

Self-directed support

Talk for Government of Latvia



Dr Simon Duffy | Director of Citizen Network Research | 19 January 2023

Outline of talk

Global perspectives

1. Basic principles of self-directed support
2. Change in England and Scotland
3. Global patterns and challenges ahead

1. Basics principles

Background

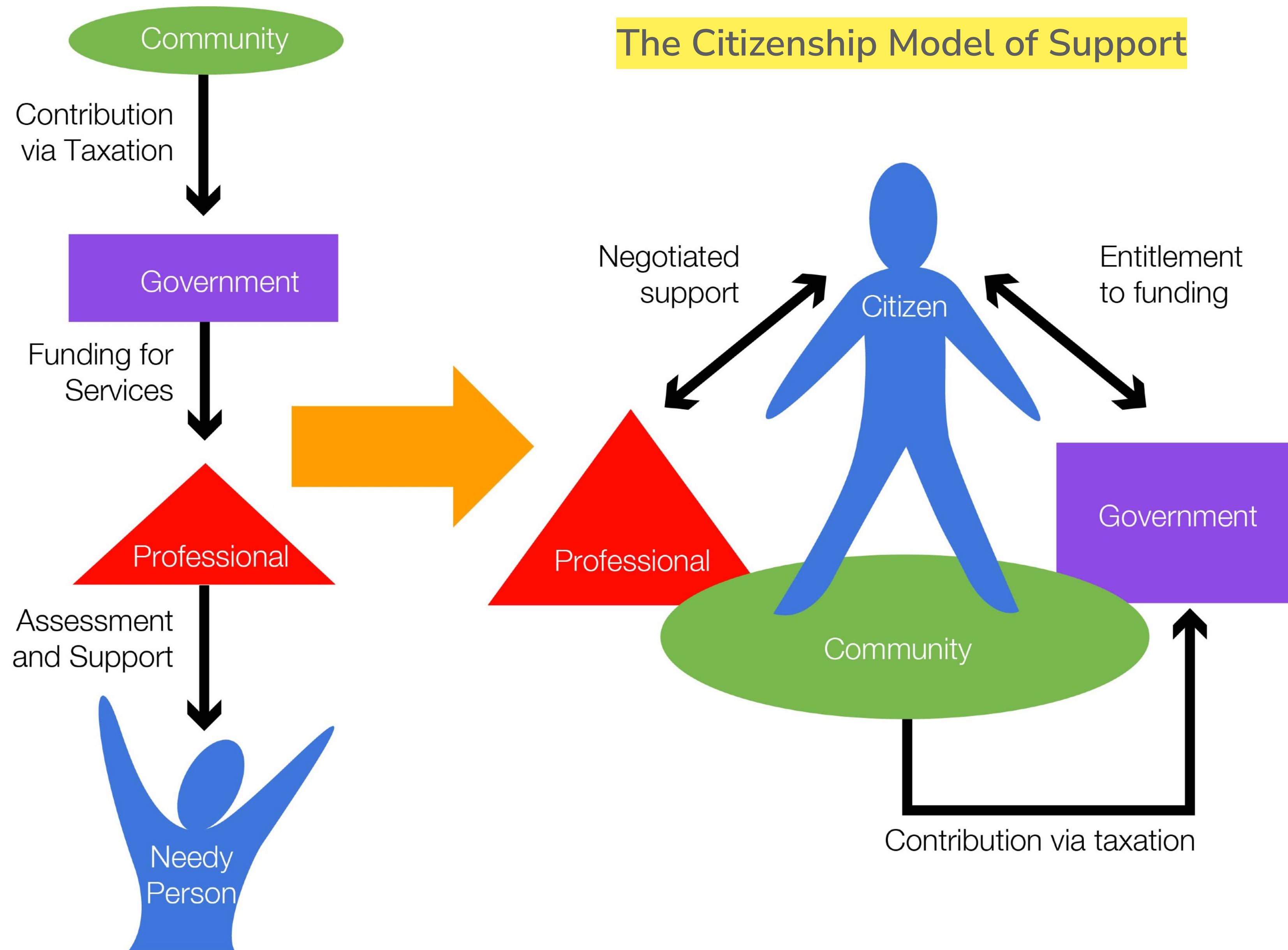
These factors seem to be promoting the shift to self-direction:

- Process of deinstitutionalisation of care
- Changing values: human rights, inclusion and citizenship
- Family and self-advocacy by people with disabilities and others
- Professional and political desire for modernisation
- Increasing evidence of improved satisfaction and other outcomes

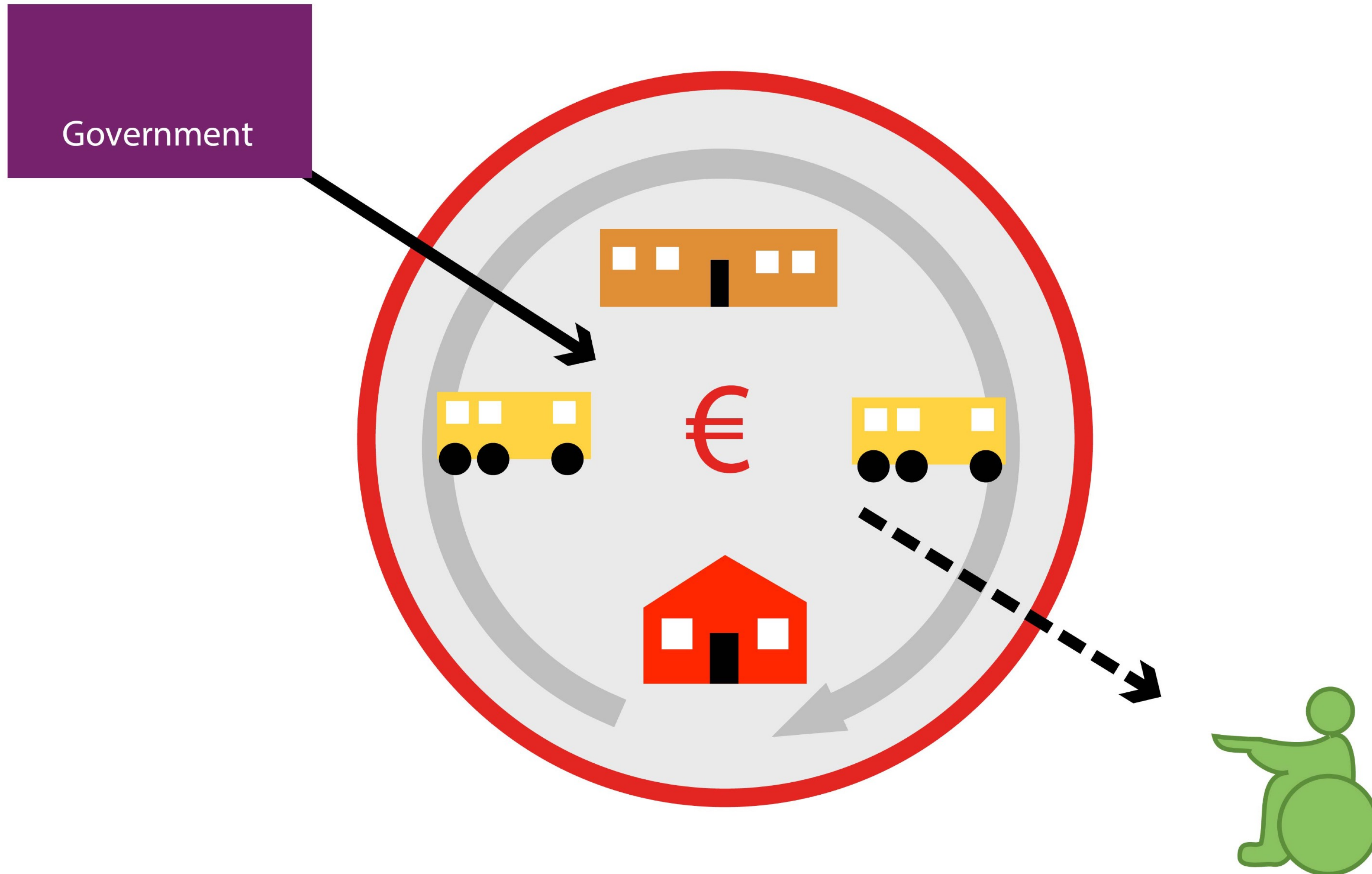
The primary problem:

*If a person with disabilities
doesn't control their support
they cannot control their life.*

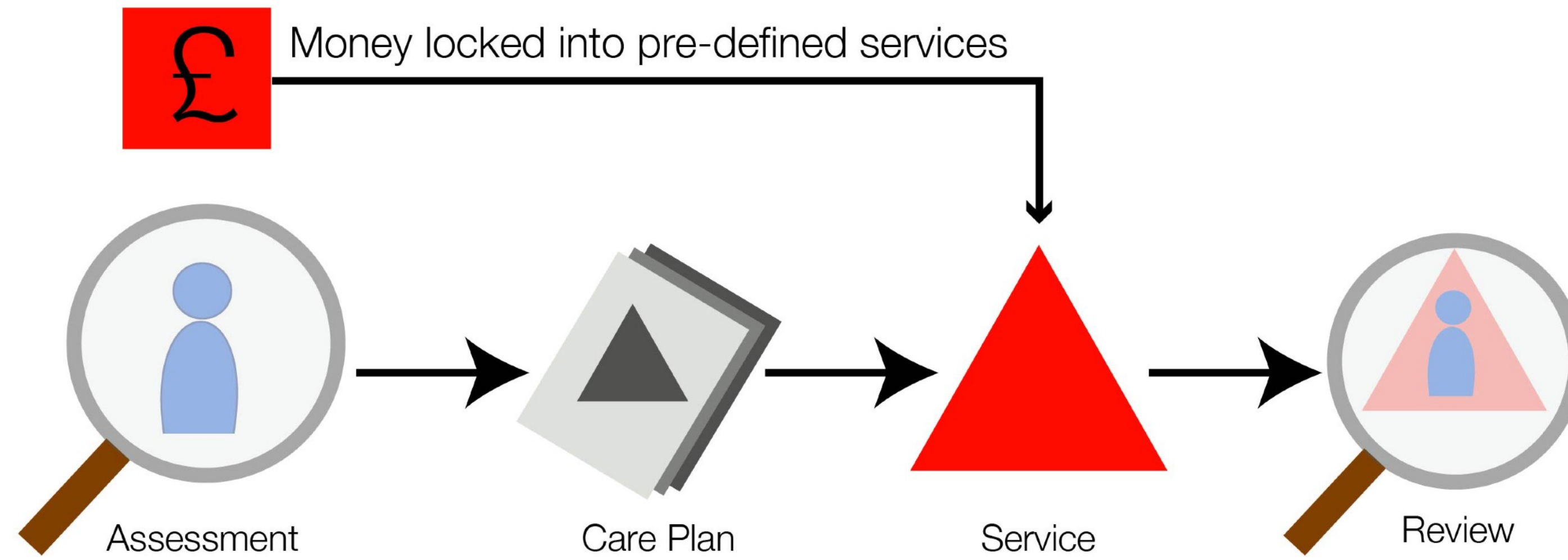
The Citizenship Model of Support



Spending people's money for them...



...on things they wouldn't buy for themselves.



Rights

+

Freedom

+

Participation

=

Citizenship

My Budget

Personal Budgets

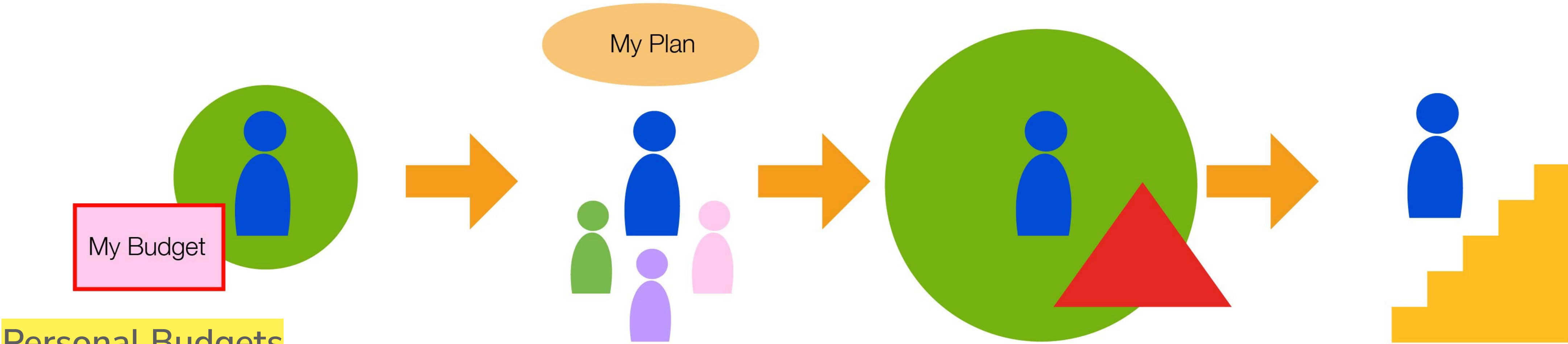
Clarify Entitlement

My Plan

Plan Together

Support in Community

Focus on Outcomes



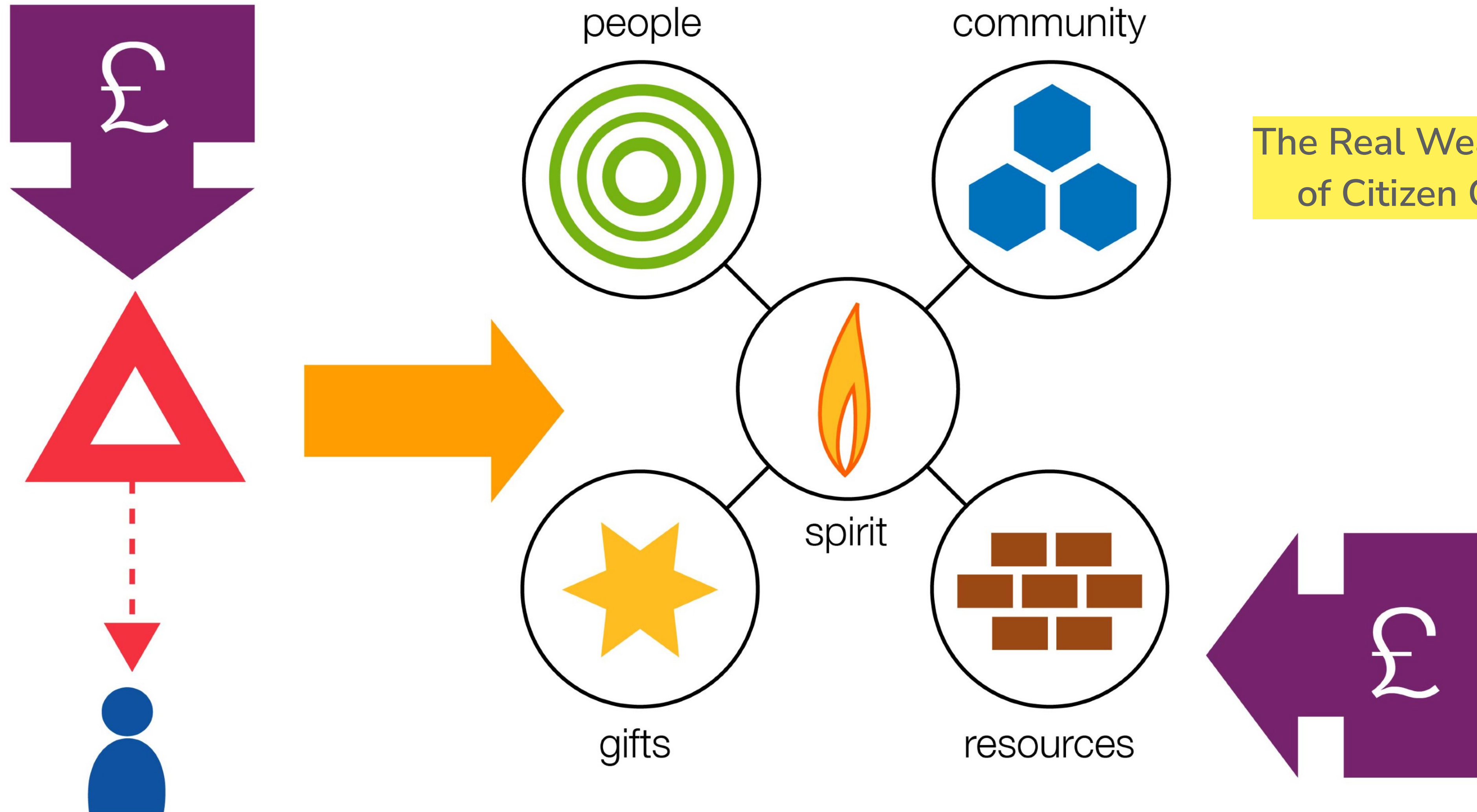
Core principles

These human rights should guide the design of the system

1. People have a right to support - and this generates **entitlements**
2. People have a right to freedom - and this requires **control**
3. People have a right to participation - and this requires **flexibility**
4. People are citizens - and this requires **recognition** of **contribution**

