



# **Southampton City Council Adult Social Care**

## **Workforce Redesign**

### **From the Perspective of the Service User**

#### **Final Report**

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**Organisation:** *Southampton Centre for Independent Living CIC*

**Name of report:** *Workforce Redesign – From the Perspective of the Service User*

**Commissioned by:** *Adult Social Care, Southampton City Council*

**Summary of report:** *An evidence based report, detailing how users of Southampton City Council's Adult Social Care department feel the workforce should be redesigned to meet the Personalisation agenda.*

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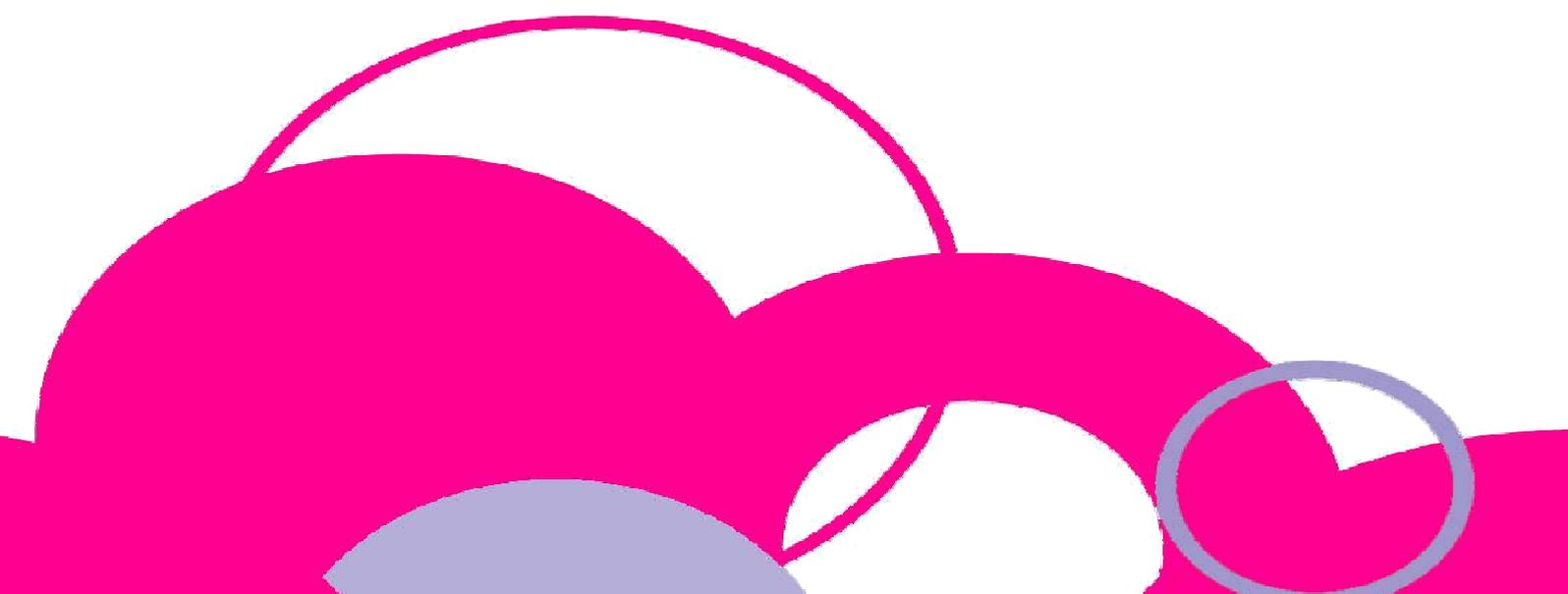
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SouthamptonCIL



## About SCIL

Southampton Centre for Independent Living (SCIL) is a User Led Organisation (ULO) run and controlled by Disabled People. We provide advice, information and support to Disabled People wishing to live independently by exercising choice and control over their lives.

SCIL supports Disabled People across all impairment groups and our principles are based firmly in the Social Model of Disability.

SCIL believes that people are disabled within society by the barriers they encounter (Attitudinal, Physical and Institutional) rather than by their individual impairment(s).

**C**hange is not a destination, just as hope is not a strategy

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Rudy Giuliani

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# Chapters

	Page
1. <b>Executive summary</b> (Including our recommended most cost effective actions) .....	1
2. Introduction .....	10
3. Methodology .....	13
4. Definitions .....	20
5. The customer pathway and journey .....	24
6. Barriers to Personalisation .....	31
7. Role of users and carers in Personalisation .....	43
8. Role of co-production .....	48
9. Training and support needs of service users.....	52
10. Functions of Adult Social Care in Personalisation.....	57
11. Skills and competencies required in the workforce .....	62
12. Training and support needs of staff .....	73
13. Evaluation/ measures to evidence change and more effective outcomes for users.....	77
14. Conclusion.....	81

## Appendices:

A. Feedback re users of substance misuse services.....	i
B. SCIE definition of Personalisation.....	v
C. Co-production case studies .....	vii

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# 1. Executive Summary

## (Including our recommended most cost effective actions)

### 1.1 Introduction

The Government's vision for Adult Social Care is of the reform of public services through "Personalisation". For Local Authorities this can be summed up as enabling everyone eligible for social care funding to have a Personal Budget that will help them to achieve:

- more **control** over their social care
- more **choice** about services
- **better outcomes** in the quality of their lives

Radical reform of this nature will require a review not only of the systems underpinning Adult Social Care, but also a redesign of the Adult Social Care workforce and its culture.

