



Implementing Personalisation in Coventry

Focus and Discussion Group Findings

September 2010

Your views on Your care

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1 Introduction

- 1.1 Coventry LINK carried out 6 focus groups during May 2010 with over 50 participants who have very different social care needs and experiences of personalisation. Initial findings were presented at the LINK's Annual Review meetings in June where there was another opportunity to gather people's views.
- 1.2 The project is exploring the issues that arise from changes in the way social care services are provided, especially in regards to people having to buy / manage their own care / services.
- 1.3 The results are intended to contribute to the effective delivery of the personalisation project in Coventry, for example in:
 - Providing appropriate information for people who do / will use services
 - Communicating, consulting and involving people in decisions
 - Setting up feedback channels to test ideas and proposals
 - Identifying development needs for staff involved in making personalisation work
 - Developing monitoring tools to see how well the project is meeting the needs of the people of Coventry
- 1.4 In the focus groups we asked first generally what is important to people in the support they receive and the different people involved in this. This stimulated participants to consider the concerns people have / might have in managing their own support package, and the support needed to make it work.
- 1.5 We followed up our focus groups by facilitating group discussion at LINK's two annual meetings held in June 2010. Here a range of people took part in table discussion about the 'pros and cons' regarding personalisation and what was required for effective implementation.

2 Our findings

Please find the results below with participants' own words in *italics*

2.1 What is important generally about the support that people receive

Key themes arising from this discussion are as follows:

- a) Support in getting out and about. Not only transport to help ***get out of 4 walls*** and go out and meet friends but also access in the home that enables us to move around with ease

- b) Clear information on and availability of services – including professional help and social support networks – that are personalised **to meet what I want not what the worker wants** so choice really does exist
- c) Feeling in control with opportunities to develop, **‘flourish’** and meet **improvement targets**: having the facts and understanding the implications, being confident in the skills to be independent, and through **good advocacy** being able to influence and have people **do things with me not for me**
- d) Knowledgeable, skilled and trusted professionals who **work out what a person needs** with **empathy, understanding** and **approachability**
- e) ‘Joined up’ support making sure we receive what is agreed in a **transparent** way that is **fair to all** with **a key support person** and **continuity of staff**

Most participants in general seemed to support the principle of personalisation and appreciated its potential benefits, as they mentioned many times the importance of ‘personalised’ support that is tailored to suit their needs. Those people who took part in the annual review broke down various benefits and opportunities provided by personalisation, for example:

- More **choice** and **variety of provision** that is **inclusive** and ensures **cultural appropriateness**.
- You are **your own boss** with the **independence** to **change your mind**. They can also **combine budgets to buy a service**.
- It is **empowering** and developmental as **you learn to fight for yourself if you are able** all of which improves **self-esteem**.
- There will also be **less chance of being stuck in a service** and it should lead to **stopping waste of unnecessary services**

2.2 What concerns we have or might have in ‘managing our own support packages’

While the principle and potential benefits of personalisation are well supported, it is difficult for most people to see through the concerns about its practical implications and therefore successful implementation. In priority order, people felt particularly strongly about the following seven themes:

2.2.1 Eligibility for personal budgets and the style and quality of assessments (40 items raised)

Many questions arose: **who understands the criteria** and **if we are not eligible, does that mean no services?** There are fears about how changes will be managed for example **getting used to a service and then they cut hours** or **if we don't use the hours – they will be lost and taken back**.

Worries also spread to the question of age limits, the inequities of means testing and who pays for care and who doesn't, and the effect of direct payments on benefit entitlement. The fact that **people not in the system are not getting anything** is unfair when on the other hand people see that **disabilities are emphasised to get more money**.

Allied to the issue of eligibility was the **questionable quality of assessment and review**. The assessment requires some common understanding as **different interpretations of criteria** and **value judgments about activities** are made by different social workers. It also requires time and skill to ensure it is **joint and supported** and to avoid **elevated expectations that may not be met**.

This effort is necessary to understand people for example who **can come across like a swan, serene on the surface yet paddling like mad underneath**, who **claim that they are better than they are in reality** or whose condition means their behaviour and capacity can fluctuate.

Carers also feel unsupported in this process as **social workers won't do carers' assessments** and it is necessary to recognise that **the needs of carers change as they get older**

2.2.2 Continuity of support and communication style (26 items raised)

Second in priority is the ongoing support and relationship with social care workers. People cited the difficulties presented by **no effective continuous case management**, for example **having to retell the story (which in some cases needs the original social worker)** and **no seamless route from acute into the community**. Results of this include **nothing in writing, cases closing too early, people not allocated a social worker in time and left at home waiting with no support** and **only support when it is too late**.

