

Anffas 60 anni di futuro
Le nuove frontiere delle disabilità intellettive e
disturbi del neurosviluppo

Nuova Fiera di Roma
28, 29 e 30 novembre 2018



Tutti possono controllare il proprio supporto

Dr Simon Duffy of the Centre for Welfare Reform & Citizen Network

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SKILLS

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Partners in the SKILLS Project



Anffas Onlus
dal 1958 la persona al centro
ASSOCIAZIONE NAZIONALE
FAMIGLIE DI PERSONE CON DISABILITÀ
INTELLETTIVA E/O RELAZIONALE



SERVICE FOUNDATION
FOR PEOPLE WITH
AN INTELLECTUAL DISABILITY



Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS

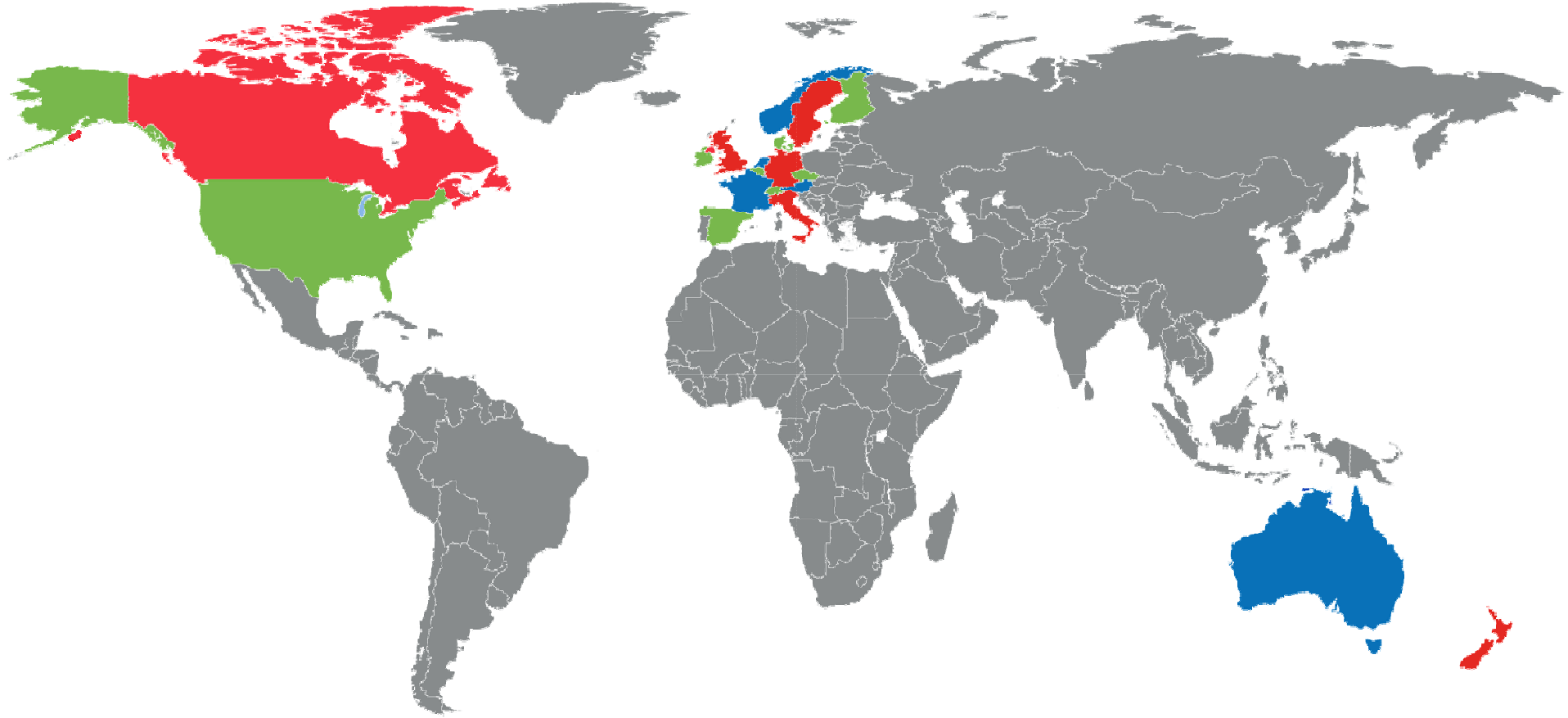


Control[®]
Scotland



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ere is over 50 years of experience of doing self-directed support all around the world -
od progress - and shared difficulties

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Self-Directed Support

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

by Simon Duffy



SKILLS

- There is good evidence that self-directed support brings benefits
- It is a matter of human rights
- But it needs a change in how systems work

1. What is SDS?

Article 1 of the **UN Declaration of Human Rights** states:

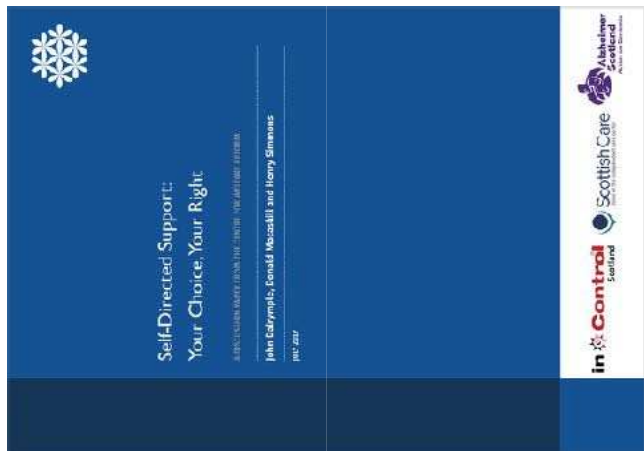
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

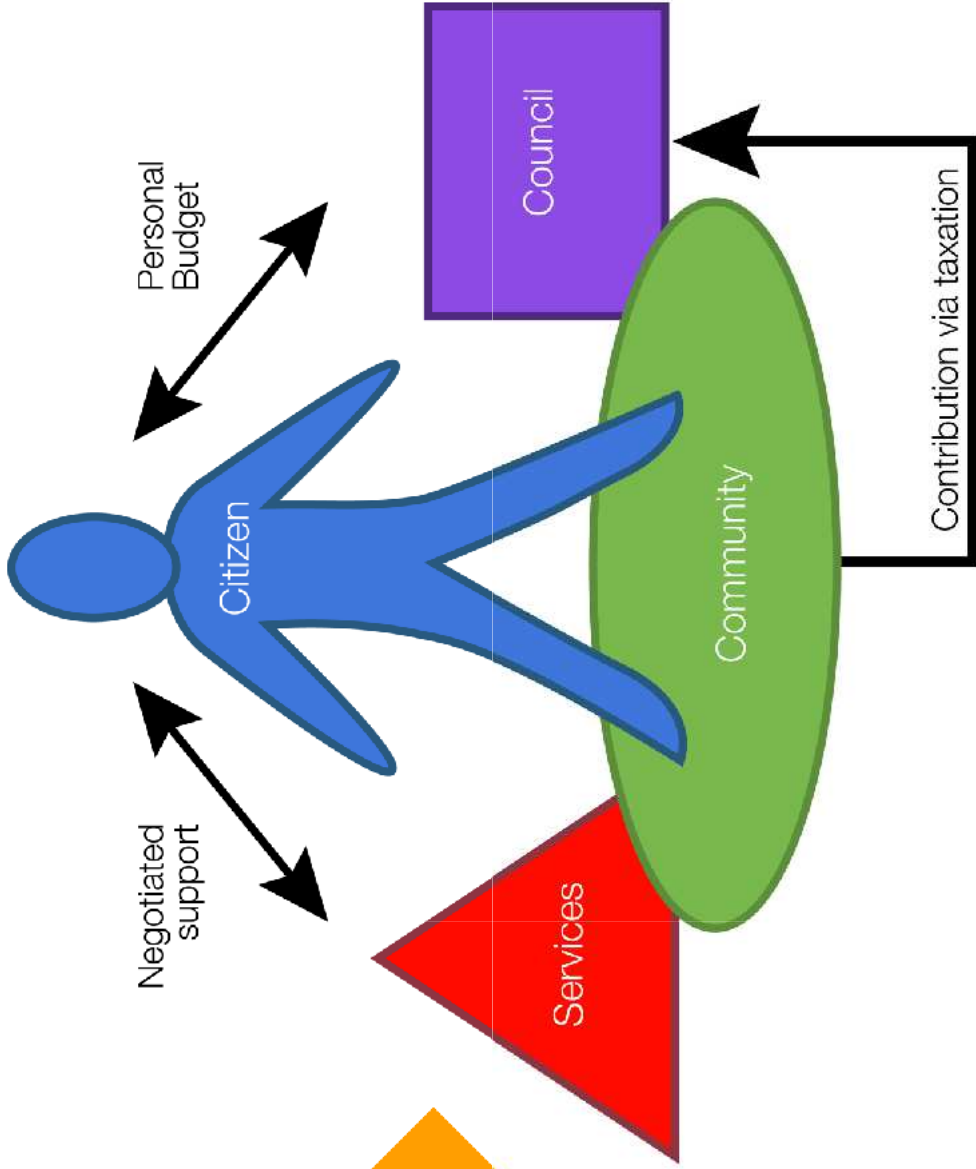
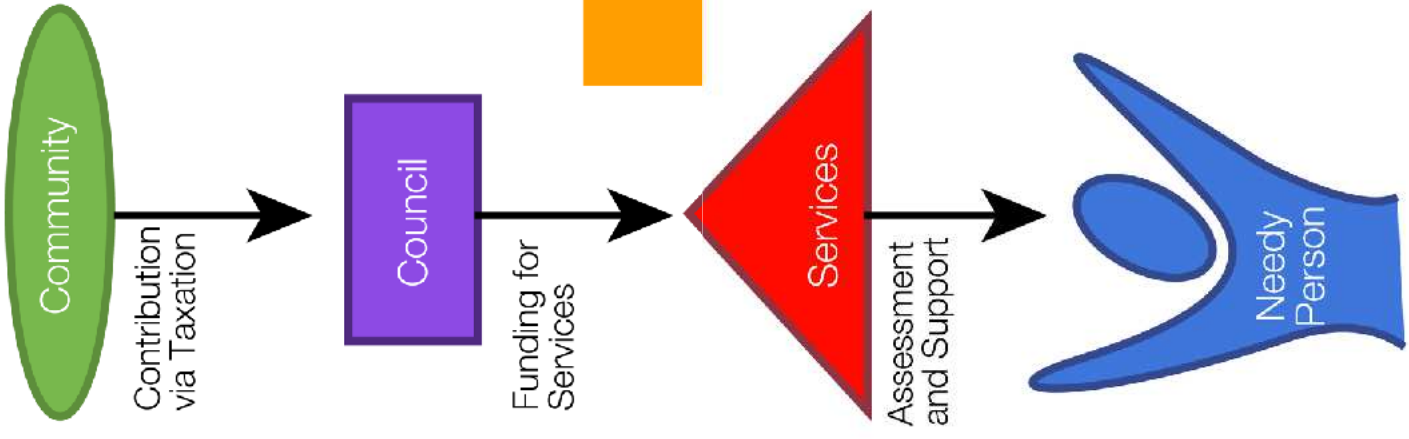
The first principle defined by the UN Convention on the Rights of Persons with Disabilities (**UNCRPD**) is:

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.

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Old model of Professional Gift Model of service delivery:

1. Community funds the state
2. State funds professionals
3. Professionals decide what people need
4. Person receives support as a gift, not a right

Self-Directed Support is based on the **Citizenship Model:**

1. Citizens are in control of their own lives
2. Citizens live as part of a community
3. Citizen have entitlements to support
4. Citizen shape the support they need



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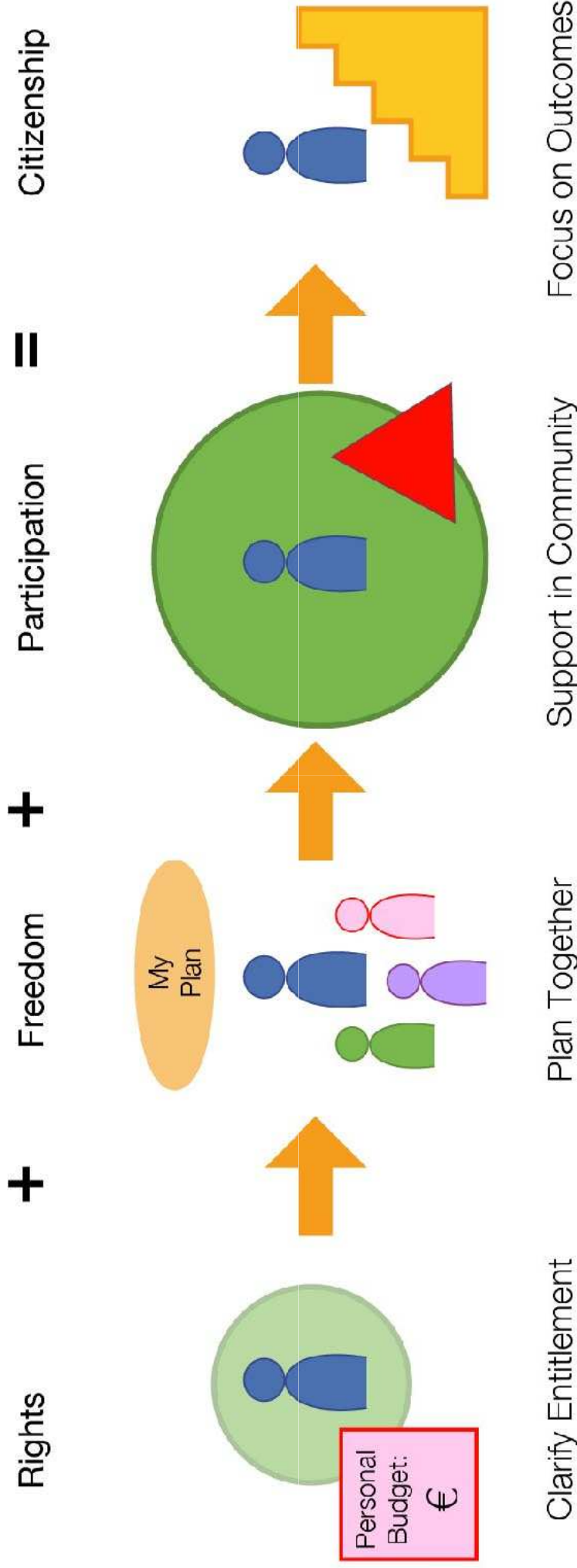
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- **Independent Living Movement** - Ed Roberts in Berkely California in 1960s
- **Family Movement** - Canadian brokerage movement in 1970s
- **Deinstitutionalisation** - social role valorisation and the movement for inclusion in 1980s
- **Human Rights** - UN Convention on Rights of Disabled People - 2006
- **AND** - Public service reform - **BUT** competing goals

