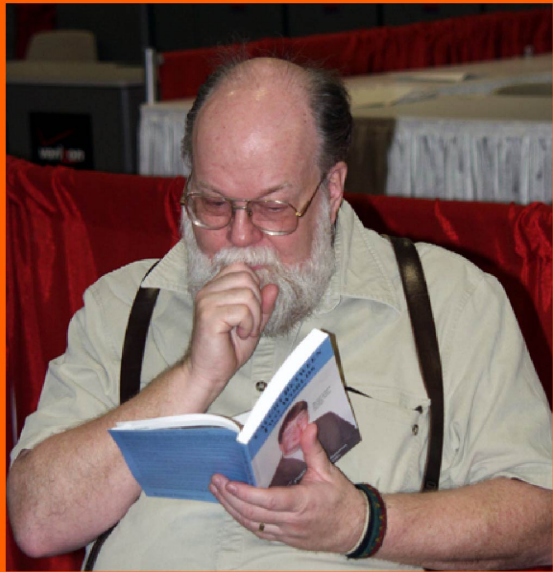


“But if you believe you’re a citizen of the world, you’re a citizen of nowhere. You don’t understand what the very word ‘citizenship’ means.”
Theresa May



Alexis de Tocqueville

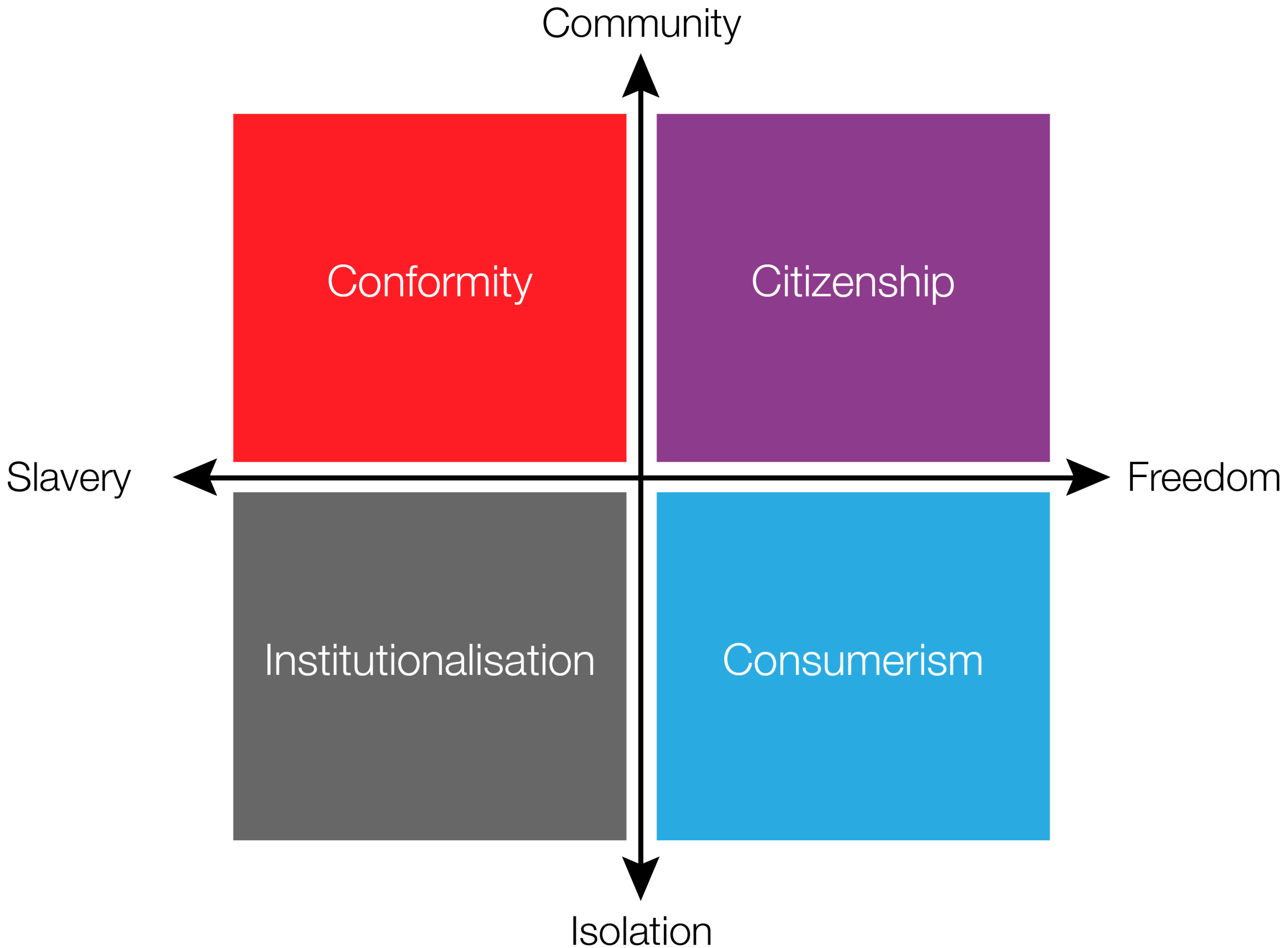
The New Englander is attached to his community not so much because he was born in it, but because it is a free and strong community of which he is a member.