From Push Economics...

to Pull Economics



Efficiency

The efficiency of self-directed support is NOT market efficiency

1. People develop their skills and capacities
2. People make better use of their networks
3. People contribute to their communities more effectively
4. People manage resources more effectively
5. People invest in things that strengthen their spirit

The secondary problem:

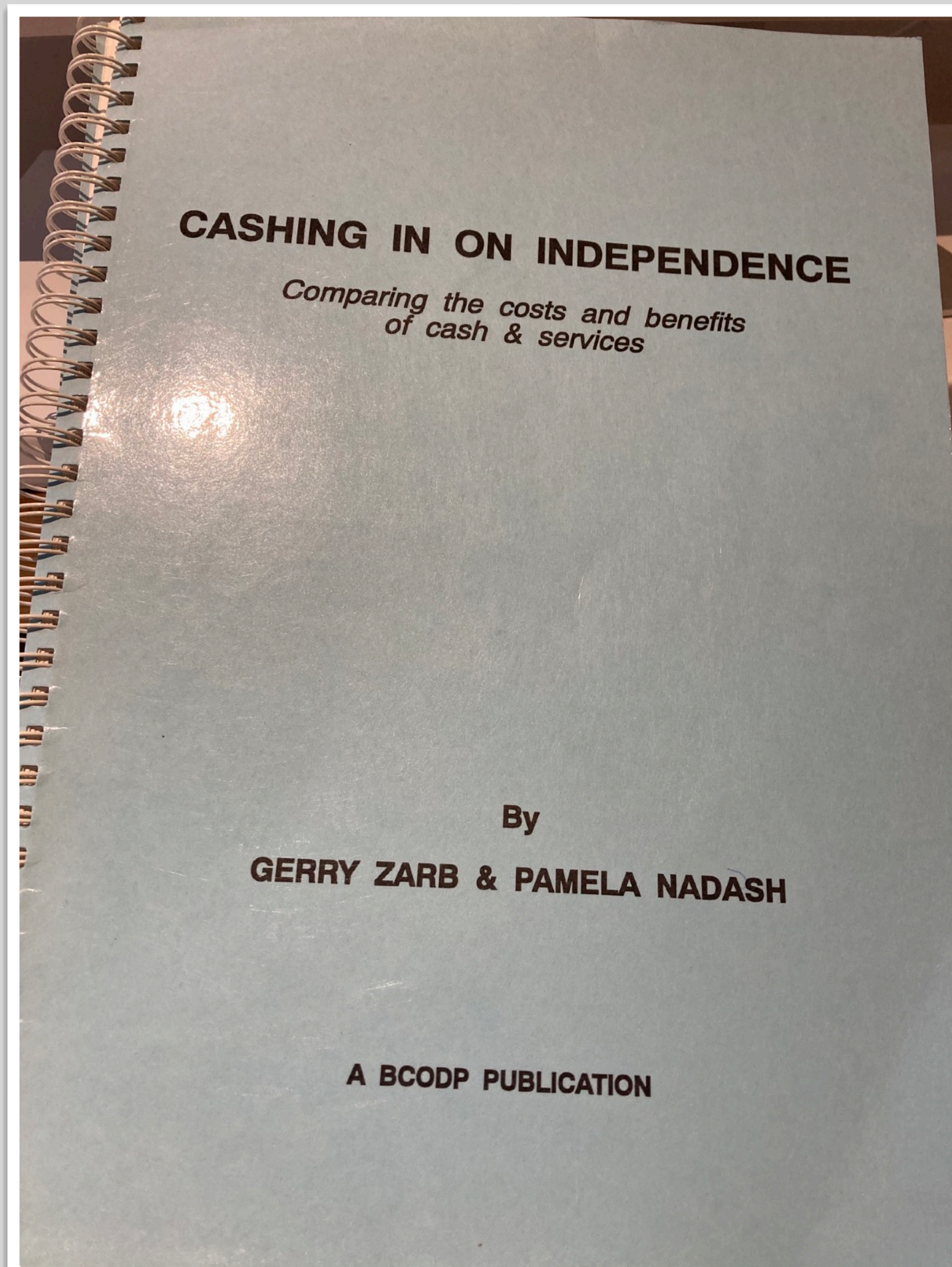
*Meaningful system change
requires changes in rules,
objectives and values.*

2. England and Scotland

Developments in England & Scotland

There are many important differences within the UK

- **Major** deinstitutionalisation programme: 1980s - 2000s
- Strong influence of **normalisation** and the **social model** of disability
- Strong advocacy **movements** for people with physical & intellectual disabilities
- **Fluctuations** in professional and political support for change

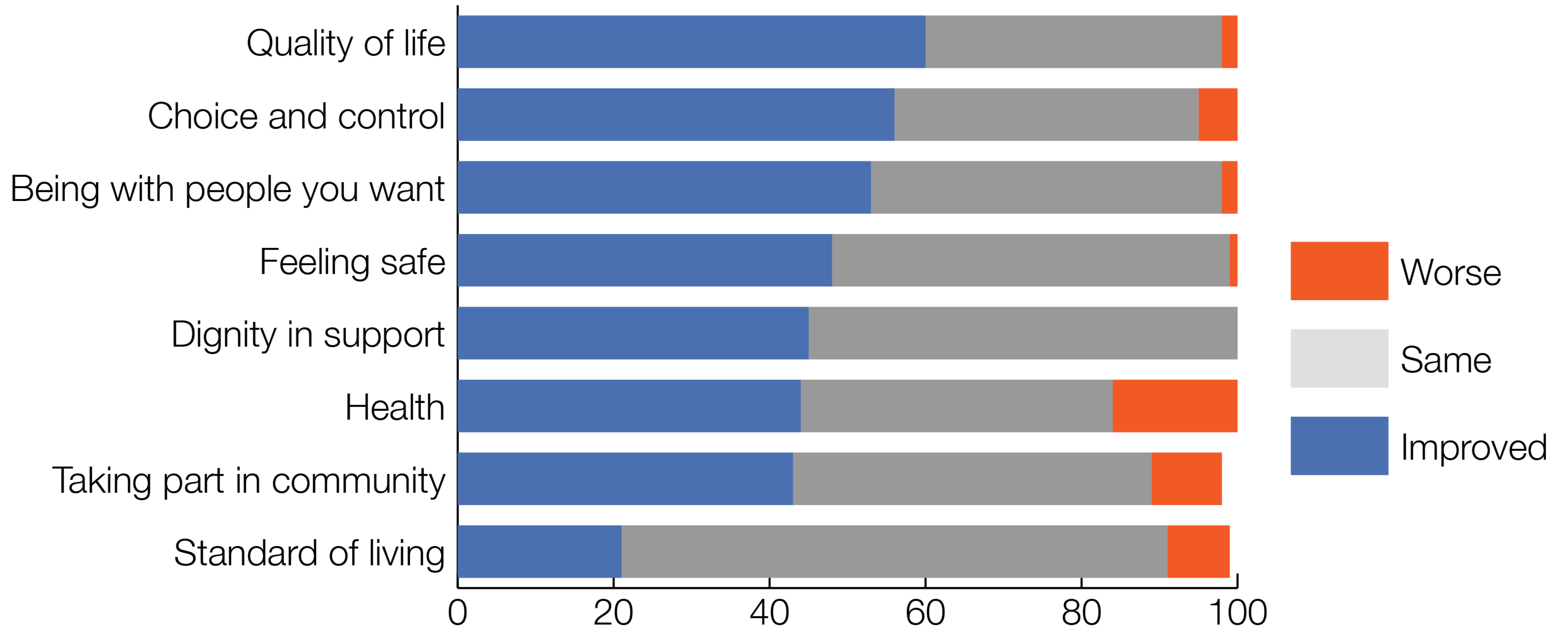


1994



2007

Data from Barnsley on introduction of personal budgets



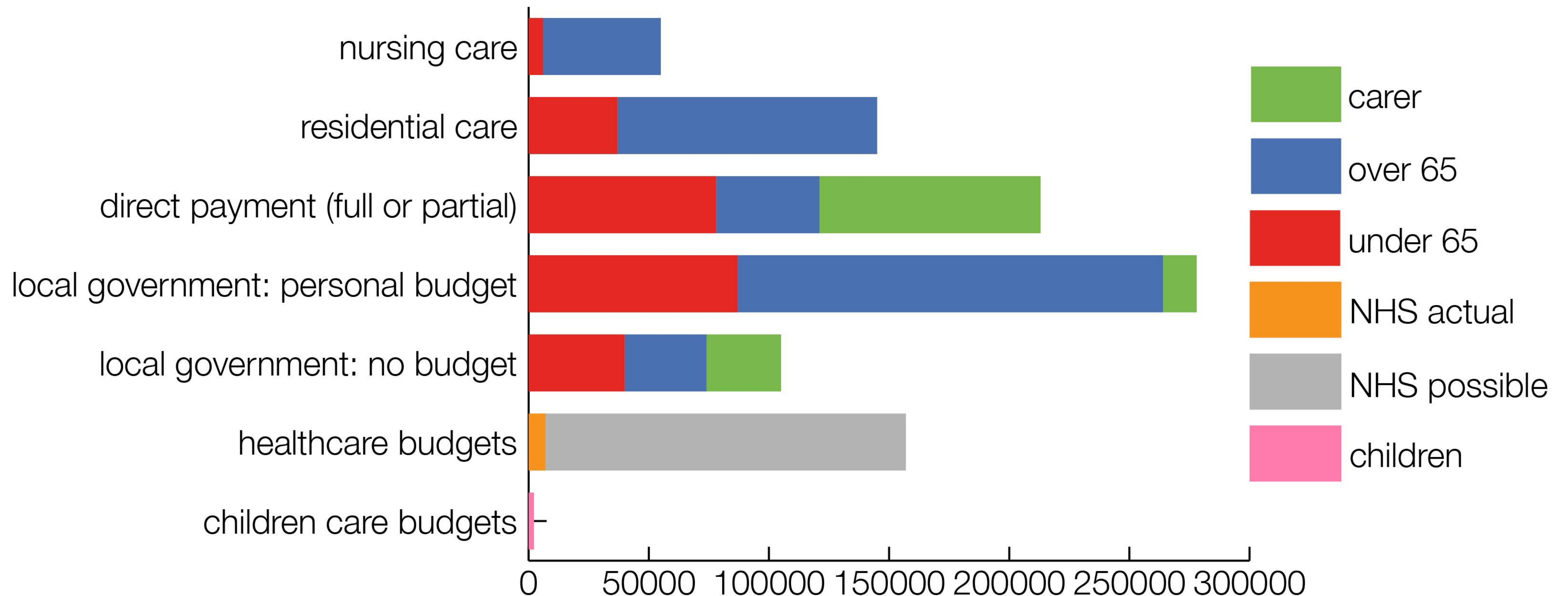
Lawson S, Pearmain G & Waters J (2010) Finding Our Way: the story of self-directed support in Barnsley. London: In Control. (n=100)

Key stages in growth of self-directed support

There has been important progress, although much of this has stopped

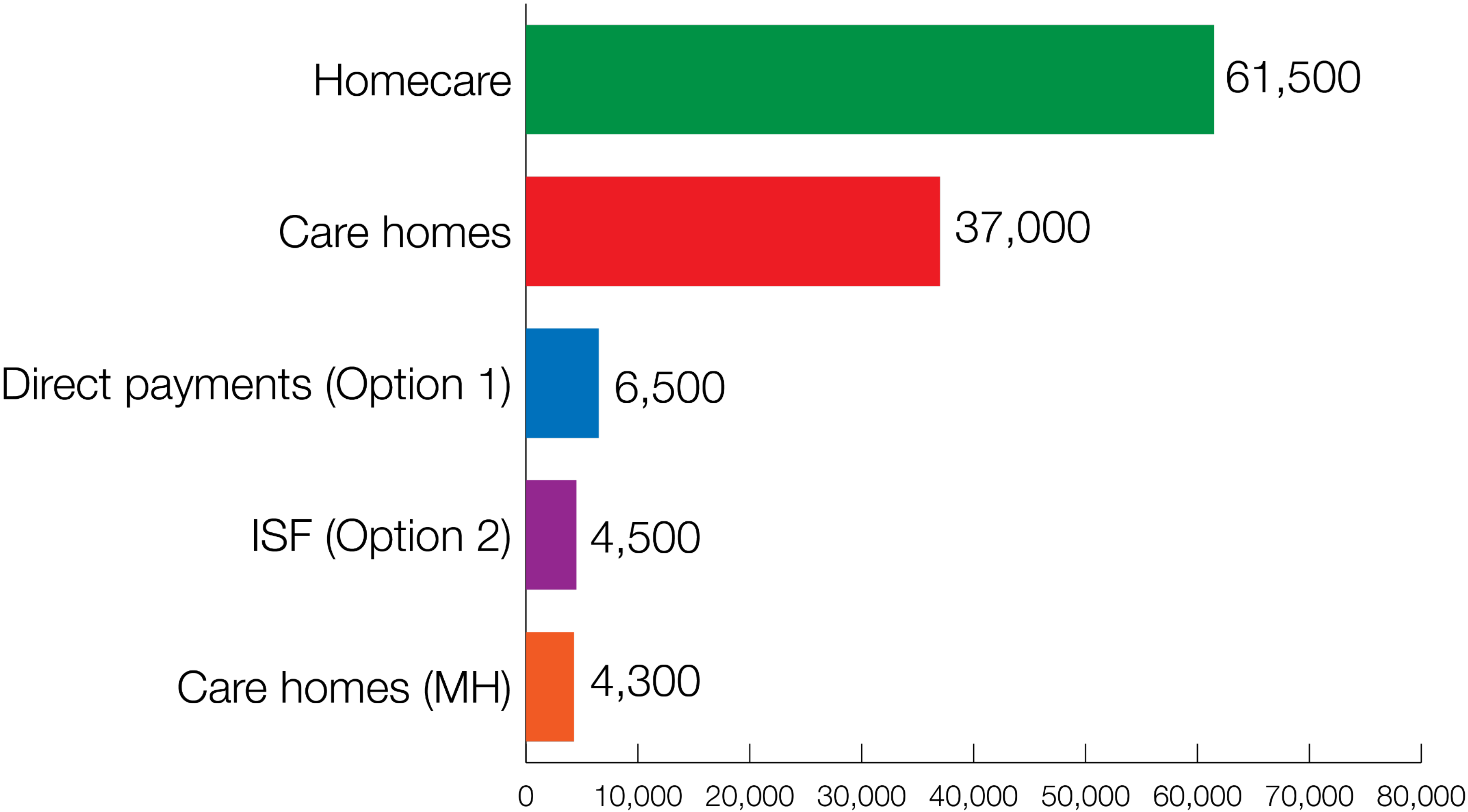
- 1970s first examples of **indirect** payments and **peer support**
- 1996 direct payments for care **permitted** (England & Scotland)
- 2000s self-direction starts to become a **policy priority**
- 2010 **austerity** policies and other priorities take over
- Effective **exclusion** of residential care from self-direction policy

