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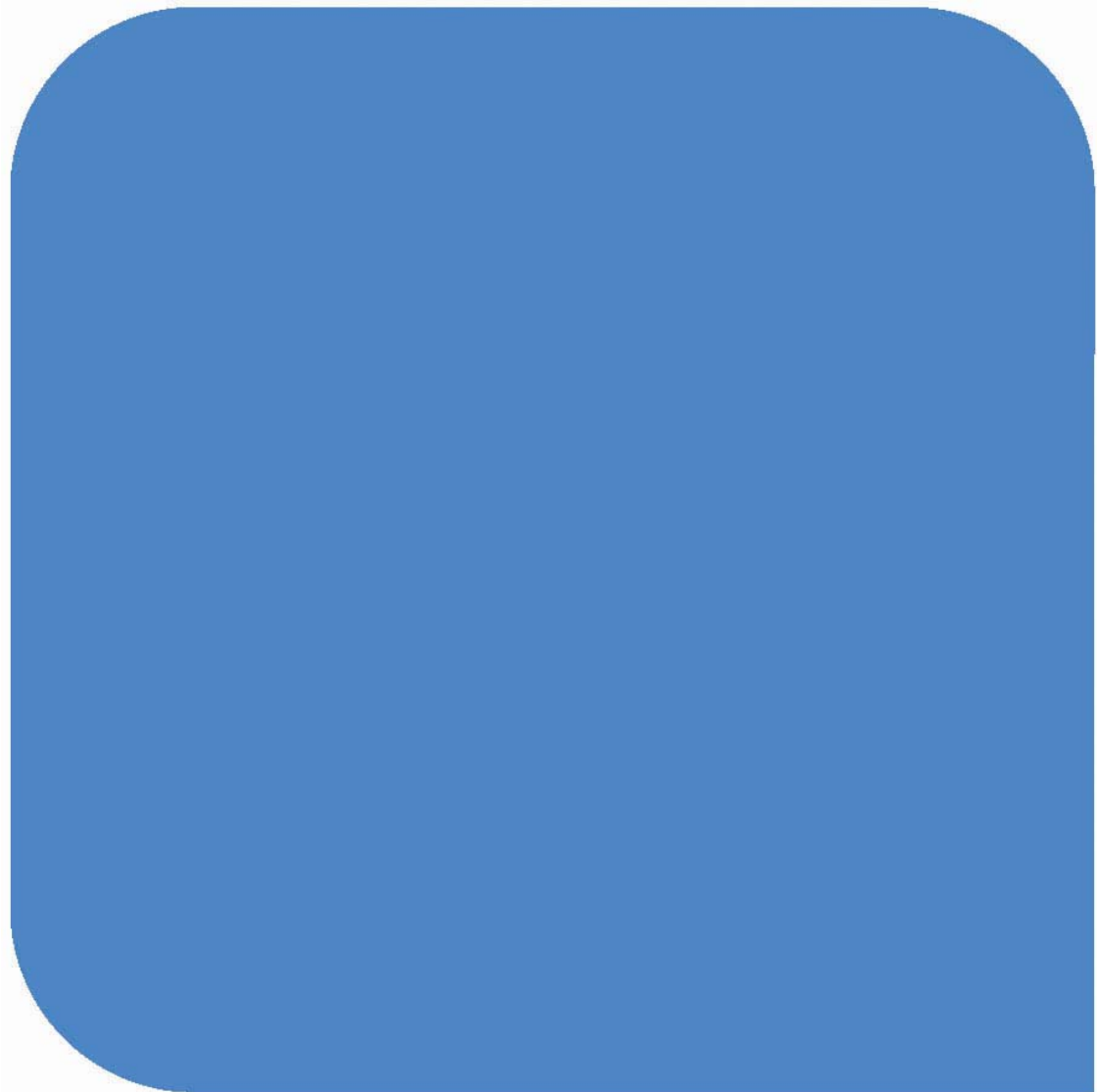
People not processes: the future of personalisation and independent living

Contents

Acknowledgements

Key messages

'Now the genie is out of the bottle, there will always be people who understand and acknowledge the fact that people who use services are the experts of their own situation. Because there are too many of us doing it.'

