

self direct

First
**Members'
Meeting**

18th April 2012
10.30am - 4.30pm
York Merchant Adventurers' Hall,
Fossgate, York

**Members' ideas from the First
self direct Members' Meeting**

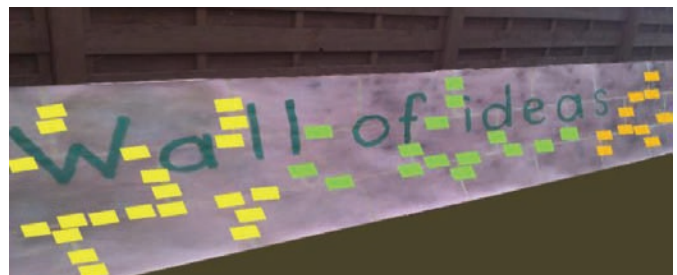
self direct First Members' Meeting, York, 18th April 2012

Members of **self direct** met together in York to listen to invited speakers and to put questions to an expert panel (see the appendix below).

The attendees at the First Members' Meeting included leading thinkers from the world of social and health care, experts by experience, self advocates, family carers, personal assistants, leaders from peer support organisations and professionals involved in the delivery of innovative services.

We had been asked by members to build into the day opportunities for networking and discussion time.

We collected ideas from the members; these ideas were posted on the 'Wall of ideas'.



The members' comments and ideas are grouped under the headings below (the red stars indicate which ideas the members thought were important to them).

Achievement



Standards



What's holding people back?



Change



Networks



The next big step



Summary of what the members are saying:

- We want to tell everyone about the people who need support, who have already taken control of their lives and are living their life in a way that makes sense to them.
- The ethical principles of Self-Directed Support should be put into practice throughout life, from childhood through to being an older person.
- The system is holding people back or worse, being used to control people. Systems that put organisational needs first should be scrapped and be replaced with ways of working that put the needs of the person being supported first.
- The Resource Allocation System and Support Plans are being used by many social care practitioners as tools to restrict what people can do and to control people and should be scrapped.
- FACS is being used to control budgets and too often results in people not getting the support they need; this should be scrapped.
- Risk assessments are being used to stop people doing things; instead they should be used to work out how people can do things safely.
- Putting people into 'silos' needs to stop, we need to bring all people that need support together to make sure there is a strong voice to demand the right sort of support and the right level of support for everyone.
- We should have a 'Community Pot' of money for people that need support. All the social care money presently in the control of Local Authorities should be transferred to a local 'Community Pot'; overseen by the community and distributed to people that need support by people who understand personally the effect on peoples' lives of decisions made about allocation of funding.

Achievement



We need to share peoples' stories on the **self direct** website using videos, written stories and photos**

Stories that show how a person or that person supported by their families are in control of their lives**

Sarah and Adam;
their story is featured in
the **self direct** book
'Helping providers
to change'



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Standards

The ethical principles that underpin Self-Directed Support should be promoted and we need to find practical ways to put these into practice

Standards

1. *****
2. *****
3. *****
4. *****
5. *****

The ethical principles of Self-Directed Support should be applied from the cradle. Schools should be educated to 'share' the journey with young families and should work together with those that provide care services and the community to help people be 'the best they can be' in preparation for adulthood*

Personalisation should be happening for older people, including people who live in residential homes**

Personal Assistants need to be trained to understand that the choice and control that Personal Budgets gives people is about the person they support not about them

What's holding people back?