Numbers of people with some kind of personal budget by 2015

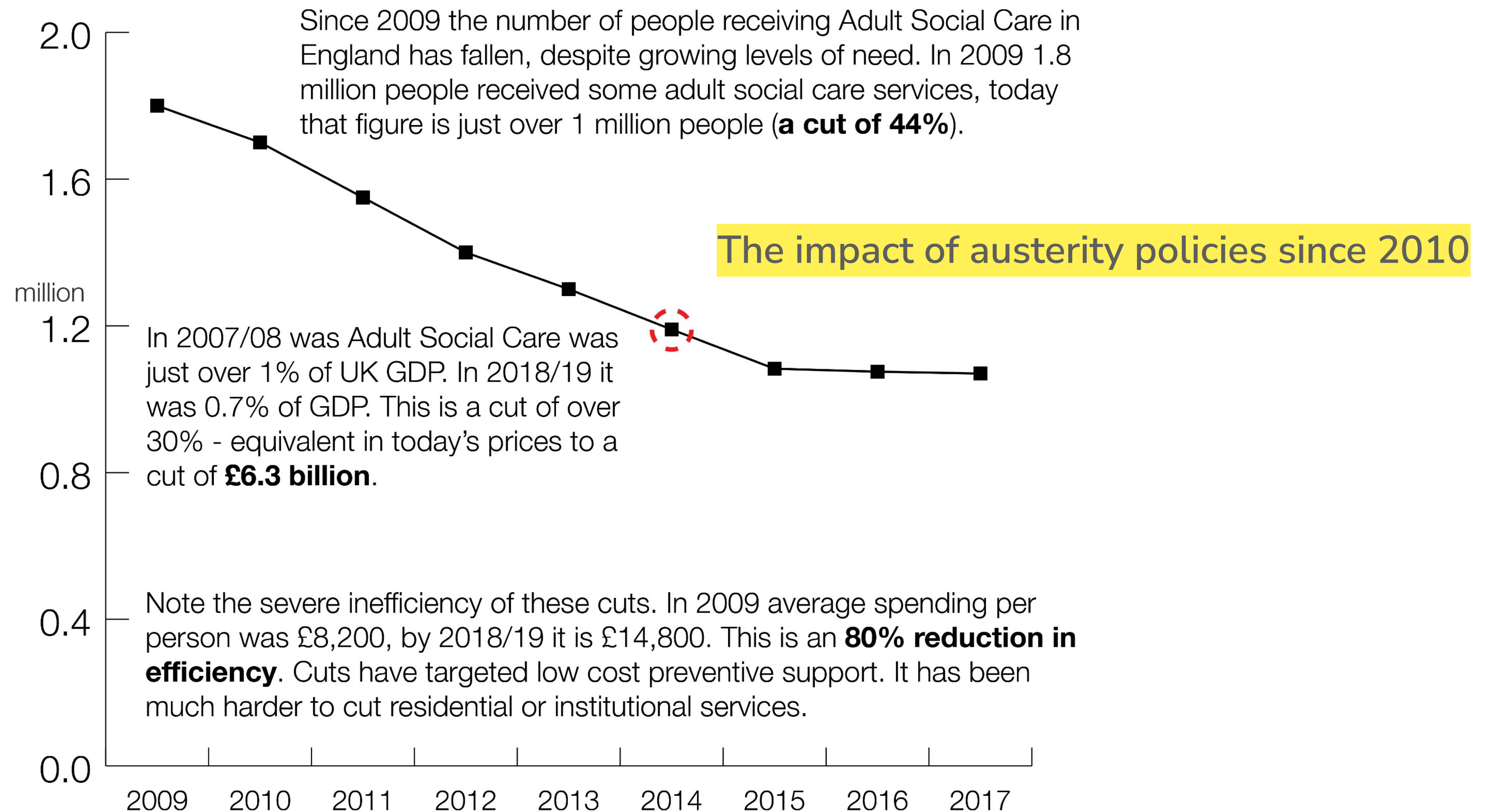


Source: Health and Social Care Information Centre (2015) Community Care Statistics: Social Services Activity, England 2014-15, Final release. Leeds, Health and Social Care Information Centre. Carer data is support provided during the year; other data is long-term support at year end (31st March 2015). NHS data provided by NHS official at London SDS Forum (July 2016) and NHS England (2016) Integrated Personalised Commissioning: Emerging Framework. London: NHS England.

Progress of self-directed support in Scotland (2014-15)



Source: Scottish Government (2016) Social Work and Social Care Statistics for Scotland: A Summary. Figure for ISFs extrapolated from data within Scottish Government (2016) Self-directed support, Scotland, 2014-15.



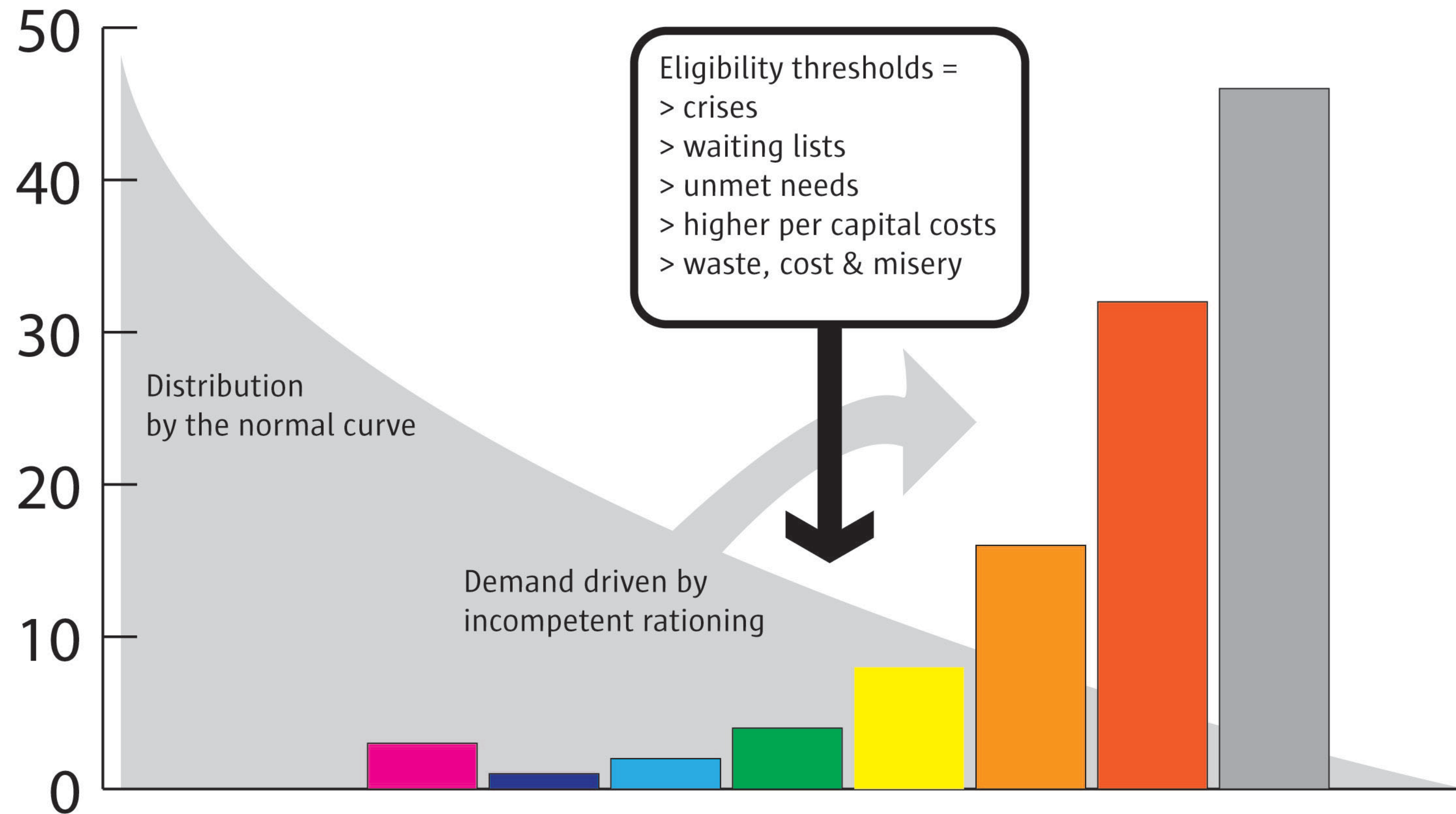
Source: NHS Information Centre: NHS and Adult Social Care Data: Community Care Statistics: Social Services Activity for various years during period. The data system was changed in 2014 and the figure for 2014 is an estimate. Data for 2018 has still not yet been published.

Practical innovations

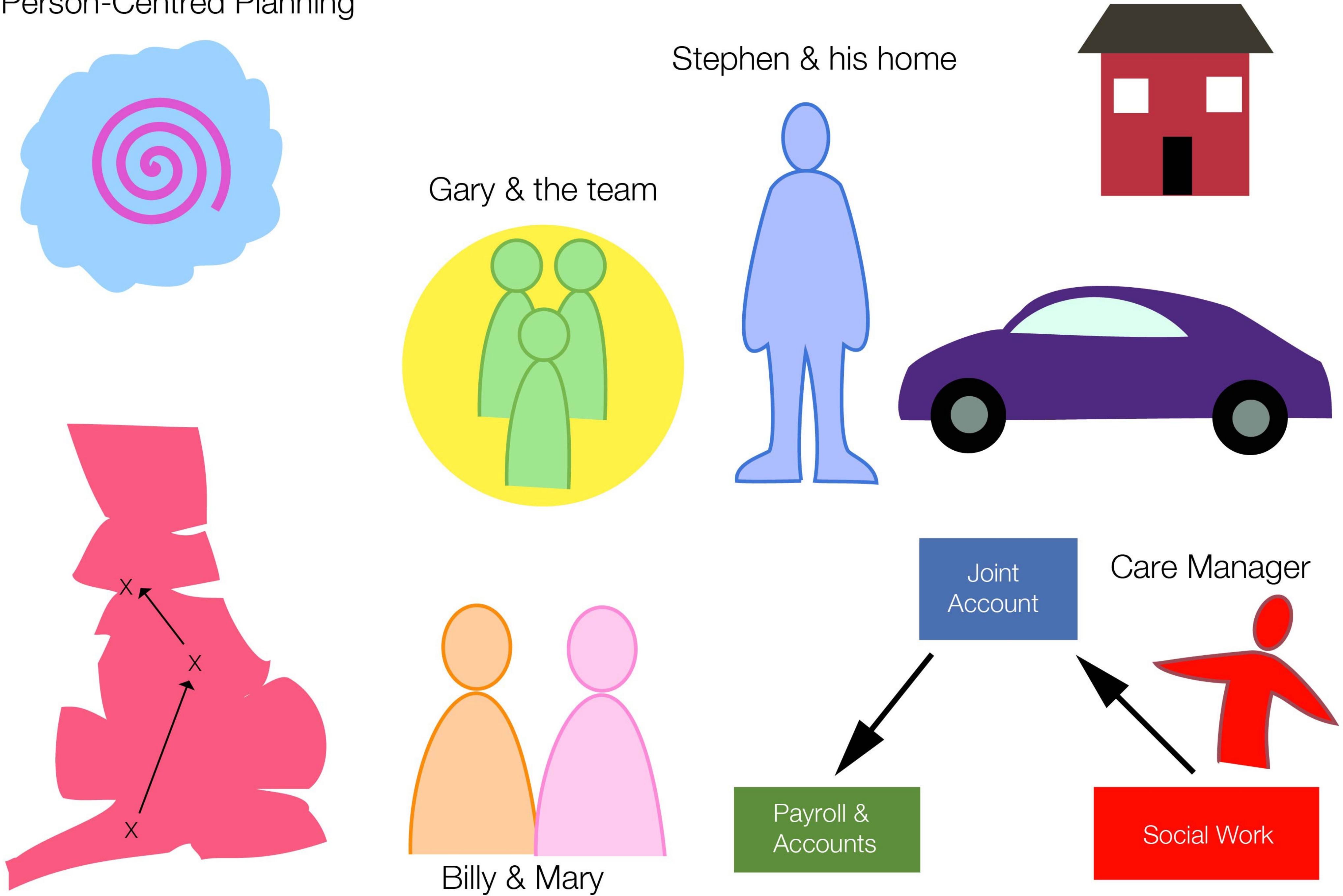
Change was driven by grassroots innovation

- Mechanisms to **clarify** and **transmit** funding to people or agents
- Willingness to **work with** people and families in designing policy
- More flexibility on **supported decision-making** and **families**
- More flexibility on the **use of resources**
- **Peer support** between disabled people

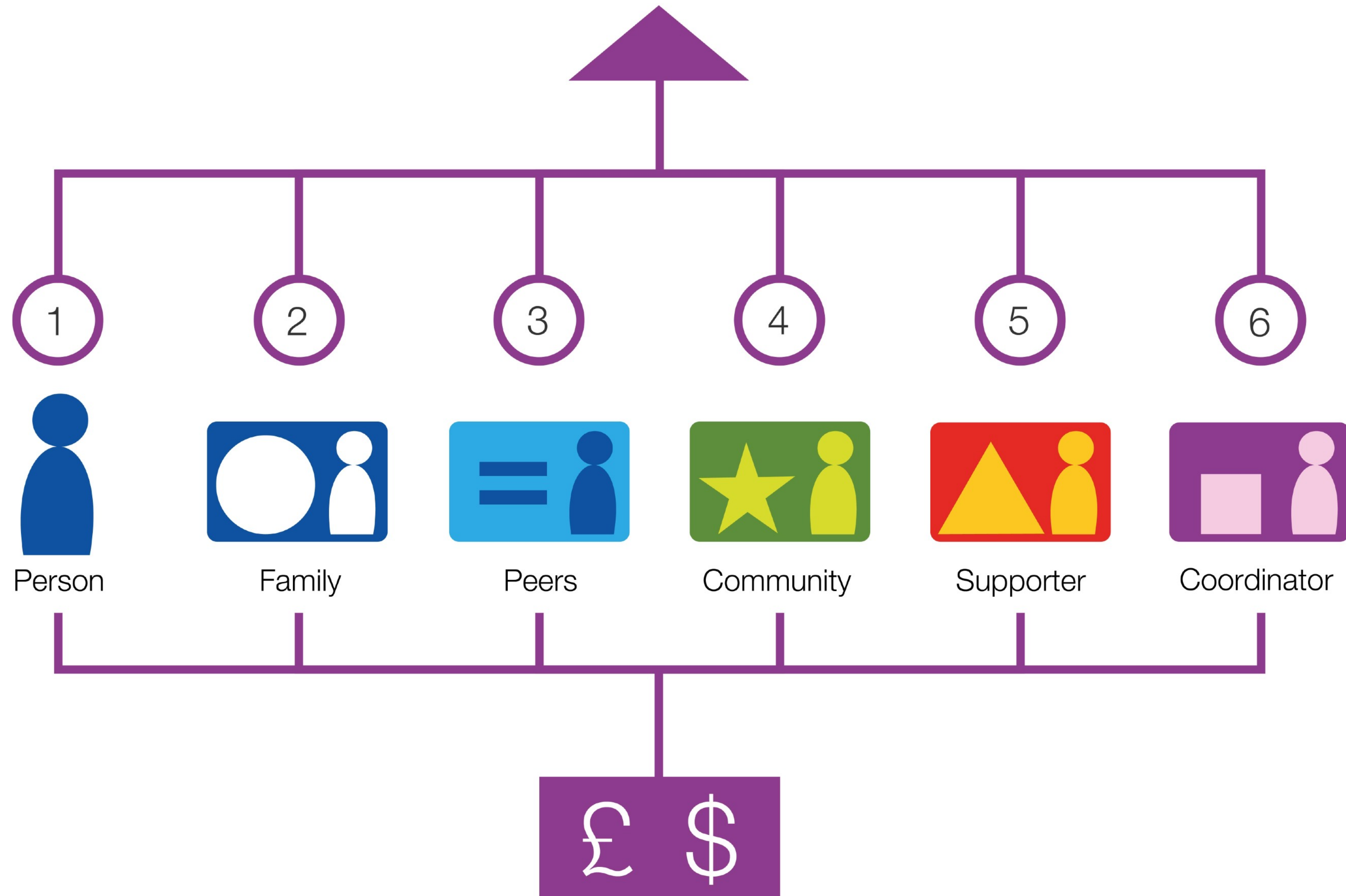
Methods for resource allocation remain contested