Baroness Jane Campbell

- it is important to define personalisation in terms based on the principles of independent living

- this should include service users and carers having choice and control and the freedom to live their lives in the way they want to

- many users and carers have positive experiences of personalisation and there are examples of good practice

- however, the number of people receiving truly personalised services remains very low and cuts to services may make this situation worse

- more needs to be done to ensure that everyone involved in service provision understands personalisation

- there needs to be better coordination of resources and services

- there needs to be more co-production with service user and carer organisations

- a stronger vision based on a return to the principles of independent living is needed to ensure that personalisation delivers better outcomes for service users and carers at the same time as ensuring resources are used as effectively as possible.

1 Introduction

'Today has been different. It's been about the reality, bad and good. And you're the best roomful of experts I've been in.'

Sarah Carr, SCIE

This report looks at the future development of personalisation at a time of limited resources. It details two seminars held in November 2011,organised by SCIE with support and funding from the Joseph Rowntree Foundation (JRF). The seminars brought together service users, carers and a select number of people involved in practice and policy development around personalisation in adult social care.

Participants at the seminars were selected to give a range of perspectives on personalisation. The focus was on adult services but several of the participants were carers of children and young people. The perspectives represented were:

- service users
    - personal assistance users
    - people with physical and sensory impairments
    - older people
    - people with learning difficulties
    - mental health service users
- carers of
    - disabled children
    - adult children who need support
    - older people
- practitioners
    - personal assistants
    - a support worker
    - care home workers
    - a care home manager
    - voluntary sector service managers
- policy makers from the Department of Health, the Department for Education and an independent think tank.

In addition to this the participants represented a range of perspectives in terms of gender, age, ethnicity and sexuality.

The programme for the seminar was designed to bring out the range of perspectives represented on how personalisation can continue to develop as a positive approach that improves the lives of service users and carers, even when financial resources have become much more limited. This was guided by an advisory group comprised of representatives of SCIE, JRF and JRF's service user panel.

The seminar was part of a programme of work by JRF to support the development of the personalisation agenda and person centred services.

2 What do we mean by personalisation?

'It's about being me.'

Workshop participant

One of the key aims of the seminar was to consider exactly what is meant by the term personalisation. This became the key theme of the first day's examination of 'where we are now' with personalisation.

The importance of this issue was highlighted at the seminars, where participants expressed concern that each local authority has a different definition of personalisation and this means there are wide variations in how it is put into practice.

In looking at 'where we are now', Baroness Jane Campbell's presentation gave an account of how we have arrived at personalisation. She described how a group of disabled people in the 1970s decided to leave the 'disabling services' of residential care and live in the community with control over the money that was used to pay for their support services. Their success was repeated by others and this became the independent living movement and led to direct payments. Personalisation has grown from independent living and direct payments and we are now in a position, 'where growing numbers of people and their families are leading and defining their own support services, rather than simply consuming them.'

Another speaker, Ann McFarlane, summed up her view of personalisation as being, 'about all of us and all our lives. It's not about social care alone, or medical support. It sits in every local authority directorate, whether it's parks and gardens, roads – whatever it is, it affects you and it affects me.'

The question 'What does personalisation mean for you?' was the key discussion point. One workshop group produced a joint statement of what personalisation meant to them:

> 'Personalisation for me is about: flexibility, choice and control.
> To make it work for me, it needs: peer support, information and advice
> If it's working well, it is: liberating with positive outcomes.
> I will be included and valued.
> No decision about me, without me.'

Other discussions highlighted several key characteristics of personalisation:

- freedom, choice and control – being an individual and being able to make your own decisions

- the focus is on the person rather than the service – delivering quality of life and happiness and enabling you to live on your own terms
- being valued as a person
- keeping people in the mainstream and in the community, being included/integrated and being citizens on equal terms
- 'nobody tells you what to do'
- liberation – including being able to take risks and make mistakes
- being listened to and heard.