Southampton City Council is committed to the successful introduction of self-directed support and personalisation and has already set an outcome of achieving Direct Payments as the preferred delivery model for the majority of its Personal Budget users, in line with Government targets.

However, like all Local Authorities, Southampton City Council has to deliver these reforms within highly challenging resource reductions.

Southampton City's rich history of progressive social care development, supported and encouraged by User Led Organisations (ULO), has ensured many service users already have access to choice and control over their services. These reforms will enable the Council to take the next step.

Government recognises that the effective implementation of Personalisation can only happen if Councils work in a co-productive way with service users to develop solutions which meet the needs and expectations of users.

SCIL was commissioned by the Council to undertake research into the user's perspective of how to redesign the workforce to enable Personalisation to become a reality for all service users. SCIL is a locally based ULO with a national reputation for innovation through user involvement.

This report provides a total of 56 recommendations, from users, of how this redesign can be achieved. These recommendations have been grouped within the following headings:

- the customer “pathway” verses the customer “journey”
- barriers to Personalisation
- role of users (and carers) in Personalisation
- role of co-production
- training & support needs of users
- functions of Adult Social Care in Personalisation
- skills / competencies required in the workforce
- training and support needs of staff
- culture change/risk management
- evaluation/ measures to evidence change and more effective outcomes for user

This report brings together the views of service users of non-residential care services in care groupings of:

- People with mental health difficulties
- People with learning difficulties
- Older People
- People with experience of substance misuse services\* (*See report notes*)
- People with physical /sensory impairments

*Whilst this is a comprehensive list, it must be recognised that further research is needed to ensure that the views of users of residential care services about personalisation are also captured.*

It is important to point out that Personalisation is likely to mean quite different things to different client groups. Personalisation will, by definition, have as many different manifestations as there are service users.

This report is to be considered alongside a comparable report from the perspective of the Adult Social Care workforce, to inform a workforce redesign strategy for Personalisation.

Additional resources, which will provide a valuable insight include:

- **Think Local, Act Personal**, A sector-wide commitment to moving forward with Personalisation. Putting People First, 2011
- **Independent Living Strategy: Support, advocacy and brokerage demonstration project**: Office for Disability Issues, 2011 (draft at time of this report)
- **Keeping personal budgets personal**, experiences of people with mental health problems: SCIE, 2011
- **Promoting the life chances of Disabled People**: Prime Minister's Strategy Unit, 2005

## **1.2 Summary of recommendations**

This summary collates the full list of recommendation into common themes. (A full list of recommendations appears at the end of each chapter)

These collated recommendations are fully cross-referenced to individual chapter recommendations. (*i.e. 'R6.4' cross-references to chapter 6, recommendation 4*)

**Most of these recommendations also cross reference 'Think Local, Act Personal' and should be considered alongside this important publication.** This sector-wide statement of intent makes the link between the Government's new vision for social care and *Putting People First*. *Twenty-four leading national organisations have endorsed this as the way forward for personalisation and community-based support.* ([www.puttingpeoplefirst.org.uk](http://www.puttingpeoplefirst.org.uk), January 2011)

**Of these recommendations, section 1.3 provides what we recommend to be the MOST COST EFFECTIVE ACTIONS for delivering Personalisation for users in Southampton.**

## **Customer journey**

**Clarity of mission:** The workforce can only effectively implement Personalisation if it has a shared understanding about what 'Personalisation', 'Co-production' and 'the Workforce' is **(R4.1, R4.2, R8.1)**

**Customer Signposting:** Develop strategies with partner organisations to enable potential service users more effective signposting to Adult Social Care, thus limiting expensive crisis intervention **(R5.1, R5.2)**

**User information and communication:** Develop accessible information for initial contact with user, to inform about the customer journey options and provide timely updates to user during the journey, with adequate time for users to consider options or seek support. Use of jargon to be minimised and fully explained. Transparency of decision making functions. **(R5.3, R5.4, R5.7, R5.8, R5.9, R6.1, R6.2, R6.4, R6.12)**

**Continuity and consistency:** Users highly value a consistent Care Manager/ Care Co-ordinator/ Occupational Therapist allocated to the service user for the duration of their engagement; together with consistent working practices. **(R5.5, R5.6, R10.4)**

## **Barriers**

**Community information and training:** Information and training regarding Personalisation and potential services on offer to be distributed to wide range of 'mainstream' services e.g. libraries, community centres, and social clubs. Information about Council Services, User Led Organisations, Social Clubs, Care Agencies and other Third Sector Organisations should be included. **(R6.3, R12.2)**

**Support for specific groups to identify relevance of personalisation:** Consideration should be given on the best method of communicating and supporting users of day services and residential care, who may feel particularly threatened by Personalisation. **(R6.5)**

**Personalisation resources via information technology:** The Council and User Led Organisations should be encouraged to work together on developing useful online resources and service directories to support users and front line staff in understanding Personalisation. **(R6.6, R6.7)**

**Core communication and listening skills required for workforce.**

**Focus more on basic social work skills:** Users felt more strongly than on any other issue, that communication and listening skills were the single most important aspect to making Personalisation a success. Current workforce skills varied alarmingly. Training should include positive risk taking, and empowering users to assess risks. Training should be co-produced with users **(R6.8, R6.17, R10.3, R12.3)**