2. How does it work?

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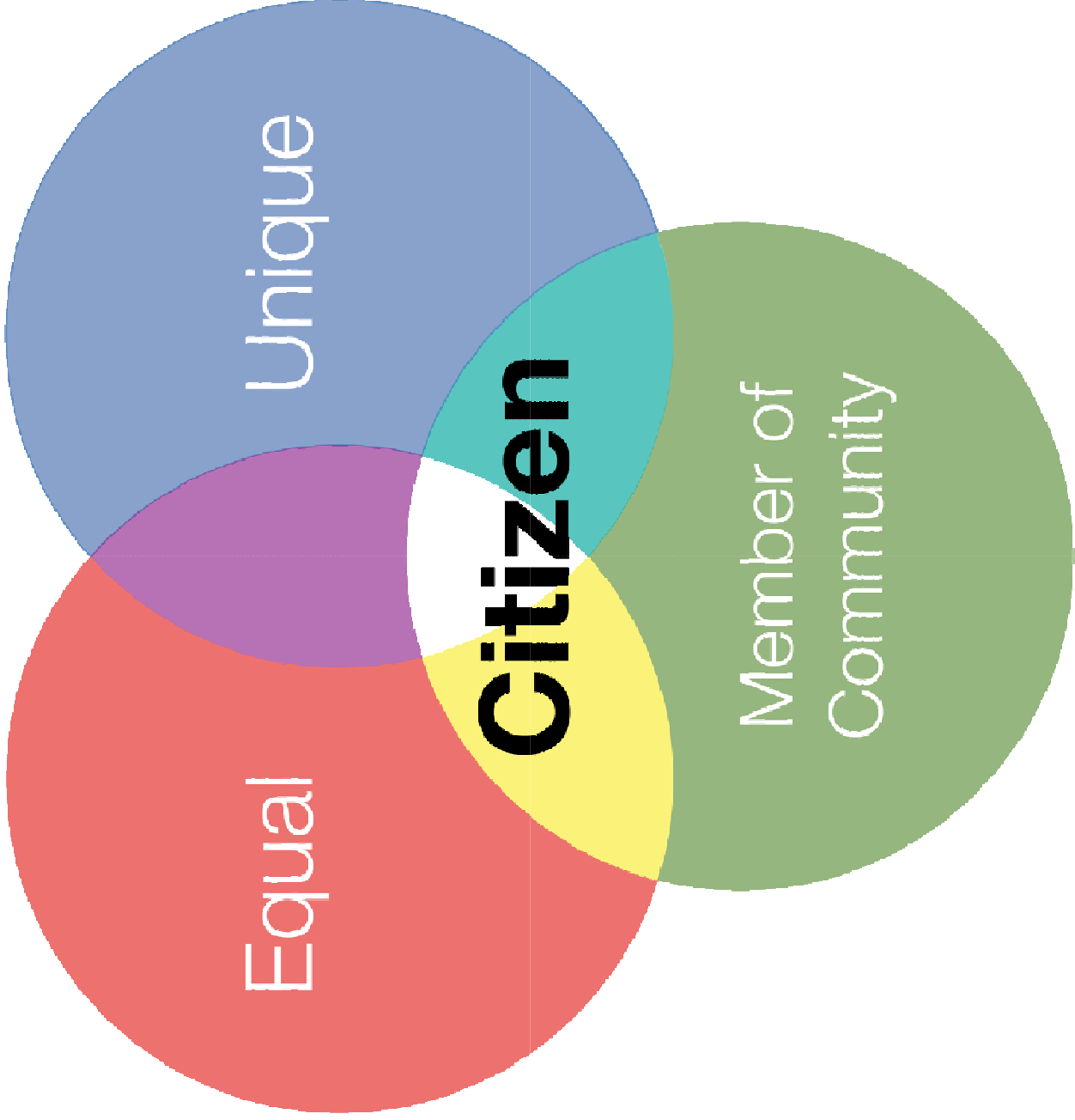
Le nuove frontiere delle disabilità intellettive e disturbi del neurosviluppo

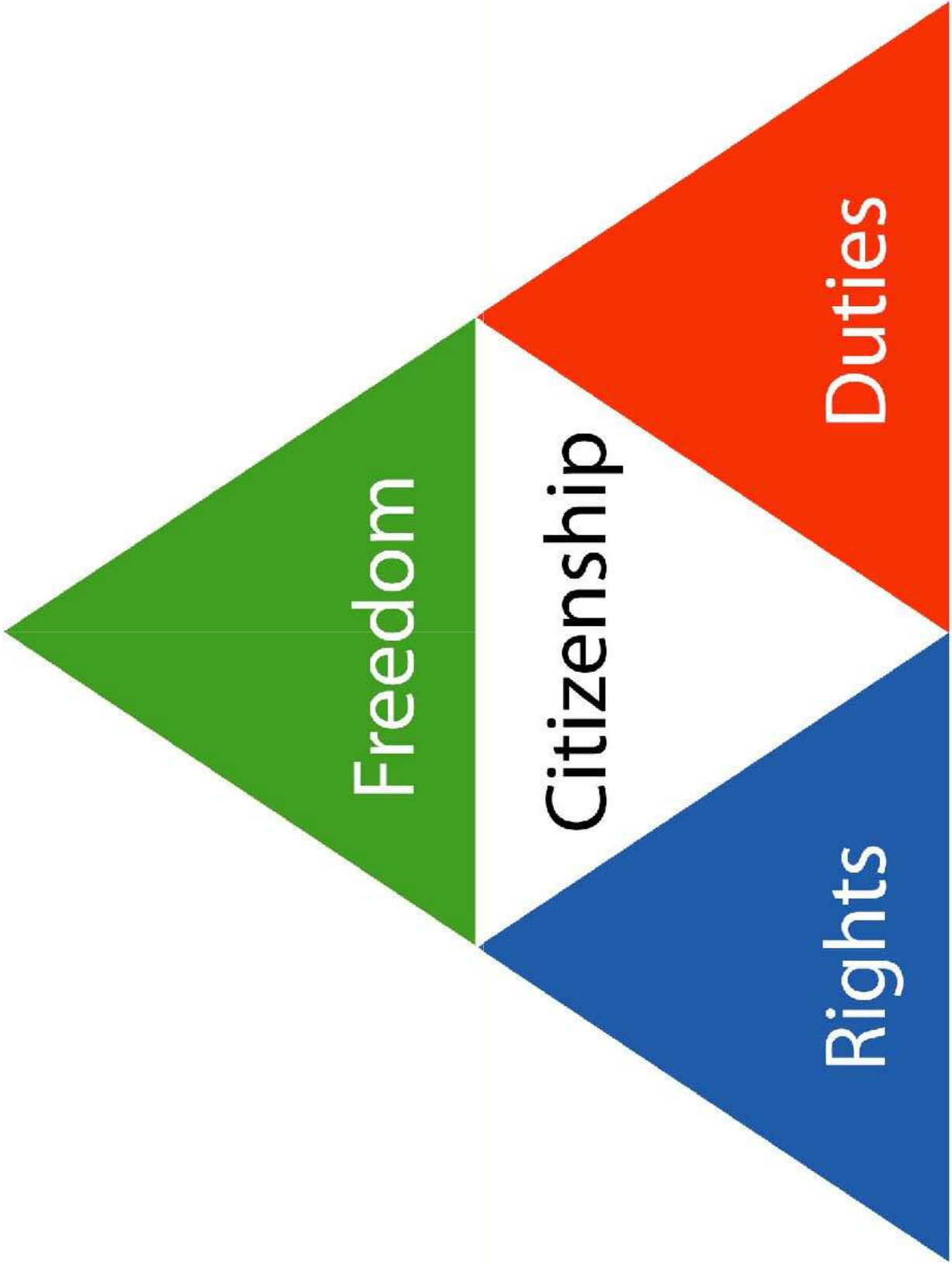




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1. People find out if they are entitled to support and if they are entitled to a budget - **Rights**
2. People make plans, with help from family, friends and sometimes professionals to decide what they want to do, using their real wealth (which includes, but is not limited to their budget) - **Freedom**
3. People live their life, getting the mixture of paid and unpaid support that works for them - **Participation**
4. People meet their needs, but in a way that is consistent with their goals, and they share what they've learned with the community - **Citizenship**





Freedom

Duties

Citizenship

Rights



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But it is not easy...

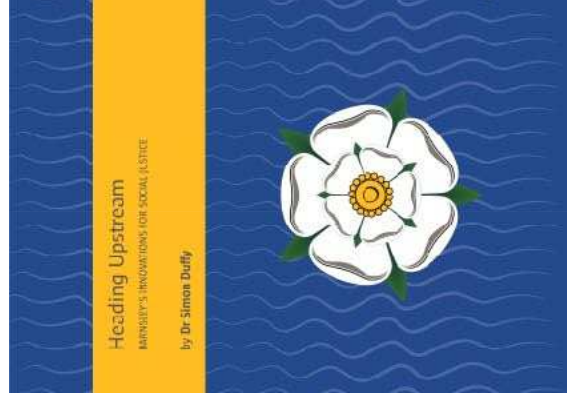
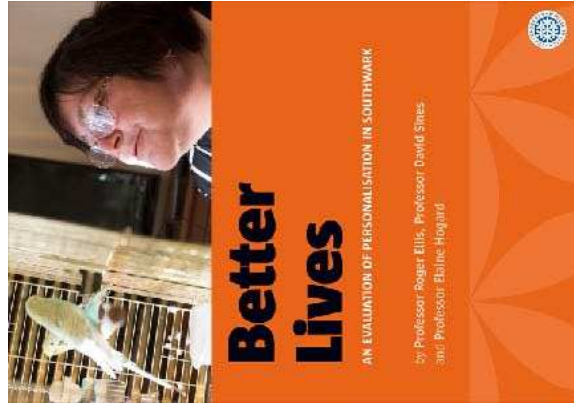
1. People **lack knowledge** of what they are entitled to
2. People are **not free to plan** and set their own goals
3. People are **not allowed** to use resources creatively
4. People are **not seen as equal** citizens

3. What's the impact?



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- **Good News I** - Research shows self-directed support helps people lead better lives
- **Good News II** - Research sometimes shows people can lead better lives and it doesn't cost more
- **Bad News I** - Research rarely helps us understand what elements of SDS help the most
- **Bad News II** - Research is rarely focused on citizenship, rights or inclusion - i.e. studying the wrong thing

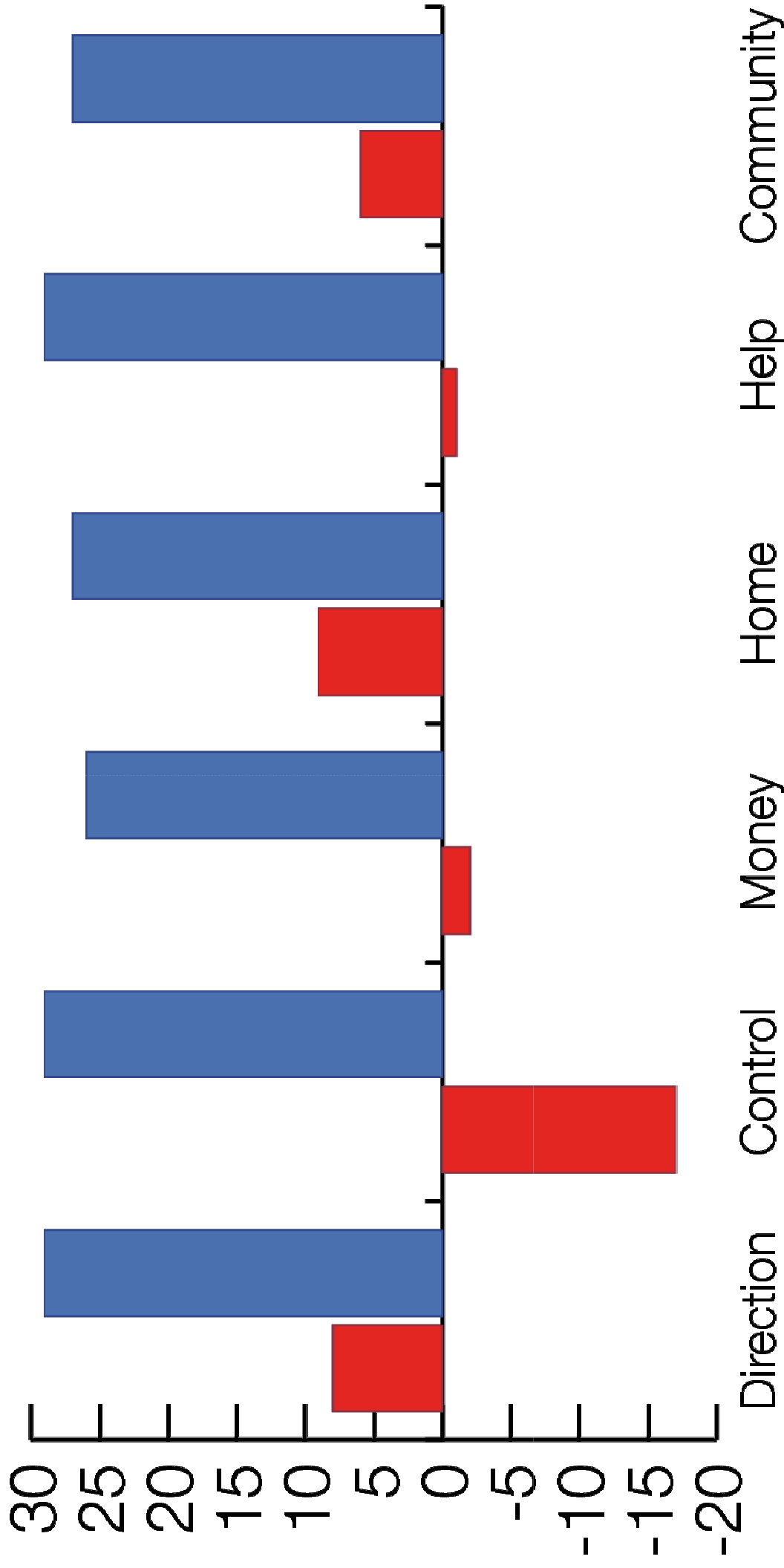


**A report on
in Control's
Second Phase
Evaluation and
learning 2005-2007**

Professor Chris Hatton, John Peeters,
Simon Duffy, Jonathan Secker,
Eisic Coakley, Carl Poul, Andrew Pross,
John O'Brien, David Howell

Edited by Carl Poul and Simon Duffy

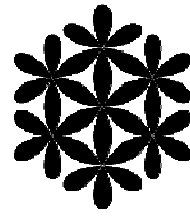
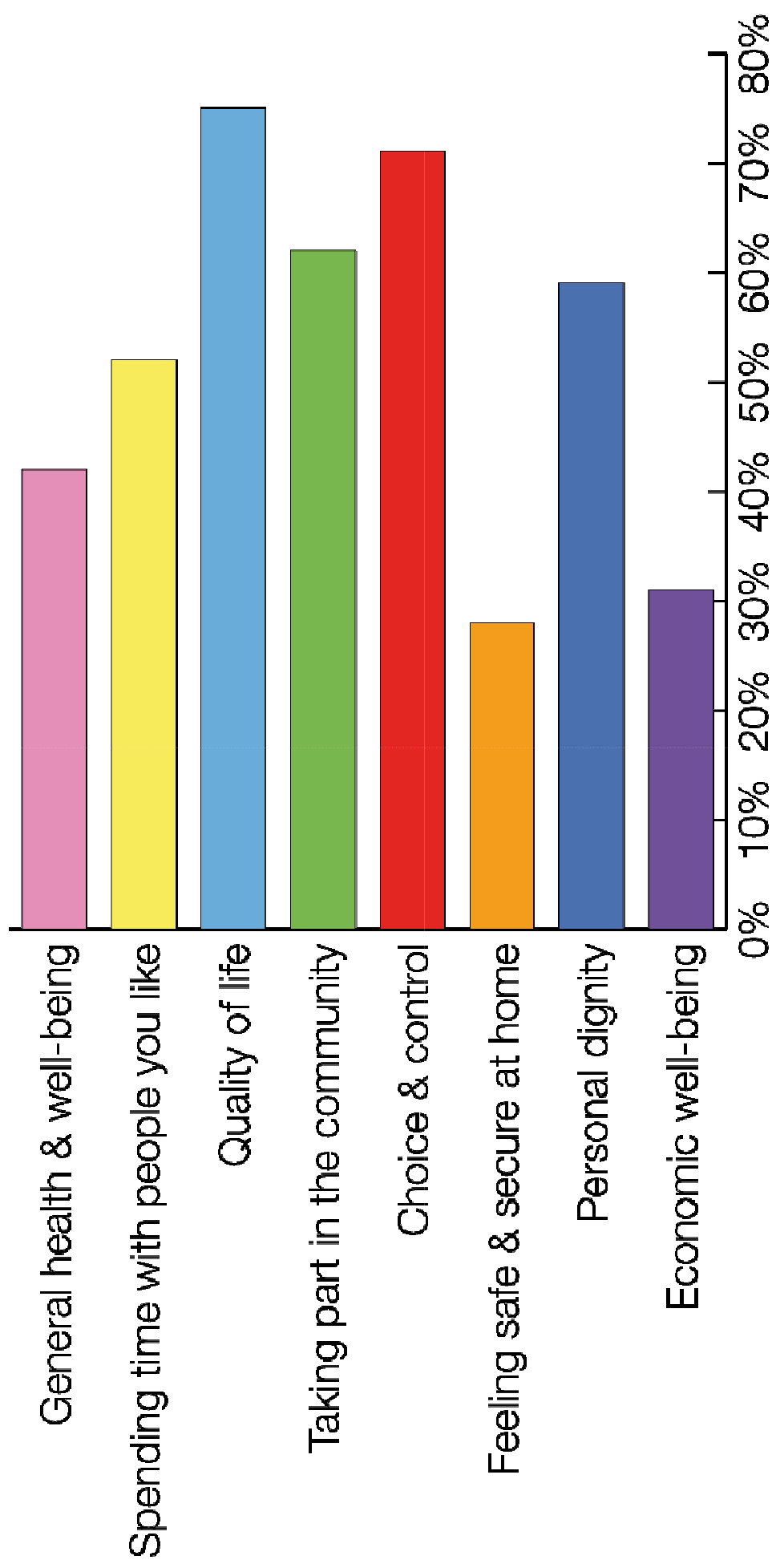
in Control



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.'