A key point to emerge was that personalisation should be about the principles of independent living as developed by disabled people. However, there was a feeling that personalisation is now being based on certain understandings that do not include the principles of independent living. It was suggested that more should have been done to make direct payments/independent living more widely available rather than spending lots of money bringing a new approach.

Another suggestion was that personalisation should include recognition of the need for low level support and how this saves money in the long run as it stops people developing higher levels of need. At the moment, problems with assessment processes and eligibility criteria mean people in this position are often left vulnerable. It is also unclear how much personal budgets can be used in a preventative way that reduces the need for more support as people's circumstances change.

3 Experiences of personalisation

Service user perspectives

Ann MacFarlane gave an account of her life and journey to personalised support. She spent much of her childhood and youth in hospitals and residential institutions which were very impersonal. While she had few opportunities for education, she taught herself typing and shorthand note taking and this opened up employment opportunities to her, although employers' attitudes made this very difficult. Ann first had personal assistants in 1988 and this enabled her to work as a consultant and become active in her local community and the disability movement.

Angela Simpson described how she had lived in a care home with shared bathrooms and staff who were neglectful or abusive. She now lives in the community and receives support from Keyring Network (see below) and is able to pursue her interests in sport, photography, arts and craft and campaigning on social justice issues.

Mark Johnson is also part of Keyring. He had lived in very difficult circumstances and was very unhappy but now has his own place to live and a network of supporters. and works on community safety issues and with local churches to increase the participation and provide safe meeting space for people with learning difficulties in churches.

Odi Oqusa, chair of the Catch-a-Fiya Black and Minority Ethnic (BME) mental health user and carer network, was one of the opening speakers on the first day of the seminar. He quoted examples where people had been given information on personalisation but had not been able to use it as it was not in their language, and another where a person had been given a personal budget but had not been able to recruit anyone. He also referred to a positive example where a mother described her son having a new lease of life after moving on to a personal budget, although even here there were difficulties with the amount of paperwork involved in the budget.

Carers' perspectives

'Direct payments gave us a whole new lease of life – we became in control of our service.'

Sally Percival

Sally Percival described the services her family first received to give them a break from caring for their son Alex as causing more stress than they solved. She now manages a direct payment on Alex' behalf and this allows him to pursue his interest in World War 2 re-enactments without needing support. As a result, Alex is finding the community involved in the re-enactments is becoming increasingly supportive and inclusive.

Sally also cares for her 80-year-old mother, Audrey, who has a physical impairment and dementia. Audrey moved into a residential home at one point but it did not work for her. She now has an individual budget that allows her to live in her own home with support and has choice and control over her life.

Alan Croner spoke about caring for his 21 year-old daughter Hannah. He was offered respite care from social services but they were unable to identify anyone to provide the service. Alan was able to use direct payments to pay people he knew locally to provide the service. When Alan became a single parent they agreed to provide further support that meant he was able to continue working.

Both Sally and Alan highlighted how having personal budgets benefited them and their families as a whole, particularly in enabling them to give time to their other children.

Practitioners' perspectives

Charlie Crabtree and Neil Turney gave social care practitioners' experiences of personalisation as workers with the Keyring Network. They described how flexible approaches were more empowering for service users and how the Network enables service users to support each other. Keyring also supports people to develop links with their communities so they are less isolated and can contribute fully to their areas.

4 Barriers and Obstacles

While participants described many positive experiences and outcomes from personalisation, there is a clear view that for many people, in many areas, there are still barriers and obstacles to personalisation. Participants thought the number of people who had truly personalised services remained very low and some said that the numbers had started to go down in their areas (one person said the number of people using direct payments in their area had gone down by a quarter).

There was a concern in the workshop discussions that current approaches to personalisation in most areas have become too bureaucratic. The principles and values of independent living, co-production and choice and control which underpin personalisation are not properly understood. As a result personalisation is not delivering the choice and control as intended.

Participants said that there are local authorities, services and practitioners who do understand personalisation and get it right, but this tends to be dependent on the individuals involved and there is no cohesive approach. People described particular difficulties where they had good workers who moved on.