A recurrent theme across the meetings was the relationship with the social worker and other professionals. It is clear to people that social services are under great pressures of workload. However, the impact of this on behaviours and relationships is highly significant for people. People feel **looked down upon** and **need to be listened to** and not treated as **nit wits**. They also expected to be treated **with common sense** rather than just on the receiving end of the **rule book**. How can personalisation work if there is not a mutually respectful relationship between parties?

2.2.3 Being left on my own and having to cope with more (28 items raised)

There are concerns about being left on my own, with **poor access to information** and **learning how to get through the maze**. A fear is **Do the agencies know me?** as it is **hard to access services unless you are already in the system**. A result of personalisation may also be that **I might lose my current networks and become isolated**. There is a suspicion that **the buck is being passed** and a worry about a steep learning curve and that my **skills are lacking** in managing a personal budget.

Who will help me? Who provides care for my husband if I'm ill? What about people who have no-one to speak for them? All are questions that are of concern especially as it is felt that there are insufficient advocates generally

This is all exacerbated by ***family worries, the stress involved in managing the books*** and concerns that ***I will not be able to deal with it*** and that it may actually ***increase hospital admittance!***

2.2.4 The amount of personal control that people really have (22 items raised)

Service users, carers and support workers gave examples where people may ***not have the ability to understand / comprehend*** the situation, for example ***people with learning disabilities who don't know they have a personal budget and nothing has changed*** and ***what about people with Alzheimers?***

This begs the question: ***who maintains control – carer, cared for or social worker?*** How can we be sure it is ***what the person wants?*** Personalisation potentially will increase the risks that ***somebody else spends it for me and I wouldn't get to see any money***

2.2.4 Services to suit (30 items raised)

There are serious concerns about the availability of services – ***if there is nothing out there we can't spend money and if we don't spend it it's taken off us.*** There is a distinct lack of information about services that has a significant effect on people's confidence in personalisation.

In addition, there are fears that valued existing services will be ***decommissioned if customers can't access them or don't know of them.*** Alternatively, this uncertainty may also put added pressure on these organisations ***because people will not know who else to turn to.***

There is a ***fear of engaging with unknown or new services*** and of ***getting ripped off.*** How will these agencies be vetted for working with vulnerable people?

Many people doubt that personalisation will lead to greater quality, choice and flexibility, for example if the market allows for ***only one person who comes to interview for the role of personal assistant.*** People also feel in the hands of others, ***confined by the timetabling of the agency*** and ***not able to make changes to times if the PA has another job*** and be subject to ***late notice of unavailability of employee.*** The pressures on the carer to restrict time with people means that the service will be ***impersonal*** and ***individual needs will not be looked at.*** Travel time is also an issue – who pays for it and how it ***impinges on care time.***

A constant underlying issue is the affordability of services - ***can I afford the services I need?*** There will also be hidden costs – CRB checks, travel

expenses, budget management, etc. This all results in **'less service' for more money**

2.2.5 As an employer and managing money (43 issues raised)

Many feel unsure that they want to be an employer, especially without an advocate on an employer's issues. **Finding the right person** is a key concern – the time and confidence required: **will they fill the role I want? Will they have the skills?** In addition, language skills were raised here.

The employment contract also changes the whole relationship. There are always dangers that **familiarity can breed contempt** and of **employees taking liberties**. With responsibility for managing a staff member's performance, it will be difficult but necessary for example to give feedback and criticise where appropriate face-to-face with staff members.

People also **might not be able to trust new providers** since, for example, employees working with **people in adult services with a personal budget** do not require CRB checks. For the sake of cost or time this may be a risk that people have to take.

Administrative headaches include dealing with insurance, holiday pay entitlements, sick pay, payroll issues, form filling, tax returns, etc. People also feel very insecure about their liabilities as employers given that **employment law applies to all**, giving rise to questions such as: **what about the rules and regulation on people entering your property? Can I be sued for accidents in my home?**

Add to this the burden and potential abuse regarding the management of money - **talks of money can be frightening** and **I've never managed my own finances**. People ask, **Who could help you manage your money?**

2.2.6 Spending Choices (29 items raised)

If we receive a personal budget or direct payment, what are the rules for spending it? **What services can I buy with my payments?** Given it is public money, **how am I accountable? How do I prove the service I use is effective? How do I provide proof?**

People of course vary in their spending habits. While some **would not spend their money but save it for a rainy day**, others ask, **What happens if you blow it all?**

Questions arise about responsibilities: **who would be responsible for the correct way to spend your direct payments? Who will keep checks on the process?** Will this include a systematic checking of receipts or something more informal?