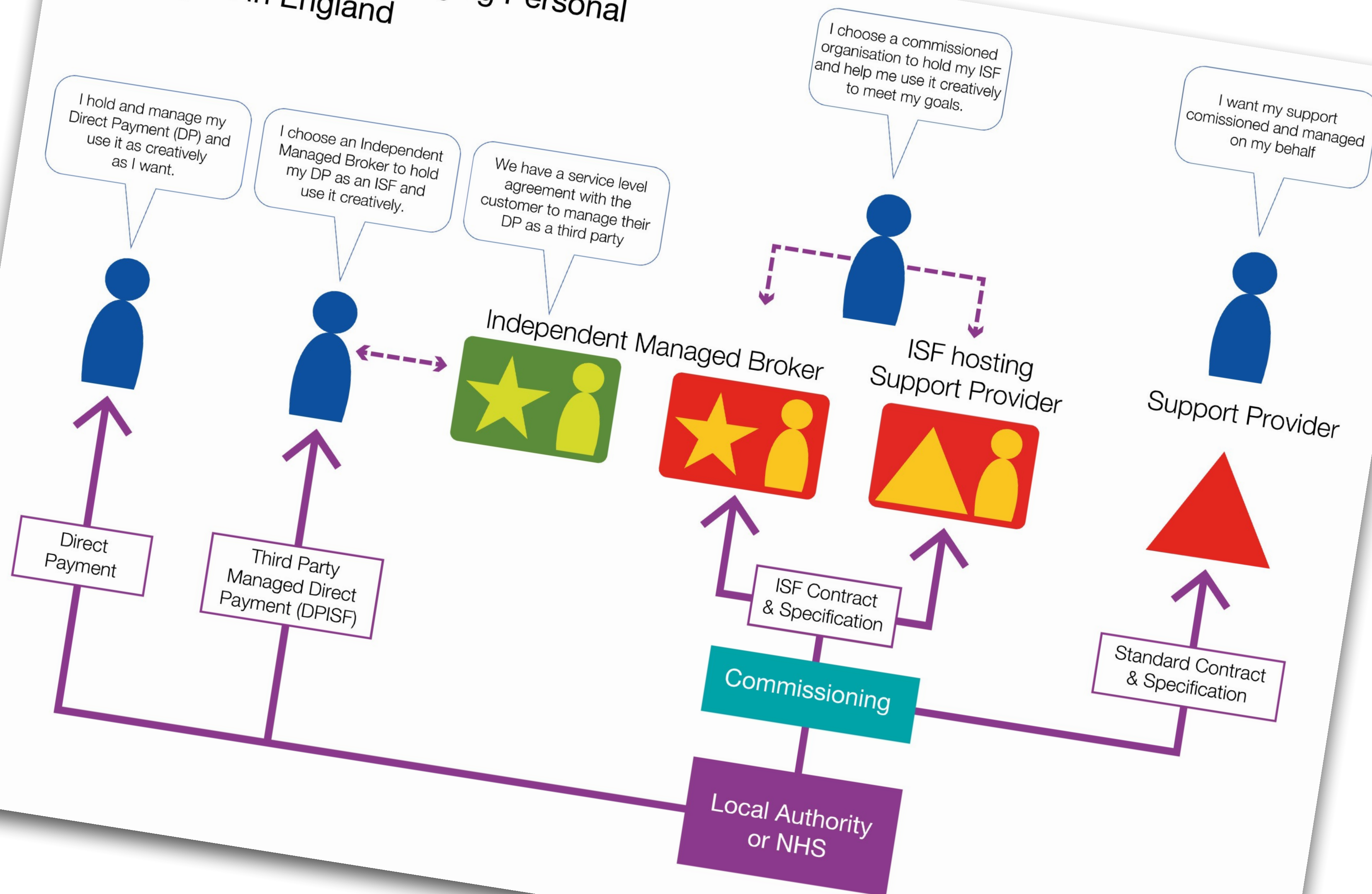
Person-Centred Planning

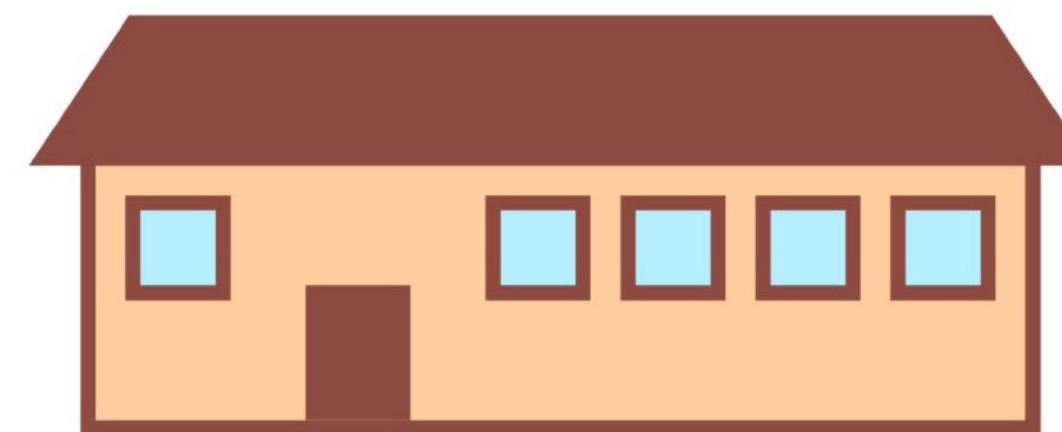
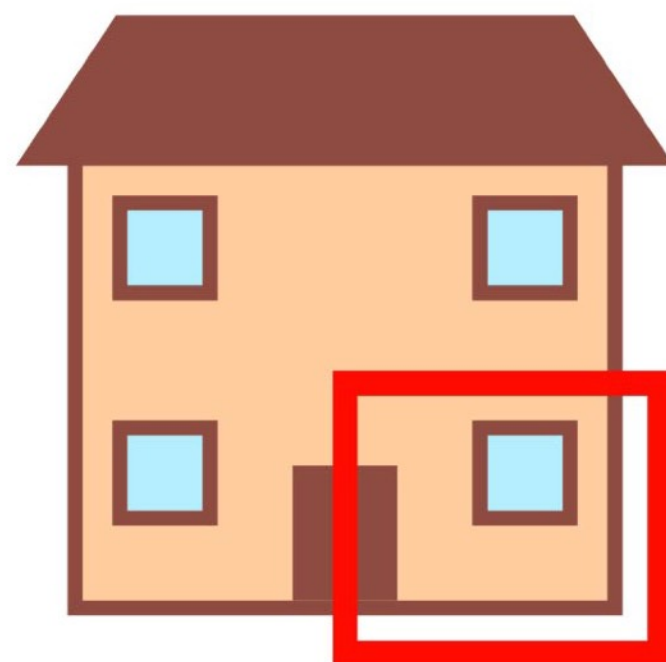
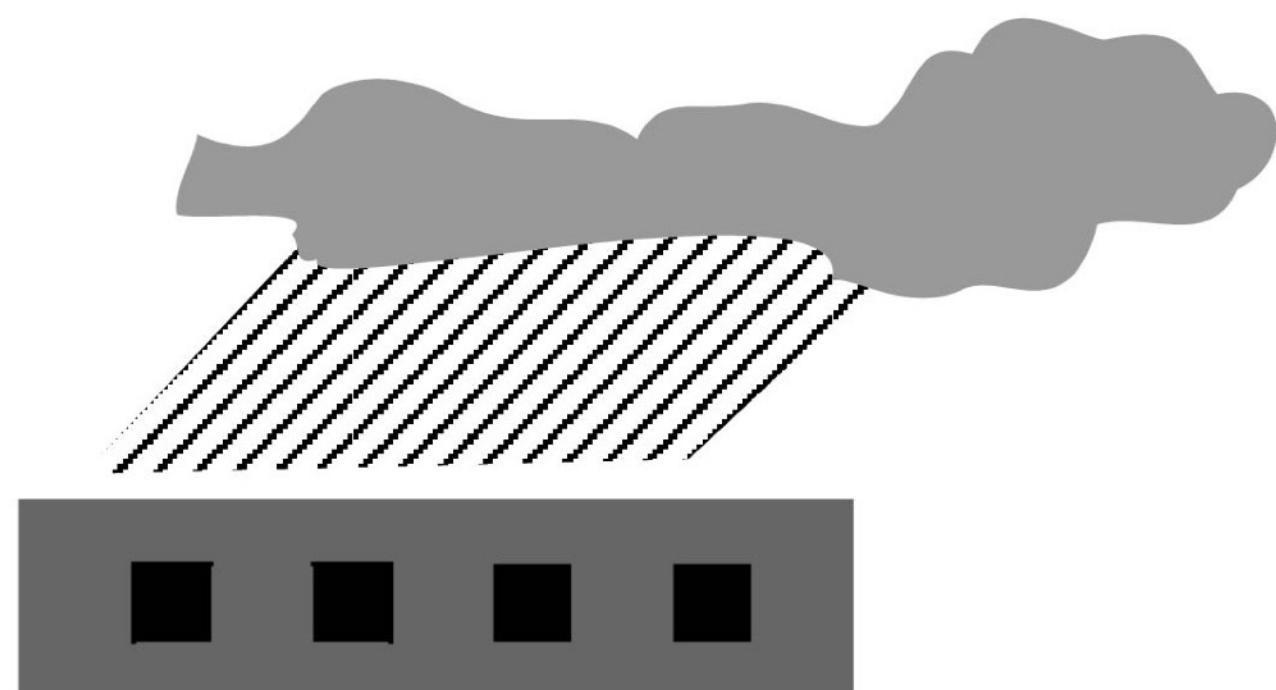


People need more than just direct control - some people need systems of support to manage budgets

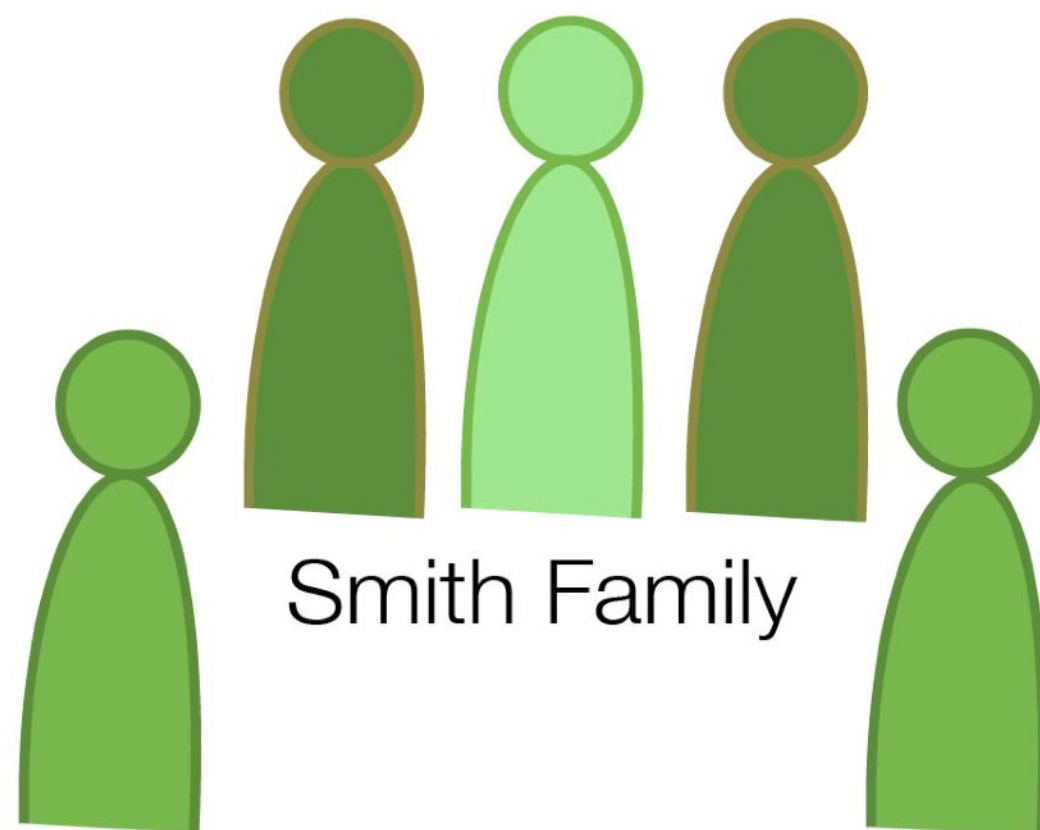


Five Options for Managing Personal Budgets in England





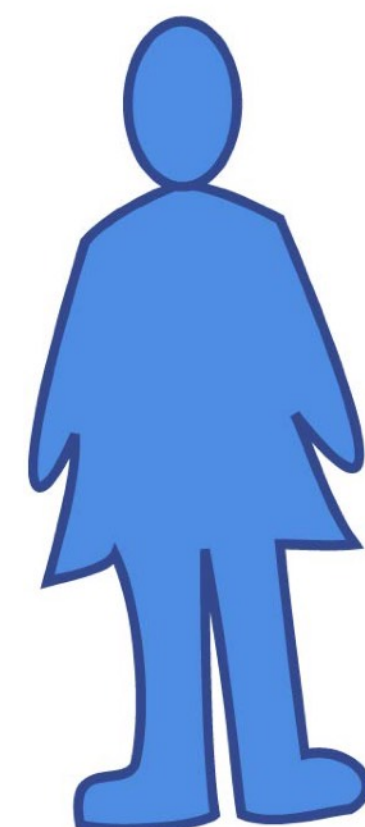
5 Bedroom House



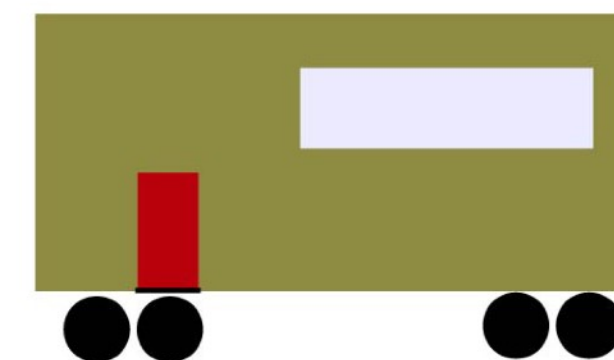
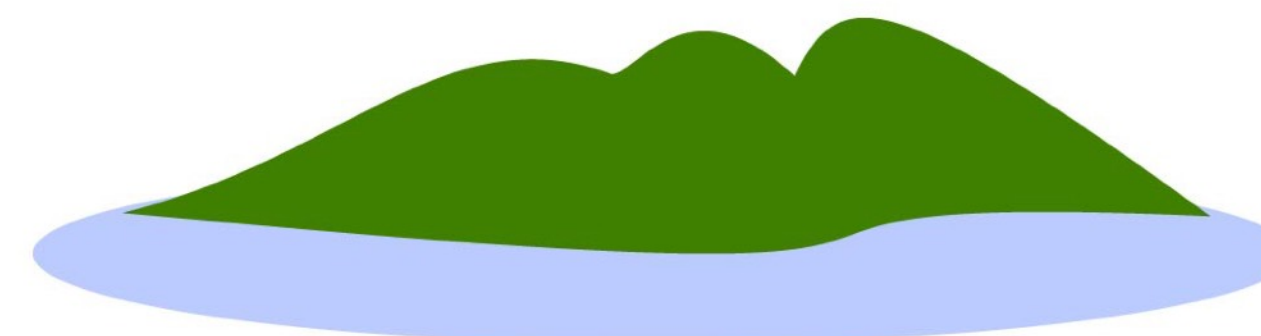
Smith Family