John O'Brien

“Citizens are people who can say “I belong to this place and it’s people and I am willing to act from responsibility for my belonging.”

Source: O'Brien J (1983) Citizenship and Person-Centred Work. Toronto: Inclusion Press p. 110



**And self-directed support
needs to be built on
into the legal system**



Patricia J Williams

Rights are the
magic wand of visibility
and invisibility, of
inclusion and exclusion,
of power and no power.

Source: Williams P (1987) Alchemical Notes: Reconstructing Ideals from Deconstructed Rights in Harvard Civil Rights-Civil Liberties Law Review.

We can't afford to duck these questions:

- How strong is our right to **life**?
- How strong is our right to **support** and are we supporting people to be **citizens** - or just to stay alive?
- What protections exist at a **constitutional** and social level to ensure our rights are respected?
- Is self-directed support **rooted in rights** or is it just a new way of the system doing things to us?
- Do we have clear and adequate **entitlements** to resources that we can flexibly control with no interference, scrutiny or restraint?

- What follows focuses on the United Kingdom.
- May be the US will prove to be immune from these problems. I hope so.
- Only you can judge.



The United Kingdom is failing to respect human rights

The Committee is **seriously concerned** about the disproportionate adverse impact that **austerity** measures, introduced since 2010, are having on the enjoyment of economic, social and cultural rights *by disadvantaged and marginalised individuals and groups*. The Committee is concerned that the State party has not undertaken a comprehensive assessment of the cumulative impact of such measures on the realisation of economic, social and cultural rights, in a way that is recognised by civil society and national independent monitoring mechanisms (art. 2, para. 1).

UN Committee on Economic, Social and Cultural Rights:

Concluding observations on the sixth periodic report of the United Kingdom of Great Britain and Northern Ireland

24 June 2016



The United Kingdom is failing to respect disability rights

...there is reliable evidence that the threshold of **grave or systematic violations of the rights of persons with disabilities** has been met in the State party... The core elements of the rights to independent living and being included in the community, an adequate standard of living and social protection and their right to employment have been affected... freedom of choice and control over their daily activities restricted, the extra cost of disability has been set aside and income protection has been curtailed as a result of benefit cuts, while the expected policy goal of achieving decent and stable employment is far from being attained

UN Committee on the Rights of Persons with Disabilities:

Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention

6th October 2016



Housing Cuts

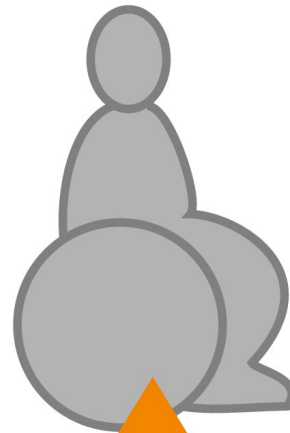
Bedroom Tax
Cuts in Housing Benefit
Cut in MIR
Cut Council Tax Benefit
Increased rents