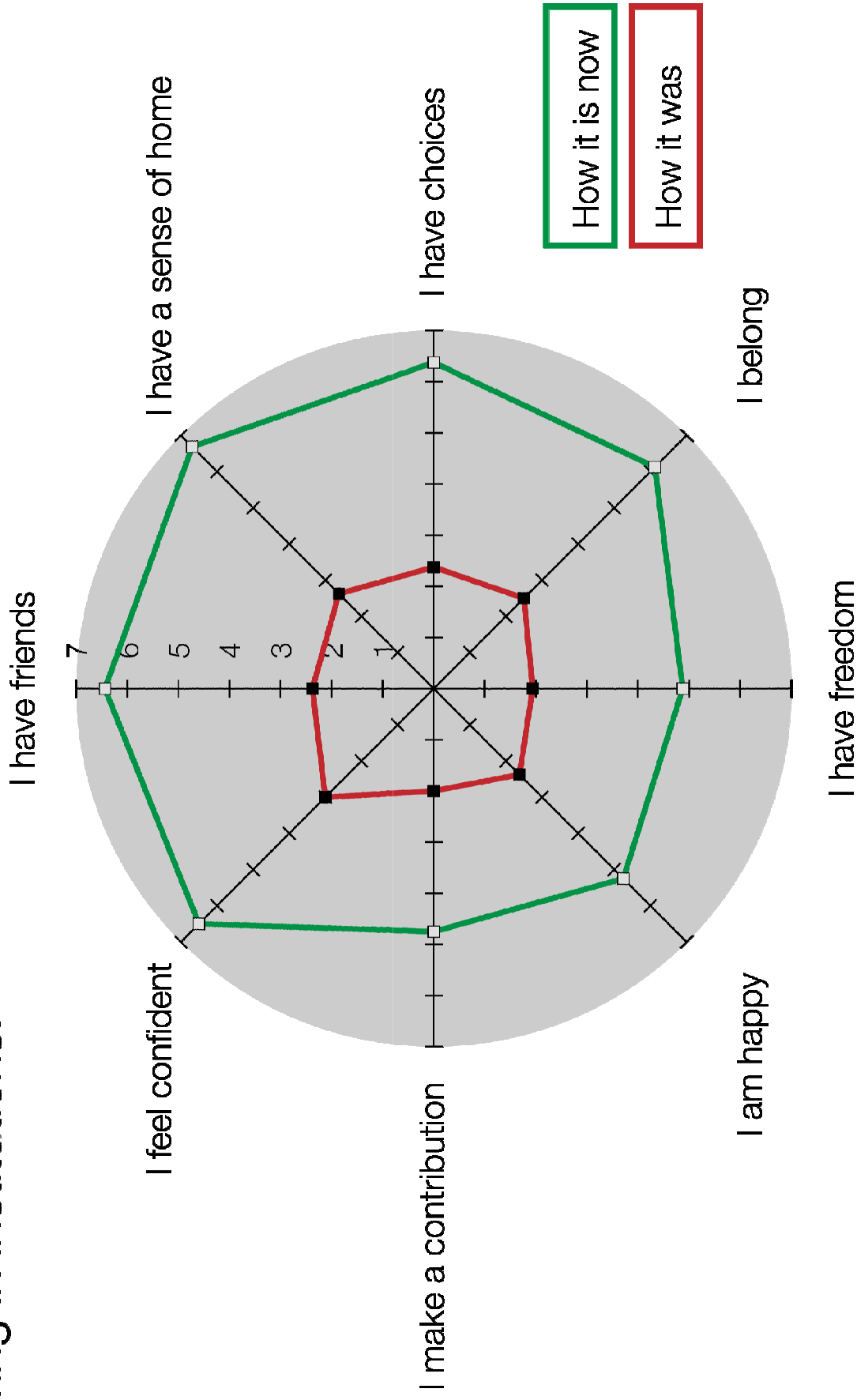
- After SDS
- Before SDS

Outcome Data from In Control's Phase II Report (2008)

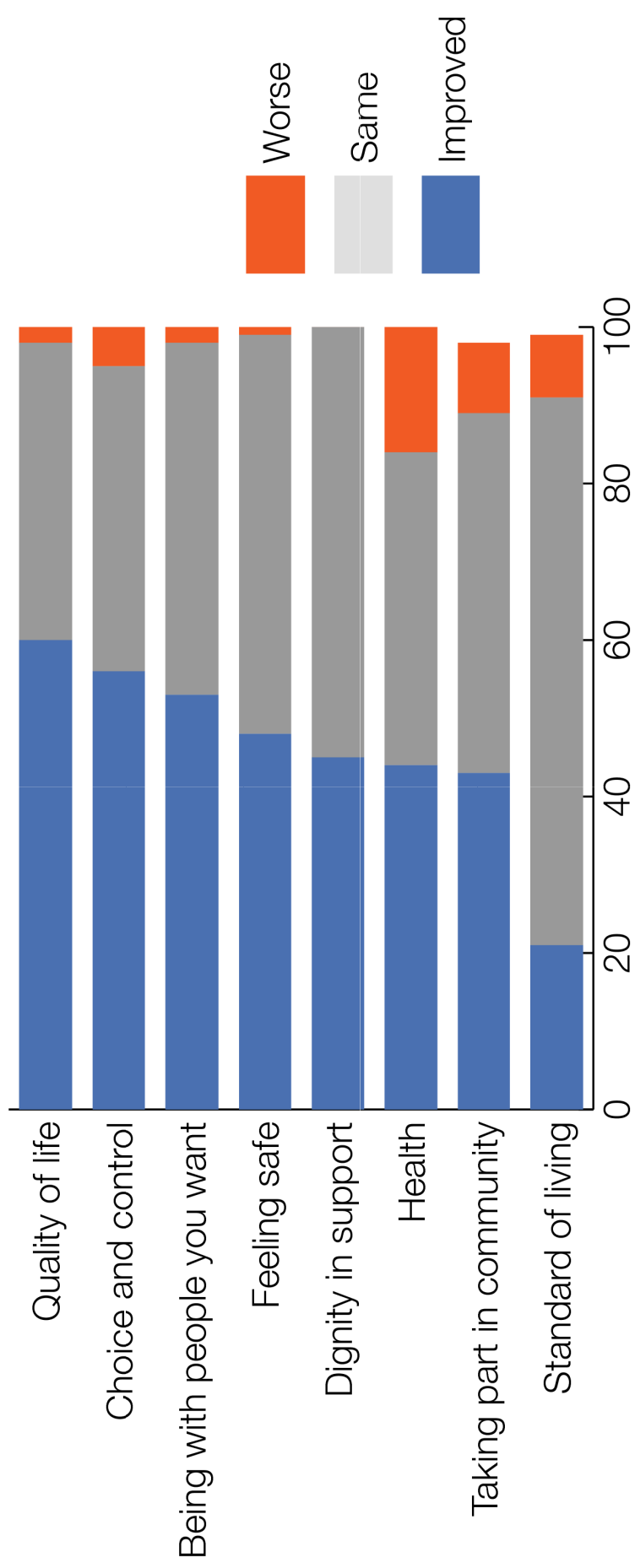


Poll C & Duffy S (eds.) (2008) *A Report on In Control's Second Phase: Evaluation and Learning 2005-2007*. London, In Control Publications. Figures show Net Percentage Improvement (N=196)

People explored how life was before and after working with Inclusion. The impact was especially positive for people who'd previously been living in institutions.

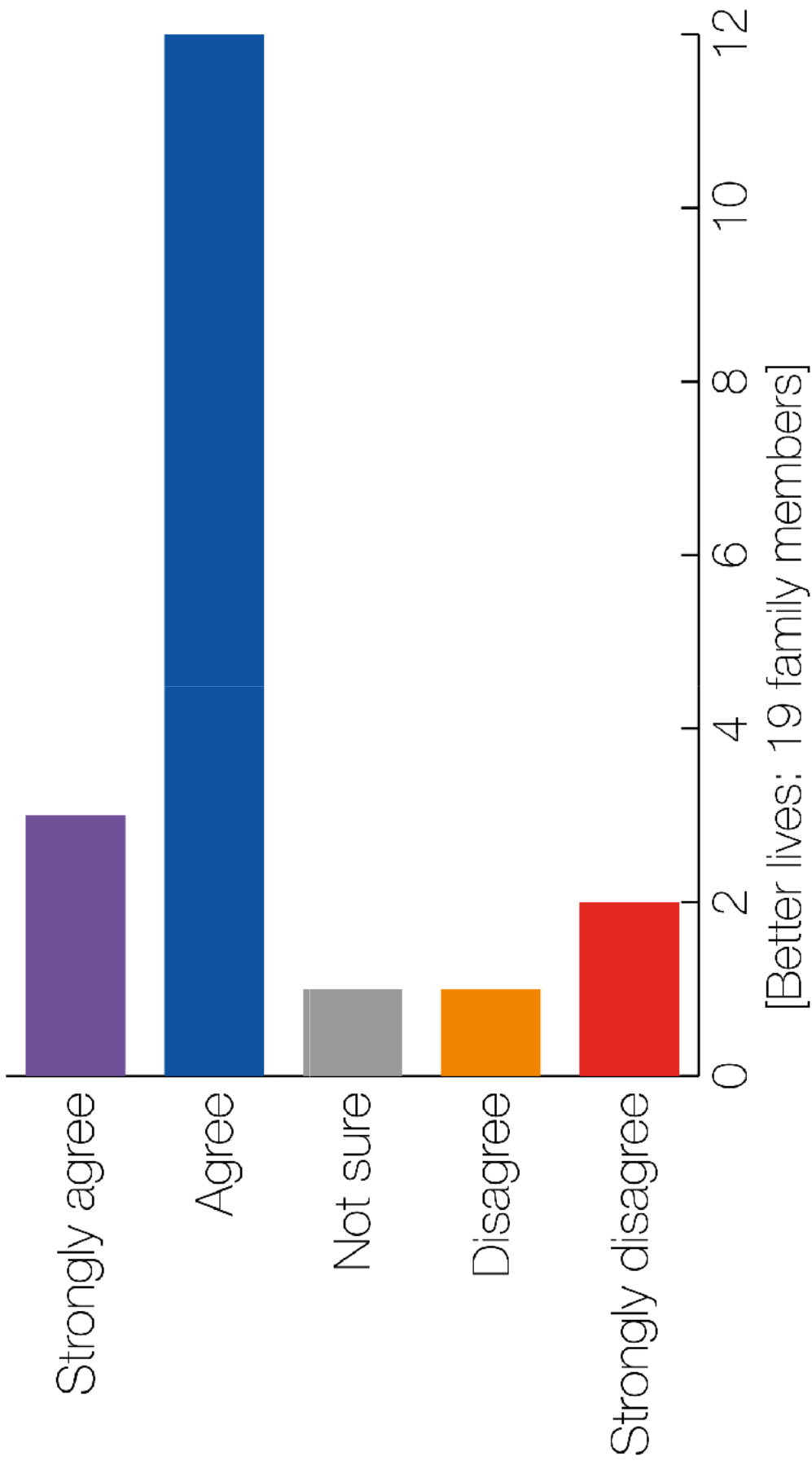


[Source: Animate (2014) Individual Service Funds. Sheffield, The Centre for Welfare Reform.]

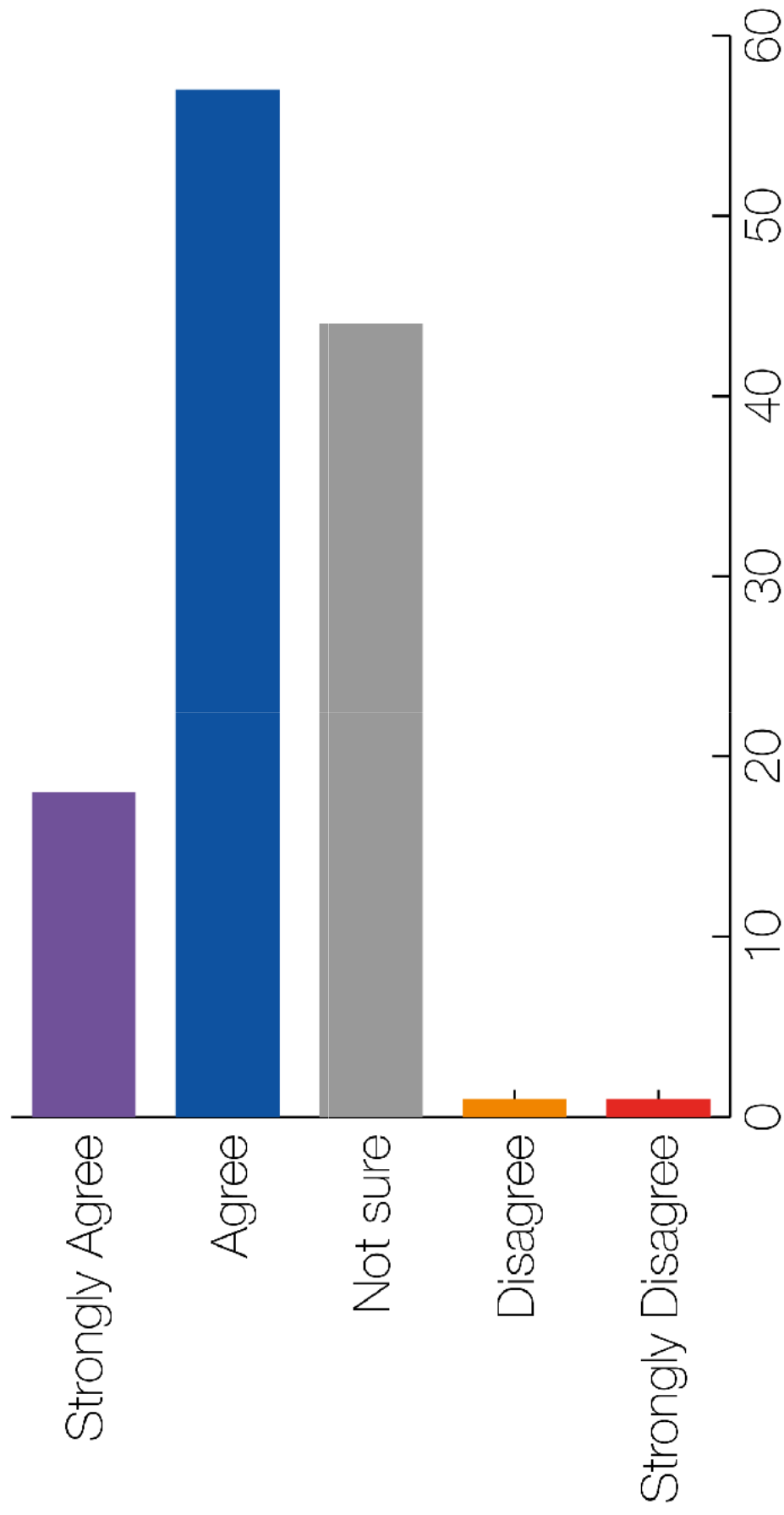


Lawson S, Pearmain G & Waters J (2010) Finding Our Way: the story of self-directed support in Barnsley. London: In Control. (n=100)

“Quality of life is better because of Personalisation & ISFs”