Where a person needs support in making spending choices, there is a danger of being **channelled into one type of services (that the person who is 'supporting' me knows of)**. There are also many different kinds of conflict. For example, **an independent person may support 'belly dancing' but mum wouldn't!** Similarly, **a person may go clubbing and be back at 4am**

but what about family disruption and also the possibility they need to be up in the morning for college. Economic pressures too mean that for a family in poverty, money will not be spent as planned since they will pay all the bills first. An additional conflict arises when a person refuses support and then blows their money.

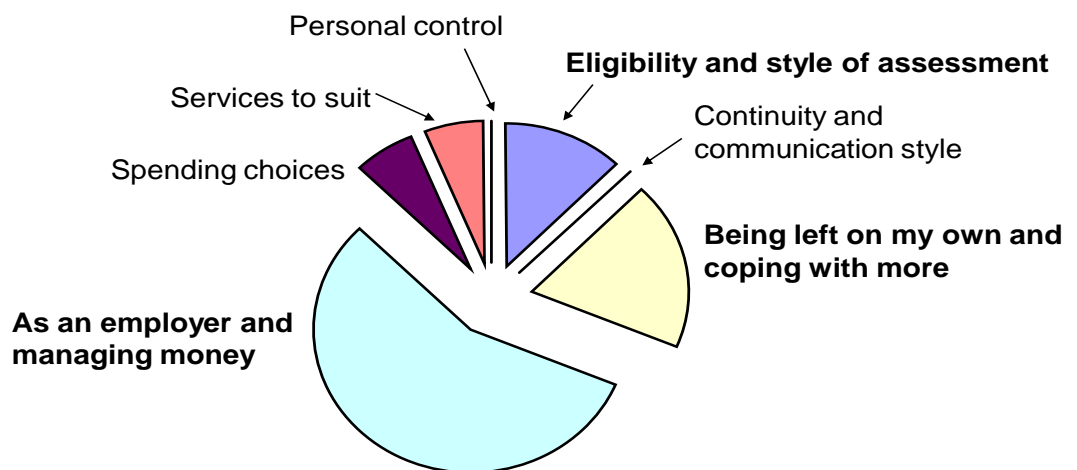
Real constraints exist here because of all the different factors to balance in allowing choice – health, safety, family needs, transport, support worker ratio, personal preparation, availability of personal assistants with very specific skills, etc.

These are the common themes across all focus groups. There were sometimes different emphases depending on the group and their experience of personalisation. For example, for those with learning disabilities, concerns centred on personal control and spending choices.

The annual review meetings strongly reinforced the concerns raised in the focus groups.

3 Different priorities

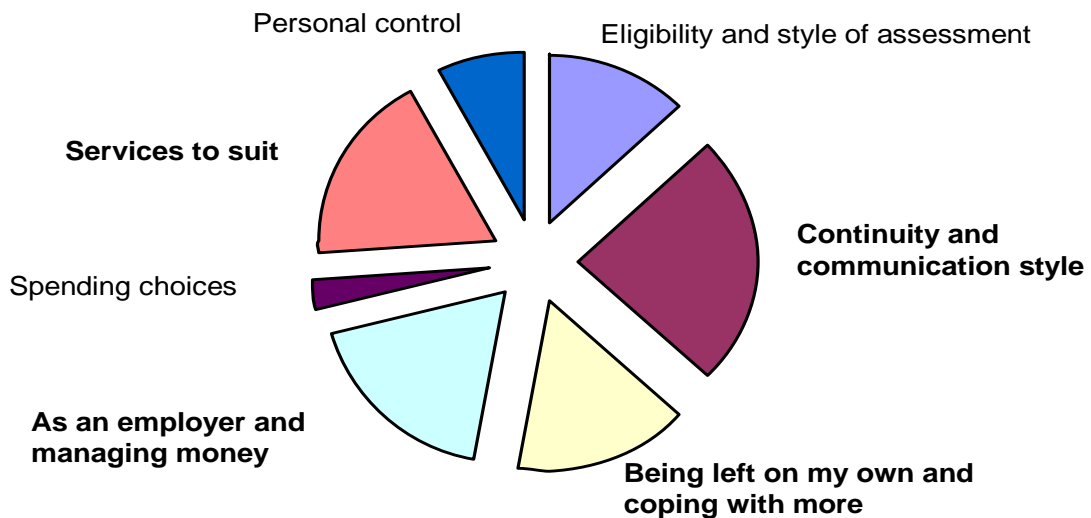
When we look at the results from the different focus group we can start to understand the different concerns people have. Older people, for example, raised concerns proportionally in each area as follows:



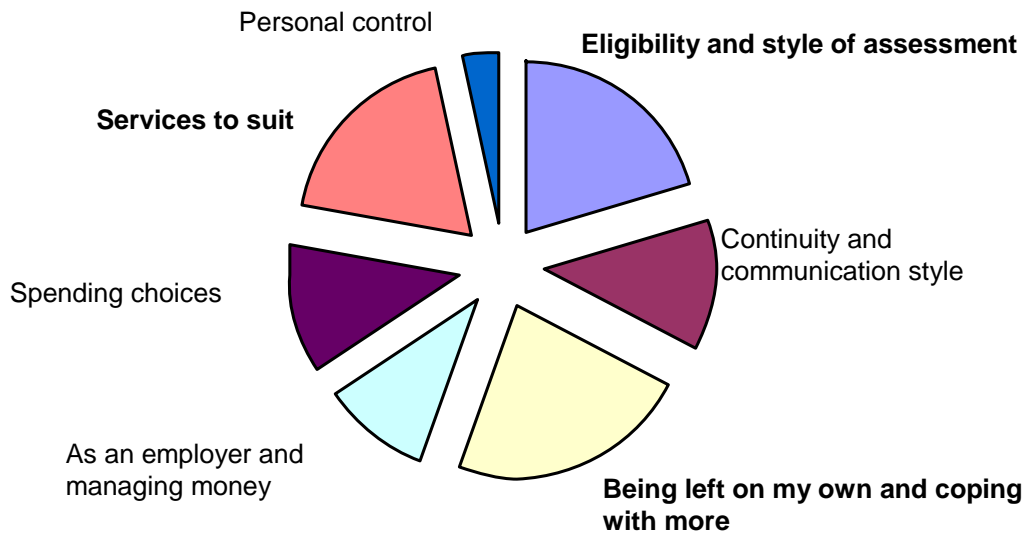
Eligibility and means testing were important issues and, in projecting forward, so too was coping with more responsibility, especially around the issues of being an employer. Not obvious from the chart, important too was the

availability of transport, consistent support, and professionals who use common sense and actively 'listen'. The last point was the most important underlying ingredient in the kind of support people wanted.

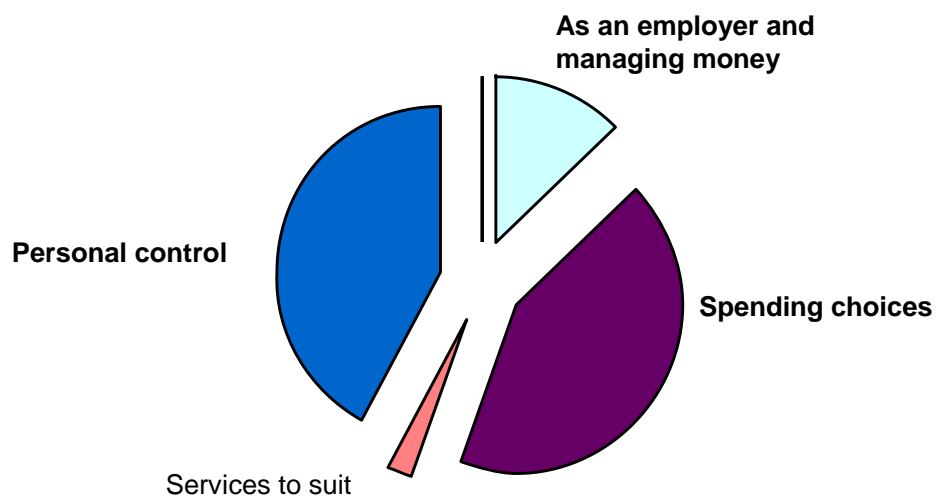
In the next chart, for carers, there was particularly strong feeling around the continuity of support from social workers, as well as poor information and clarity about eligibility criteria, and fears about what will happen in the carer is not there:



A key concern for those with mental health issues, to whom in many cases personalisation is a new concept, is people's lack of knowledge about mental health and therefore the impact on eligibility decisions, as well as the affordability of services and continued existence of important social support groups.