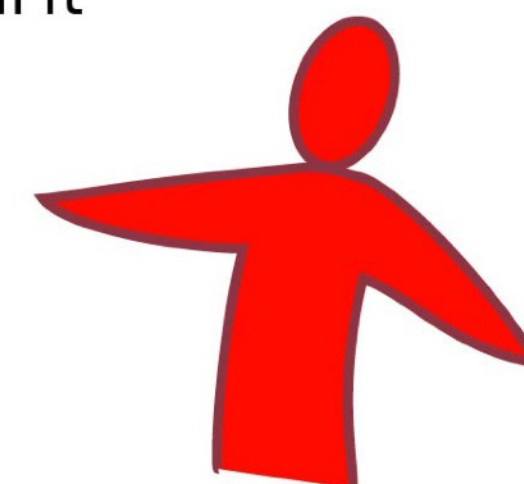
Person-Centred Planning



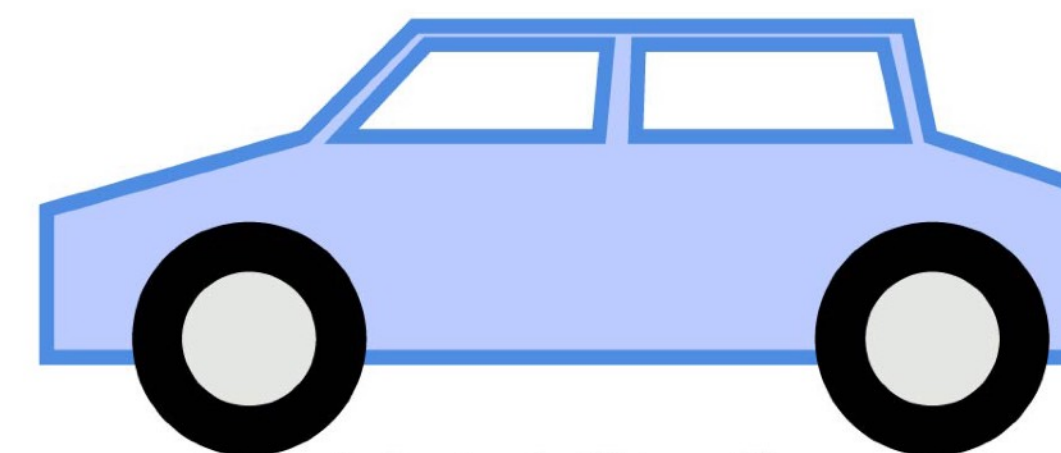
Aunt



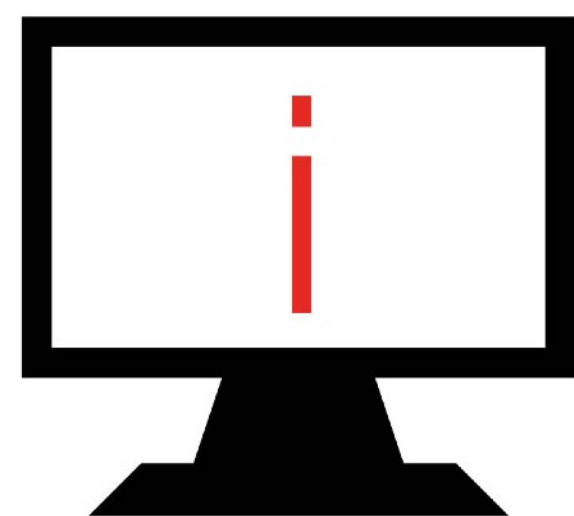
Alternative 'respite'



Service Coordinator

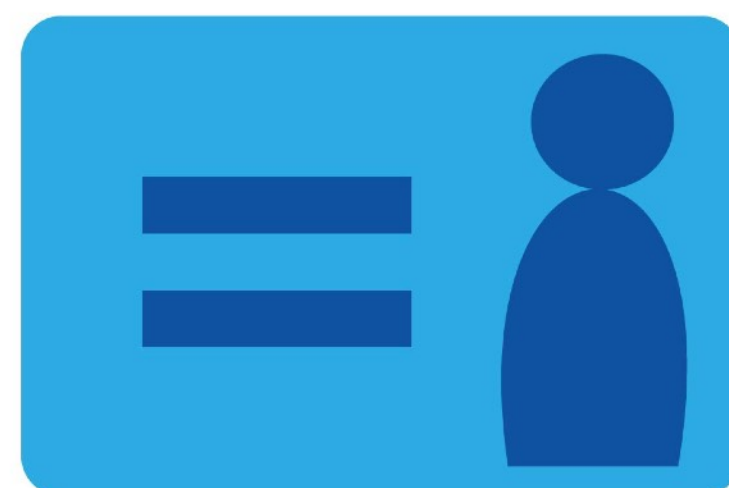


Motability Car



1. Give useful information

2. Connect to peers and other families

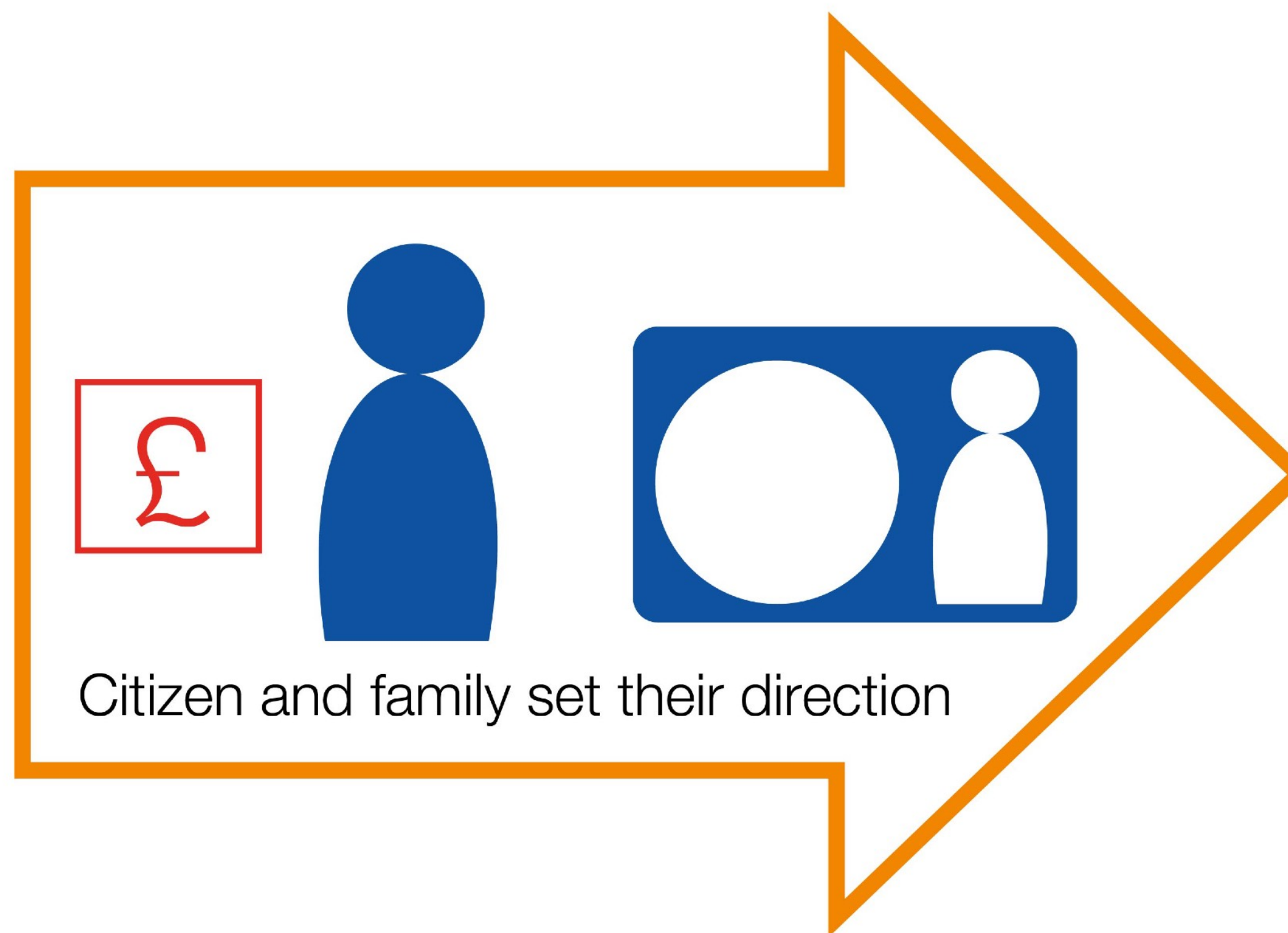


3. Direct to community organisations

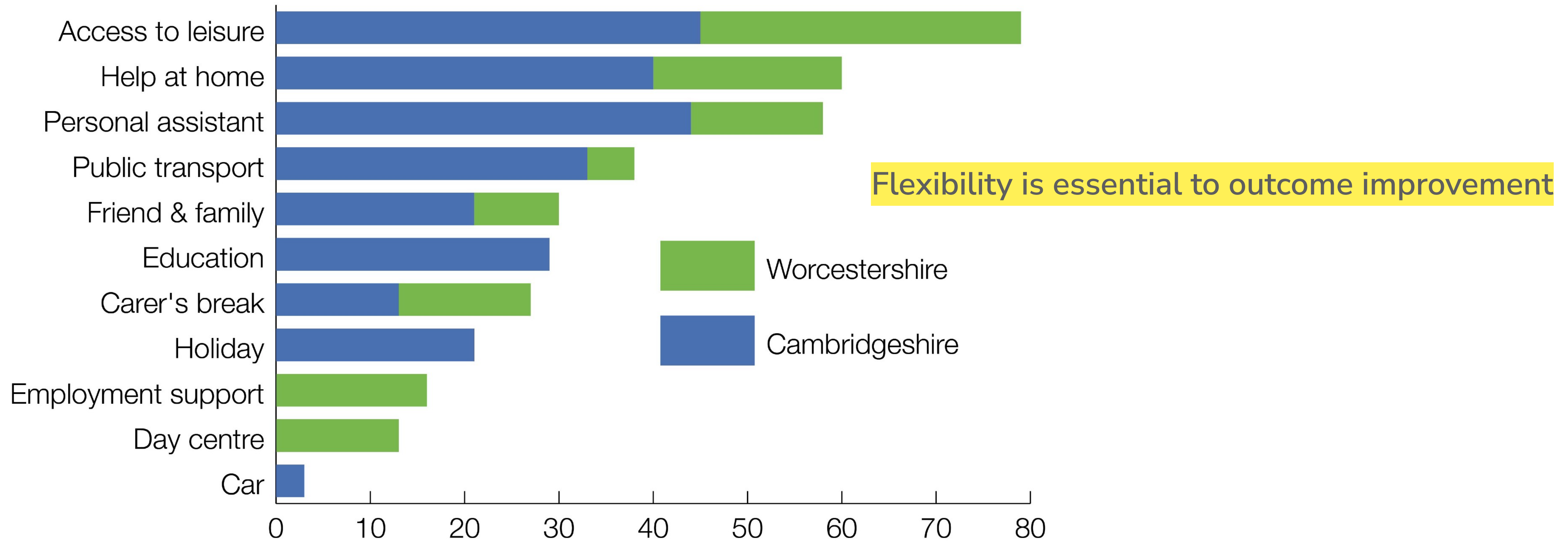


4. Recommend appropriate providers

People will still need support to make decisions - but that support should build community and capacity

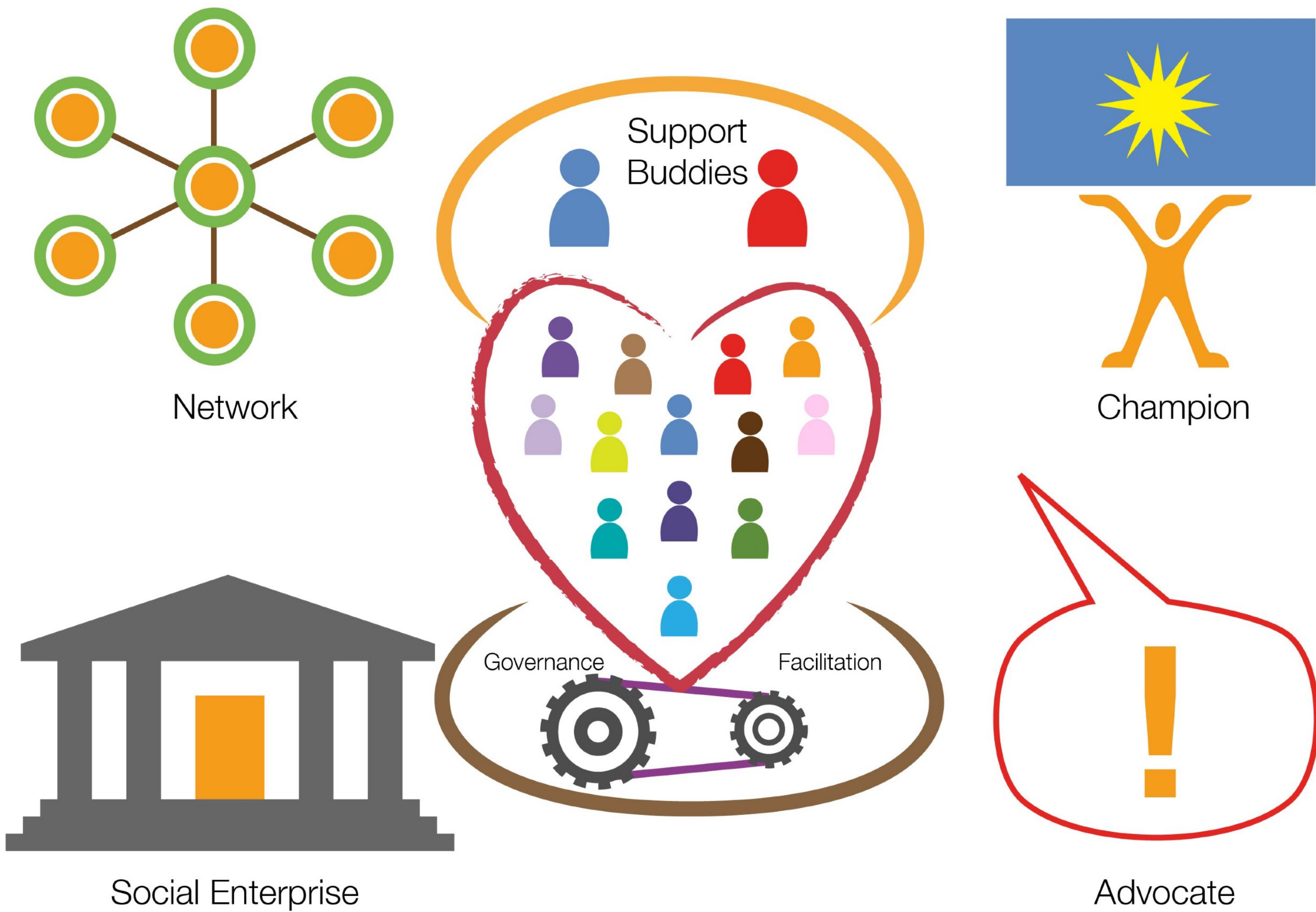


Use of Individual Budgets (Worcestershire & Cambridgeshire, 2008)



