

York Health Overview and Scrutiny Committee Personalisation Review

Notes from session one

1.00pm - 3.00pm on 23rd April 2013

On 23rd April 2013, City of York Council held two sessions for people who use services and support and family carers in York. They were a chance for people to share their experiences of how things are working now as well as to consider the priorities for the future. The focus was on making services and support more person-centred and is part of the Health Overview and Scrutiny Committee Personalisation Review. These are the notes from session one.

We used the *Making it Real* process as a framework for people to think about how Personalisation is working. *Making it Real* sets out what people who use services and family carers expect to see and experience if support services are truly personalised. They are set of "progress markers" - written by real people and families - that can help an organisation to check how they are going towards transforming adult social care. The aim of *Making it Real* is for people to have more choice and control so they can live full and independent lives.

<http://www.thinklocalactpersonal.org.uk/Browse/mir/> or search online for 'Making it Real'

As citizens, some people will need extra support to live a full and active life, or they will know or support someone who does.

Personalisation is about making sure that when this support is needed, people are able to live as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity.

Through Personalisation, City of York Council want to make sure that:

- The City offers the opportunity for everyone to live full and active lives
- People can easily find good clear information and advice
- People can find support to live their life as they wish, stay well and independent
- Support is co-ordinated, flexible and readily available when needed
- Anyone who is eligible for social care support will have access to a personal budget and know what money they have to plan their support
- People will have control over the way the money is spent, so they can plan their own lives
- People will receive the support they need to manage the money and decide how best they can live their lives

For more information about Personalisation in York, please go to the My Life My Choice pages of the City of York council website: www.york.gov.uk



Making it Real asks people to think about how well Personalisation is working under six themes:

1. Information and advice: having the information I need, when I need it
2. Active and supportive communities: keeping friends, family and place
3. Flexible integrated care and support: my support, my own way
4. Workforce: my support staff
5. Risk enablement: feeling in control and safe
6. Personalisation and self-funding: my money

We started the session by working in small groups to think about each of these themes. We recorded what we thought is working well in York and what is not working so well. We used green and orange cards:

Things that are
working well...

Things that are NOT
working so well...

The photos over the next few pages show what you said.

① Information

I get support to make choices

I can speak to people who know about my support

Information is easy to understand

I get the right information when I want it

I get information about what's going on locally

working

COMMUNITY FACILITATORS USEFUL

Community facilitators are a good source of information

ILS have a set of information sheets but CYC staff don't know much

PERSONALISATION
If walked into West Office & asked about (P) & getting info - what would happen?

Great Theory

All valuable info came from other users ⁹⁹Lives Unlimited

^{NOT ENOUGH}
CASE STUDIES
- BEST PRACTICE THINGS ARE WORKING

Information since withdrawal of Independent Living Fund not clear on how these people will be supported in future

not working

Where can you get help for the little things, like putting on a coat?

STILL NEEDS 'BUT-IN' FROM SOME PROFESSIONALS

LANGUAGE
IS IT ALWAYS ACCESSIBLE?

Not clear how it works with in-house carers who work at Gale Farm. Can people here still get a PB?

MENTAL HEALTH UNKNO AS SOMETHING SEPARATE FROM PHYSICAL HEALTH

LANGUAGE
Is it understandable

Older people not getting good messages about personalisation - worried they will be forced to sort everything out themselves

PERSONALISATION IS ONLY PART OF THE SOLUTION - WHAT ABOUT THE NOT FACTS ETC

Knowing where to look for information!

Some information is not reaching all employers

Need to be aware of all implications of having own budget

A need to share and promote information from all services and voluntary organisations

Don't find ILS have enough knowledge regarding employment law etc.

Access to information seems limited or my knowledge is assumed

② Community

I've got friends

I can choose how I spend my time

I feel welcome in my community

I've got the support I need to live my life

working

It has lifted a worry about my mother's well-being

PEOPLE LIVING INDEPENDENTLY (NO LONGER LIVING IN HOSPITALS). LAND MARK TIME

Live, Learn and Progress at own pace.

Access to whole community.

Good access to community places in Acomb.