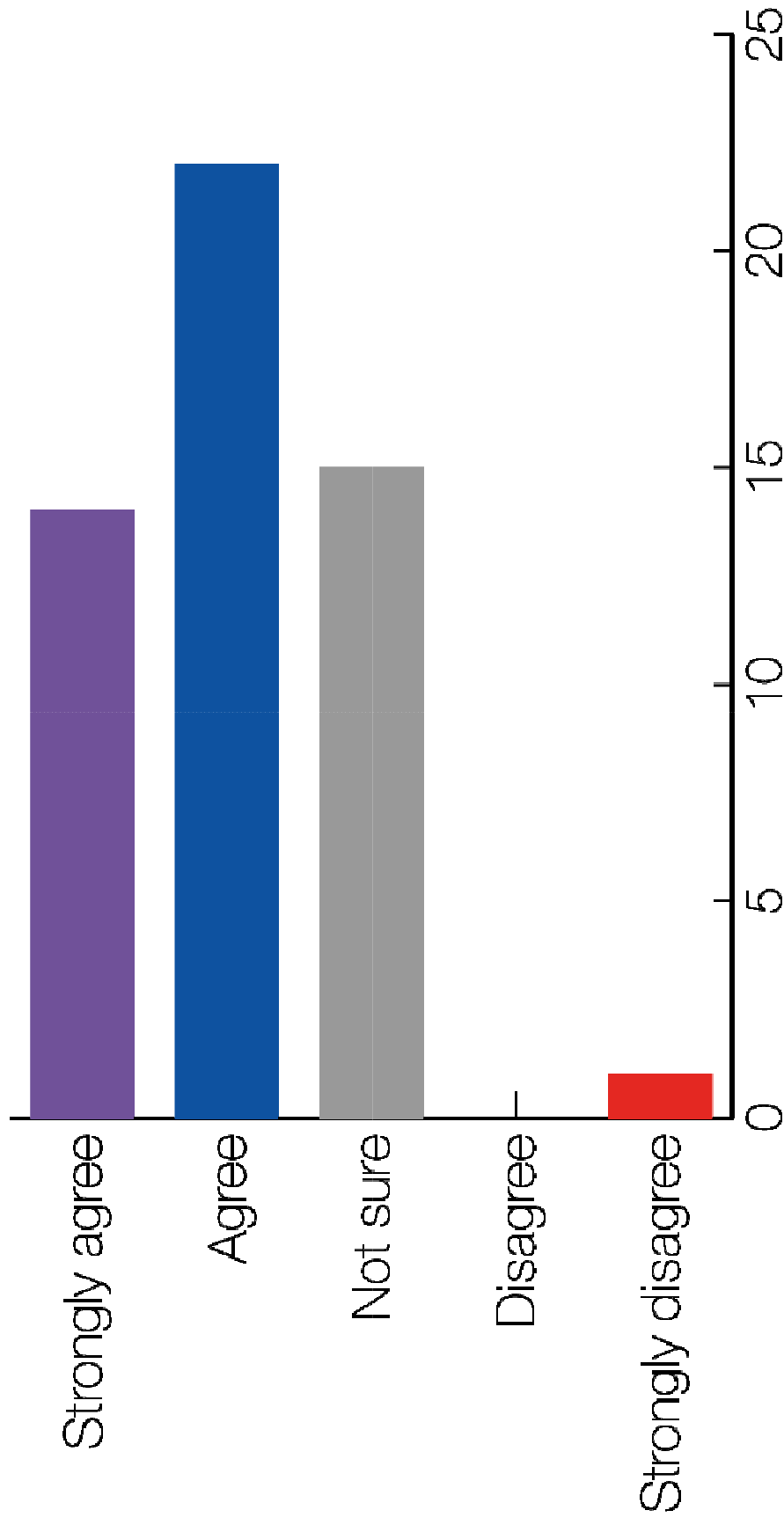


“Savings have been made without harm to quality of life”



[Better Lives: 121 people, representative, social service staff or care staff]

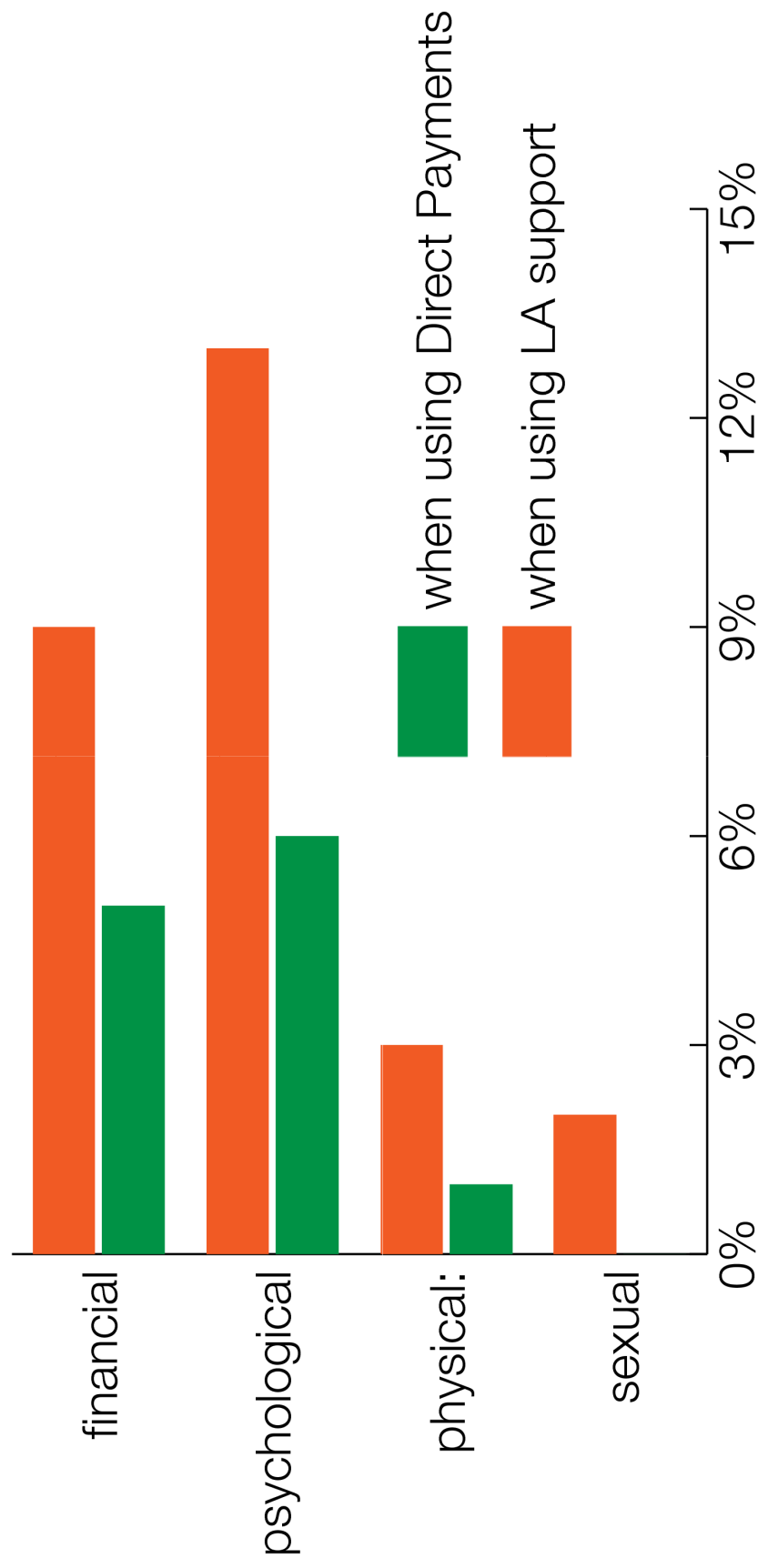
“ISF work was the most significant initiative of my working life”



[Better Lives: 35 support staff, 17 social workers]

Ellis R, Sines D & Hogard E (2014) Better Lives.
Sheffield, Centre for Welfare Reform

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

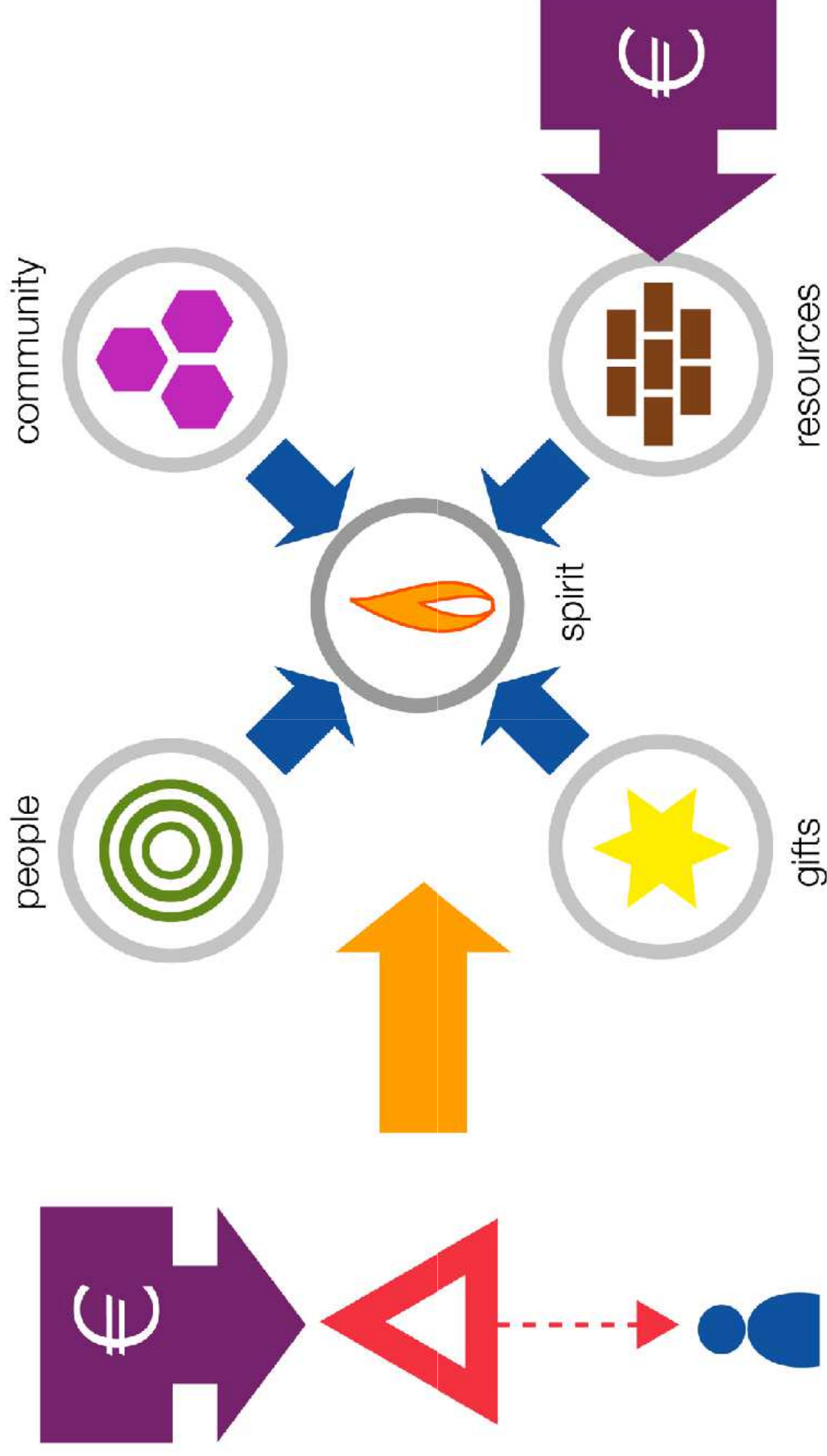


IFF Research (2008) Employment Aspects and Workforce Implications of Direct Payments. Leeds: Skills for Care.

4. Why does it work?

From Push Economics...

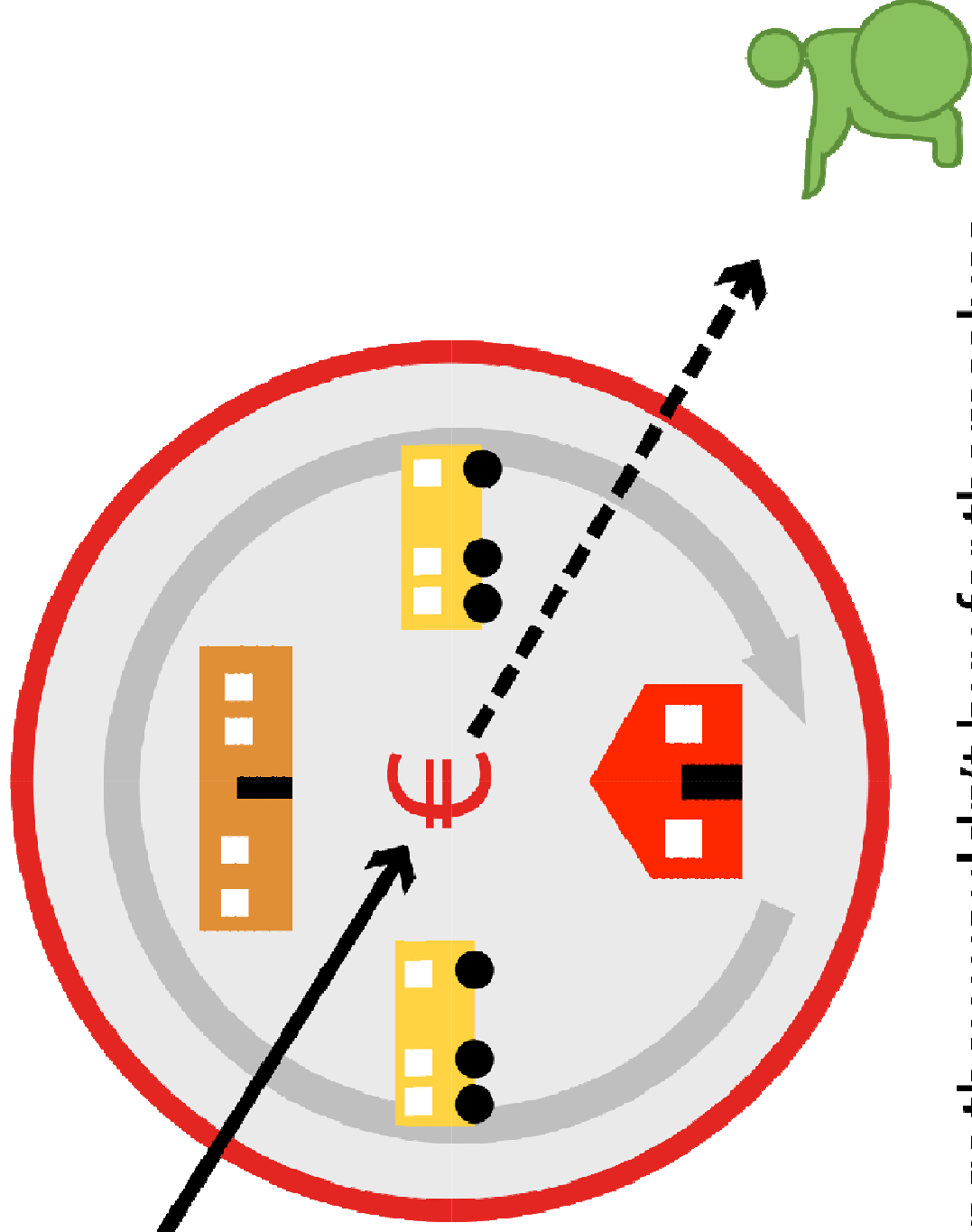
to Pull Economics



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.