In contrast, people with learning disabilities were on personal budgets already, yet not much had obviously changed. They saw the main issues around personal control of the budget and also unclear rules about what money could and could not be spent on.



4 Support we need to deal with these concerns and make Personalisation work

During the focus groups, participants identified the following key areas as a start point for where support is needed to make personalisation work.

4.1 Information and guidance

4.1.1 On the overall process including:

- A clear definition of Personalisation – what it is / isn't
- A clear definition of 'support package' – what it is / isn't
- Clarity of terms – direct payment / individual budget. What is used / not used?
- Being clear about where Coventry is different in its approach to other Councils
- What has been learnt from pilot projects
- Who is entitled to apply? How is this done?

4.1.2 Before agreement to a personal budget:

- Balanced advice on the pros and cons of each option
- Assessment – eligibility criteria and thresholds for the 3 indicative bands / amounts
- A service standard – what can people expect – for example complaints procedure, response times (for example in assessment), and a named social worker who will be continuously responsible, etc
- What is the personal budget be spent on? How tightly will this be defined?
- What happens if don't use budget?
- Effects on other benefits of receiving a personal budget
- Does 'means testing' play a role?
- What is in place to account for different interpretations of criteria?

4.1.3 For each holder of a personal budget

- What is the frequency of review? Why? How formally will this be done? What information will need to be provided by both parties?
- How am I accountable? How do I prove the service is effective? What proof is needed?
- What if a person refuses support and the personal budget is spent 'unwisely'?
- If people are not able to manage their own budget, who makes spending decisions on their behalf? How is this decided? How is spending monitored?

4.1.4 On what support is out there

- An accessible, directory of all services.
- A one-stop shop
- People to know the full cost of services on offer
- Open days for services to show what they offer
- Independent brokerage to ensure we don't just end up with existing services

4.1.5 Continuity and communication style

- Listening to, understanding and meeting personal needs by engaging in a real partnership – through mutual respect, active listening and putting in writing and delivering what is promised
- Assessment open, honest and witnessed by independent body
- A named person responsible as the contact point to ensure consistent and continuous support
- Strict guidelines used by social worker – simple, signed and face-to-face. Including benefits entitled to, personal budget and full entitlement
- Skilled and trained practitioners to apply the process practically.
- Independent body for complaints – not social worker. Complaints to trigger review of support plan.

4.1.6 Support in personal planning

- Support plan that meets outcomes
- Good templates for support planning important to work out indicative budget in order to manage expectations
- Support in prioritising services needed

- Recognition that time is needed to develop a support plan – meetings with all necessary people

4.1.7 Support with practical issues of personalisation

- Developing independent advocacy, free to access, while developing self-advocacy for those that need it and with the capacity to develop it
- Advice on how to be an employer and support on the practical issues of managing the budget, money, employees and legal aspects
- Training and education also for the family

4.1.8 Managing day-to-day activity

- Carers need to work to a different pattern when personal assistants, more flexible in timing and also in the work they do.
- For safeguarding reasons, where appropriate, personal budgets to be managed by agencies
- Support for parents / carers at work if 5-day day care is no longer available. If not managed, they will withdraw.

5 LINK Annual meeting discussions: findings

5.1 In order to gather views from a wider audience Personalisation was given a platform at LINK's two annual meetings held in June 2010. Group discussions were held about the pros and cons of personalisation and the actions need to ensure successful implementation.

5.2 Benefits

The participants were asked what the benefits were of Personalisation to the people of Coventry.

Many of the responses reflected having more choice and control with comments such as:

- More freedom to choose services
- Less likely to be excluded
- You're the boss
- Empowering
- Less chance of being stuck in a service

Several people highlighted that Personalisation should bring an availability of appropriate services and made comments on:

- More types of services available
- Flexibility individualized support
- Greater variety of provision
- Cultural appropriateness

In total the participants identified 30 positive things that Personalisation could bring, it was acknowledged that some people would need different support to achieve some of the positives mentioned, for example 'living independently' and 'choosing your carer'.

5.3 Barriers

Participants shared their views on what they perceived to be barriers to the effective implementation of Personalisation. They identified 21 barriers, many of these were related to:

- safeguarding,
- finance,
- shifting responsibility
- and access to Information.