There was also a view that areas that are not doing well are not always prepared to learn from those that are delivering successful personalised services.

The way that the medical model continues to underpin the approaches of many service providers is seen as a fundamental obstacle to the future development of personalisation. Independent living is based on the social model of disability which was developed by the disability movement and focuses on people being disabled by society's responses or lack of responses to impairment. The medical model focuses on people's impairments as the problem and personalisation's focus on this approach undermines the outcomes that it can deliver.

One workshop group said the medical model approach is also frequently accompanied by what they called the 'professional gift model', with users and carers having to feel grateful for what they are given rather than it being based on rights and empowerment.

Staffing and workforce issues were another important area of concern. People primarily see a need for the social care workforce to be more focused on delivering person centred support and for better training to enable them to do this. At the same time, some people suggested that training and qualifications can be unhelpful and that common sense, being practical and kindness can be more important than training. They also thought social care workers need greater empathy with service users and carers.

Another difficulty identified was around high staff turnover. In particular, this caused the difficulty of having to deal with duty social workers who do not know their details.

Odi Oquosa said many of the barriers that exist with traditional services continue with personalisation, so users and carers from BME communities continue to experience difficulty accessing services, do not have choice and control over their support (particularly where mental health service users receive involuntary and coercive care), and language and lack of cultural understanding are not addressed in the assessment system or staff training.

He also believes that there is not enough understanding of what personalisation and person centred/self directed support are in BME communities. While mainstream services continue to be inaccessible and inappropriate he thinks BME communities will continue to develop their self sufficiency and establish their own care and support services.

Other barriers identified

- lack of market to purchase services with personal budgets
- funding cuts are leading to the closure of some services and organisations and this is reducing the choice people have over the services they can use
- funding cuts to support services – this includes those that relate directly to the personalisation of social care services and cuts to broader services such as Citizens' Advice Bureaux and Legal Aid
- local authorities not listening to what people want
- inflexibility around use of personal budgets and direct payments – an example was given of someone who had saved some of their money for a holiday but the council clawed it back
- risk assessment panels blocking some people's choices
- dividing people/fragmentation – personalisation strategies only supporting people to do things on their own, not with other service users, which works against collective approaches like pooling budgets
- lack of support for people who are isolated and do not have independent support
- personalisation is only on the agenda in health and social care services and there is little awareness of personalised approaches in other local authority services.

5 Getting it right - what it looks like

'Nothing is beyond the limits of personal budget as long as it is with the law and meets an assessed need.'

Michelle Parry, IF We Can Help

The second day of the seminar opened with three presentations by service providers running personalised services.

Pooling personal budgets: HACT/Up2Us

Andrew van Doorn and Christine Bond spoke about HACT, which works with housing providers such as housing associations, to improve the lives of people who live in their accommodation. HACT is part of a project called Up2Us which is running six pilot projects to explore group buying of social care services by people receiving personal budgets.

They see group buying as a way to increase what individuals can afford to buy with their personal budgets, and other resources where available, as a way to improve choices and develop new relationships between service users and service providers. It is also supporting new approaches including co-production.

HACT is running an Up2US pilot project in Norfolk and has included groups of people pooling their budgets to pay for day care services and services at home. The people buying day care have found they now have greater control over the service and a group of tenants in a housing association successfully pooled their budgets to buy night care.

Learning from the Norfolk pilot so far indicates that user involvement and co-production can be the difference between whether or not a pooled budget approach works and that small changes can make a significant difference to people's lives. There is still a lot of learning needed around personalisation, and that pooling resources is another layer of new thinking that all involved in social care will need to adapt to.

User-led service provider: Leeds Survivor Led Crisis Centre

Sarah Fennel gave an overview of the personalised approach of the crisis centre that has been run by service users in Leeds since 1999.

The Centre gives choice and control through a personalised approach to support. This involves services being accessible at times when people are most likely to be in crisis, users directing the support they receive and the service being in voluntary

sector and not having statutory powers. People are able to refer themselves to the service.