Care Cuts

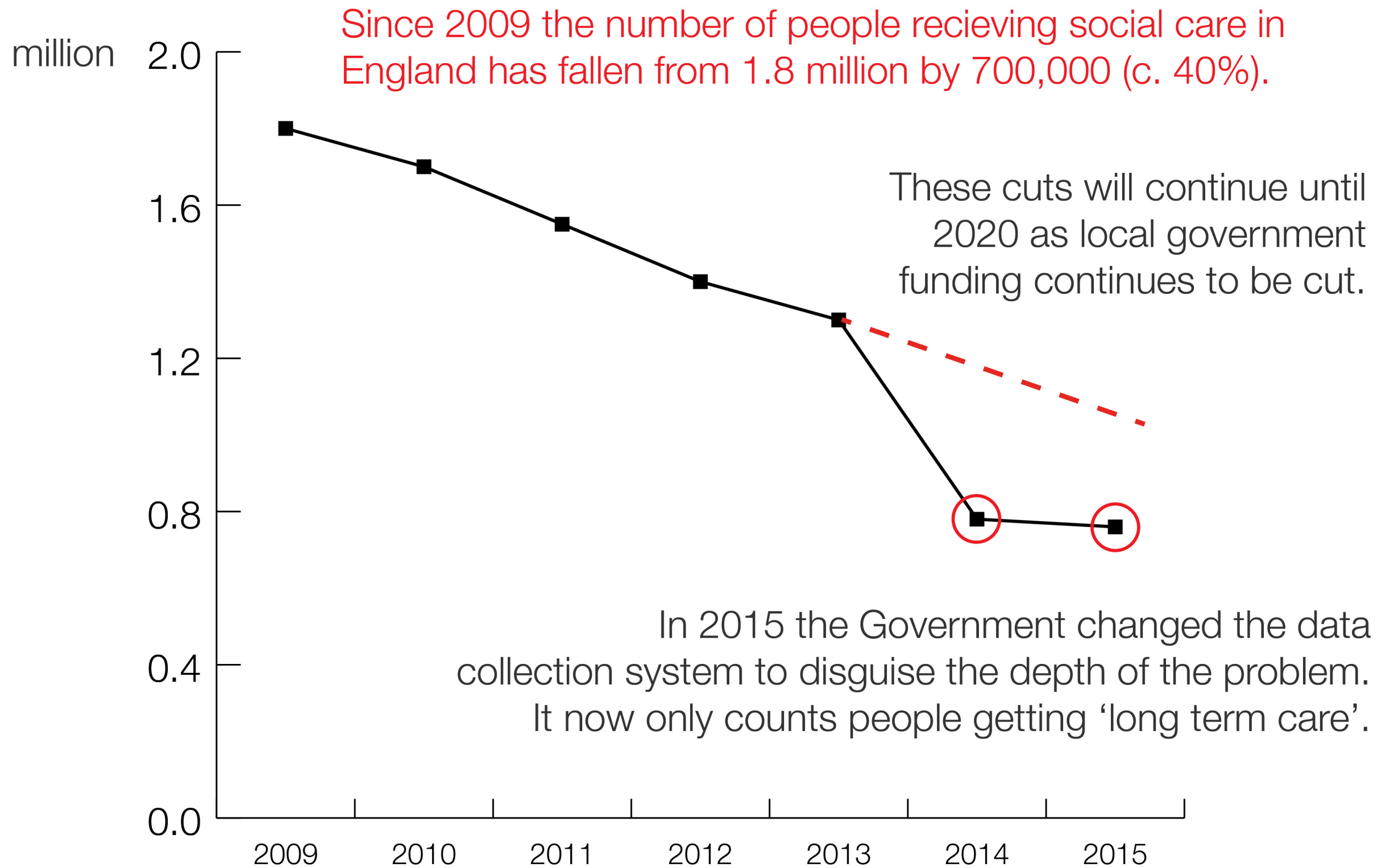
Increased means-testing
Higher eligibility
Cuts in Adult Social Care
Cuts in Children's Services
Closure of ILF
Cuts in Supporting People
Cuts to Personal Budgets