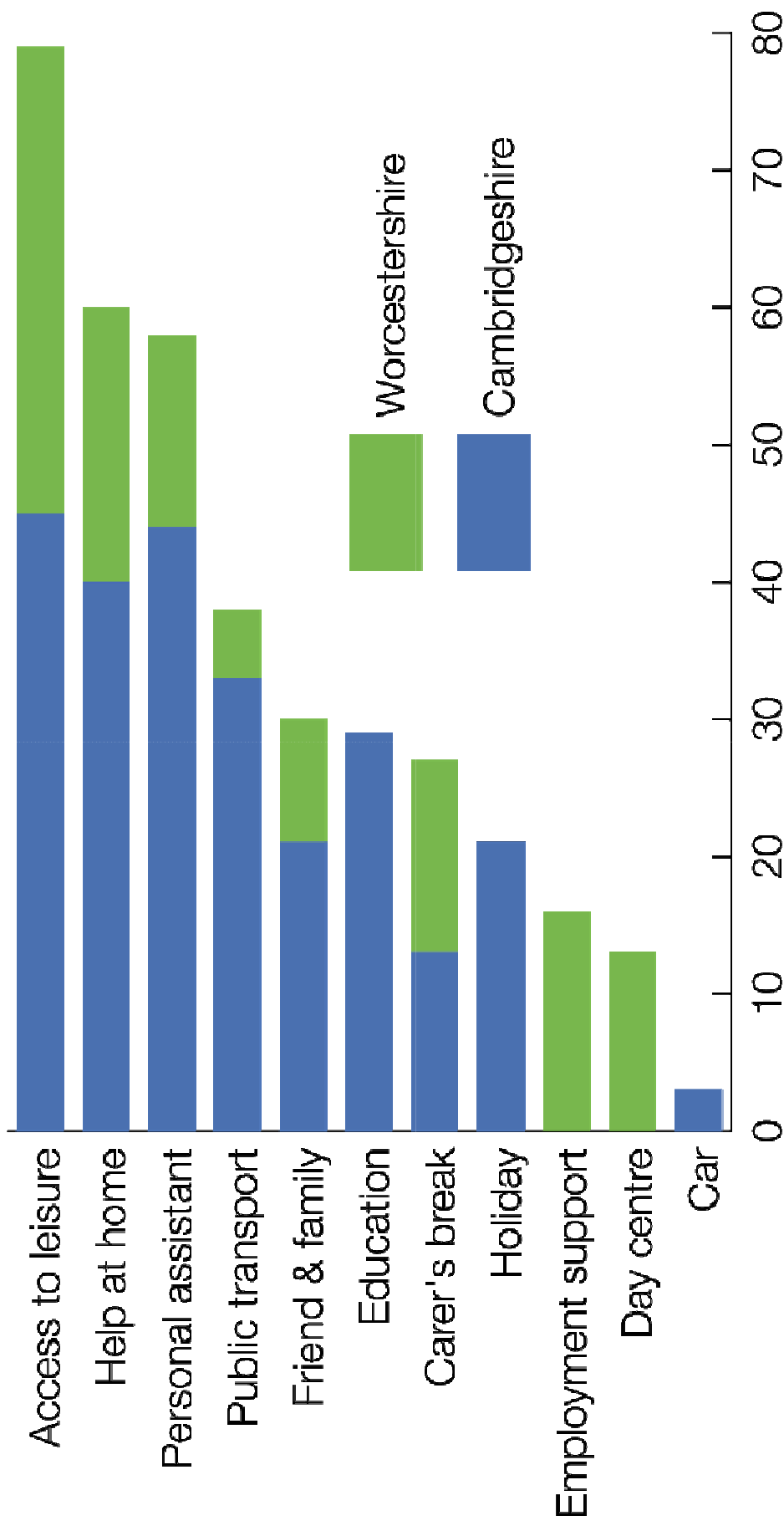
Spending people's money for them...

Government

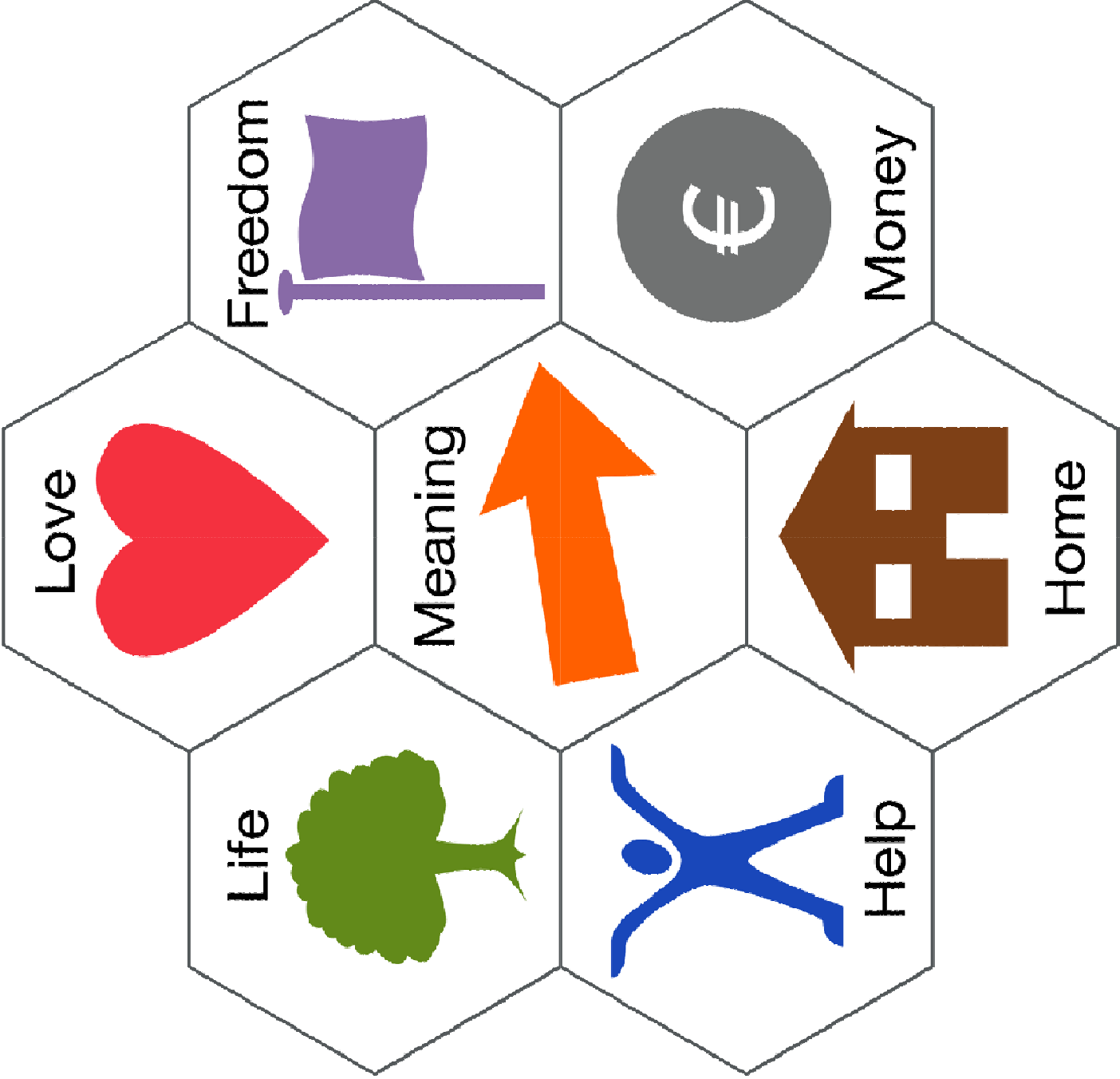


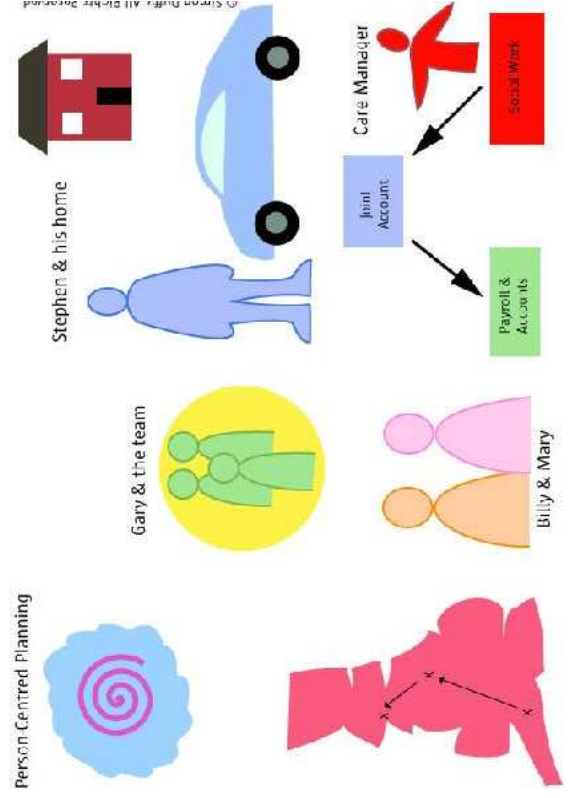
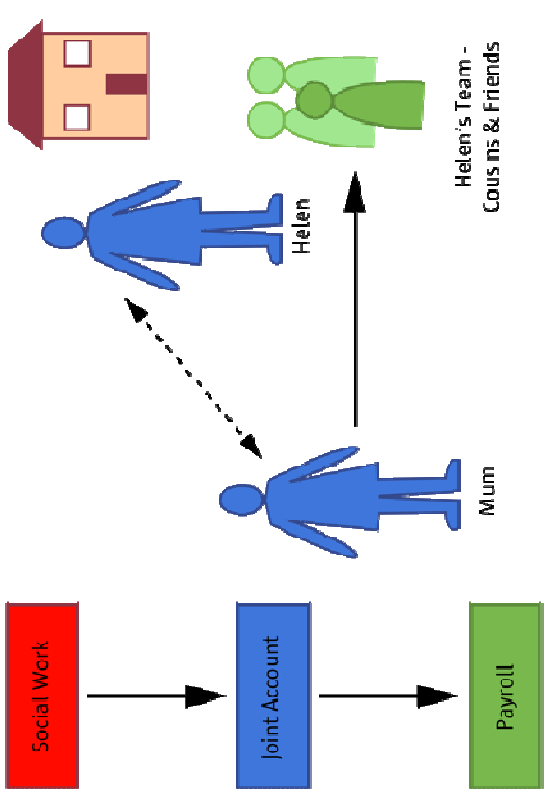
...on things they wouldn't buy for themselves.

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.





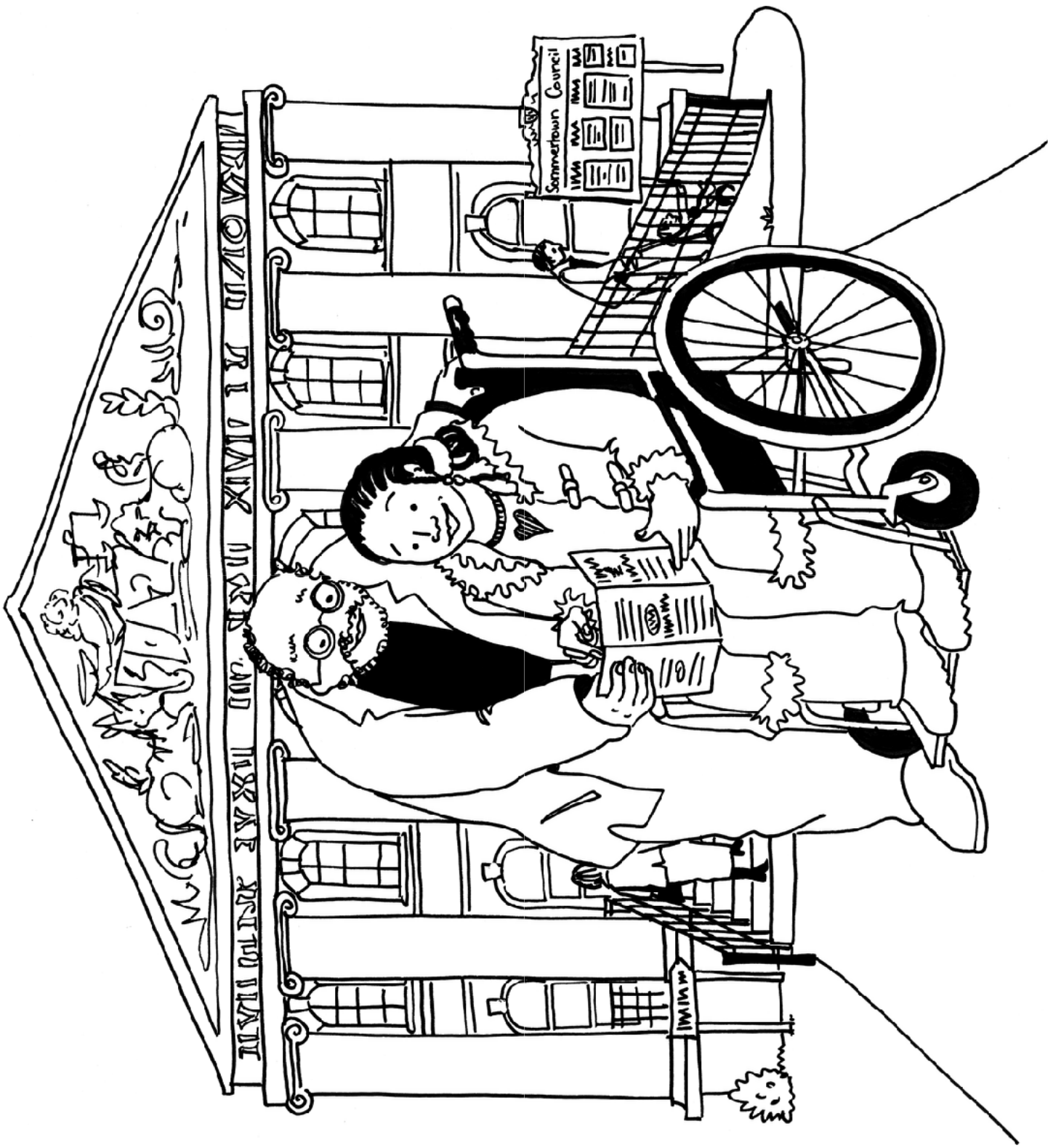
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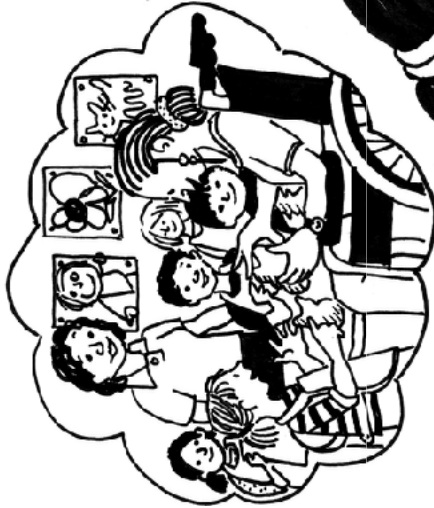
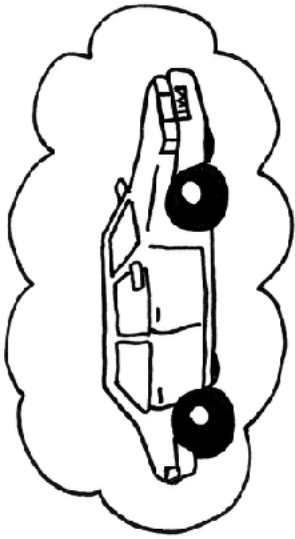
What the research suggests is that Self-Directed Support works because:

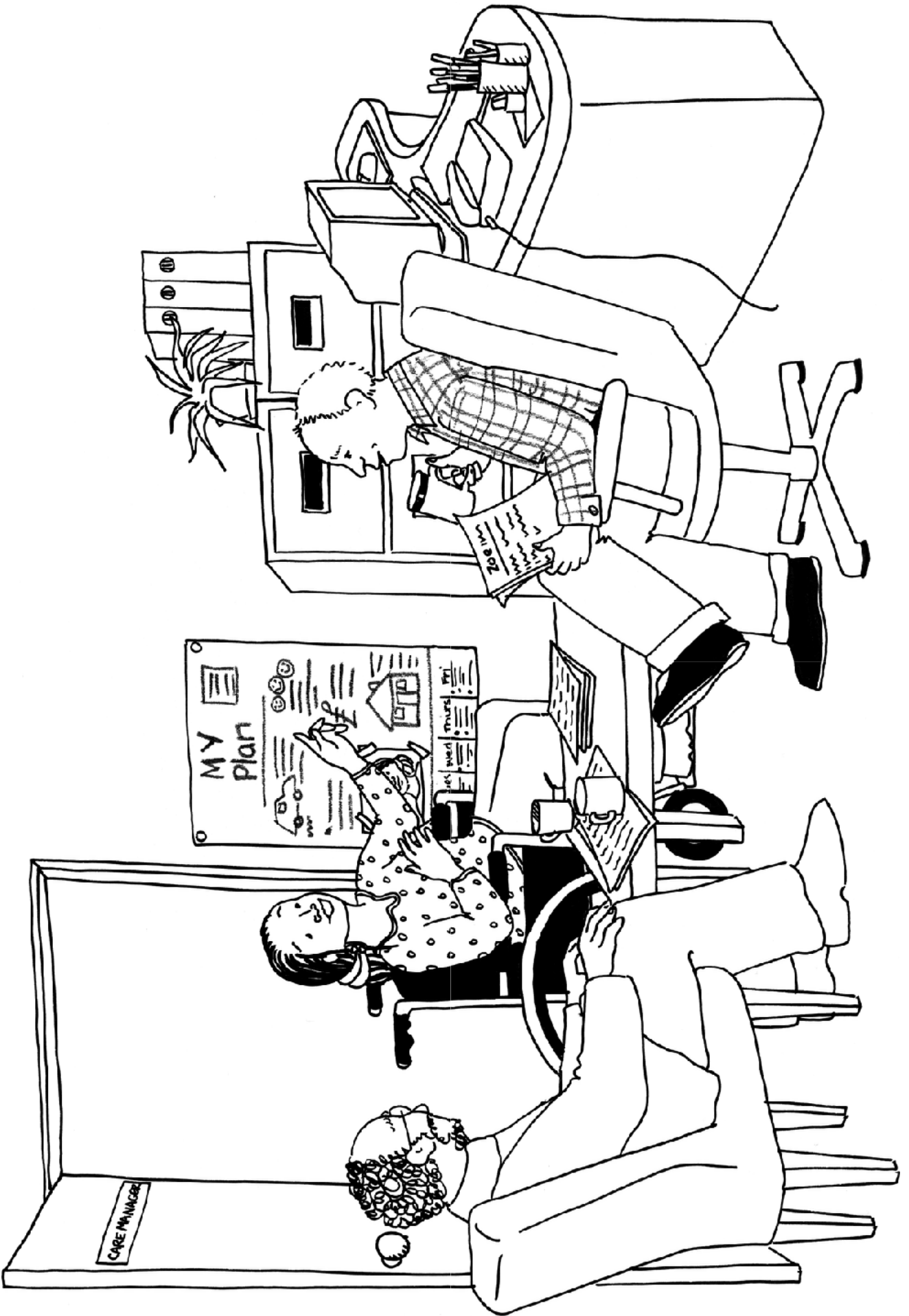
1. People can focus on things they really want to do
2. People can stop doing things they don't value
3. People can select professional support they really value
4. People can use budget to enhance their community life
5. It is NOT about markets or competition