They identify five key elements to effective support:

- listening
- treating people with warmth, kindness and respect
- ensuring people don't feel judged or assessed
- being in a different and calm environment
- peer support through service users supporting each other.

Everyone involved in providing the service has experience as a service user. Sarah described working at the centre as being rewarding, freeing and empowering.

While the centre has a personalised approach, it is not funded by direct payments or personal budgets. The Department of Health recognises that crisis/emergency services need to be block funded as it is difficult to budget for crises on an individual basis. However, the centre's individualised approach clearly fits with the personalisation agenda and the group work they offer would lend itself to individual budgets.

Carer-led information and advice service: IF We Can Help

Michelle Parry is the carer for her teenage son and runs training on personalisation and a website called IF (Individual Funding) We Can Help which promotes personalised approaches to carers and social care professionals.

The information she shares through her website and training has a number of key messages about personalisation. She described personalisation as being focused on the outcomes service users and carers want to achieve and in some cases this means providing support in ways that do not fit with traditional models of social care.

Examples of this given by Michelle included alternative therapies, gym membership, exercise equipment, computer equipment, travel and holidays. While such support might be questioned by some, they do deliver better outcomes and in some instances will be substantially cheaper than traditional services.

Michelle illustrated this with the example of a family who were given a personal budget to buy a hot tub. Their son had very disturbed sleep patterns as a result of autism and they received night-time support at a cost of over £14,000 a year to the local authority. During a holiday they found that using a hot tub before going to bed helped him sleep and applied for a personal budget to buy one. This cost £3,500 and meant they did not need the night time support, saving the council these significant ongoing costs.

Michelle stressed that nothing is beyond the limits of personal budget as long as it is with the law and meets an assessed need.

6 Hopes and fears for the future

'Some of my friends and I have had a really harrowing year because our local authority, like many others, has introduced a really draconian charging policy and some of us are going to be wiped off the agenda.'

Ann McFarlane

The clearest message to come out of the seminars was that service users and carers are very fearful about the future of their services and support. At times this made it difficult to focus on developing approaches for the future of personalisation because people were very concerned about their day-to-day lives.

Where people had been seeing good practice they thought this was beginning to slip back. There was particular concern that the voices being heard at this event and others like it are the tip of the iceberg and that there will be many service users and carers who are losing services and not able to complain.

Working together to do more with less

Jane Campbell recognised that the future is going to be difficult with resources becoming much more limited. She thinks the future will mean having to do more with less money and doing things more creatively, and this will make working together more important. She argued that involvement should be the last thing that service providers should cut back and it will be more important than ever to involve users and carers to ensure that the resources that are available are spent on the right things.

Jane particularly highlighted Article 19 of the UN Convention on the Rights of Disabled People (which states that people have a right to live in the community) as a useful tool for challenging local authority cut backs to services.

Involvement

Participants think that it is important for local authorities to involve service users and carers in the difficult decisions they need to make around finances. They said that local authorities need to understand that there is actually more value for money through personalisation than traditional services. This is because users are generally happier and have better quality of life if they can choose their care package, as was illustrated by the example Michelle Parry gave of the family who were able to buy a hot tub for their son.

Michelle went on to say in her presentation that the current situation as being like trying to fit a jet engine to an old, propeller driven bi-plane. She believes that we

need to move away from the old model of social care for personalisation to achieve its full potential.

As well the concern about shrinking financial resources, people thought that budget cuts were also being used as an 'excuse' for not giving people greater control over their support and lives. In particular, participants thought this is being used to unnecessarily add to growing list of restrictions on how people can use their personal budgets.

Keeping the person at the centre

Despite the weight of these doubts and fears about the future, participants also had clear ideas about steps that need to be taken to try to ensure a positive future for personalisation.

The fundamental message was the need move back to the ethos of independent living. There was recognition that personalisation had helped many organisations develop and improve their services but there was a feeling that service or local authority driven forms of personalisation had taken over from the approaches developed by disabled people in the independent living movement which had brought in direct payments. People wanted to see a move back to this ethos in order to ensure that the choice and control of users and carers at the heart of services and social model approach.