People are unaware of their right entitlement and Personal Budgets and how to manage them is not being presented properly****

Care managers just don't get it, they need educating and to be given the time they need to correctly put Personalisation into practice*

A lot of providers still don't get it

Partnership working between Local Authorities and providers is not effective, providers are taking the risks

We are still not engaging with the wants and needs of people that need support

Change



Stop doing that	Start doing this
X Virtual care management*	✓ Have one to one meetings with people. Social workers need to 'know' their local community
X Putting people in silos - older people, people with mental health problems, people with a learning disability, people with sensory impairments, people with autism, people affected by drug or alcohol misuse	✓ Treat all people as people that just need support, share together and stand up for each other 'many small voices make one big voice!''****
X Scrap the Resource Allocation System (RAS)	✓ Develop a system that is easier to use and easier to understand
X Reducing the benefit and Social Care budget	✓ Make sure everyone has what they need to get the support they need

Stop doing that	Start doing this
X Scrap Fair Access to Care (FACS)	✓ Control the Local Authority Social Care Budget differently (Community Pot)
X Using Care Plans and Support Plans as a way of controlling what People are 'allowed' to do	✓ Simply ask people if they are able to get what they need to achieve their outcomes
X Excluding families	✓ 'Reclaim' the family as critical for support**
X Using risk assessment as a reason for not doing something	✓ Use risk assessment as a 'tool' to enable someone to do something safely and train families to do this*
X Organisations putting the organisation's needs first	✓ Train organisations to stop putting the organisation's needs ahead of people they support*

Can **self direct** link with other businesses to support charities, organisations and providers with the transition?***

Working with commissioners will get providers to change automatically as they 'chase' funding!

Networks



Embrace all people that need support and bring them together!

Connect communities, support local community leaders and peer support*

Keep people connected and get people connected, keep talking to each other

Self help groups are vital! Start a peer group in York
Peer support for black and ethnic groups*

Have meetings and more conversations between **self direct** Members (including individuals, families & providers) and Care Managers and commissioners in each Local Authority area***

Set up a link network to link organisations or people with similar dilemmas and challenges in order to work in partnership***

Voluntary register of what members do and what they could help others with (and if a charge would be made)*****

self direct should take their 'road show' to other parts of the country to engage with more people and organisations to provide information*

Interacting with wider society and bring them on board to promote the rights of all people who need support***

Can **self direct** advocate for disable people?

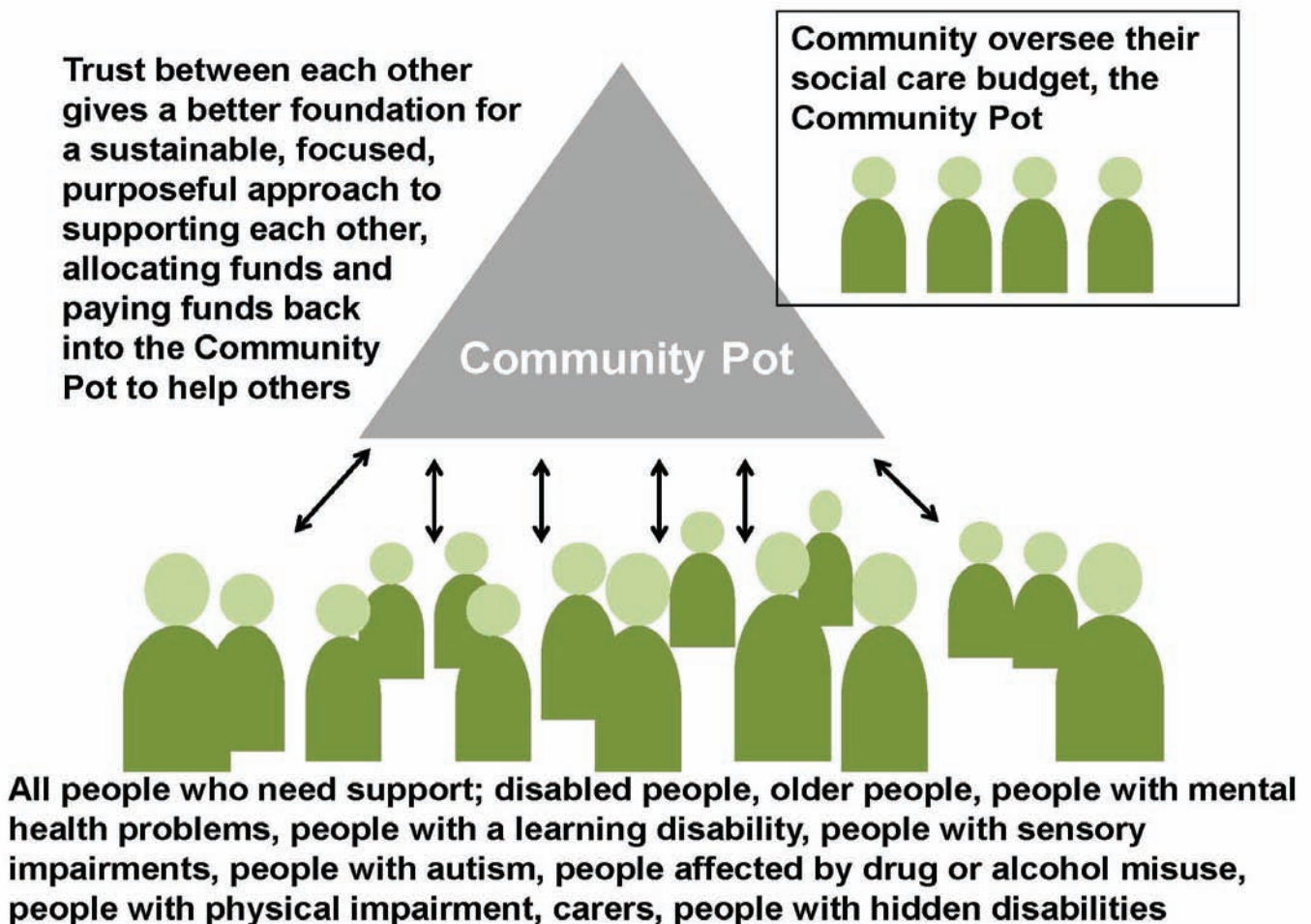
The next big step?