Keep own home and family around her + support.

Improved family + friend relationships having a PA. Set boundaries in our relationship, feel less reliant.

Lack of funds to invest in community support systems like timebanking

Health + social needs cannot be separate:

I don't have a social care bank.

not working

Need to think about access of infrastructure not just individual buildings of training centres

FREEDOM TO TRY THINGS, TAKING RISKS.

ARE WE THINKING "OUTSIDE THE BOX". SERVICES / MEETINGS / GROUPS ACCESSIBLE.

Not enough is done to get people into employment opportunities

Poor transport from different parts of the city - need circular routes not just in + out of the centre

Social Isolation.

still a bit isolated as not in any community networks.

Not recognising what skills + knowledge you can bring to community, seen just as a taker

Problems getting around on the footpaths.

③ Choosing my support

I can change my support if I choose

I have the support I want

I've got someone to talk to about changing my support

working

Able address all needs → health is affected by well being → quality of life

CHOOSING WHO SUPPORTS YOU
(INVOLVED IN INTERVIEW PROCESS)

For my son it was important to choose his support - people with the same interests

SERVICE USERS WHO HAVE CAPACITY - HAVE THE FINAL SAY

Great to have DP/PB once it's set up

FLEXIBILITY OF SUPPORT FROM P.A.'S
(ONE TO ONE)

IB is a good way to promote sense of value and being in control

Our son is becoming more independent

The gap between rhetoric and reality. Going to an assessment and finding your support plan is already completed ^{before you talk.}

NOBODY IN MENTAL HEALTH SERVICES UNDERSTANDS SYSTEMS PEOPLE PASSED AROUND & AROUND

A lot left for Carers to do + find out themselves. Not much information from Care Managers

Lack of support / withdrawal of support for moderate needs means I struggle with basic tasks, like having a bath

People who lack capacity (eg dementia) expected to be able to choose services + manage budget - get. They may be unaware of their need for help + unable to manage day to day tasks

Personalisation will only work if there is enough family support.

NEED IMPARTIAL, INDEPENDENT BACKLOGUE, SUPPORT PLANNING

Process of getting a DP/PB frustrating and challenging.

Too much pressure on care managers to work quickly rather than well.

PEOPLE ARE LYING ABOUT/FAIR. LOTS OF TALK FOR YEARS BUT NO ACTION

not working

Choosing who supports me - difficult for individuals with v. complex needs.

MENTAL HEALTH SERVICE LEADS NOT GIVEN OPPORTUNITY TO TAKE A PERSONAL BUDGET

LACK OF MARKETPLACE FOR PEOPLE TO CHOOSE SERVICES FROM

DPI form is causing lots of problem. Saying it's not received / got lost. Causing delays to payments

Issues around the gap between health & social care, and wanting to address my health needs

④ support staff

I can get advice from people in a similar situation to me

support helps me really get + stay part of my community

I've got support from people who really know + understand me

working

My sons PAs are great they work for him not an agency ☺

POSITIVE EXPERIENCES OF INDEPENDENT LIVING SCHEME. - SUPPORT + INFORMATION

PAs are working well in terms of continuity and developing relationships

ILS (Independent Living Scheme) have helped me as can get support as and when I need it.

PAs employed directly are more flexible - can meet needs of person - and not rigid service provision.

Employing a personal assistant has helped me to get my independence back.

Older people constrained by Home Care shift patterns etc... Task focussed. ^{Not holistic}

not working

Risks need to be monitored closely so that it can be put right quickly

Success due to self directed care is a worry in case budget is then cut

Wasn't allowed to make my own decisions about the support I choose.

Couldn't find the right person to speak to about getting the support I want

Washed... Fed...
You're done (!)
(No emotional support)

Care manager didn't understand or want to share the process for getting personalised services

⑤ feeling in control and safe

things get fixed quickly --- before they go badly wrong

I feel safe where I live

I can take risks (safely!)

I've got plans for if things go wrong

Working

Being in control is about being ordinary and sometimes things go wrong

Lack of control over shared spaces in residential care means don't feel safe, don't feel at home.