This would also mean taking the emphasis away from processes and mechanisms and focusing on what personalisation should be about – the human, emotional and political dimensions - the whole person. This could be called the 'spirit' of personalisation which is found in the people, not in the processes.

At the individual/family level this would translate into a focus on outcomes. Service providers also need to ensure people are given sufficient support to operate direct payments and personal budgets without experiencing problems. People also need to have appropriate choices that take account of their background, culture and locality and there needs to be greater recognition of the way people's needs can change over time.

Participants saw the current government target of all service users on a personal budget by 2013 as overly ambitious. Some suggested this could not be delivered within the time allowed as it involves such a major culture change. Some participants suggested the target might be achieved on paper but the reality would be very different. They also questioned how this target relates to the government's localism agenda.

Policy and practice

Participants identified specific measures that need to be taken by national and local government, policy makers, service providers and practitioners need to take to deliver real improvements:

- **Holistic approach** – the government needs to replace the current system with a holistic approach that addresses all aspects of people's lives. This needs to be supported with overarching legislation that sets out a shared vision and understanding of what personalisation should mean.

- **Pool and coordinate resources** - bring together current funding that is divided between the Department of Health, Department for Work and Pensions and Department for Education in order to reduce bureaucracy. It was suggested that the Office of Disability Issues could take on a coordination role for this new approach to budgeting for personalisation.

- **Better and closer collaboration** between national and local policy makers and service providers.

- **Develop clear and independent evidence** of what is and is not working in relation to personalisation

- **Develop co-production** with service user and carer organisations on the basis of equality, mutual respect for expertise and power sharing.

The final point was seen as a key part of a successful approach to personalisation. However, at present co-production is often seen as too much of a risk by service providers and there need to be changes in attitudes so a co-production approach becomes embedded in organisations' culture.

Odi Oquosa particularly highlighted the importance of funding for BME organisations, though noted that in many cases this is being cut back at present. He also pointed out the need for specific research to develop a better understanding of the effectiveness of personalisation for service users and carers from BME communities. He also suggested that BME service providers should be supported to find practical ways of involving families and communities in delivering personalisation.

What service users and carers need to do

Participants also identified important actions that service users and carers need to take to support the progress of personalisation. They felt that service users need to be inspired to have confidence in themselves. Parents with disabled children should work with disabled people as allies as they would benefit from their experiences.

Service users and carers need to work together and form good support networks so they can influence policy makers, commissioners and others involved in service provision. This could be supported by a network of champions who will work to share knowledge and good practice. Service user/disabled people's organisations could play a key role in this.

For all the problems which were discussed over the course of the seminars there were also clear signs of hope. Jane Campbell said at the start of the seminars:

'Now the genie is out of the bottle, there will always be people who understand and acknowledge the fact that people who use services are the experts of their own situation. Because there are too many of us doing it.'

7 Conclusions

Personalisation has brought benefits for many service users and carers but the view of participants at the seminar was that has come at a cost. That costs has been the loss of collective perspectives where service users and carers work together to achieve common individual aims, just as the disabled people who said up the first independent living scheme in the UK in 1970s worked together so they could live the way they wanted to.

The other cost has come in terms of the creation of a new bureaucracy concerned with processes and mechanisms like resource allocation systems and cost containment. Some users and carers have achieved better outcomes from the new system but it continues to be a struggle, particularly where better outcomes can be achieved with radical departures from traditional services.

Concerns about the difficulties with personalisation are compounded significantly by users and carers strong fears about the impact of cuts in public expenditure. While the aim of the seminars was to look at what can be achieved at a time of limited resources, it is important convey the level off people's fears, and, as Alex O'Neill from the Joseph Rowntree Foundation put it, 'politicians need to feel the fear.'

This said, there were many constructive ideas about how the situation can be improved. Alex O'Neill went on to draw parallels between the present and 1948 when the National Health Service was established. While that was also a time of great economic problems, the vision of creating the new service and deliver improvements to people's lives overcame the economic restrictions of the time.

