

York Health Overview and Scrutiny Committee Personalisation Review

Summary of issues raised during workshops May 2013

Introduction

As part of the Health Overview and Scrutiny review into Personalisation, Tricia Nicoll Consulting was commissioned to facilitate two workshops for people who use services and family carers and other people involved in the Personalisation agenda. These were held on 23rd April 2013 at the City of York Council West Offices. The aim of the workshops was to offer participants the chance to share their views and experiences of how Personalisation and self-directed support is working in York and to offer suggestions for what needs to change. 15 people attended the first workshop and 9 people attended the second workshop.

The workshops used the Think Local Act Personal *Making it Real* markers for progress (www.thinklocalactpersonal.org.uk/MIR) as a framework:

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. Personal budgets and self-funding: my money

For each of these markers, participants were asked to consider;

- ★ What is working well at the moment in York?
- ★ What is not working so well at the moment in York?
- ★ What needs to change?

There is a photographic report of both events available, showing people's responses across all the markers. This report is a summary of the issues.

1. Information and advice: having the information I need, when I need it

- *I have the information and support I need in order to remain as independent as possible*
- *I have access to easy-to-understand information about care and support which is consistent, accurate, accessible and up to date*
- *I can speak to people who know something about care and support and can make things happen*
- *I have help to make informed choices if I need and want it*
- *I know where to get information about what is going on in my community*

What's working well at the moment in York?

People were particularly happy with the information and support provided by the Independent Living Scheme (ILS) and by the Community Facilitators, both of whom were seen as extremely valuable resources. There was complete support for the theory behind Personalisation and self-directed support and how this is articulated by City of York through My Life My Choice. People talked about getting good information from other people who use services and family carers and from user-led groups such as Lives Unlimited.

What's not working so well at the moment in York?

Participants felt that the knowledge of staff within the Council is patchy and that organisations and services do not always share information; *'if I walked into West Offices and asked about Personalisation and how I could get information, what would happen?'* People talked about not knowing where to go for information, about needing to ask for rather than automatically receiving it, about a reliance on families and loved ones to source the information they need, and about language being confusing (individual budget, personal budget, Direct Payment, Personalisation). People questioned the 'buy in' from some staff about Personalisation as a way of thinking and working, and, in particular cited the experience of older people and people living with mental health issues; do they get the right message about Personalisation? Participants wanted to see more sharing of stories of people's experience of self-directed support - how things can be different.

Participants' ideas about what needs to change:

- Care Managers are kept up to date with personal budgets
- Ensure social services staff understand about Personalisation
- Promote/sell Personalisation as the 'the way'

- The public to have/be equal stakeholders in decision making. Consultation to be taken seriously
- Prepare a comprehensive database in partnership with Healthwatch
- Better transition support from children's to adult services
- Information is accessible (we all know what we mean by that - recognisable standards)

2. Active and supportive communities: keeping friends, family and place

- *I have access to a range of support that helps me to live the life I want and remain a contributing member of my community*
- *I have a network of people who support me - carers, family, friends, community and if needed paid support staff*
- *I have opportunities to train, study, work or engage in activities that match my interests, skills, abilities*
- *I feel welcomed and included in my local community*
- *I feel valued for the contribution that I can make to my community*

What's working well at the moment in York?

Everyone talked about how self-directed support and personal budgets have given them the chance to live ordinary lives and be involved in their communities, with access to live, learn and progress at their own pace, supported by family and friends.

A specific comment was made about how getting support from personal assistants had 'set boundaries' in the person's relationship with their family and enabled them to become a mother/friend again. Another participant talked about how it had, '*lifted worry about my mother's wellbeing*'.

What's not working so well at the moment in York?

Several participants felt that social isolation is still a problem. They shared practical problems, e.g. with the way transport is organised in the city (focused on into and out of the centre rather than on more circular routes) and in the accessibility of buildings - including availability of changing places. Participants also noted a more fundamental issue about how we view older and disabled people and acknowledge the skills and knowledge people bring to their communities; moving from a deficit focus to an asset-based approach requires more investment than currently exists in community support systems, e.g. time-banking.

Participants' ideas about what needs to change:

- Care Management could work in creative ways - in area teams
- 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
- All agencies work together to make York a welcoming place for all citizens
- Society - people's views need to change and reduce ignorance
- I feel part of my community and play an active role in it
- Neighbourhood based teams - with other departments as well as health, developing community care/enabling networks

3. Flexible integrated care and support: my support, my own way

- *I am in control of planning my care and support*
- *I have care and support that is directed by me and responsive to my needs*
- *My support is coordinated, cooperative and works well together and I know who to contact to get things changed*
- *I have a clear line of communication, action and follow-up*

What's working well at the moment in York?

Participants talked about the importance of being genuinely in control of choosing support staff (for themselves or for a loved one) and how the self-directed support process has enabled this to happen. Support from personal assistants has enabled people to get support that is more flexible, is from people who share the same interests and who facilitate greater independence and a, '*better quality of life*'

The role of ILS in supporting people to put together a job description, advertise and recruit for personal assistants was really appreciated.

What's not working so well at the moment in York?

The biggest issue people brought was, '*the gap between rhetoric and reality*'. Participants all shared examples of issues with the end to end process of self-directed support; assessment taking a long time, support plans being completed by a worker and issues around changing eligibility and charging; '*the process of getting a personal budget/Direct Payment was frustrating and challenging*'.

Participants reported a specific issue in mental health services with people not being offered the opportunity to know their personal budget; '*no one understands the system and people get passed round and around*'.