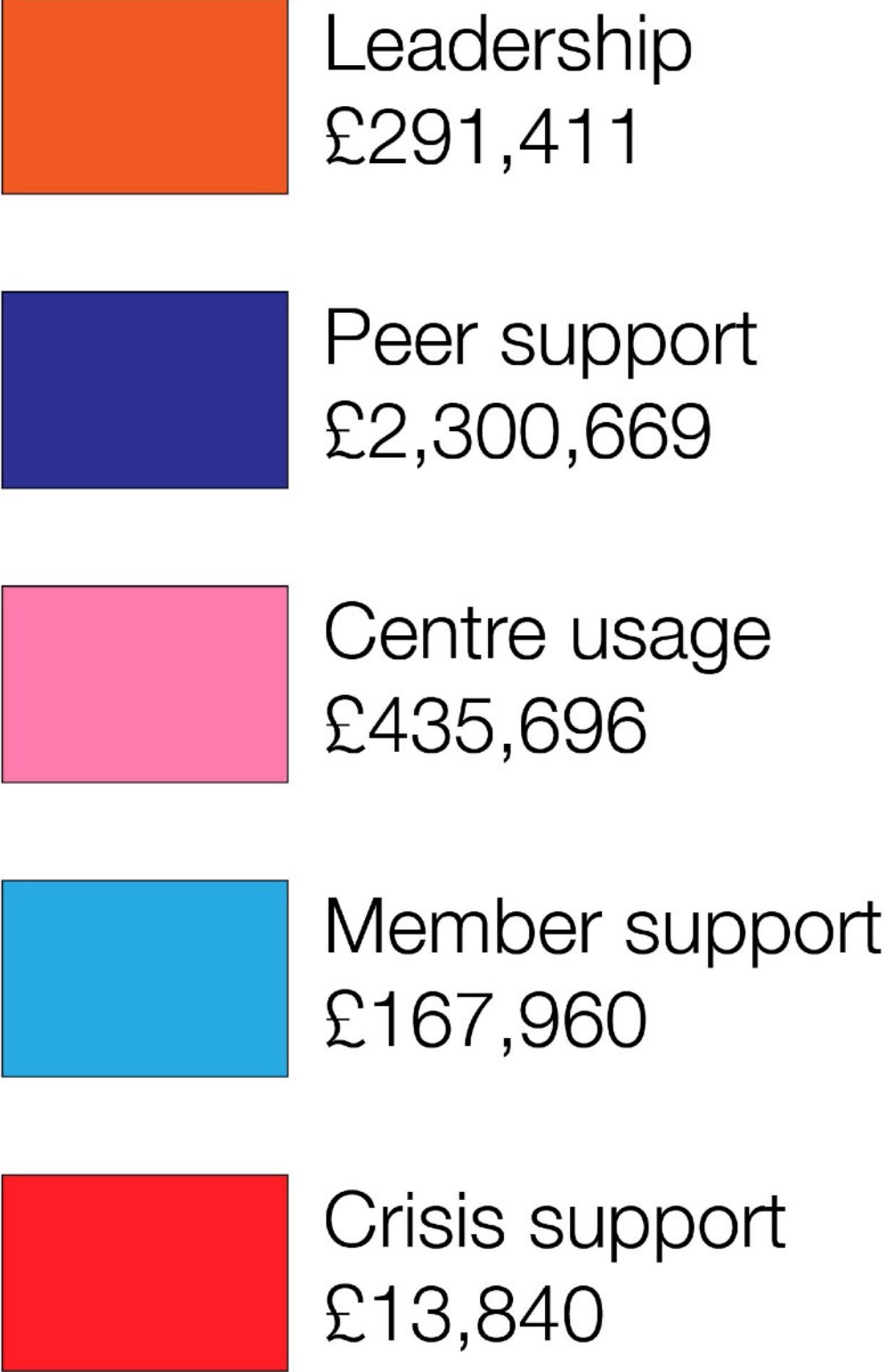
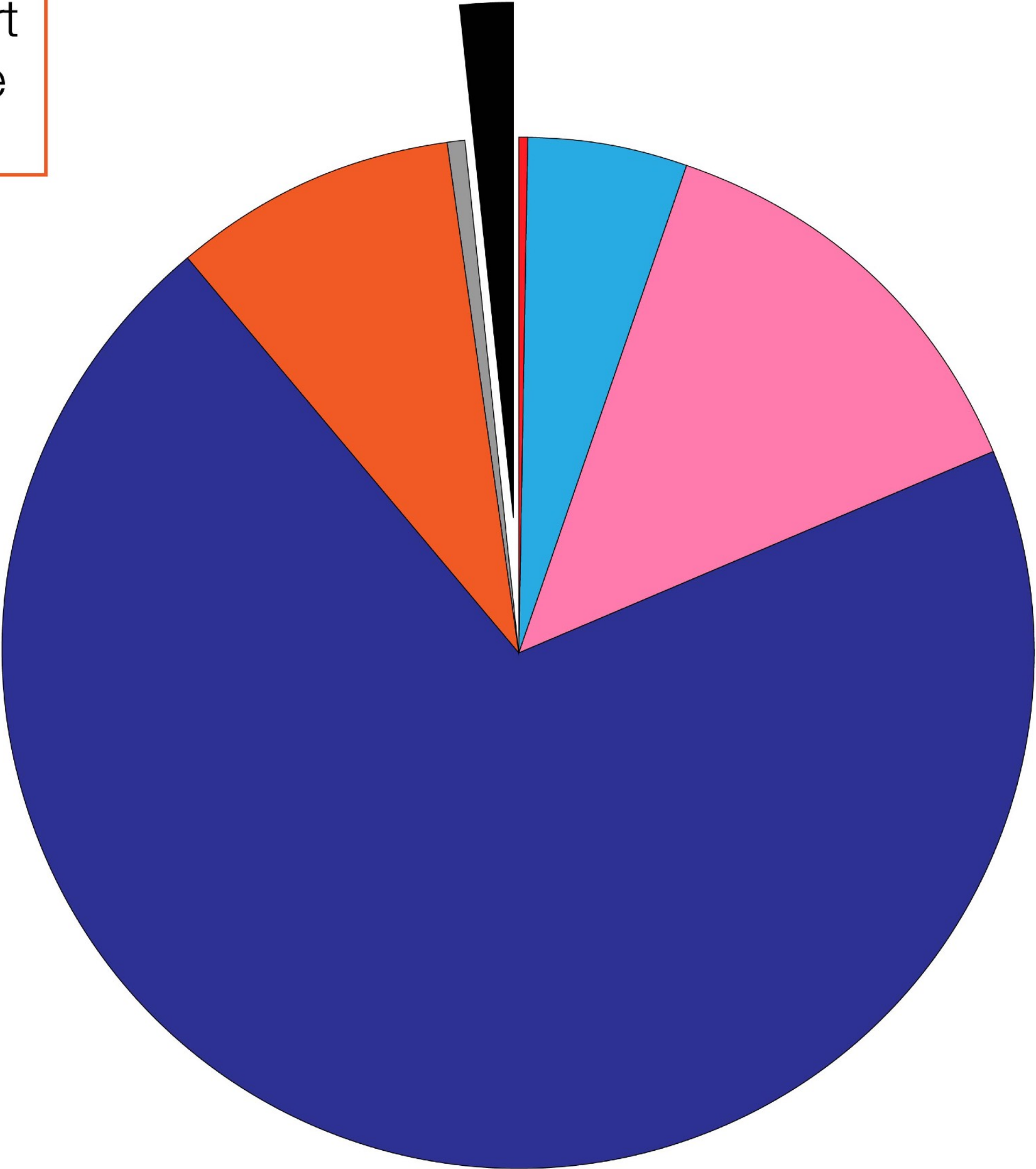
Data has been combined from Pitts J, Soave V and Waters J (2009) Doing It Your Way: the story of self-directed support in Worcestershire. London, In Control Publications; and Hay M and Waters J (2009) Steering My Own Course: the introduction of self-directed support in Cambridgeshire. London, In Control Publications.

Peer support is very powerful and should be encouraged at every stage



In 2019 statutory financial support was only **1.5%** of the social value created by PFG Doncaster.

In 2019 the social value created by PFG Doncaster's was more than **£3.2 million.**



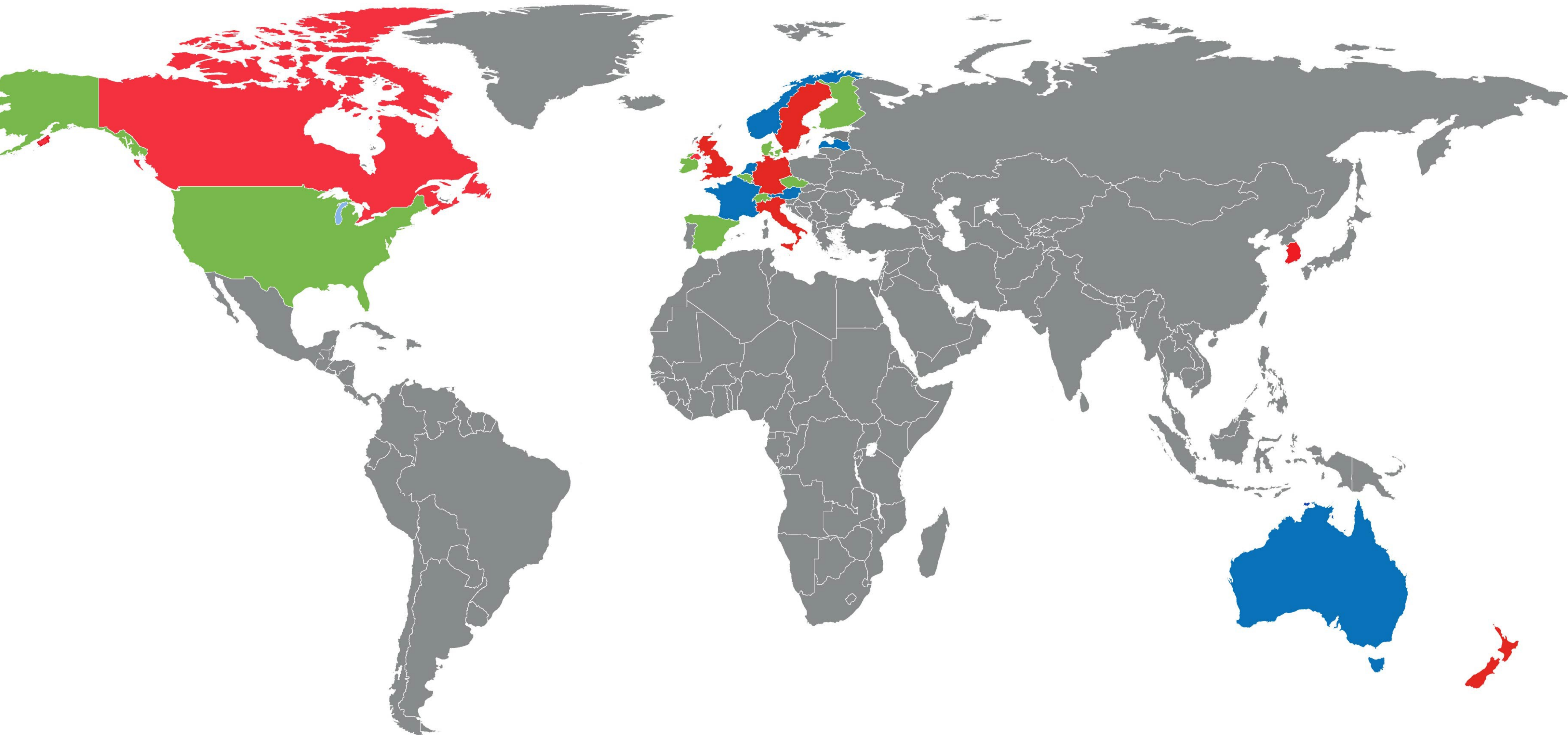
See Duffy (2021) Growing Peer Support. Sheffield: Centre for Welfare Reform for the story behind this data.

3. Global patterns

Global development

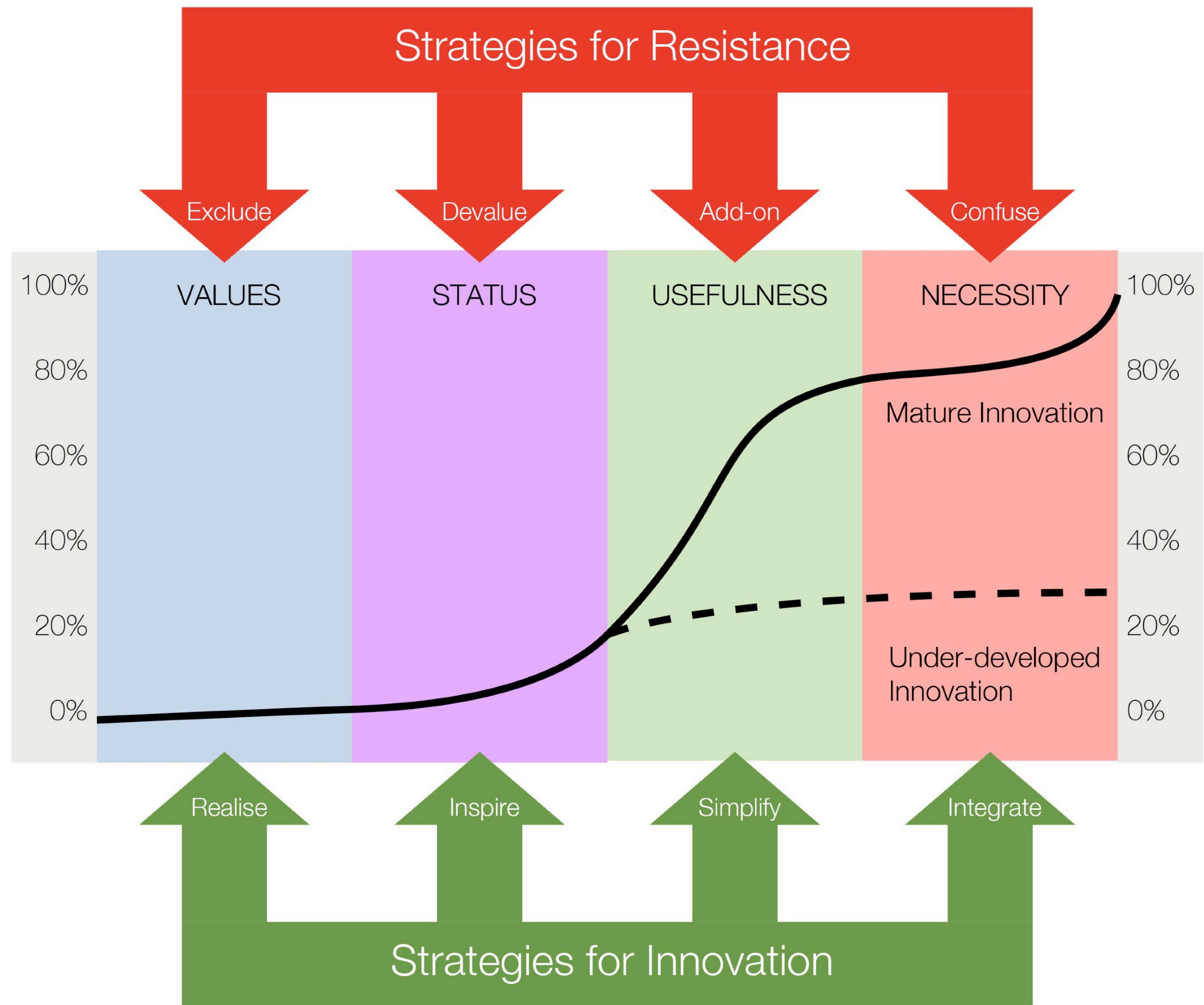
Progress has been **patchy** and it comes in waves since **1965**

- Sometimes limited to some groups or ages or more **universal** (e.g. England)
- Sometimes taking decades or quite **fast** (e.g. Flanders)
- Sometimes very local and diverse or fully **national** (e.g. Australia)
- Sometimes very bureaucratic or quite **flexible** (e.g. Germany)



The primary challenge:

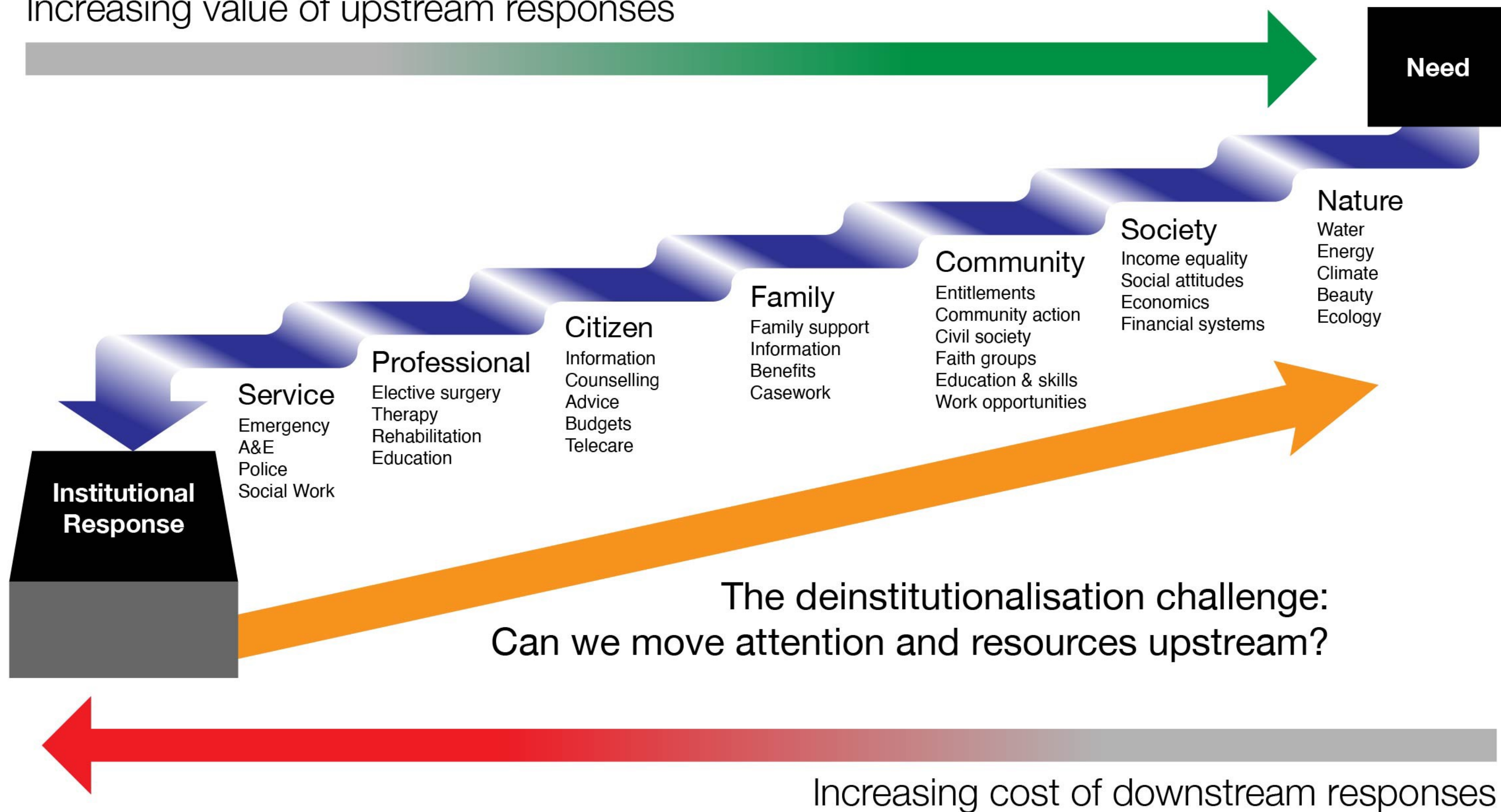
*How ambitious and fast should
we make the changes?*



The secondary challenge:

How do these changes fit with other changes we want to make?

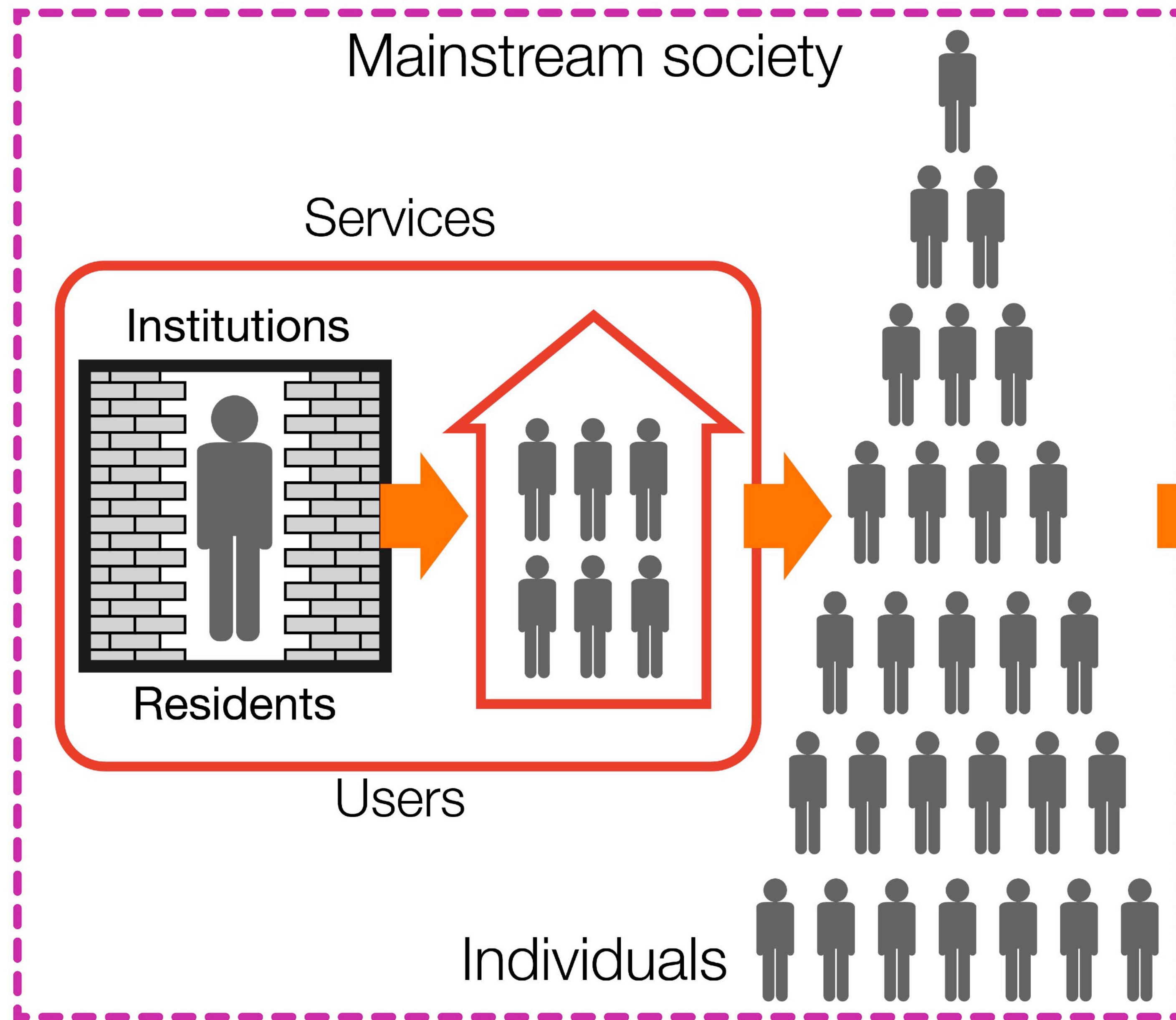
Increasing value of upstream responses



Some challenges

Looking to the future

- Will self-direction drive forwards deinstitutionalisation and inclusion?
- Can we build around the values of citizenship?
- Should we be thinking about this alongside income security? e.g. UBI+
- How does this link to neighbourhood and economic development?

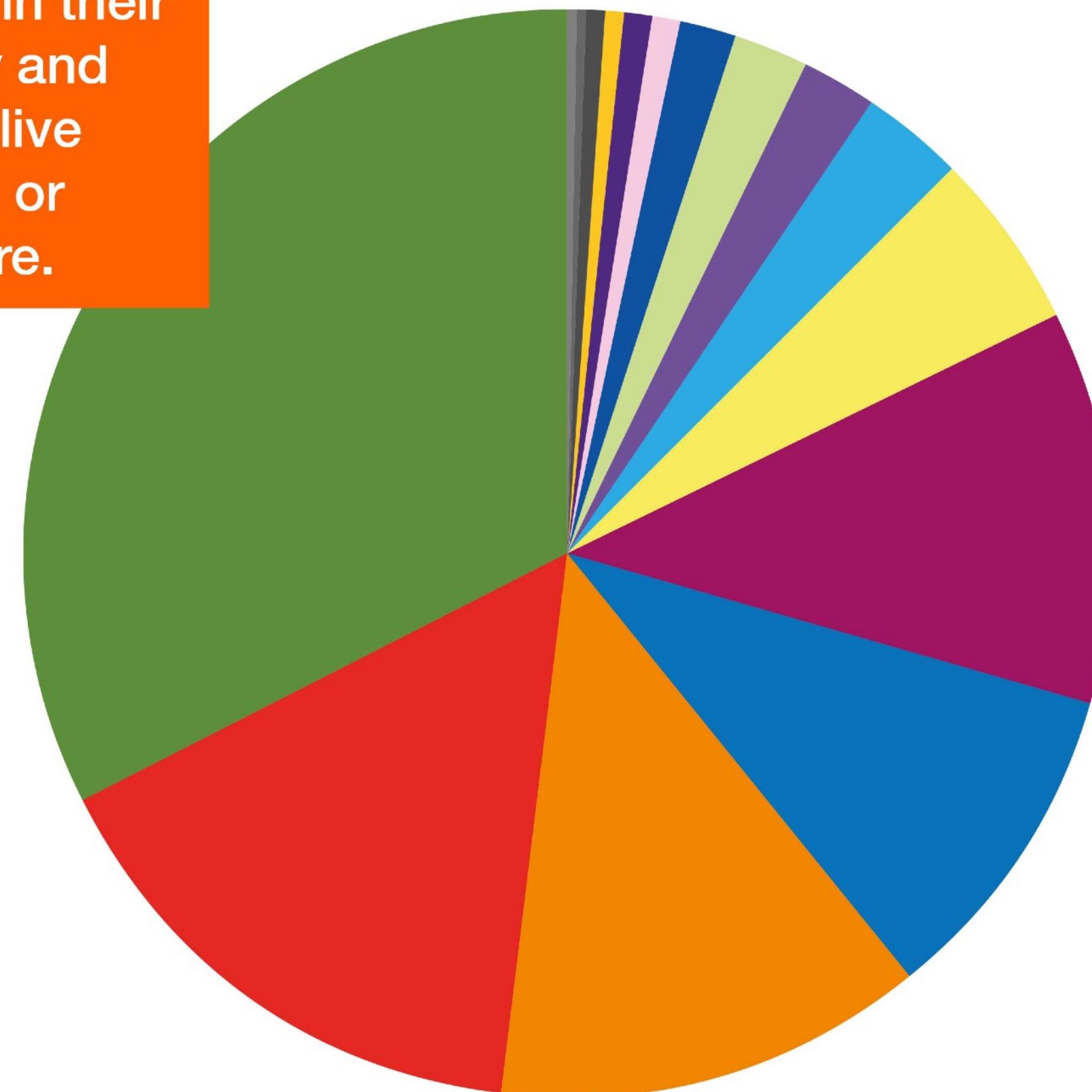


Diverse communities



A world of citizenship

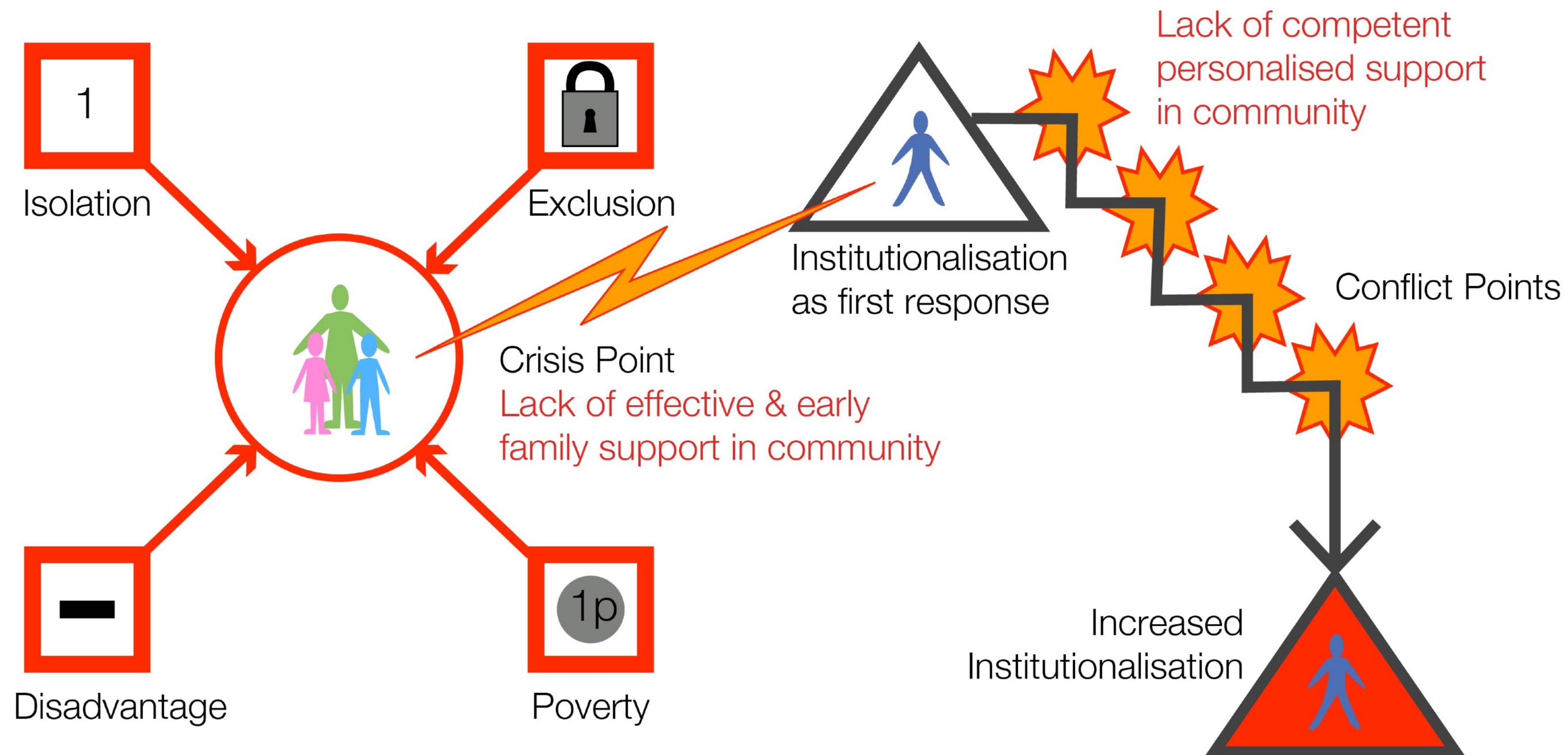
Only 23,845 people with learning disabilities live in their own home. 35,340 do not live in their own community and 77,470 people live in institutional or residential care.