5.4 Ideas for effective implementation of Personalisation

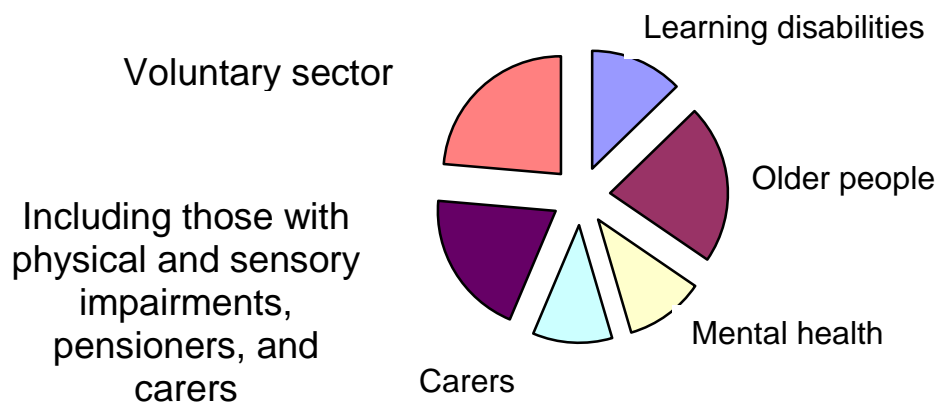
The discussion groups identified a number of steps which they felt would help the implementation of personalisation. Key themes included the effective provision of information; support for those taking on the role of being an employer; transparency in the system; advocacy support; engaging arrangement of service providers; and guidance on safeguarding.

6 Research Method

6.1 The 6 focus groups were carried out as follows:

	Date	Participants		Venue
1	11 May 10	12	People aged 65 years plus	Risen Christ Day Service
2	13 May 10	13	Voluntary sector staff representing a wide range of groups	Coventry Foyer
3	13 May 10	6	Carers	Coventry Foyer
4	26 May 10	7	Learning disabilities and support staff	Grapevine Drop In Centre
5	26 May 10	11	Those with physical and sensory impairments, pensioners, and carers	Coventry Foyer
6	27 May 10	6	Mental health issues	AIMHS Koko Building

6.2 Participants represented



There were 52 different participants in total from a wide range of groups in the community with over 16% from ethnic minority backgrounds. Some had direct experience of personal budgets, either knowingly or unknowingly, while others had never come across them.

Participants were first asked:

- What is important to people about the support they receive?
- Which different people are involved in the support of a person?

Altogether they were then asked to identify the concerns they had or might have in managing their own support package, writing each on a sticky note. The number of items raised in the meetings ranged from 16 to 58.

Individually they weighted their concerns - the most serious, the average, and the least serious. The results showed that participants were able to do this quite accurately and provide valuable comparisons.

The final question was about the support they need to deal with these concerns.

There were two exceptions to this process. Due to time constraints, at Risen Christ we didn't ask about the people involved in support and at Grapevine we didn't ask participants to weight their concerns.

In analysing the concerns, the method was as follows

- Cluster all the concerns under key headings
- For the weightings given by individuals, allocate a 3 for the most serious, 2 for the average, and 1 for the least serious.

- Calculate an average score for each concern and then calculate an average for all the concerns under each cluster.

Throughout the events, it is very much appreciated that people contributed freely and were very happy to offer their views. They represented a very wide range of sectors in the community. Views were captured in participants' own words. Inevitably not everyone is able to attend focus groups - however, many of the participants were from wider representative organisations. The findings do indicate common concerns, and the strength of feeling about these, and also some concerns that are more specific to certain sectors.

Upon conclusion of the 6 focus Groups, the Personalisation agenda was given a wider platform at LINKs AGM for which there were 85 participants from a range of communities which broadly reflected the demographic make up of Coventry, across two events. The findings from widening this piece of work generally reflected the focus group findings. Three questions were posed to the facilitated groups which were:

- **What are the benefits that Personalisation can bring?**
- **What are the barriers preventing these things being implemented smoothly?**
- **What Recommendations do you have to bridge the gaps in order to roll out personalisation effectively?**

The findings from the third question contributed to developing the recommendations contained within the report.

**Coventry LINK is an independent network supported by the charity
Voluntary Action Coventry, which acts as the Host organisation.**



Coventry LINK is one of 151 LINKs in England.

Coventry LINK C/O Voluntary Action Coventry, 3 Castle Yard,
Hay Lane, Coventry, CV1 5RF