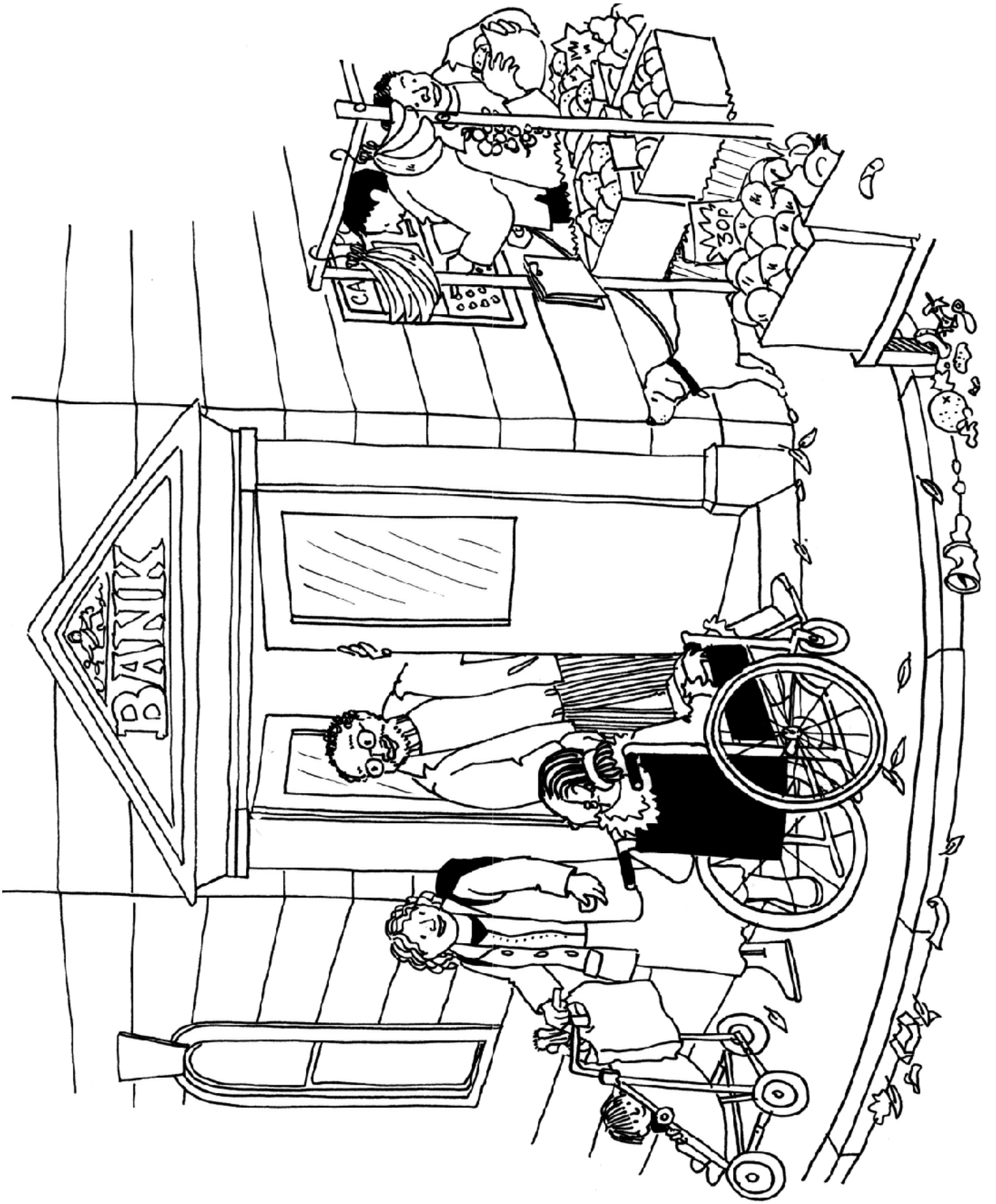
5. Why is it different?

1. People would be told their personal budget as **early as possible** so that they knew whether they were entitled to support and if so, how much.
2. People could make their **own plans**, with the people they wanted to.
3. People would finalise and **agree their plan** with the social worker who worked for the local authority.
4. People could take this **budget** as cash or ask for it to be managed for them by the local authority or by a third party.
5. People can use their budget **flexibly** and either organise their own support or pay someone else to organise their support for them.
6. The objective is to enable the person to get on to live their own life as a full **citizen**, actively involved in their community.
7. The **review** process should be human and should focus on whether the person is safe, living well and able to follow their own goals.