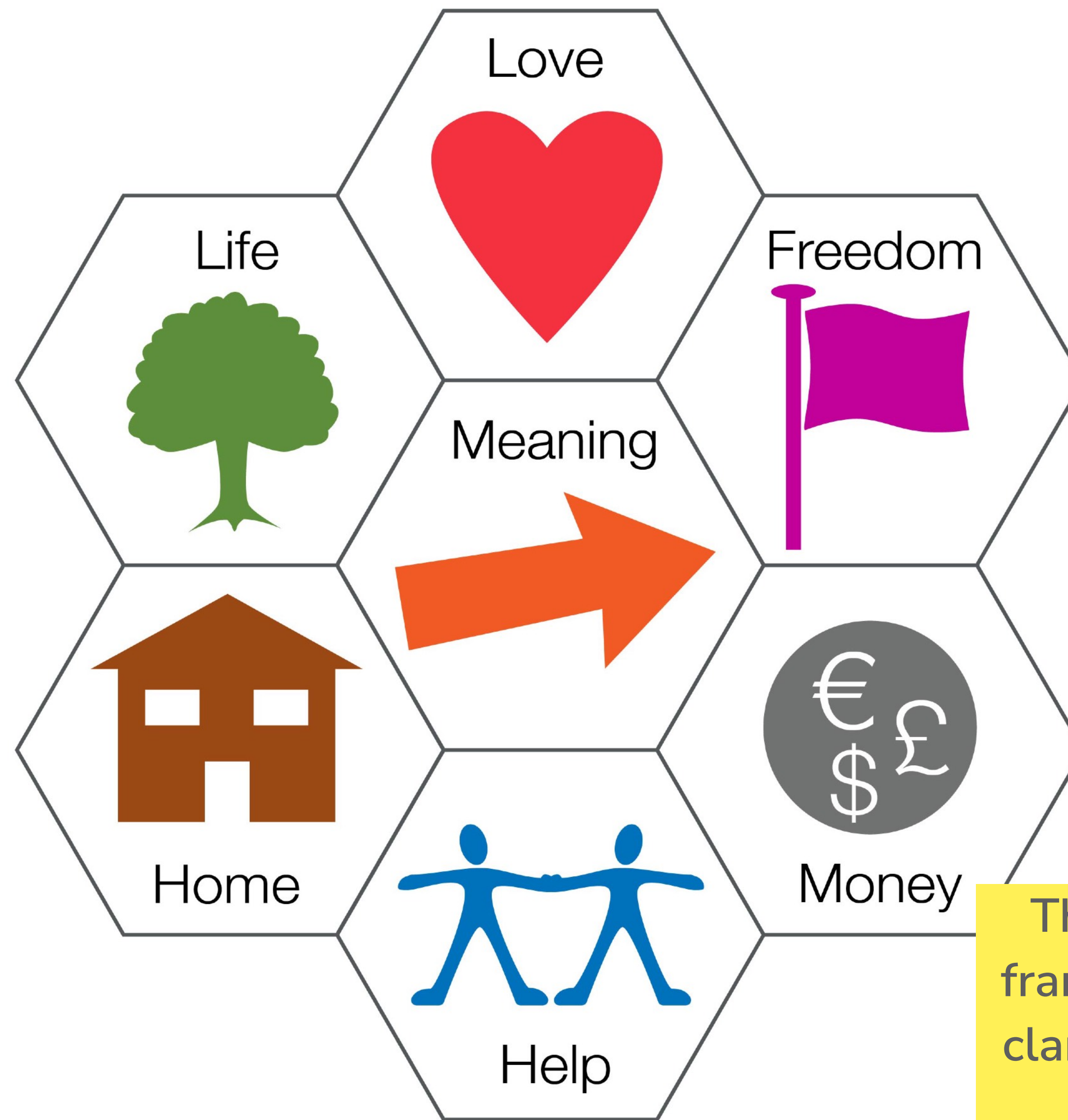


- Family or friends
- Group homes
- Prison (not on books of LA)
- Social landlord
- Registered care home (in area)
- Registered care home (out of area)
- Private tenant
- ATUs (mostly out of area)
- Adult placement
- Owner occupier
- Registered nursing home
- Hospital
- Sheltered housing
- Sofa surfer
- Other
- B&B
- Emergency hostel
- Prison (on books of LA)
- Probational
- Mobile home
- Rough sleeper
- Refuge

Sources - This data covers 158,000 people with learning disabilities who have come to the attention of LAs as outlined in Public Health England (2014) People with Learning Disabilities 2013. Data on people in out of area placement is from National Mental Health Development Unit (2011) In Sight and in Mind - A toolkit to reduce the use of out of area mental health services. London, National Mental Health Development Unit. Plus prison data.

People end up in private hospitals with challenging behaviour reputations because of a failure to support families and provide personalised support

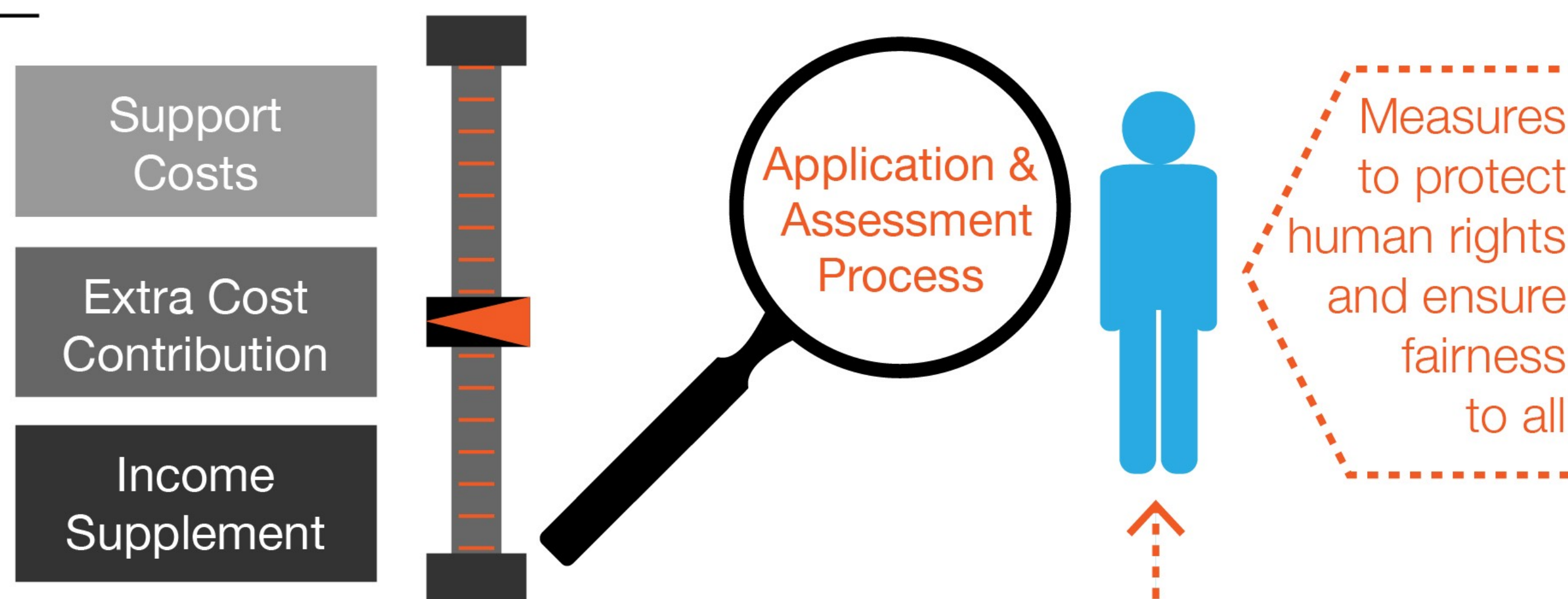




The Keys to Citizenship framework is used to help clarify purpose in a way is both personal and consistent with wellbeing.



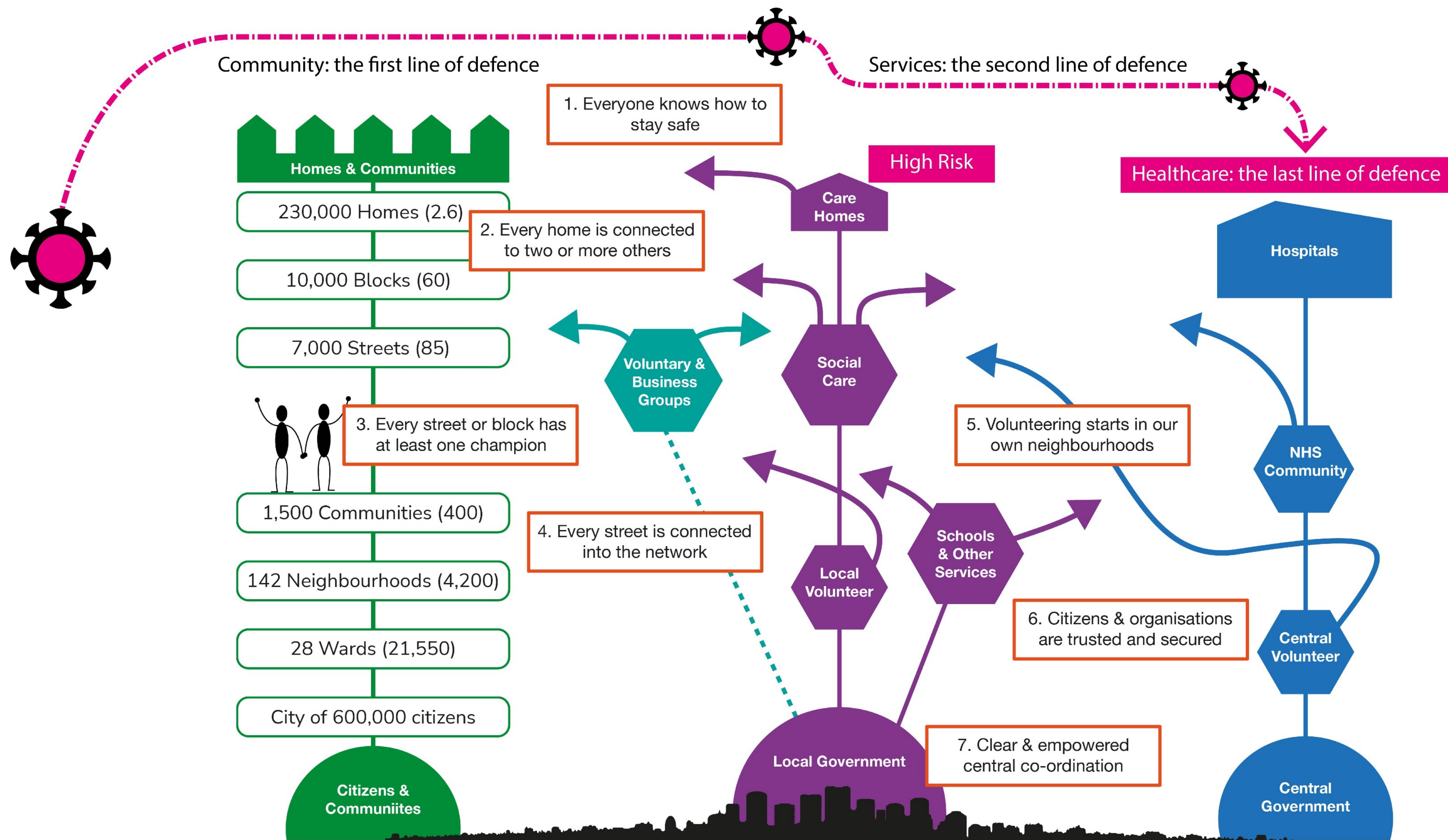
Some of us
get UBI+



Basic income (UBI)

Everyone
gets UBI





The ecology of social justice - we need a deeper democracy where citizens can work together for the good society only we can create



Useful communities



UNIC

TOWARDS USER-CENTRED
FUNDING MODELS
FOR LONG TERM CARE



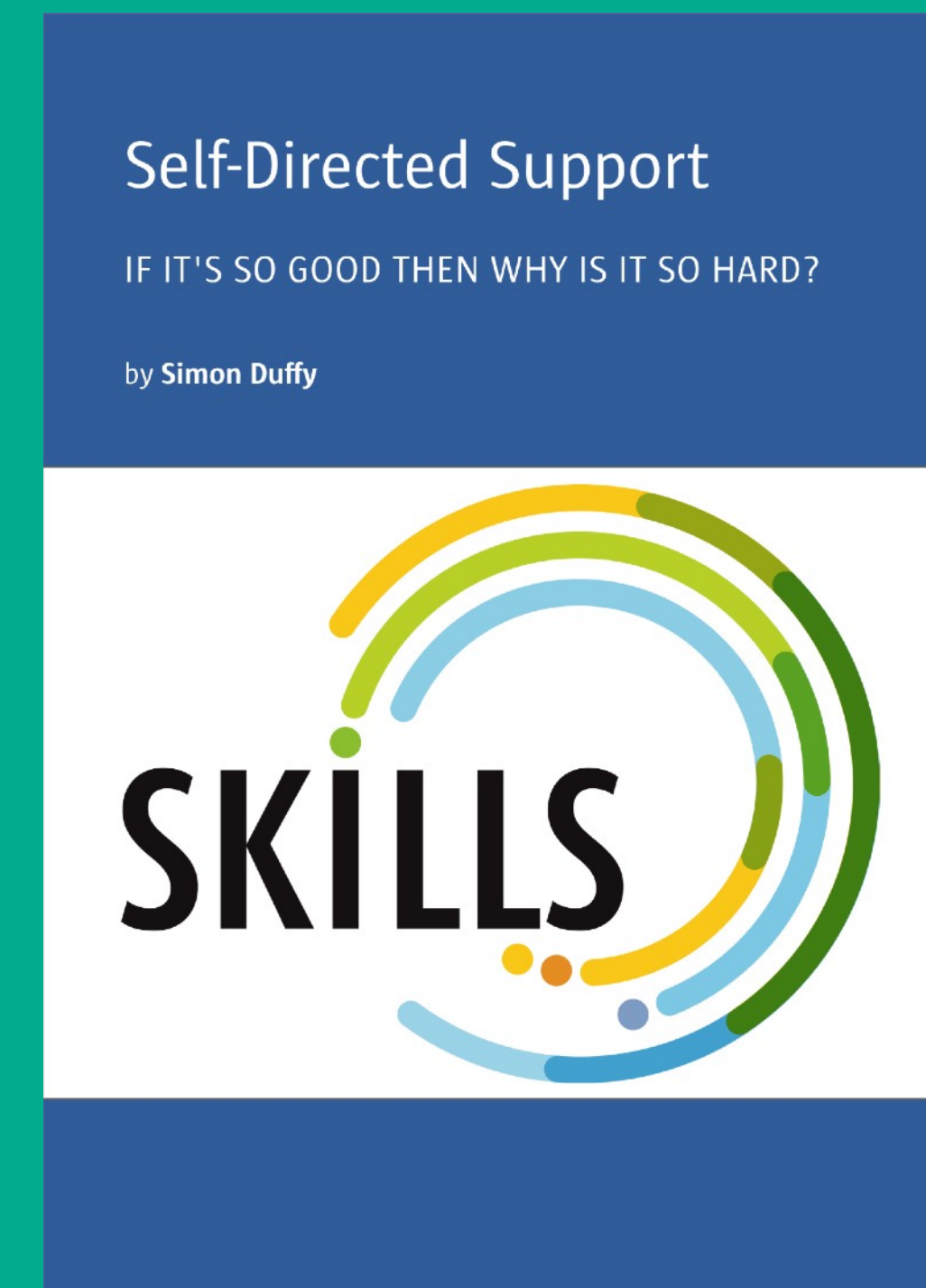
This project has received financial support
from the European Union Programme for Employment and Social Innovation "EaSI"
(2014-2020)



unicproject.eu



Global expertise:



<https://www.selfdirectedsupport.org>



CITIZEN NETWORK

FOR A WORLD WHERE EVERYONE MATTERS

Now and Next

AN INNOVATIVE LEADERSHIP PIPELINE FOR FAMILIES WITH YOUNG CHILDREN WITH DISABILITY OR DELAY

by **Sylvana Mahmic and Annick Janson**



Personalised Transition

Innovations in health, education and support

by **Alison Cowen**
with additional material by **Simon Duffy and Pippa Murray**



Individual Service Funds

a guide to making Self-Directed Support work for everyone

by **Sam Smith and Frances Brown**
on behalf of **In Control Scotland**



Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS

Growing Peer Support

PEER-LED CRISIS SUPPORT IN MENTAL HEALTH SERVICES

by **Simon Duffy**



Power and Connection

THE INTERNATIONAL DEVELOPMENT OF LOCAL AREA COORDINATION

by **Eddie Bartnik and Ralph Broad**
with contributions from **Nick Sinclair, Al Etmanski, Michael Kendrick**
and international colleagues



<https://www.citizen-network.org>