Community Pot

Social Care Fund held by and overseen by the community.

Boosting the voluntary sector to deliver support*, more Community Interest Companies as providers



Personal comment by Don Derrett, Chief Executive, self direct

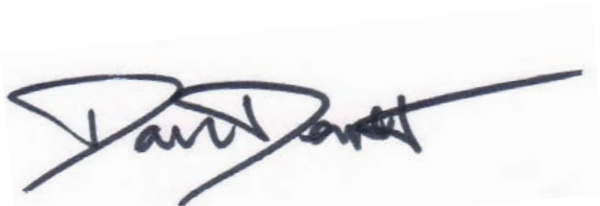
The members of **self direct** have some big ideas; I am particularly struck by the idea of the 'Community Pot'. Perhaps this may take the form of a local Community Interest Company (CIC) that is monitored to ensure it operates for the sole benefit of people in the community who are able to use money allocated to them for their support. There should be an option to pay unused support money back into the local 'Community Pot' for the benefit of others. This CIC would have to work in partnership with the Local Authority, with the Local Authority continuing to fulfil its legal duties, i.e. to assess people and ensure their needs are met. However, being independent of the Local Authority, people would be motivated to 'reinvest' money, i.e. pay unused money back into the 'Community Pot'. This may also encourage others, i.e. philanthropists, to 'invest' in the 'Community Pot' for the benefit of the community?

This idea and the other ideas members have will need expertise from across the social and health care field to help to develop them into a practical way of working and we will also need a strong united voice to ensure these ideas are put into action in a way that benefits all people.

self direct already has a strong membership base of people and organisations with the will to take forward these progressive and radical ideas. **self direct** members are based in every region of England and in Wales and the **self direct** member organisations support over 107,000 people. We have a great opportunity, working together, to develop these ideas further and to bring about the changes needed.

I would like to encourage members of **self direct** to contact other people and / or organisations that they feel would wish to join with **self direct** in putting these ideas into practice and direct them to the **self direct** website, www.selfdirect.org for information about becoming a member.

Or people can call me directly on **07814574307** to discuss the **self direct** members' ideas and find out how to join with us to take these ideas forward.