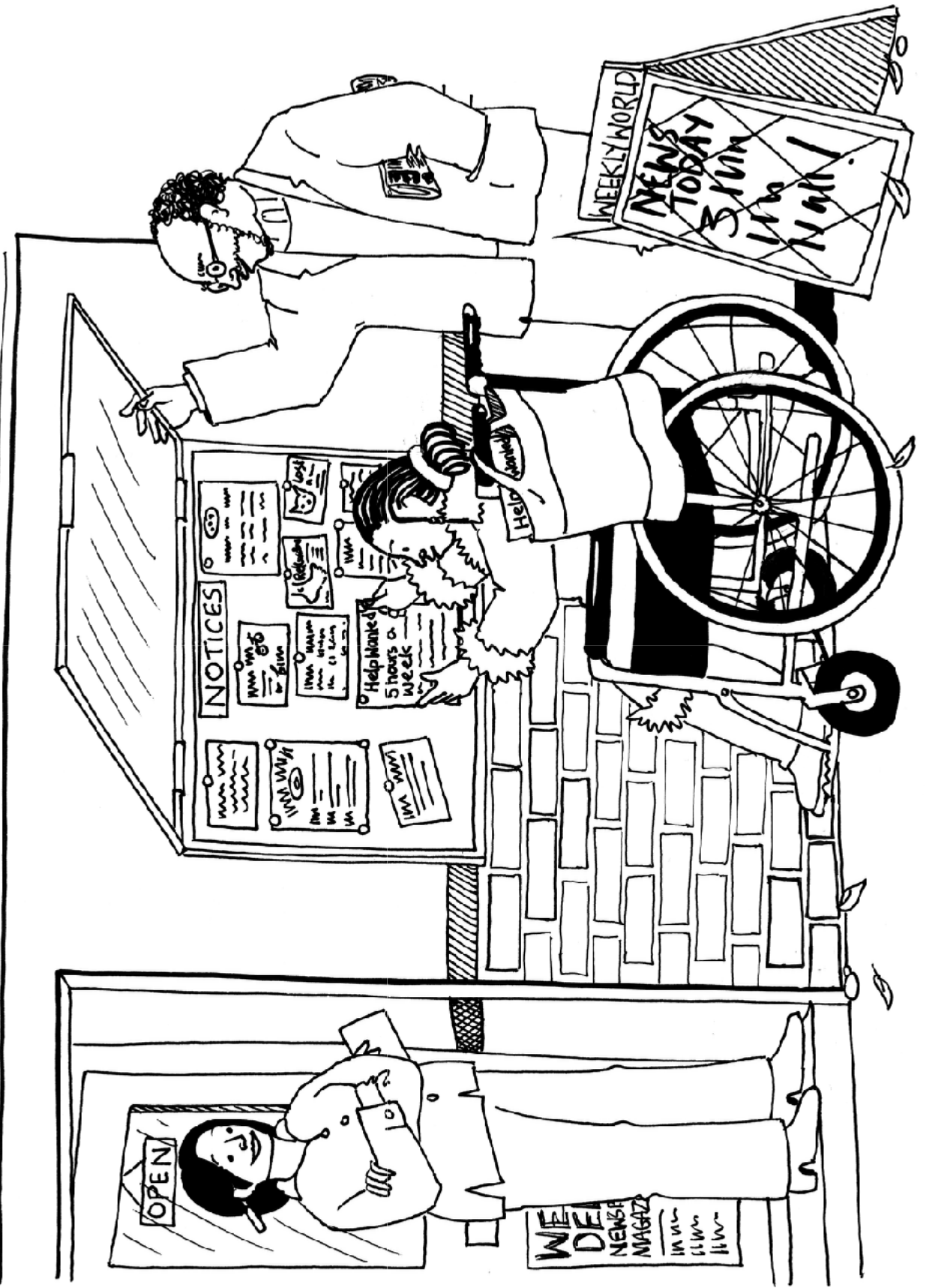


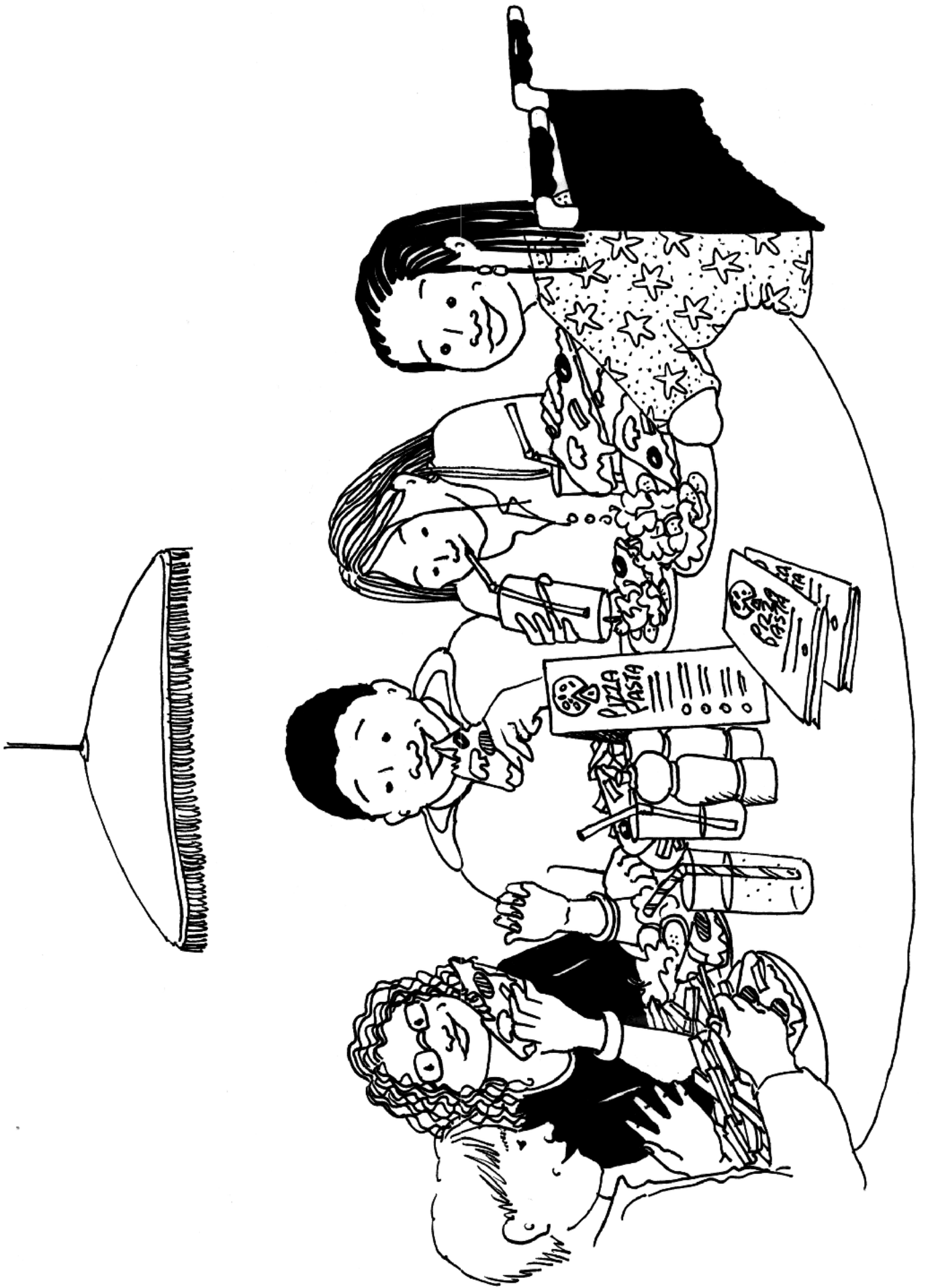


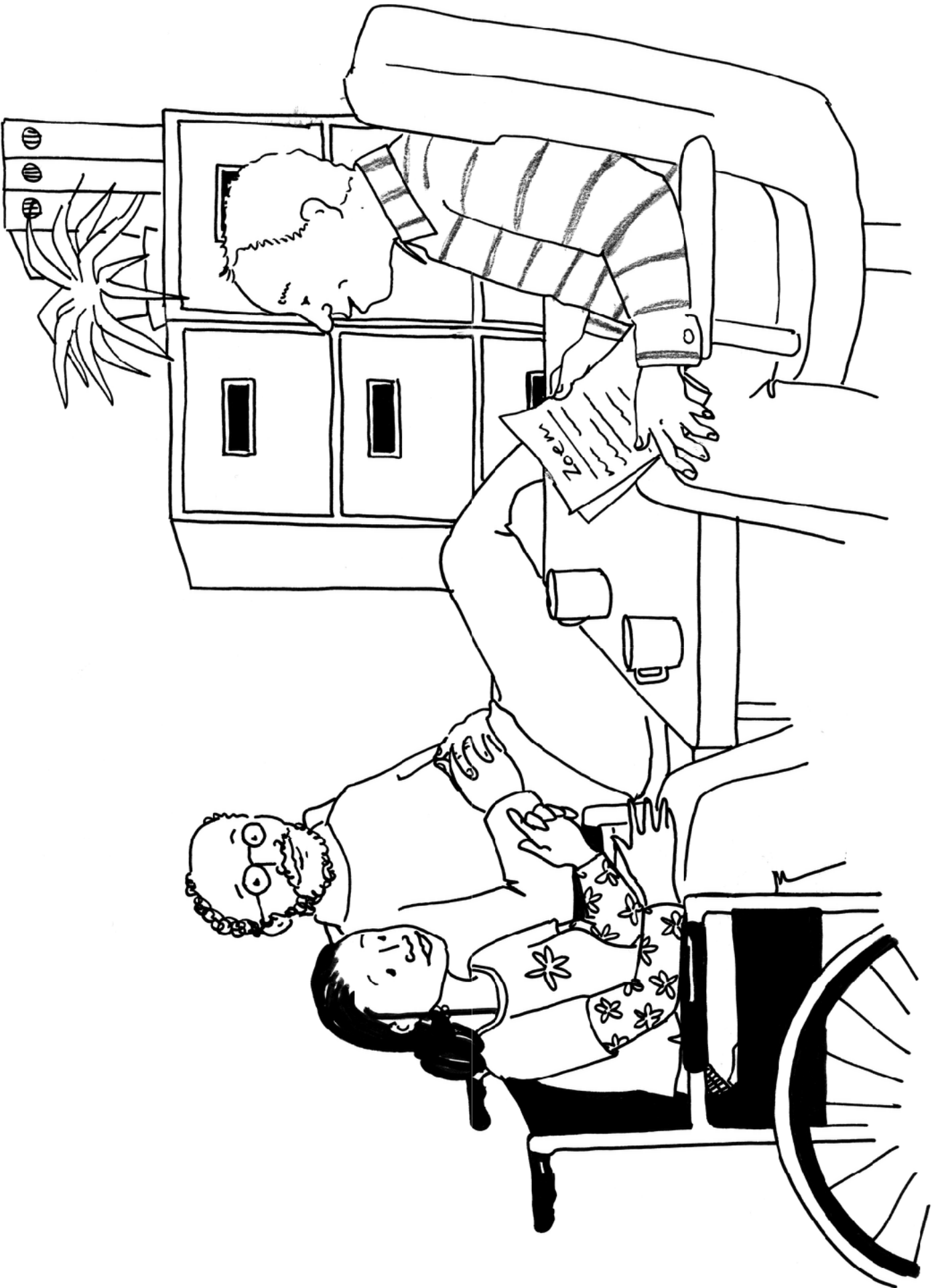


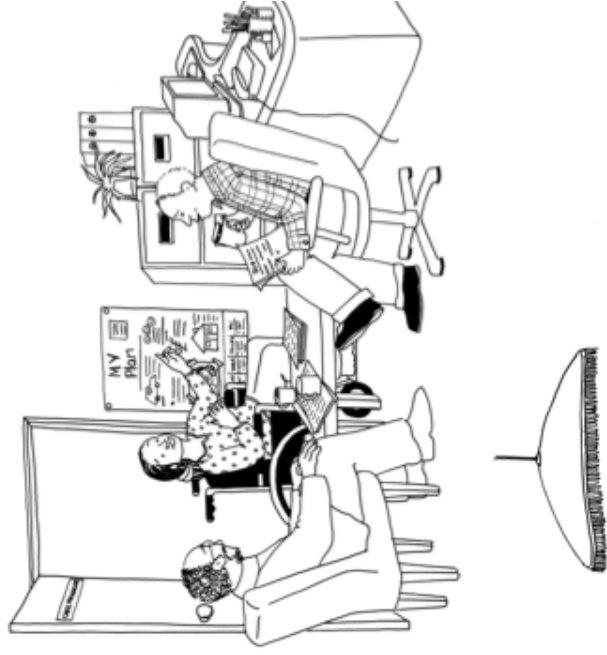
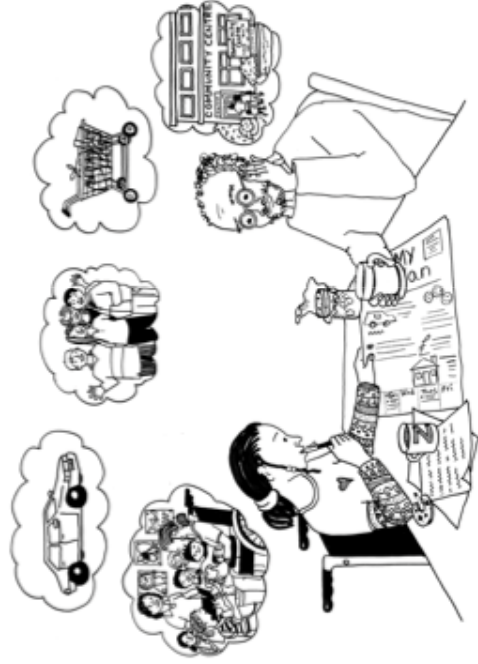
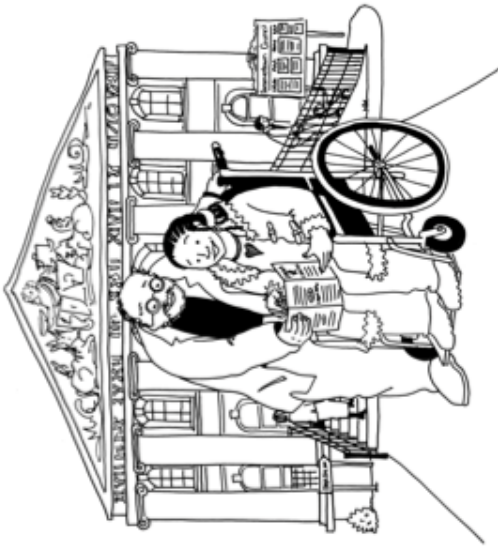


NEWS agents

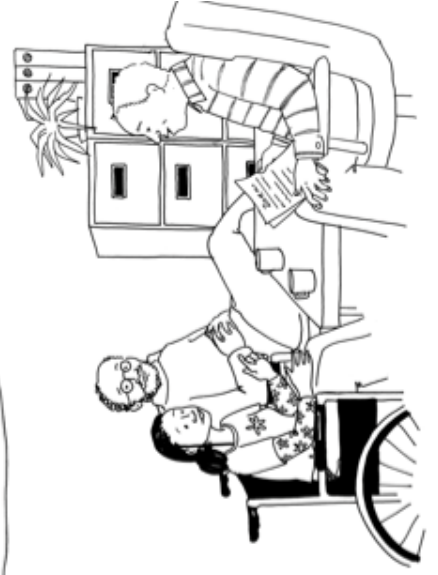
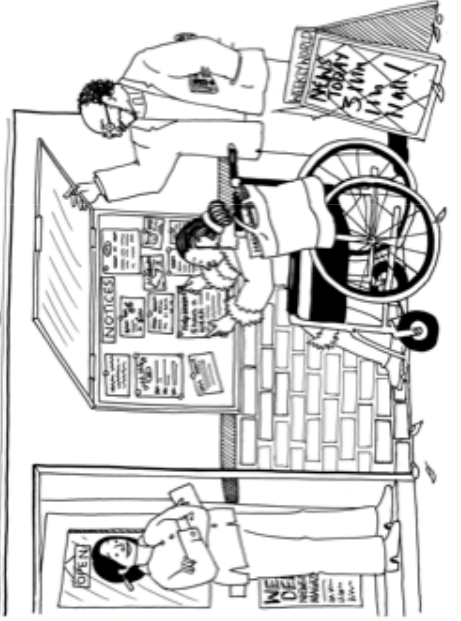


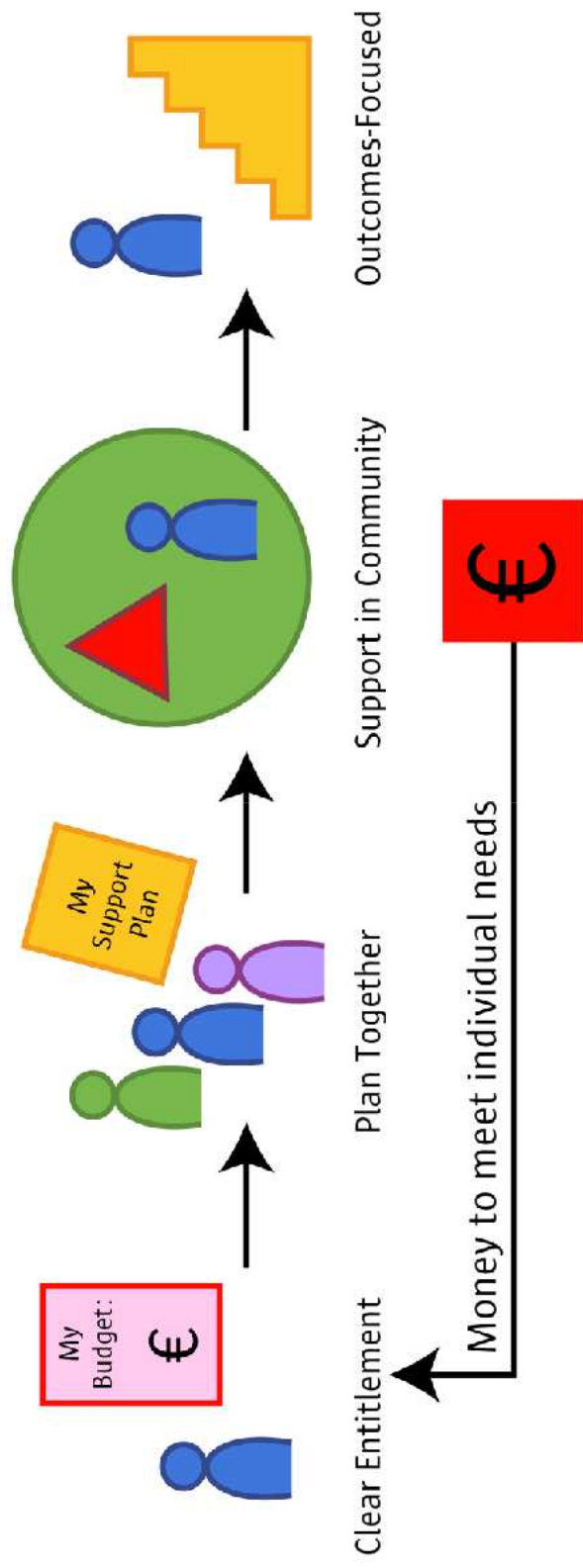
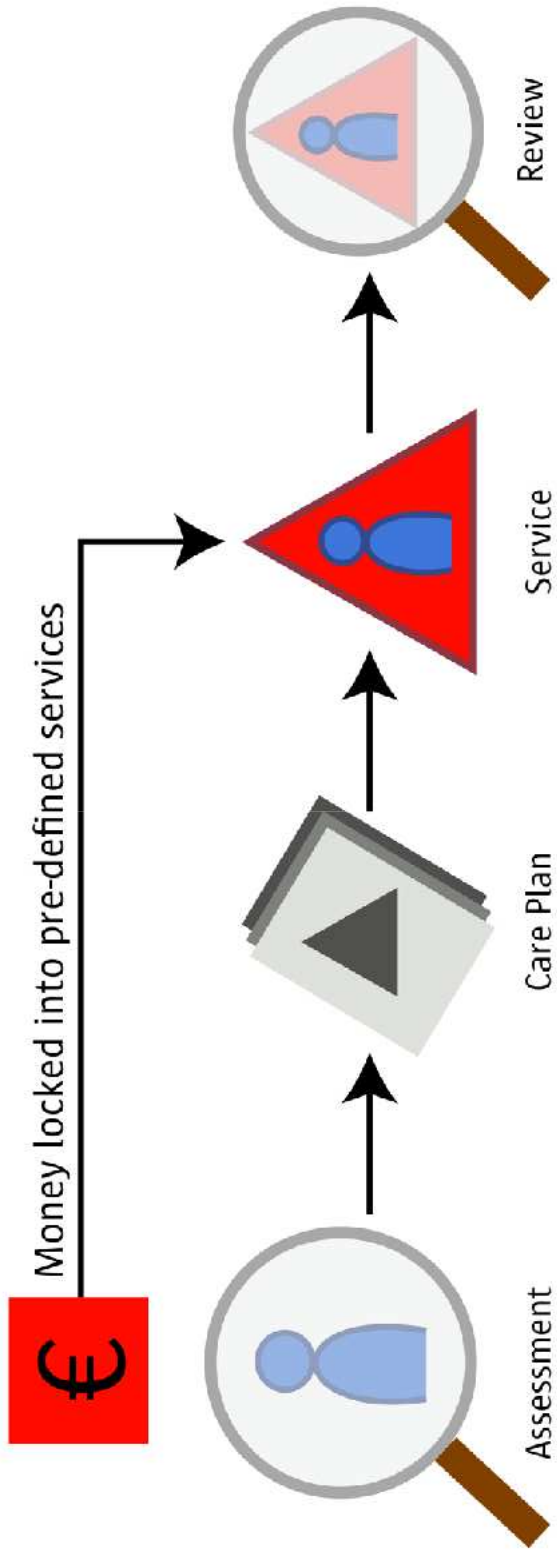