Income Cuts

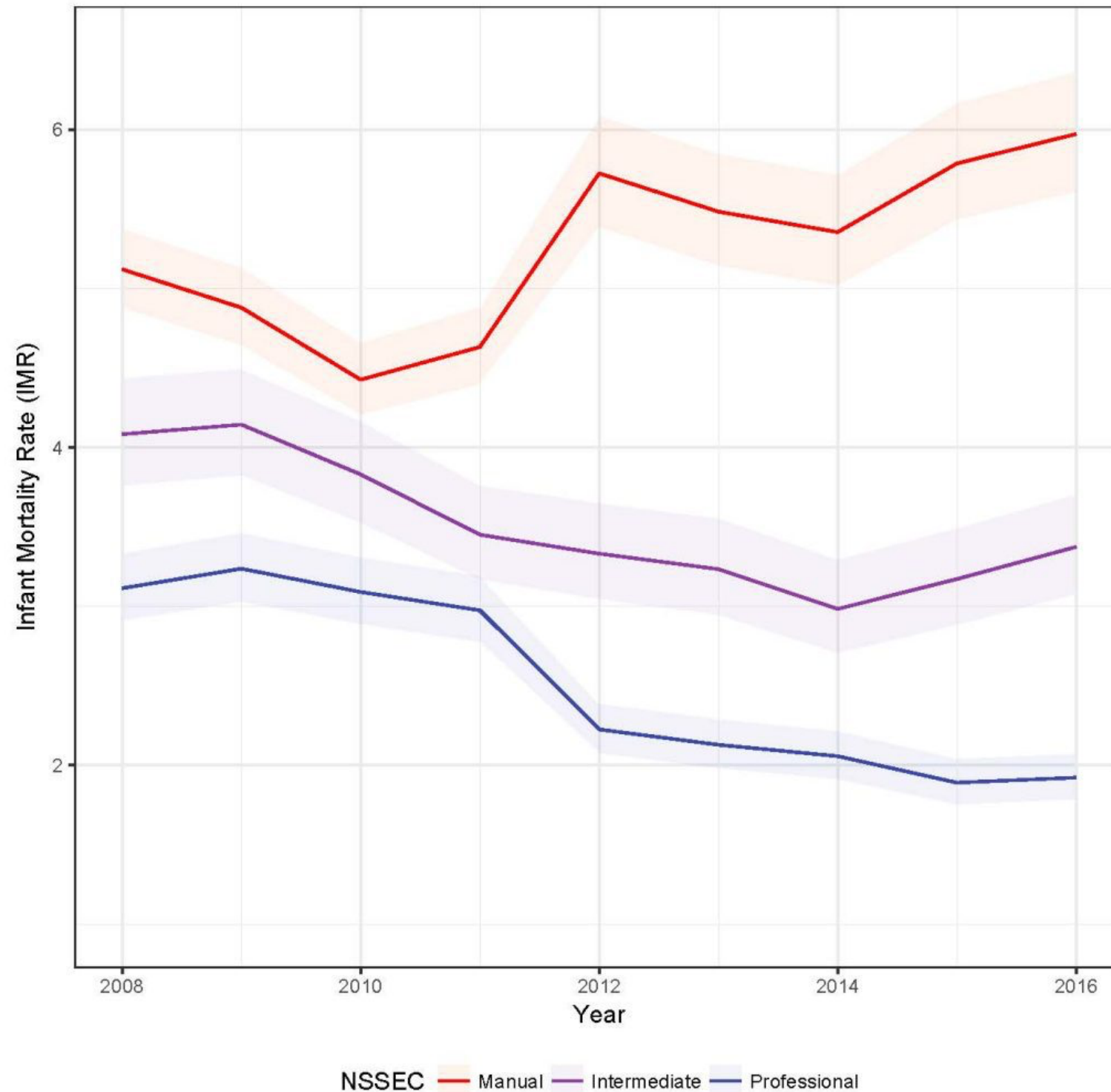
VAT increased to 20%
Utility bills increased
Indexation rules changed
DLA replaced by PIP
Failing Work Programme
ATOS and WCA
IB being replaced by ESA