**Finance decisions to be Personalisation friendly:** Conduct an audit of financial decision making processes to ensure they are 'fit for purpose' and compatible with outcome focus of support plans to enable successful and timely delivery of Personalisation. Empower front line staff to discuss issues of resources in an honest and transparent way **(R6.11, R6.13)**

**Prevention:** Investigate with users, cost effective ways to provide preventative and lower level service provision to avoid crisis. Users are likely to already have solutions. **(R6.14)**

**Users to lead in culture change:** Users should be much more involved in training and supporting the workforce on what Personalisation achieves for the lives of users. This will assist in achieving culture change and to win hearts and minds. Discourage 'professional knows best' attitude. However, understand that culture change takes time. Training will not provide culture change on its own. **(R6.15, R6.16, R12.4)**

**Supporting family and friends of users to understand personalisation:** Provide appropriate information aimed at family and friends to reassure them and explain their role within the process of Personalisation to support the empowerment of the user. **(R6.18)**

**Space for people with learning difficulties to have a say:** Care managers should provide options to enable users to say what they want, rather than family members being in control. **(R6.19)**

## **Role of users and carers in Personalisation**

**Facilitate and support development of peer support and general support groups:** Develop a strategy to invest and encourage development of user controlled peer-support groups to enable users to

find empowering solutions to their lives, with availability of specialist support when users need it. **(R6.10, R7.2)**

**Facilitate and support development of collective support provision:**

Develop a strategy to enable and support small groups of users to pool budgets to meet their collective needs, and to compliment individual solutions. **(R7.3)**

**Provide opportunities for users to train and support the workforce:**

Users have a valuable role working with the workforce to improve the understanding of how Personalisation changes lives and therefore effect culture change in service provision. **(R7.4)**

**Develop a Southampton PEP, based on co-production:** Users welcome the establishment of a Personalisation Expert Panel for local users and Carers to work jointly with officers from Southampton City Council to monitor and review workforce developments to ensure they are aligned to the Personalisation agenda and meet agreed outcomes. Co-production is felt by users to be particularly effective for designing and delivery of training, and future service developments. **(R7.1 R8.2, R8.3, R12.1)**

## **Training and support needs of users**

**Provide training for users about what Personalisation is** and how they can use it to live independently and achieve goals. Provided by users experienced in Personalisation **(R6.9)**

**Develop modular training programme for users:** Users provided with appropriate skills based training to enable effective use of Personalisation. (See **R9.1, R9.2, R9.5, R9.6, R12.5** for details)

**Personal development:** Investigate provision of personal development training to meet user needs for confidence building, self-worth, assertiveness, understanding of empowering models such as the Social Model of Disability and Independent Living. **(R9.3)**

**Training in mentoring role of peers:** Consider development of a training, support and mentoring scheme where more confident users can support less confident users. **(R9.4)**

## **Functions of Adult Social Care**

**Main roles for Adult Social Care in Personalisation:** Should be focused on: transparent allocation of resources, monitoring risk, provision of safety net, quality monitoring, and safeguarding. **(R10.1)**

**Internal or external service provision decisions to be based on best provider of skills and competencies.** Users don't care who the provider is, if they have the required skills and competencies **(R10.2)**

## **Skills and competencies in the workforce**

**Skills and competencies which users felt to be most important:**

- a. Ability to communicate with a diverse range of service users, service providers, and statutory agencies
- b. Ability to support users with self assessment and person centred planning
- c. Knowledge of statutory, community and voluntary resources within Southampton
- d. Ability to support users with financial and budget management
- e. Ability to provide advice and information (social care legislation, knowledge of disability benefits, employment support and advice)
- f. Ability to support users with risk assessment and positive risk management (including safeguarding)
- g. Advocacy skills
- h. Training on philosophy and values of Personalisation, including case studies and success stories **(R11.1)**

## **Evaluating Personalisation**

**Develop evaluation methods which measure how Personalisation has benefited service users:** Users valued the following four methods. **(R13.1, R13.2)**

- a. **Quality of life questionnaire:** With baseline measurement at initial assessment and annually thereafter to measure impact

- b. Service User feedback forms for customer satisfaction:** Initial Contact and Care Manager/Care Co-ordinator assessment and review processes and Occupational Therapy assessment and equipment delivery
- c. Web-based feedback forum on quality of care providers:** Users providing feedback on how effective service providers were at enabling users to achieve personalised outcomes. This feedback would help inform other users considering different providers. (User review sites such as [www.tripadvisor.co.uk](http://www.tripadvisor.co.uk) could provide a template)
- d. Use of Personalisation Expert Panels:** Co-production forums such as those used by Hampshire County Council and the ODI are felt by users to provide effective methods for evaluation

**Consider POET and ASCOT evaluation tools:** Adult Social Care may find these pre-existing web-tools a useful pro-forma for evaluating Personalisation in Southampton. (R13.3)

### **1.3 The most important actions in delivering Personalisation**

The summarised recommendations above, are all important, however, we recognise that it is not realistic to expect all of these to be implemented at once.

The following actions, if prioritised, will consolidate the most important of our recommendations, and make the most cost effective impact to delivering Personalisation to users in Southampton.