There is a feeling that CYC don't want personalisation to work - too costly?

not working

Warden call - waited 40 mins for a response to a fire. What options are there really: choice & control.

Need to tackle disabling hate crimes to allow me to feel safe in my community

Older people - box ticking is not a personal process

PA's great when all in place, but who can help me when it goes wrong? What is my back-up support system?

TIME commitment from family members is very high - can be a barrier to IB

I don't feel safe in my community

You need to acknowledge stress and work for family members

6 Money

I know how much money is in my budget for support

I can get my support budget quickly

I can get good advice about planning my support

working

GIVING PEOPLE INDEPENDENCE - PERSONAL BUDGETS DIRECT PAYMENTS.

Flexible use of DP/PB allows me to employ PA to help me in work

Don't know what Care Managers remit is - are they social workers? or social workers?

Feels like a fight not a right - we all want it to work don't we??

Council reliant on providers to lead process away from block contracts rather than leading it.

DIRECT PAYMENTS
- Explanation about assessed contribution, people may not wish to pay

How can appeal and how can get an independent review?
'conflict of interest' - cyc - services v budgets

Assessments and processes for getting a budget traumatic

Real concerns about contributions to budgets - debts are not taken into account

Not sure service is flexible enough to respond to change (buying back service)

NO MONEY IN SYSTEM TO ALLOW MENTAL HEALTH PERSONAL BUDGET

LACK OF CLARITY ABOUT AMOUNT OF FINANCIAL SUPPORT AVAILABLE IN MENTAL HEALTH

The scheme doesn't feel 'safe' as central/local gov. goal posts changing.

NOT CLEAR HOW DIRECT PAYMENTS LINK WITH PERSONAL HEALTH BUDGETS

not working

Funding - serious concern
↳ Gaps in service *
↳ lack of joined-up thinking

Block contracts

↳ Too rigid.
No individual service funds.

There appears to be no appeals process for budgets

Budgets are not explained - people do not share calculations

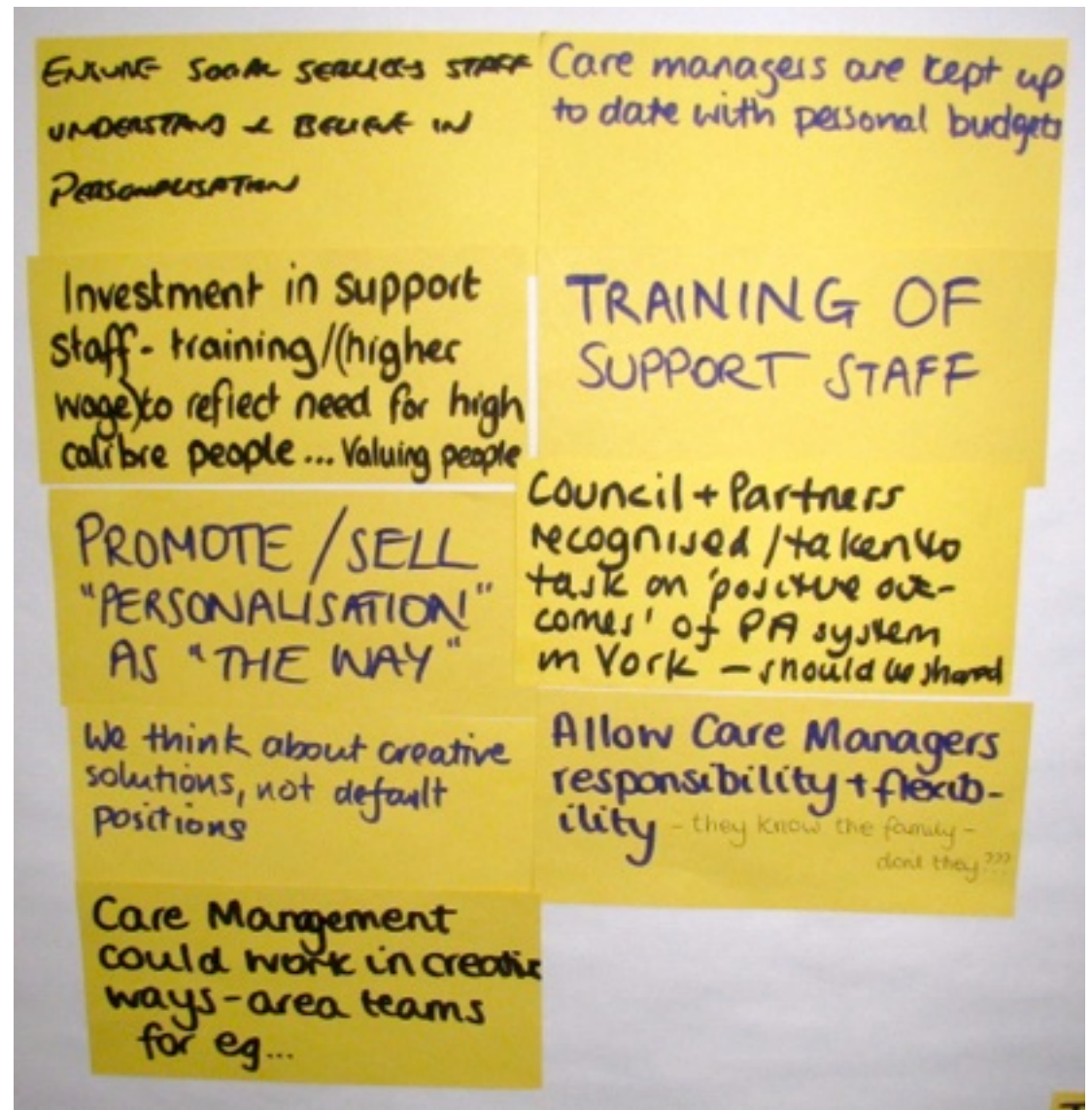
Some people with higher support needs not getting enough help to manage their money & understand how they can use it.