People with most severe disabilities
have been hit 6 times harder by cuts
than the average person.

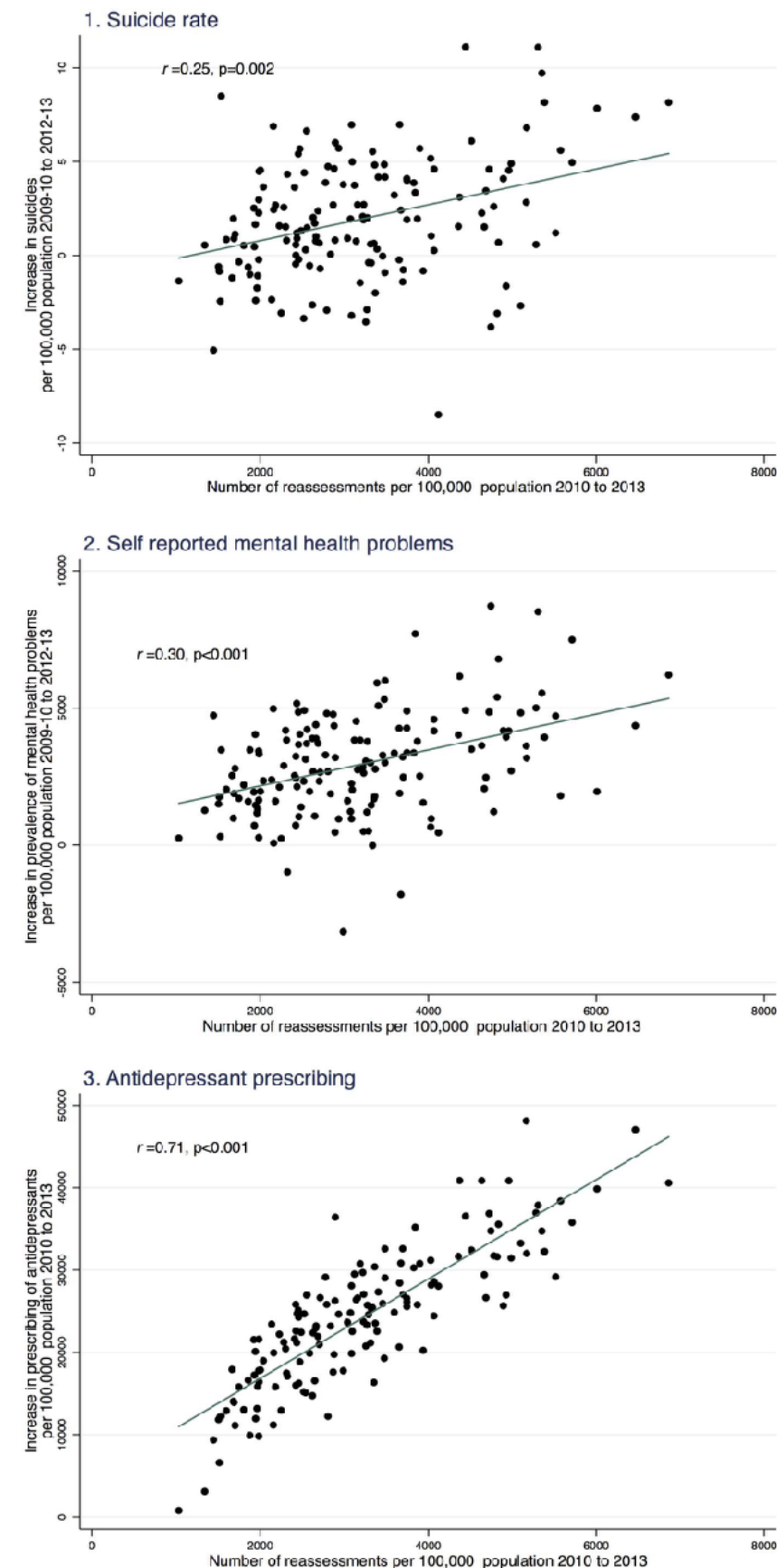


For vulnerable groups rates of mortality, suicide, malnutrition, homelessness are increasing



In total, across England as a whole, the WCA disability reassessment process during this period was associated with an additional **590 suicides** (95% CI 220 to 950), **279,000 additional cases of self-reported mental health problems** (95% CI 57,000 to 500,000) and the prescribing of an **additional 725,000 antidepressant items** (95% CI 406 000 to 1 045 000).