- 1) Core communication and listening skills required for workforce.**  
**Focus more on basic social work skills:** Users felt more strongly than on any other issue, that communication and listening skills were the single most important aspect to making Personalisation a success. Current workforce skills varied alarmingly. Training should include positive risk taking, and empowering users to assess risks. Training should be co-produced with users.
- 2) Raising awareness of the benefits of Personalisation:** The workforce and users alike can only feel positive and work together to deliver Personalisation if both groups understand the benefits. By 'benefits' we

mean developing a much better understanding of the philosophy of Personalisation and empowerment. Users have been particularly neglected in respect of personal development / empowerment training up until now. Without this awareness, neither users nor the workforce are likely to feel enthusiastic or positive about personalisation.

**3) Users to lead in culture change:** Users considered it essential to develop a Southampton Personalisation Expert Panel (PEP), based on co-production for local users and Carers to work in partnership with officers from Southampton City Council to monitor and review workforce developments to ensure they are compatible with the Personalisation agenda. Co-production and feedback of this nature is felt by users to be particularly effective. Users want to be much more involved in training and supporting the workforce on what Personalisation achieves for the lives of users. This will assist in achieving culture change, to winning hearts and minds and improving consistency.

**4) Finance decisions to be ‘personalisation friendly’:** Conduct an audit of financial decision making processes to ensure they are ‘fit for purpose’ and compatible with the outcome focus of support plans to enable successful and timely delivery of personalisation. Empower front line staff to discuss issues of resources with users in an honest and transparent way.

## **1.4 Conclusion**

This report details the views of service users on how the Adult Social Care workforce in Southampton should be redesigned to meet the challenge of Personalisation.

Personalisation is about giving users control, with support if needed, to manage which services they use to meet their social care needs. It follows that the views of users should be taken fully into account in ensuring Southampton City Council’s Adult Social Care is redesigned to better meet the expectations, experiences and needs of the user.

A summary of this report will be provided to all service users who participated in our research. This summary will include Southampton City Council Adult Social Care’s formal response to this report.

SCIL, April 2011

## **2. Introduction**

**Personalisation** offers major opportunities and challenges for both users of services and the workforce which designs, commissions, provides or facilitates the service.

Personalisation's aim is to put the user of social care services at the heart of, and in control of how services are delivered.

People receiving personalised services should expect to exercise choice and control over the support they receive whether they are self-funding their care or being funded by the Local Authority.

### **2.1 Adult Social Care is changing.**

The successful introduction of self-directed support and Personalisation will require a review not only of the systems underpinning Adult Social Care, but also the Adult Social Care workforce and its culture.

Southampton has a rich history at the forefront of progressive social care developments which deliver choice and control to the service user. Users have worked closely together to develop their voice through the establishment of a User Led Organisation (Southampton Centre for Independent Living [SCIL]). Southampton City Council recognises that the effective implementation of Personalisation can only happen if the Council works in a co-productive way with users to develop solutions which meet the needs and expectations of both user and Council.

This report provides user suggested solutions to this challenging objective, but within the context of substantial Government budget reductions imposed on Local Authorities.

### **2.2 The research**

Southampton City Council's Adult Social Care department commissioned SCIL to research service user perspectives on Personalisation and in particular to focus on two key areas:

1. What changes do users think would deliver an improved “Customer Journey”?
2. What skills and competencies do users think are required in the workforce to support customers to best realise the 7 person-centred goals of Putting People First (PPF)?

These 7 goals are, that all people irrespective of illness or impairment are supported to:

- Live independently
- Stay healthy and recover quickly from illness
- Exercise maximum control over their own life and where appropriate the life of their family members
- Sustain a family unit which avoids children being required to take on inappropriate caring roles
- Participate as active and equal citizens both economically and socially
- Have the best possible quality of life irrespective of illness or disability
- Retain maximum dignity and respect

## **2.3 Research group**

The project brief was to focus on users of non-residential care services and the major adult care groupings of:

- People with mental health difficulties
- People with learning difficulties
- Older People (including Older People with dementia)
- People with experience of substance misuse services
- People with physical /sensory impairments

We hope this report will provide a valuable service user perspective, enabling Southampton City Council to realise the potential of the Personalisation agenda. A parallel report has also been commissioned on the subject, seeking the perspective of the Council’s Adult Social Care workforce.

## **2.4 This report**

This report provides recommendations based on service users' perspectives on the following aspects of Personalisation:

- definition of Personalisation
- the customer “pathway” (flowchart provided by SCC)
- the customer “journey”
- barriers to Personalisation
- role of users (and carers) in Personalisation
- role of co-production
- training & support needs of users
- functions of Adult Social Care in Personalisation
- skills / competencies required in the workforce
- training and support needs of staff
- culture change/risk management
- evaluation/ measures to evidence change and more effective outcomes for user

This report is structured accordingly.

## 3. Methodology

This chapter explains how we delivered the project, sub-divided as follows:

- Project management, work planning and staffing
- Research methods used
- Diversity
- Access
- Workshop arrangements
- Evidence collation and report production

### 3.1 Project management, work planning and staffing

Representatives from Southampton City Council met with SCIL to discuss their initial ideas to engage with users to inform the Council's workforce redevelopment plans. The Council subsequently issued a **project specification** (*Appendix A(1)*). SCIL developed a **workplan** (*Appendix A(2)*) to enable the specification to be delivered within the prescribed time frame.