Some people felt that they were not allowed to make their own decisions about the support they get and that they had a, *'feeling of no choice or control'*. Some people said that they could not find the right person to speak to about getting the support they want.

People talked about the need for good support in the self-directed support process; *'impartial, independent brokerage and support planning'* and some people felt there was an over reliance on the role of a supportive family, particularly if someone has complex and complicated needs.

Some participants talked about the lack of a varied marketplace to choose services from.

Participants' ideas about what needs to change:

- Ensure support plans promote recovery and independence and reduce reliance: improve their quality
- Offer choice, e.g. Brokerage or training to manage own budget - not just ILS
- Allow Care Managers responsibility and flexibility - they know the family don't they?

4. Workforce: my support staff

- *I have good information and advice on the range of options for choosing my support staff*
- *I have considerate support delivered by competent people*
- *I have access to a pool of people, advice on how to employ them and the opportunity to get advice from my peers*
- *I am supported by people who help me to make links in my local community*

What's working well at the moment in York?

Again, the importance of being able to directly employ personal assistants was seen as central to Personalisation and self-directed support, and the role of ILS in supporting people through the employment process was really appreciated. Participants talked about getting continuity, flexibility and more person-centered support through personal assistants.

What's not working so well at the moment in York?

The main issue participants shared was the difference in the experience of people who are not managing their own budget and who are using Council managed or agency staff; *'there is limited choice if you are not managing your own budget'*. In

particular, people talked about the inflexibility of Home Care shift patterns and of support being very task focused; *'washed Fed ... you're done'*. People also felt frustrated when they did have good support from an agency and then the rules appeared to change about what tasks carers could carry out.

Another key issue for people was the limited range of formal peer support in York; *'peer support is valuable but there is not enough'*.

Some people felt that there was little support around employment issues for personal assistants.

Some people were concerned that, if they were successful in using self-directed support then their budget would be cut.

Participants' ideas about what needs to change:

- Support planning cafe - open to the public
- Set up a support network for individual employers to support and share experiences
- Nothing about us without us
- Things to be user-led and support to be user-decided
- Underpin everything with the social model of disability
- Create simple contracts/structures to facilitate creative carer/personal assistant working
- Care agencies get contracts based on quality of care, not just based on the cheapest
- Training, supervision and team leading for personal assistants should be included in budgets
- Providing care is seen as a vocation and is celebrated
- Before embarking on employing personal assistants, training and support manual given to the person/main support/family member
- Forum or lobby a service group to promote Personalisation and share experiences
- Set up own personal assistants group of family members to collectively manage our budgets
- Positively support and fund user-led organisations to give information and support to other people

5. Risk enablement: feeling in control and safe

- *I can plan ahead and keep control in a crisis*
- *I feel safe, I can live the life I want and I am supported to manage any risks*
- *I feel that my community is a safe place to live and local people look out for me and each other*
- *I have systems in place so that I can get help at an early stage to avoid a crisis*

What's working well at the moment in York?

Participants reflected that the framework of self-directed support enables everyone to take a more practical and pragmatic approach to risk and accept that, *'being in control is about being ordinary and sometimes things go wrong'*.

What's not working so well at the moment in York?

People talked about having to, *'wait until its too late'* before things got changed, and of a feeling that, *'City of York Council don't want Personalisation to work - too costly?'*. Some people shared an anxiety about support from personal assistants; *'great when all in place but who can help when it goes wrong? What is my back-up support system?'* There was a sense of a huge time commitment and contribution from wider family and other networks in ensuring plans are successful.

People brought specific examples of not feeling safe at home or in their local community and people agreed that, *'we need to tackle disability hate crimes to allow me to feel safe...'*

There were no suggestions about what needs to change.

6. Personalisation and self-funding: my money

- *I can decide the kind of support I need and when, where and how to receive it*
- *I know the amount of money available to me for care and support needs, and I can determine how this is used (whether its my own money, Direct Payment, or a Council managed personal budget)*
- *I can get access to the money quickly without having to go through over-complicated procedures*
- *I am able to get skilled advice to plan my care and support, and also be given help to understand costs and make best use of the money involved where I want and need this*

What's working well at the moment in York?

Participants appreciated the principles of Personalisation and that Direct Payments and personal assistants give people more independence. One person reflected that, *'the flexible use of Direct Payments allows me to employ personal assistants to help me in work'*.

What's not working so well at the moment in York?

Participants had many concerns about the process of assessment and calculating an indicative budget, the result of which people felt varied depending on who supported the assessment process; *'assessments and the process of getting a budget is traumatic.'* and *'It feels like a fight not a right - we all want it to work don't we?'*

People talked about confusion over what personal budgets can be spent on.

Financial contributions were an issue, with some people not having the financial assessment process explained to them. People also shared frustrations about the lack of an independent appeals process if they were unhappy about their indicative budget.

People felt that the unpicking of block contracts is an issue, with a reliance on providers to lead this work, and there was a particular frustration at the lack of use of individual service funds.

There are specific issues in mental health services, where people appear not to be able to find out their indicative budget.

Participants' ideas about what needs to change:

- Look at the hourly rate for Direct Payments - is it giving you full choice in who you can employ (compared with agencies)?
- Why is York Direct Payments rate lower than other local authorities?
- Make better use of resources
- Think about creative solutions, not default positions
- Need an honest and open assessment process that families and everyone understands
- The process of getting a personal budget is easy and understandable
- Person-centred review process
- Centralised funding pot, i.e. Simplified
- Support voluntary sector to transform into fee-paying providers