Barr B, et al. J Epidemiol Community Health 2015;0:1–7.
doi:10.1136/jech-2015-206209



**What makes this even
worse is that it is
all so unnecessary**

- We have never been so **wealthy** - overall - we have enough to meet all our needs
- We have never had so much **knowledge** and so many well educated people
- We have never had the level of **technology** and capacity to solve natural problems
- We are not at war (much), we are not suffering from a a famine or drought, no natural disasters (yet)
- So, **how did we get in this mess?**

- The UK's fundamental problems are caused by **inequality**... resources are distributed very unequally.
- The UK **democratic system** is broken... checks and balances don't work - elites who control the system are not accountable to the people.
- Our values have become fixated on **material success**, out-doing our neighbour and passive entertainments.
- We are **not citizens**, because we don't act like citizens.



True security
can only be
found in a
community of
citizens who
honour their
obligations to
each other

Image: It's a Wonderful Life
Words: Duffy S (2018)

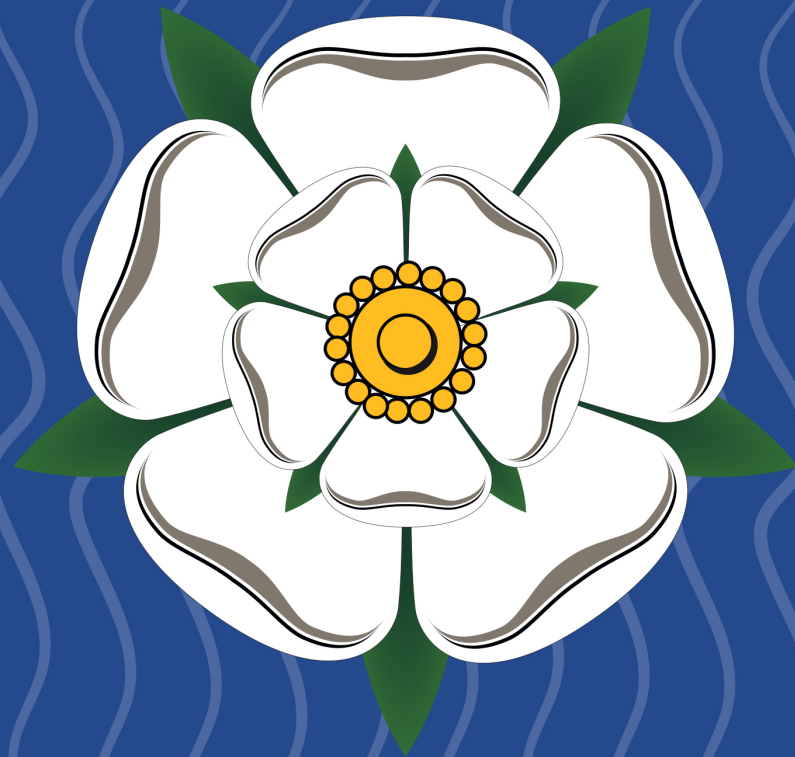


**The good news is that
these problems can all
be solved**

Heading Upstream

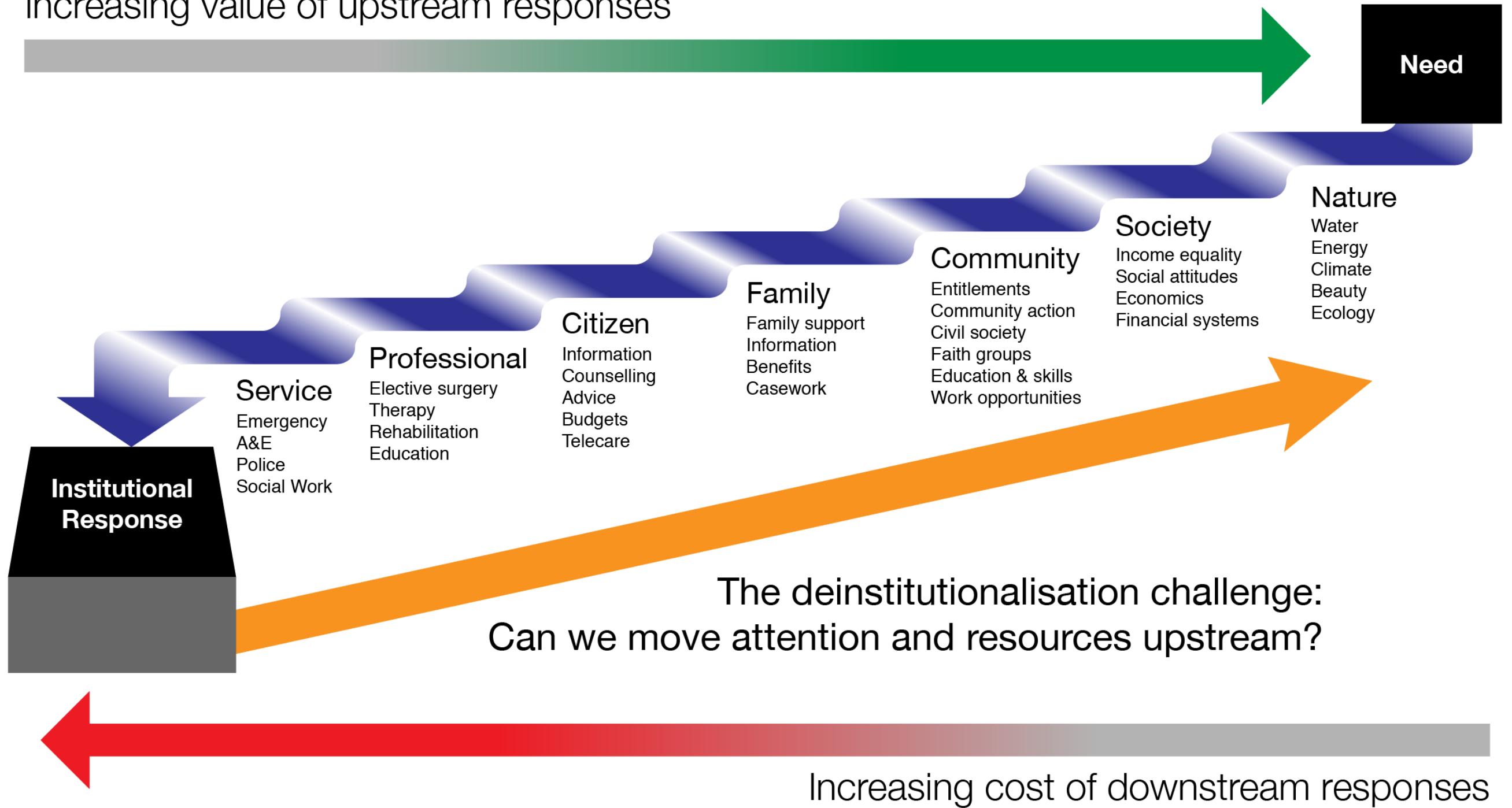
BARNSLEY'S INNOVATIONS FOR SOCIAL JUSTICE