The specification prescribed regular Project Board meetings, consisting of Southampton City Council representatives from Human Resources, Training and Development, Health and Adult Social Care Directorate; as well as SCIL's Chief Executive and their Independent Living Team Leader, who was SCIL's Project Manager for the work.

The Project Board met throughout the project to be updated and advise on the progress of the project, to be informed of the preliminary findings and to comment on a draft version of the report.

SCIL's Project Manager assembled a team of with 3 Disabled People with experience of Independent Living issues, to undertake the research (including facilitation of workshops). One of the team was a researcher, experienced in consumer based audit skills. There was also administration support.

## **3.2 Research methods used**

The primary aim of the project was to ascertain user views on how the workforce should be redeveloped to achieve the core values of the Personalisation agenda. The research was therefore based on collection and analysis of data from service users accessing Social Care Services.

Given the complex subject matter, we assessed that in order to achieve good qualitative opinions; there was a need to enable users to develop a good understanding of Personalisation. It was therefore decided that using a questionnaire method would not deliver the required outcomes, and that conducting a number of workshops, coupled with one to one interviews if necessary, would be the most efficient way of gathering a wide range of qualitative views.

Four Workshops were scheduled over four consecutive weeks in November and December 2010, although one had to be cancelled due to very bad weather. (An additional Workshop was subsequently run at Prospect House, as none of their users could attend the third workshop). Workshops were organised at weekly intervals to keep motivation and levels of knowledge high, but also to fit within the tight timescale for the project. The questions posed by the project specification (Appendix A) were split into topic areas which formed the basis of each workshop.

An invitation pack was prepared that included an invitation, background information about the project, a booking form, and a FREEPOST envelope.

A total of 485 invitation packs were sent out.

## **3.3 Diversity**

The project specification (Appendix A(1)) required us to ensure our research focused on users of non-residential care services and the major adult care groupings of:

- People with mental health difficulties
- People with learning difficulties
- Older People (including Older People with dementia)
- People with experience of substance misuse services
- People with physical /sensory impairments

In order to maximise the diverse mix of participants for the focus groups, it was decided to target particular types of service user, as follows:

- **Users who were already receiving a personalised service from Southampton City Council:** SCIL sent 200 invitations to a random sample of Southampton users who had received support from SCIL with Direct Payments and Personal Budgets over the previous 6 months. These invitations were to a broad cross section of adult care groups, broadly compatible with the general diversity of users of these services.
- **Users who had experience of day services:** SCIL provided 200 invitations to service providers which were distributed to people who attended day services at:
  - Sembal House (physical impairment)
  - Prospect House (learning difficulties)
  - Bedford House (mental health difficulties).
- **Users who had experience of substance misuse services:** One of the research team discussed the research with the Support Broker for Substance Misuse, who agreed to distribute 50 invitations to users of the Morph project and The Bridge. Both services offer drop in sessions for users of substance misuse services.
- **Users who were Older People:** We circulated 15 invitations for distribution to users of local Older People's groups.
- **Users who were interested in social care reform and local policy development:** 10 invitations were distributed each to the Citizen Leadership Group and the Citizen Safeguarding group. Both groups are serviced by Southampton City Council and encourage local user involvement in developing Local Authority services regarding Adult Social Care.
- **Carers:** The project specification did not ask us to gain evidence from Carers. However, some of the service users attending our workshops attended with informal Carers. At relevant sections in this report, the perspective of these Carers is recorded.

To enable analysis of the diversity of workshop participants, all workshop booking forms were colour coded so that we could ascertain response rates from each of the user groups we had targeted.

Booking form returns were collated as follows:

Users expressing an interest in attending at least one of the four scheduled focus groups	37
<ul style="list-style-type: none"> <li>• Direct Payments or Personal Budgets users</li> </ul>	12
<ul style="list-style-type: none"> <li>• Day service users</li> </ul>	17
<ul style="list-style-type: none"> <li>• Substance misuse service users</li> </ul>	Note 1
<ul style="list-style-type: none"> <li>• Older People</li> </ul>	Note 2
<ul style="list-style-type: none"> <li>• Users interested in social care reform and local policy development</li> </ul>	8
Users who attended first workshop	19
Users who attended second workshop	15
Users who attended third Workshop ( <i>including parallel Workshop run at Prospect House due to inability of users to attend main workshop</i> )	14

Table note 1: **Substance misuse:** We could not encourage users of substance misuse services to attend the workshops. In order to mitigate this, one of our researchers discussed a draft of this report with the Solent Healthcare Personal Health Budgets Lead for Alcohol Dependence. The same Workshop questions were asked, asking for responses based on user experiences and the development of a Personalised Services for substance misuse. Although the service provision for alcohol dependency does not offer cash payments in lieu of services, there are similarities in the approach being holistic and offering a greater choice and range of services. **It should be noted that this feedback was the Broker’s views of what users would think, rather than the users views themselves, and therefore should be viewed with an appropriate ‘health warning’.** Responses from this feedback are therefore recorded separately within each chapter.

**NB: Full feedback comments are recorded: Appendix A**

Table note 2: Whilst Older People using Direct Payments did attend the workshops, no-one attended explicitly from the Older People's groups we targeted. The researchers believe that more work is clearly needed to help Older People to see the relevance of Personalisation in their lives.

### **3.4 Access**

SCIL's policy is that all people should expect to have their access needs met as a given, and that any failure of access is an organisational failure.