With a similarly strong vision for personalisation it would be possible to bring the benefits of improved outcomes to a far greater number of service users and carers. There are suggestions that this may lead to savings, as in the example of providing a hot tub that helps someone sleep better rather than night staff, but there is no clear evidence that personalised services for all would deliver global savings.

However, truly personalised services, or independent living, would enable service users and carers to achieve the outcomes that they want to achieve and ensure that resources are spent effectively and usefully.

Appendix 1: Agendas for the two seminars

Day 1: Where are we now? – Wednesday 2 November

10.30 Registration

10.45 Welcome from Chair for the day Bill Davidson, Think Local, Act Personal

10.55 Getting to know each other – introductions to others at your table.

11.25 **Setting the scene**

Baroness Jane Campbell (video)
Odi Oquosa (Chair of Catch-A-Fiya network of mental health service users/survivors and carers from Black and Minority Ethnic communities)

11.50 **Speakers – the realities of independent living/ personalisation**

- User experiences
- Ann McFarlane
- Mark Johnston and Angela Simpson, Keyring Network

- A carer experience
- Sally Percival and Alan Crone

- A practitioners' experience
    - Charlie Crabtree and Neil Turney,
Keyring Network

12.30 **Lunch**

1.20 **Entertainment**
Music for People

1.45 **Workshops** *(Main session will be split into 3 groups)*

Whose life is it anyway? What do we mean by personalisation, person centred, independent living?

2.45 **Plenary**
Feed-back from workshops

3.20 **Summing up**
SCIE and JRF representatives will look at what have we learnt

3.30 **Close**

Day 2: Where are we going – Tuesday 29 November

10.30 **Registration**

10.45 **Welcome and recap of day one**
Bill Davidson and rough edit of video from day 2

11.00 **Panel discussion: Getting it right – what services look like when they get personalisation right**

Up2Us – Andrew Van Doorn and Christine Bond

Leeds Survivor Led Crisis Service - Sarah Farnell

Discussion: what does personalisation look like for you when it's right?

11.35 **Break**

11.50 **Getting it right continued**

IF We Can Help Michelle Parry

Discussion – examples of services

12.20 **Lunch**

1.20 **Entertainment**
Laurence Clark, Comedian

1.45 **Workshops**
Who needs to do what to make personalisation happen for everyone?

2.45 **Break**

2.55 **Plenary**
Feed-back from workshops

3.20 **Summing up**
SCIE and JRF representatives on what have we learnt from the seminars and what will happen now.

3.30 **Close**

Appendix 2: Examples of innovative user-led services discussed at the seminars

Keyring Network

HACT/Up2Us
Andrew van Doorn andrew.vandoorn@hact.org.uk
Christine Bond
Christine.bond@norfolk.gov.uk

Leeds Survivor Led Crisis Centre
Dial House
12 Chapel Street
Halton
Leeds LS15 7RW
Telephone: 0113 260 9328
Email: survivor.led@lslcs.org.uk

IF We Can Help

www.IFwecanhelpblackpool.co.uk
ifwecanhelpblackpool@gmail.com

Appendix 3: Summary of examples of positive outcomes for service users and carers from good practice in personalisation

A group of disabled people in a residential home secured direct payments so that they could use the resources that would have been used to pay for the residential home to live in the community.

Direct payments giving flexible support to a disabled woman with the outcome that she was able to develop her employment as a freelance consultant.

Support networks with other service users and the local community enabling people with learning difficulties to live independently in the community. The outcome is that people have better relationships with people in the community, are able to pursue interests in the community and make a contribution to the community.

Three carers gave examples of where personal budgets to support their adult children had enabled the children themselves to achieve outcomes in terms of pursuing their own interests and their carers had experienced improved family lives and been able to maintain their support to other children and continue in employment.

A group of older people pooled their money to pay for activities at their day care. As a result they took control of the programme.

People who have personal budgets for night care and live in the same housing association have pooled their budgets and taken control over the selection of the staff who provide the night care.