Providers want to encourage people to explore different options, but can't afford to keep places open whilst they do.

What needs to change?

Everyone then imagined they were in charge and shared what they would change....

The photos on the next few pages show what you said.



NEED an honest and open assessment process... (That families etc can understand)

ENSURE SUPPORT PLANS PROMOTE RECOVERIES & INDEPENDENCE & REDUCED RELIANCE : IMPROVE THEIR QUALITY

The process of getting a personal budget is easy & understandable

Person centred Review Process.

Offer choice eg: brokerage or training to manage own budget not just ILS

Centralised Funding Pot. (ie. Simplified !!) ^{we'll explain!}

Information is accessible (if we all know what we mean by that - recognisable standards.)

Assistance is there when you need it.

Training, supervision + team leading for PAs should be included in budgets it is in agencies/services!

Providing care is seen as a vocation, and is celebrated (massive SKOL, but no one talks about it!)

Before embarking on PA - training and employ manual given to main support/family member

Set up own PA group of family member to collectively manage our budgets

FORUM OR ^{LOBBY} A SERVICE GROUP (TO PROMOTE (P) & SHARE EXPERIENCE)

Positively support + fund utb etc to give info and support to other people

The police are able to support people experiencing hate crime to stop it happening. Reporting a hate crime is easy.

More creative use of Volunteers in communities
→ Tackling social isolation etc.

SOCIETY

- PEOPLE'S VIEWS
NEED TO CHANGE
REDUCE IGNORANCE

All agencies work together to make York a friendly welcoming place for all citizens

I feel part of my community
& play an active role in it

SUPPORT VOLUNTARY SECTOR
TO TRANSFORM INTO FEE-CHARGING PROVIDERS

DECOMMISSION EXISTING SERVICES TO PROVIDE FUNDS FOR PERSONALISED ARRANGERS

Better transition services from age 18 → Adult services...

What next?

This session was part of the Scrutiny Review into Personalisation in York. Outcomes from this review will be pulled together into a series of recommendations. If you came to this session, you will be invited to attend a future meeting of the Health Overview and Scrutiny Committee at which the priorities for action will be discussed.

For more information about the review, contact:

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Thankyou for taking the time to come to the session and for sharing your thoughts and ideas.