To meet the access needs of users, all invitations and documentation for the project used a non serif 'Arial' font at a minimum point size of 14. We also developed larger print and CD based versions and advertised their availability.

In order to ensure we were able to meet user's individual access needs, we used SCIL's standard booking form to gather information about user's access and dietary requirements to ensure we were as inclusive and accessible as possible. *(For example, one user experienced regular panic attacks so they requested a nominated person from SCIL sat next to them at all times to help allay their anxiety)*

To enable users from Prospect House (learning difficulties) we liaised before the workshops and agreed to send **Easy Read** workshop documentation in advance of each workshop, and to enable Prospect House users' support workers to provide support during each workshop.

To further aid communication, comfort and confidence, our research facilitators generally stayed with the same group of users through all of the workshops.

### **3.5 Workshop arrangements**

Questions were developed in advance, focussing on the 8 main topic areas:

- Personalisation
- Co-Production

- Barriers to Personalisation
- Opportunities to Personalisation
- Positive Risk Management
- Skills and Training for Staff
- Training for Users
- Support Mechanisms for Users

Each of the 3 Workshops had a similar format, with a focus on maximising time allocated for user input:

Housekeeping, Aims of the project	5 Min
Presentation - outline of first topic and questions	5 Min
Discussion period 1 - <i>Participants split into small groups (5 – 8 people) to discuss the questions. Each with a facilitator and a scribe to record group answers</i>	50 Min
Comfort break	10 Min
Presentation – outline of second topic and questions	5 Min
Discussion period 2	50 Min

A £10 gift voucher was given to all participants as a thank you at the end of the project, in addition we committed to meeting all participant expenses.

In addition to our workshop research with users as described above, the research team felt it would be valuable to engage with service users involved in working in co-production with statutory services in Hampshire. Two research team members visited the Hampshire Personalisation Expert Panel (PEP). There were 12 service users and Carers at the meeting we attended, who are '**Experts by Experience**' actively involved in issues around social care reform. Four senior members of staff from Hampshire County Council were also present. The panel provided us with first hand evidence of how Personalisation through co-production had worked in a neighbouring Local Authority and provided us with valuable feedback on our areas of research.

### **3.6 Evidence collation and report production**

All evidence was collected during workshop sessions and other discussions, was immediately typed up and submitted to the project manager to review any evidence gaps or points of clarification needed and resolve as appropriate.

The project manager assembled the first draft of this report from collective input of the researchers; two further draft versions have received constructive feedback from Project Board members and researchers.

The report has adopted a qualitative approach to the evidence as it was not thought helpful with a relatively small sample size to try to draw any statistically significant conclusions from the data. Where it has been apparent that there are different views between impairment groups, this has been highlighted.

Recommendations are derived from user evidence unless indicated otherwise. Recommendations are listed at the end of each chapter, in the form which correlates to the chapter number.

**Where it has been felt appropriate to provide comments, opinion or views from SCIL, these have been presented within a pink break out box in this style to differentiate it from the evidence of users**

This full report was written for Southampton City Council Adult Social Care. A summary report will be produced for all service users who attended the workshops.

*(NB: Service Users who request the full report will be provided with it)*

## 4. Definitions

**This chapter prescribes definitions used during our research:**

- Definition of ‘Personalisation’
- Definition of ‘workforce’
- Definition of ‘co-production’

### 4.1 Definition of ‘Personalisation’

From our research it was clear that whilst most people had an opinion about aspects of the term ‘Personalisation’, they found it difficult to properly define.

For the purposes of this research, we wanted to agree a common understanding of Personalisation which users would feel comfortable with and therefore agree a common understanding of what we were talking about.

The Social Care Institute of Excellence (SCIE) 2010 publication: ‘Personalisation: a rough guide’ provides an admirable, but lengthy definition, which SCIL’s researchers feel is valuable for policy makers/implementers and is therefore reproduced as appendix E.

***NB: SCIE definition of Personalisation: Appendix B***

We also found the following paragraph to be a valuable contribution towards an understanding: *“Across Government, the shared ambition is to put people first through a radical reform of public services. It will mean that people are able to live their own lives as they wish; confident that services are of high quality, are safe and promote their own individual needs for independence, well-being, and dignity.”* (Ministerial concordat launched 10 December 2007)

SCIL researcher’s collated a working definition from these sources, which users subsequently adopted at the first workshop session as their shared understanding.

Therefore the following amended SCIE definition, as proposed by SCIL researchers was agreed as the definition of Personalisation to be used for the purposes of this research:

**“Personalisation means thinking about care and support services in an entirely different way; Starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives.”** *SCIL amended from (SC IE 2010 publication: ‘Personalisation: a rough guide’)*

## **4.2 Definition of ‘Workforce’**

The brief of this project defined ‘workforce’ in terms of the Adult Social Care workforce; this report’s aim being to make recommendations from users about how the Adult Social Care workforce needs to be redesigned, to enable it to meet the challenge of Personalisation.

**For the purposes of our research, we used a broad definition of Adult Social Care workforce to encompass not just, Care Managers, Care Coordinators and Day Service Staff but also Managers, Administration, and Finance staff.**

**Caveat 1:** However, during our work it became clear that users do not see their lives in terms of the Adult Social Care services they receive just from Southampton City Council, but from a holistic perception which includes the full gamut of services, support and advice that they have access to, including user’s own life solutions. In other words, Personalisation will only become a reality if all of these factors are brought together with a common vision.