A family used a personal budget to buy a hot tub for their son who disturbed sleep patterns as a result of autism. This enabled him to sleep better, improved the families quality of life as they were not disturbed at night and meant they no longer needed carers during the night which saved the council significant costs.

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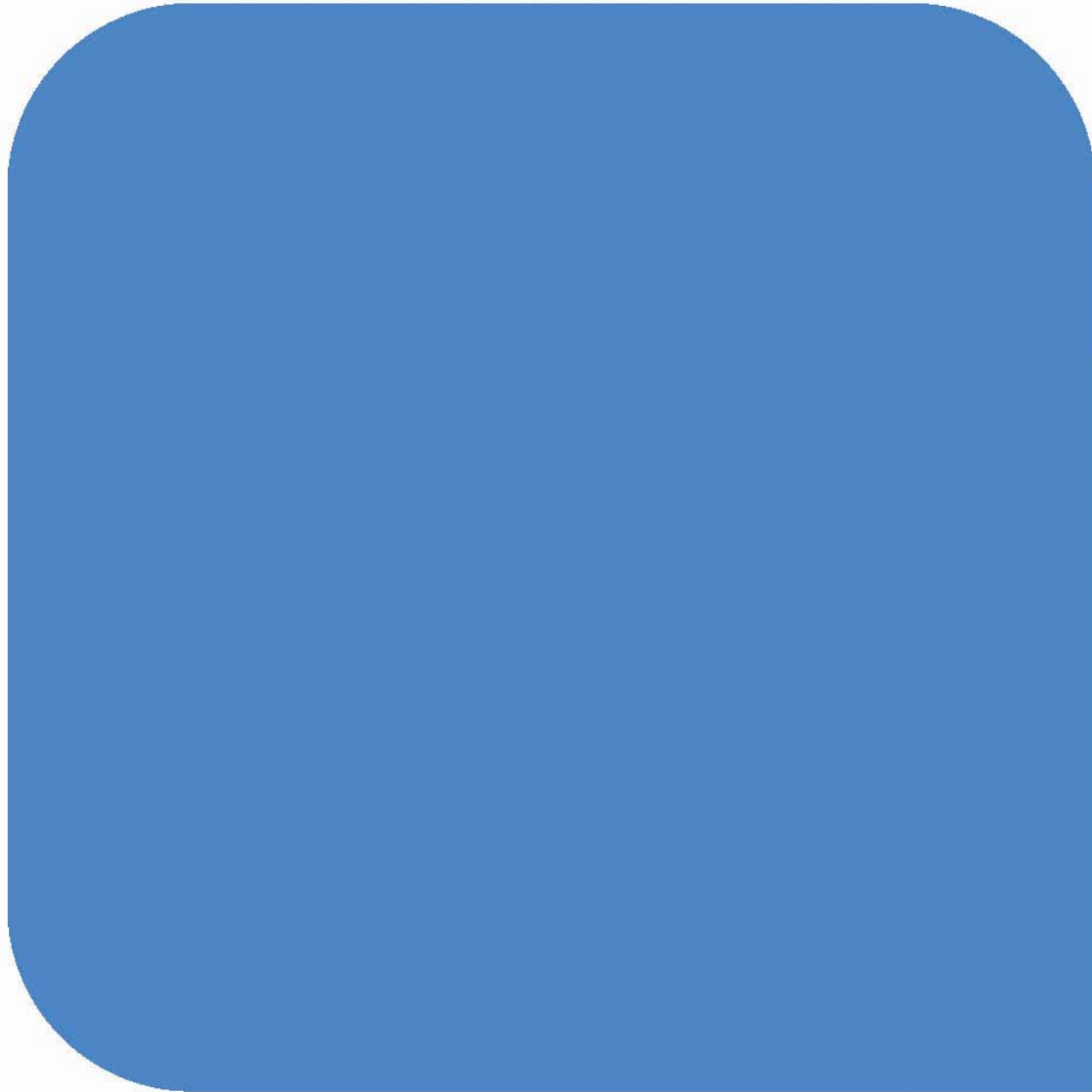
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