A handwritten signature in dark ink, appearing to read 'Don Derrett', with a long horizontal stroke extending to the right.

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Appendix

Attendees / contributors included: Speakers, panel members and members of **self direct**, listed below.

On the day we had support from **self direct** associates & volunteers, members of **self direct** and volunteers from York Older Peoples' Assembly.

Pavilion, under their Learning Disability Today banner, helped to promote the Members' Meeting on behalf of **self direct**.

Learning Disability
Today

Speakers and Panel Members:



Andrea Broadway-Parkinson

As a disabled person for 26 years, (following a spinal cord injury in a car accident in 1986 aged 16 while living in Zambia), Andrea has had much experience of using all manner of services over time, especially health services.

She lives a fully inclusive and independent life which she attributes mostly to self help and much support from her fantastic parents and friends, plus her two private sector based NeuroPhysiotherapists! Following academic studies in Social Policy and Health Education, alongside other roles, Andrea has run her own part time disability consultancy, '**Dispel**', based in York since 1998. She is a retired GB Paralympian (Women's Wheelchair Tennis, Atlanta 1996) and has worked in the voluntary, public and private sectors nationally and regionally. She is currently **specialising in "expert patient" and patient experience/quality advisor roles** within the NHS and research fields and is a Self Direct Associate.

Bob Towner

Bob is the acting chair of York Older People's Assembly. YOPA members are all over 50 and member organisations represent the main groups working with older people in York. YOPA aims to raise awareness of policy issues affecting the lives of older people in York, to be well represented on the boards of the Council, Hospital Trust and Primary Care Trust through YOPA Champions, to sit on policy-making committees, and to speak out in the press and media on local and national issues of concern to older people.



www.yorkassembly.org.uk

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Don Derrett

Don is the Chief Executive of self direct. Don set up self direct with the 3 other co founders in Feb 2008. Since then self direct has grown into a nationally recognised social enterprise, working with hundreds of social and health care professionals across the UK to change the way services are delivered.



Doreen Kelly

Doreen is the Director of Partners for Inclusion which she set up 10 years ago. Partners for Inclusion provide support that is

tailor-made rather than trying to fit people into services that often don't suit. Partners for Inclusion works with 45 people, some people live alone and have come-in staff, some people have flatmates or live-in staff and some people live with families. The organisation is committed to person centred values and focuses on making the most of community supports and relationships in the individual's life.

www.partnersforinclusion.org



Di Lofthouse

Di is a self direct associate. Di played a leading role in changing Mencap's constitution to include people with a learning disability in the decision making process across the organisation. She was the first person with a learning disability to have a place on **Mencap's National Council**. Di now works locally to speak up and campaign for people with a learning disability and health problems. In 2010 Di was **appointed an MBE for her work** raising awareness of hate crime against people with a learning disability.



Les Scaife

Les has a son with a learning disability and has been involved in developing support mechanisms since 2000

when his family and three others first received Direct Payments. At that time the local authority offered no support, so the four families decided to design their own support system. Since then Les has been involved in assisting others to form their own groups in the UK, where he has worked on **Direct Payments and Peer Support**. He has also spent 4 weeks per annum for the last 5 years in Australia, assisting and advising those in need of support services.

www.ukpar.org

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Mark Baggley

Mark is a Regional Ambassador for the Office for Disability Issues and the founder of Choices and Rights Disability Coalition in Hull and East Riding. He has been involved

in disability rights for 25 years, has managed services in independent living and housing. He made headlines in the media when he confronted the former Deputy Prime Minister, John Prescott over his abuse of a disabled car parking space. Choices and Rights Disability Coalition currently employs 7 staff, deals with over 3500 enquiries per year and provides key services to disabled people including community care, independent living, training, housing and disability discrimination issues.

www.choicesandrights.org.uk



Sarah Wood

Sarah is self direct's Family Carer Involvement Lead.