Therefore we have to recommend that for Personalisation to truly meet its potential, a more holistic view of the Adult Social Care workforce should be adopted to include other

agencies that deliver social care services, such as health services, third sector workers, care agency workers, support workers etc.

**Caveat 2:** Whilst it is clearly outside the brief of this report; we feel it essential to point out that, from the feedback of users, the implementation of Personalisation must include, and impact on all six of the Council’s Directorates. This reflects clarity from users that they do not exist within the narrow confines of Adult Social Care services, but that all council services will need to rise to the challenge of Personalisation if it is to achieve its full potential.

For the purposes of clarity, we did not include groups in caveat 1 or 2 in our working definition.

### **4.3 Definition of ‘Co-production’**

As Government expects personalised services to be ‘co-produced’ with the people who will use these services, we wanted to produce a definition of ‘co-production’ which could also be adopted as a common understanding by users during this research to guide their thinking.

The following definition of co-production was adopted:

**“The co-production model of care and support recognises people who use services and carers have assets and expertise that should be valued. Co-production means moving away from “doing the same thing, only trying to do it more cheaply” towards sustainable public services that meets needs and provides better outcomes. Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered”** *SCIL amended from (Dept of Health, 2010 Practical Approaches to Co-production) (Boyle and Harris 2010 P9, taken from the report “Personalisation, productivity and efficiency” SCIE report no. 37) (Department of Health’s Personalisation Communications Toolkit)*

It is, of course, worth highlighting that the Disabled People's Movement have adopted the phrase "*Nothing about us without us*" as a plain English description of how policy and services must be developed with users, if they are to be enabled to use personalised services to live independently.

## 4.4 Recommendations: Definitions

**R4.1 Definitions:** Southampton City Council should adopt and communicate their own definition of the terms 'Personalisation' and 'Co-production' as a shared understanding of what they are seeking to achieve. If a shared understanding is not achieved, consistency will be lost and terms will lose identity. This report recommends the Council adopts the definitions agreed by users during this research

**R4.2 Workforce boundaries:** Southampton City Council should decide whether or not the boundaries of 'workforce' are limited to Adult Social Care or a wider definition adopted. Develop Personalisation strategies accordingly

## 5. The customer pathway and journey

**This chapter investigates the quality of journey that the user ('customer') of Adult Social Care experiences.**

The quality of the journey taken by users during the process of gaining receipt of personalised services will impact significantly on the quality of outcomes realisable from the personalised service.

This section compares the planned '**customer pathway**' against the '**customer journey**' experienced by users to produce recommendations of how improvements could be made to produce a better experience for users of Personalisation.

### 5.1 The 'Customer pathway'

Southampton City Council Adult Social Care has been developing a new customer pathway to assist their workforce to move towards a personalised approach for new service users. The current pathway is outlined below and has been compared with people's comments about their actual experience – i.e. their customer journey – as discussed at our workshop focus groups. The comparison has aided the research team in identifying the barriers that the workforce would need to address.

***The current Southampton City Council Adult Social Care Customer Pathway for New Service Users (as at December 2010) is as laid out overleaf:***

**Synopsis of: SCC Putting People First Care Manager  
Guidance Sheet Process Overview  
(PPF Team v2 4<sup>th</sup> July 2010)**

**Initial Contact:**

Initial contact is usually made by the service user or their representative through, Gateway or Adult Services Contact Centre. The Contact Centre screens for eligibility under Fair Access to Care Guidance and assesses the urgency of need and where applicable refers for a Health and Community Care Assessment or to:

- Rapid Response
- Safeguarding Adults
- Occupational Therapy

**Eligibility:**

Service Users who do not meet the eligibility criteria are signposted to other services, or advice agencies

Service Users who meet the eligibility criteria will go through the following process:

Where there is a likelihood of eligibility for Continuing Care an initial screening will be carried out. Where there is no likelihood or eligibility for Continuing Care the service user will be referred to, or offered the appropriate service or assessment:

- a) Intermediate Care
- b) Re-ablement Services
- c) Putting People First (PPF) Supported Self Assessment Process (SSAQ)
- d) Specialist Assessment, Risk Assessment,
- e) Financial Assessment (FAB assessment is triggered automatically by PARIS when Service Users given SSAQ)

It appears from the documentation provided to the research team that Southampton City Council has a clear written customer pathway.

## **5.2 Current ‘Customer Journey’**

With an understanding of the Council’s proposed ‘Care Pathway’, the research team focussed its attention on the user experience Adult Social Care and more specifically the journey they experienced as Adult Social Care’s ‘customer (customer journey).

It is important to note that many of the workshop participants were already Adult Social Care service users and therefore will not have experienced the new personalised customer journey that a completely new service user is likely to have.

However many participants were being reviewed due to the introduction of Personal Budgets and the proposed changes to Day Services.

To gain evidence around the customer journey, we asked the following questions:

- How can your social care services meet your personal choices better?
- How can you get good services near to your home when you want them?
- Personalisation is about thinking about care and support in a different way - starting with the **person** rather than the service. How can you have control over the services you receive?
- How can Social Services help you have more choice and control in the services you receive?

## **5.3 Evidence gained**

Research found that many users particularly valued having a main point of contact, usually the Care Manager, Care Co-ordinator or Day Service Staff.