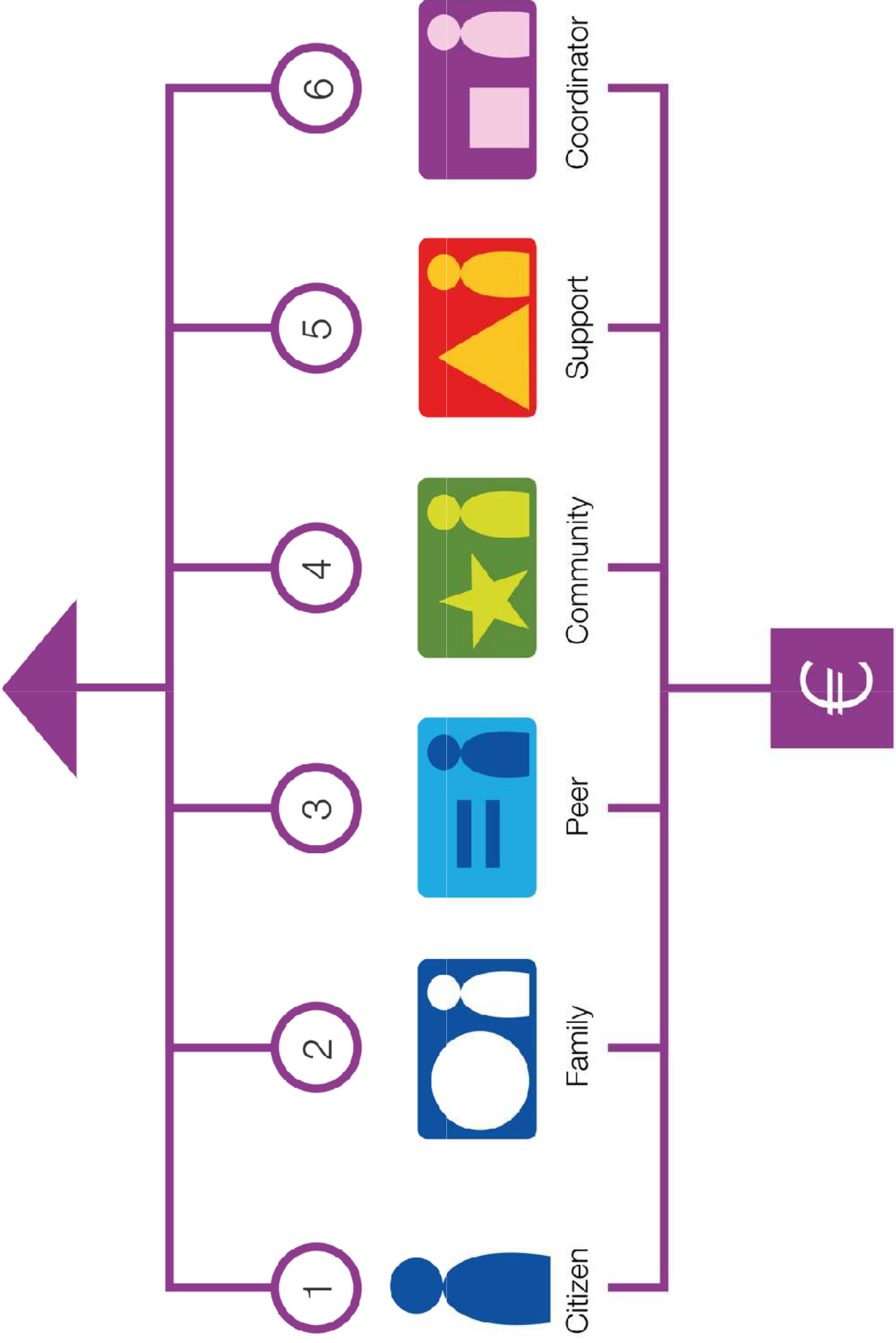




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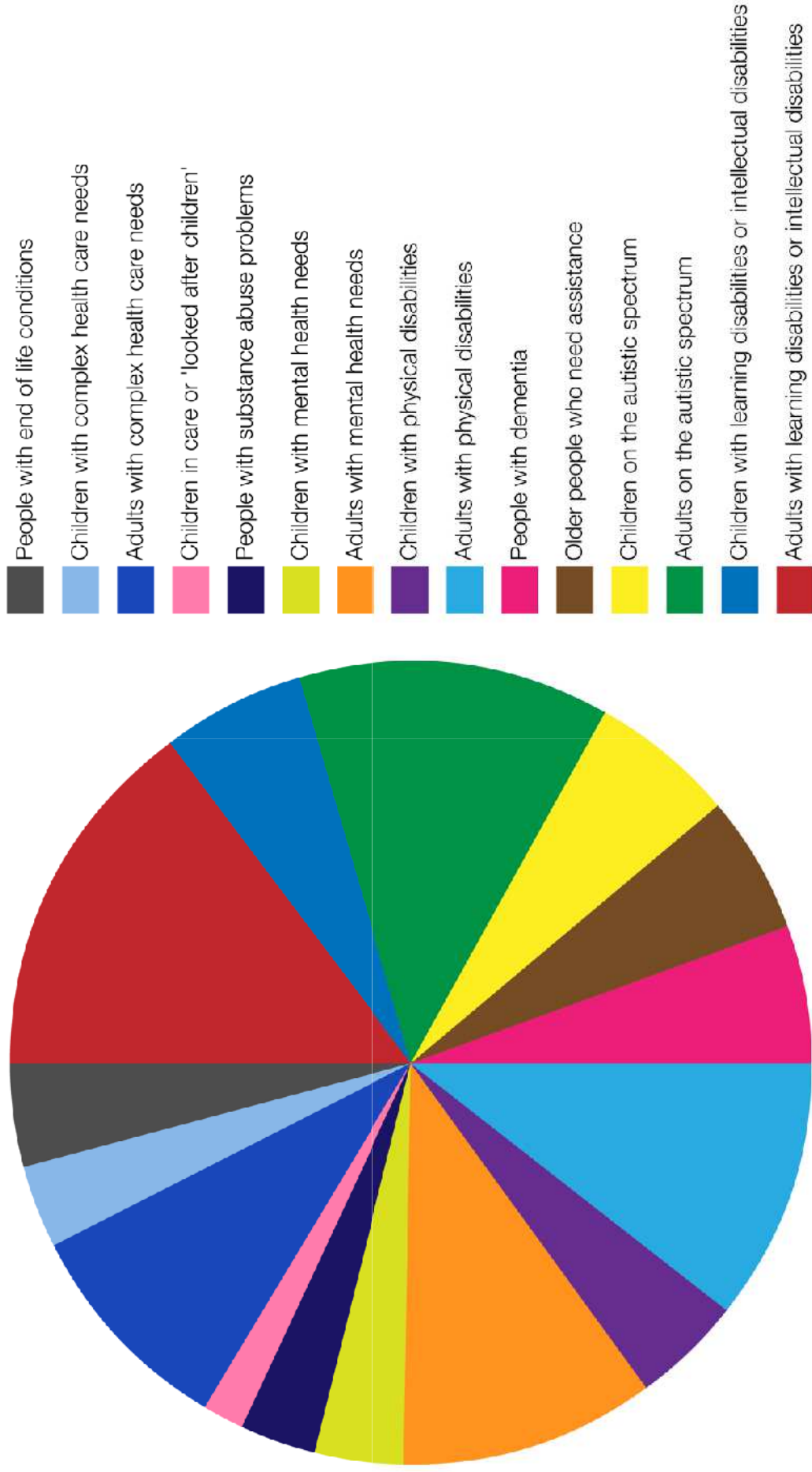






6. How is it going?

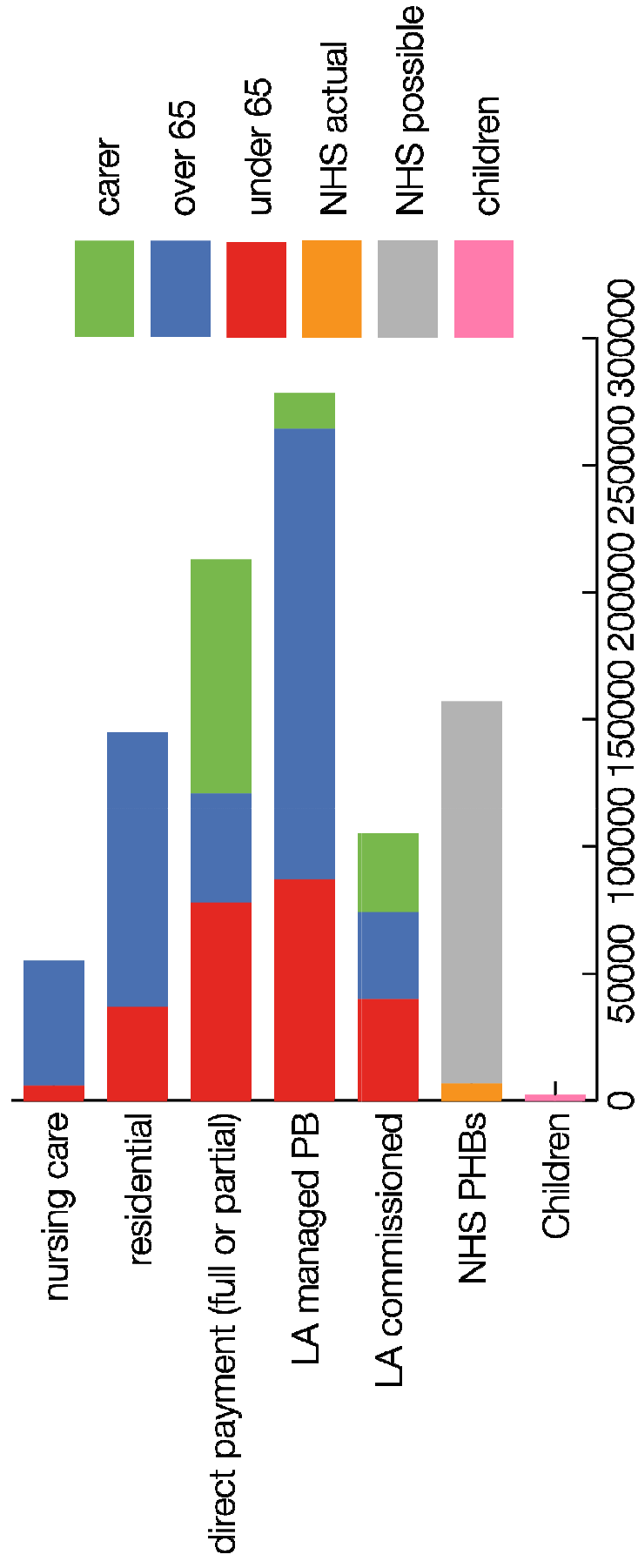
Who is using Personalised Support?



Source: Duffy & Sly (2017) Progress on Personalised Support. Sheffield: Centre for Welfare Reform

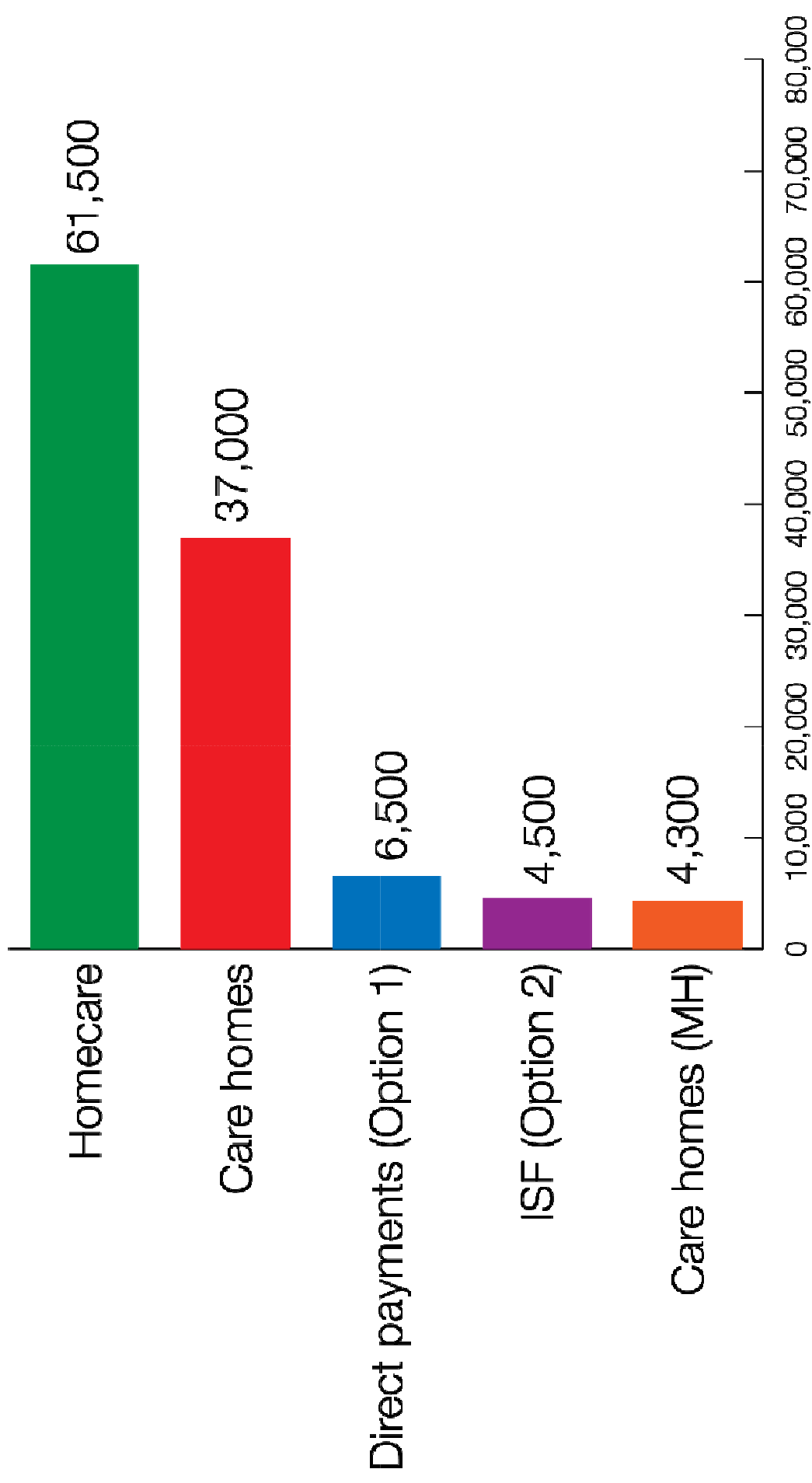
- People with **physical disabilities** may need much less help around decision-making and may want to employ their own personal assistants. Hence Self-Directed Support or independent living often focuses on employment of your own staff team.
- People with **intellectual disabilities** may need more help with decision-making and this has led to a greater focus on advocacy or brokerage systems.
- **Older people** may be much less likely to employ staff and may be more willing to purchase services from existing community organisations.
- People with **mental health problems** may be focused on solutions that include counselling and peer support to provide support while making decisions.

Numbers of people controlling their own budgets in health and social care compared to other numbers for adult social care and other personal budget systems.



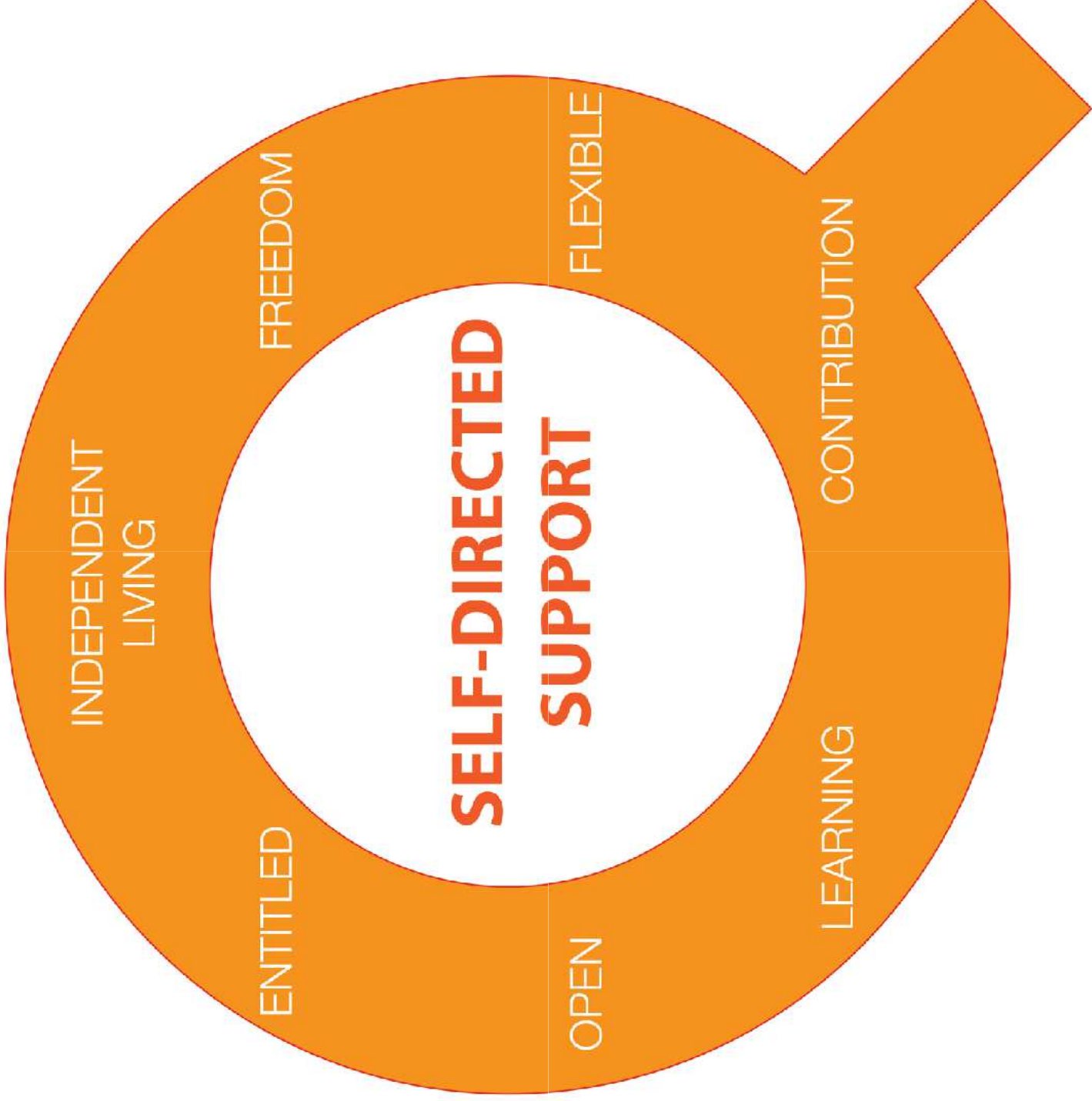
Source: Health and Social Care Information Centre (2015) Community Care Statistics: Social Services Activity, England 2014-15, Final release. Leeds, Health and Social Care Information Centre. Carer data is support provided during the year; other data is long-term support at year end (31st March 2015).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

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.

7. How should you do it?



1. Independent living - we have the right to be a citizen with full access to ordinary lives - I have a right to live my life in a way that makes sense to me.
2. Entitlement - we are each entitled to enough support to achieve citizenship - I have a right to enough support and also the right not to be over-supported.
3. Freedom - we should be in control of our own lives - I have a right to make decisions about how I live my life and, if needed, I have a right to be supported by people who know me and love me to make those decisions with me.
4. Openness - we should be clear about any rules or systems - I have a right to be told clearly and simply how the system of entitlement works and how the rules affect me; including how much money I am entitled to for my support.
5. Flexibility - we should be free to use our own entitlements as we see fit - I have a right to use my money in any way that helps me to live my life; including the freedom to take risks, make mistakes and learn from them.
6. Learning - we should share what we are learning to help everyone - I have a responsibility to share with others what I have learnt, what works for me and what doesn't work for me.
7. Contribution - we have a responsibility to contribute and to build stronger communities - I have a right and a responsibility to use my skills, talents and knowledge to play a full part as a citizen in my community.

Things that help

- Permissive legislation and guidance
- Positive national policy
- Examples of creative innovation
- Examples of good leadership
- Learning from each other

Things that don't help

- Low level of public knowledge, people only experience these problems when disability or illness affects their own family
- Fears and resistance from many professionals
- Unequal access to Self-Directed Support, where some groups are seen as lacking capacity or as too difficult to be able to achieve greater control
- Administrative complexity at a local level

Good strategies...

1. Support pioneers - Encourage practical change in the real world or identify existing innovations and help people see them as part of the new wave of change. Unless change seems real most people will not be persuaded.
2. Build understanding - Share stories, research and accessible materials that make the new ideas seem exciting and positive.
3. Keep innovating - Develop a pro-innovation approach to change, instead of fixating on one model encourage people to share good examples and learn from each other. Welcome new ideas and help people to see how different ideas can fit together.
4. Work from the inside - Build alliances with frontline workers and managers who want to make changes and ensure that solutions also help solve problems within existing systems. Create legitimacy for making these changes within the systems that need to change.
5. Go public - Develop a social movement for change which encourages people to see these ideas as relevant to their lives. The Australian campaign Every Australian Counts is a good example of creating an inclusive campaign for change with a positive message.

Who to trust

1. People with disabilities
2. Families
3. Frontline workers & social workers
4. People who've done it already