Sarah co designs and co delivers training to social and health care professionals; speaking at conferences and training days to share her family's story. Sarah has a son with Autism/ learning difficulties who is in receipt of an Individualised Budget. Sarah and Adam like to discover new, imaginative ways to use his money to realise his dreams and contribute to life in his community.



Shaun Lavery

Shaun Lavery is a member and Trustee of York People First. Shaun is an associate

of self direct. Shaun was involved in the production of the Pavilion publication, 'Training Personal Assistants. Shaun, representing York People First, was invited to lunch at the Mansion House in York with the Queen on her recent visit to York as part of the Queen's Jubilee celebrations. He was there along with other winners of the Community Pride Award, which York People First was awarded for the best community project.

www.yorkpeoplefirst.co.uk



Simon Cramp

Simon is one of the 4 co founders of self direct, Simon is self direct's Field Marketing Adviser. As a person with a learning difficulty Simon

works with and for people with learning disabilities, enabling them to get the right support and information. He offers expert advice on all issues to do with learning disability, based on his extensive experience working as a consultant throughout the learning disability sector. Formerly a member of the Department of Health's project board that produced the 'Survey of adults with learning difficulties in England 2003/4, a consultant and speaker on the 'In Control' initiative, the Chair for New Dimensions Group's 'New ways of working' project, funded by Skills For Care, a member of an advisory board for the General Social Care Council, advising on the new Social Work degree, a Trustee of Mencap and member of OfCom's 'Older people and disabled people' committee.



Simon Duffy

Simon is a well known social innovator and writer who is working to redesign the current welfare system so that it will better support citizenship and strengthen our community life. Simon is best known for defining key

concepts such as Individual Budgets, Self-Directed Support, the Citizenship Model and many others. He is the author of Keys to Citizenship and many articles and papers. He now runs The Centre for Welfare Reform. Simon has found a number of ways of putting his ideas into practice. He founded and led In Control from 2003 to 2009. He also founded Shop4Support.com and Altrum. From 2000 to 2003 Simon worked as Director of Consultancy for Paradigm leading on Person-Centred Planning and Self-Directed Support. In 1996 he founded the service provider Inclusion Glasgow to provide radically individualised support to people leaving institutional care. From 1990 to 1994 Simon led early experiments in individual funding and brokerage within Southwark Consortium (now Choice Support).

www.centreforwelfarereform.org

Members of self direct

Age Concern Hereford and Localities

www.acherefordandlocalities.org.uk

Angela Hueting

Aspire Living Ltd

www.aspirehereford.org.uk

Avalon Group

www.avalongroup.org.uk

Christopher Watson

Colton Macey

www.coltonmacey.co.uk

Community Integrated Care

www.c-i-c.co.uk

DABD (uk)

www.dabd.org.uk

David Wolverson

Enable Housing Association

www.enableha.co.uk

Helen Webber

Heritage Care Limited

www.heritagecare.co.uk

Home Instead York

www.homeinstead.co.uk/York

Home Care Direct

www.homecaredirect.co.uk

Home Farm Trust, Family Carers Team

www.hft.org.uk

Heantun Housing

www.heantun.org

Integracare

Jane Livingstone

Jean Riley

Manchester Metropolitan University

www.mmu.ac.uk

McIntyre

www.macintyrecharity.org

New Concept Care and Nursing

www.newconceptcare.co.uk

Postural Care PIP

www.posturalcareskills.com

Rachel Mason

Robert Owen Communities

www.roc-uk.org

RightWay, Michael Richmond

Sunnyside Rural Trust

www.sunnysideruraltrust.org.uk

The Centre for Welfare Reform

www.thecentreforwelfarereform.org

The Wilf Ward Family Trust

www.wilfward.org.uk

Turning Point

www.turning-point.co.uk

Ubu

www.ubu.me.uk

West Lancashire Peer Support

www.ukpar.org

York People First

www.yorkpeoplefirst.co.uk

*Get in
touch!*

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Visit **www.selfdirect.org** Call **078145 74307**