by Dr Simon Duffy

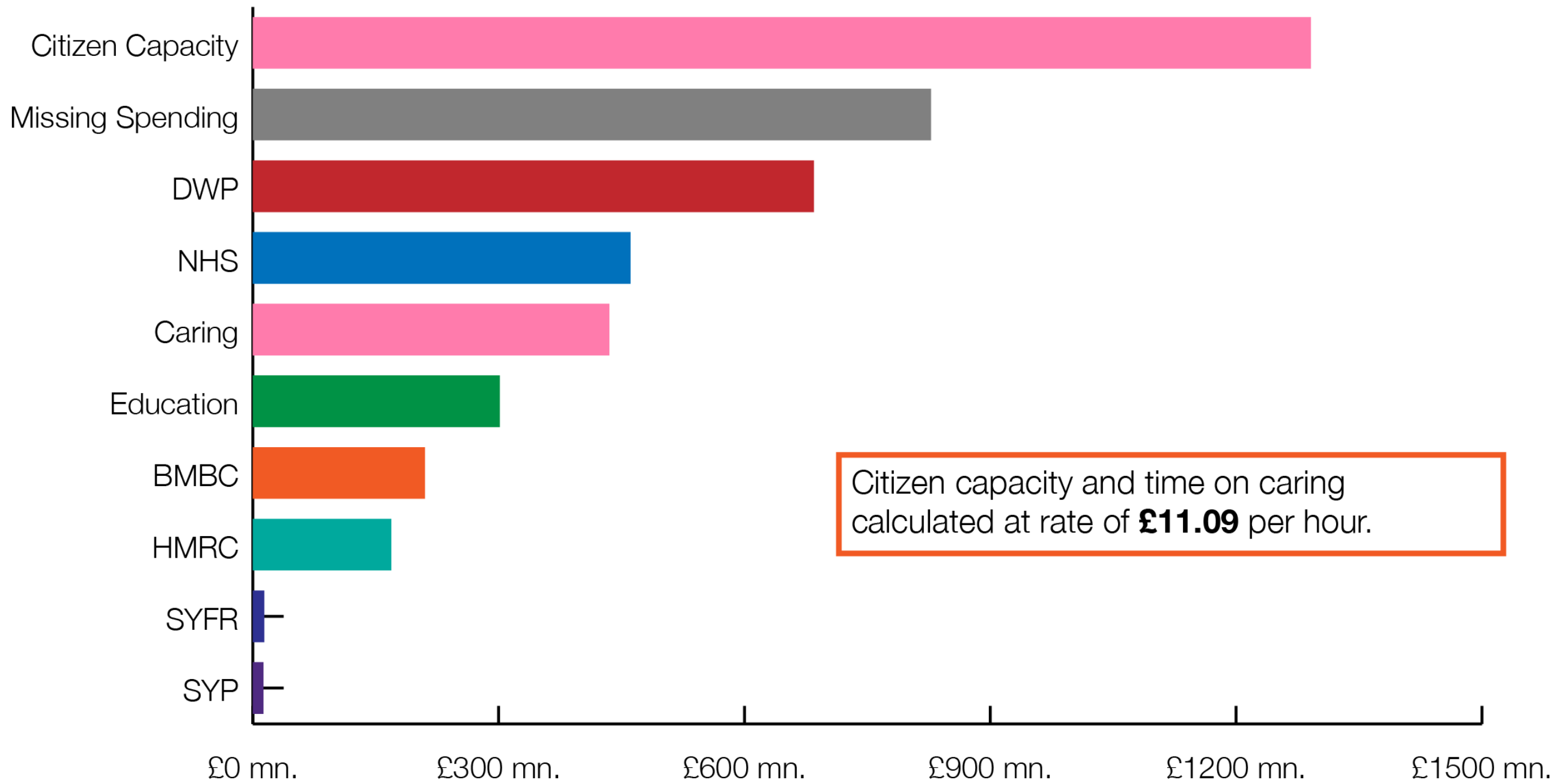


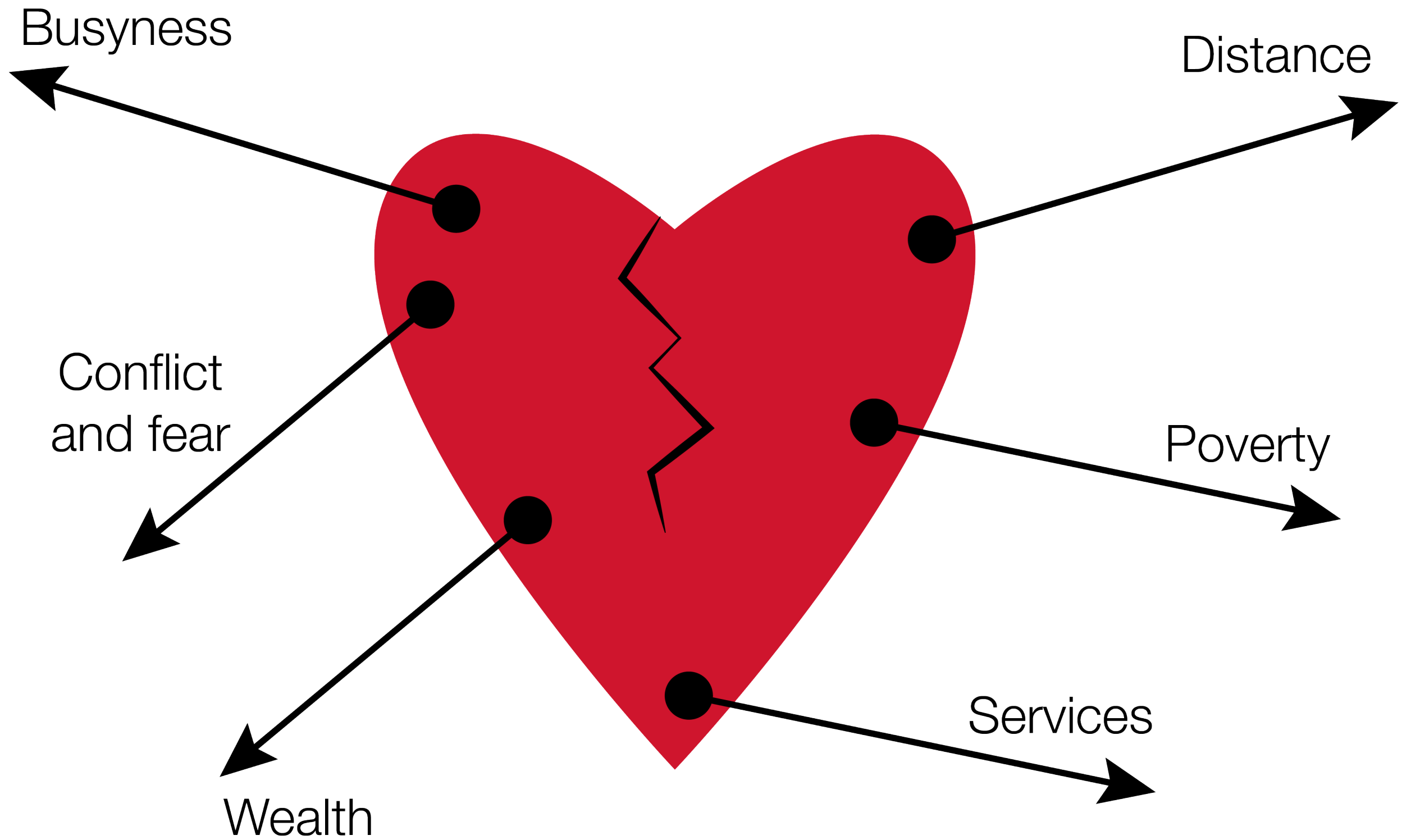
- We need to solve problems earlier and protect the social and economic structures that make life meaningful.
- We need to focus on local, peer and community solutions.
- We need to shift power and resources to citizens, families and communities

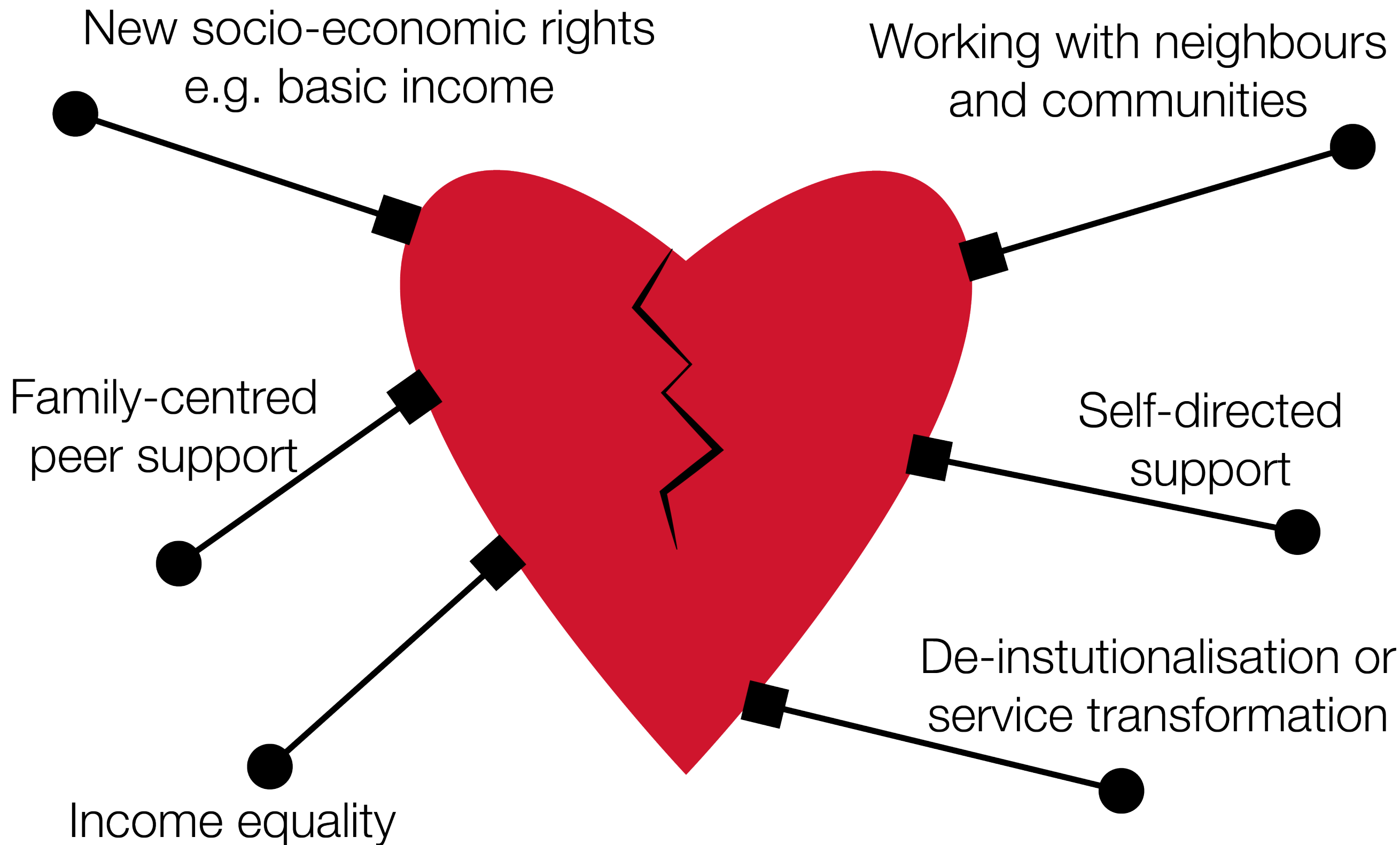
Increasing value of upstream responses



Centralisation and the failure to support people in their family and citizen roles is impoverishing all of us







- Systems of self-directed support need to be an easy and the default - **not an option**
- Support needs to be embedded at a community level, be as self-organising as possible - **staff are citizen too**
- Professionals need to rethink their role - they should be **teachers**, carriers of knowledge, innovators, researchers
- Information must be everywhere - in the mainstream media and reinforced by **peer-based** support
- Institutional services must be **closed** or **transformed** - market mechanisms will not be enough
- **Expect families and neighbours** to be the support base - build systems to reward, support and reinforce that expectation





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Like fb.me/centreforwelfarereform



More information at www.cforwr.org



Contact simon@centreforwelfarereform.org

1. Support pioneers - the change you want already exists
2. Build understanding - others need to see what you see
3. Keep innovating - your purpose will change as you go
4. Work from the inside - allies (must) exist everywhere
5. Go public - your ideas cannot survive inside a bubble