**“We want low-level support - they often seem to know when we need help, when we’re ill”**

**“People assist us with filling in forms at the day centre”**

**“Care Managers are friendly and helpful”**

However, many users additionally felt that front line staff then got bogged down with the process and the focus was then no longer on the individual user:

**“Flowchart – the Service User should be at the top”**

**“When the Social Worker gets back to the office, there are too many processes going on”**

**“Process is council driven and not customer focussed”**

There was a common view from the user experience that there was no clear or obvious structure to the customer journey.

There were a number of key themes which emerged from the workshop sessions, these were:

<p>1. Service Users’ lack of awareness about Personalisation</p>	<p><b>“There needs to be a dedicated information and advice service for disabled, carers, Social Care, service users”</b></p>
<p>2. Care Managers’ lack of awareness about Personalisation</p>	<p><b>“Process of Care Manager Assessment and OT assessment and equipment provided needs to be quicker and streamlined”</b></p>
<p>3. Poor and unclear information about eligibility for services</p>	<p><b>“A separate appeals procedure from Complaints procedure for eligibility assessment”</b></p>

4. Poor communication between Health and Social Care Services	<b>"It is wearying when then keep asking the same questions'</b>
5. Length of time from initial contact to seeing somebody	
6. Assessment process complex and unclear	<b>"It's a process lead service and approach, not responsive to individual circumstances"</b>
7. Lengthy process for Personal budget paid as Direct Payments	
8. Time taken to process Financial Assessment and poor information	
9. Lack of consistency in personnel dealing with service user	

These themes are picked up in later sections, particularly with respect to availability of suitable training for the social care workforce to ensure the smoothest customer journey.

Research feedback from users indicates that a number of adjustments to the customer pathway would assist in delivering a more robust customer journey, as detailed in our recommendations.

## **5.4 Feedback re substance misuse service users**

Feedback, from the broker, indicated that there was, already in place, a clear understanding of the differences between 'traditional' pathways and the new personalised pathway, described as:

Traditional Pathway:

- Service user given block contracted service: Priory, Home Detox, or Outreach Community Support

In the new Pathway:

- Scores from SADQ and SDSS calculate budget
- Service user given menu of service options, or can find and suggest alternatives provided they are safe and meet outcomes
- Wrap around services.

## **5.5 Recommendations: Customer journey**

**R5.1 Signposts to first contact:** Develop communication strategies with partner organisations to enable potential service users to be more effectively signposted to Adult Social Care, rather than waiting for (expensive) crisis intervention

**R5.2 Service user focus:** Develop working practices to ensure that the focus genuinely is on the user, rather than Council process or service led

**R5.3 Service user focus:** Ensure the service user is kept in the loop so they know what is happening throughout the customer journey

**R5.4 Information:** Should be clear and accessible, provided on initial contact before the customer journey starts, about:

- Eligibility Criteria: How eligibility is assessed, options if user not eligible
- The Assessment Process: Before assessment, user provided Supported Self Assessment Questionnaire (SSAQ) copy with completion instructions and highlight choice of support options (family, friend, advocate or support broker)
- The SSAQ: Once processed, user provided with copy, outcome and indicative budget
- Personal Budget process: What this is and how it works
- Support Planning: Advice and support options
- Brokerage: What this is, what support, advice is available

- R5.5 Continuity:** A consistent Care Manager/ Care Co-ordinator/ Occupational Therapist should be allocated to the service user for the duration of their engagement
- R5.6 Consistency:** Ensure consistent working practices are applied across all Locality Teams and impairment groups to ensure equity
- R5.7 Communication and accessibility:** Provide appointments that take account, where possible, of the needs and availability of the service user
- R5.8 Accessibility:** Ensure systems and practices ask the service user what their communication needs are, ensure this is recorded and that all future communication is in this agreed accessible format
- R5.9 Responsiveness:** Referrals to Financial Assessment and Benefits team and/or to Independent Support Broker should be in a timely manner to avoid unnecessary delays and uncertainty for the service user

## 6. Barriers to Personalisation

**This chapter presents the research we did with users concerning the barriers they felt should be removed to help make Personalisation a reality in their lives.**

This section adopts a Social Model of Disability perspective, looking at disabling barriers.

Our findings from users are categorised into 6 barrier categories.

### 6.1 Considering barriers

Having already identified that users experienced some difficulties undertaking the customer journey; the researchers wanted to identify what other barriers might exist to Personalisation.

To help identify potential barriers, users were asked to discuss the following questions:

What do you think are the main barriers to Personalisation producing good outcomes for service users?

Do you think the social care workforce presents barriers and if so how?

- i. Care Managers and the system
- ii. Staff delivering the service

How does the social care workforce need to change to remove these barriers?

- i. Care Managers and the system
- ii. Staff delivering the service

What could prevent Service Users having real choice and control?

## 6.2 Evidence gained

From discussion of these questions, users identified a range of barriers which have been categorised as follows:

1. Information and jargon barriers:
2. Communication and empathy barriers
3. Structures and system barriers
4. Resource barriers
5. Cultural change and risk barriers
6. Attitudes of family and friends

### 6.2.1 Information and jargon barriers

Information was identified by many users as the key to allowing both users and the workforce to understand the values and philosophy underpinning the Personalisation agenda.

<p>Many users felt it would have been helpful to have received a booklet about how the system was changing before the Care Manager visited them to do the assessment</p>	<p><b>“I would have felt less worried about the meeting if I had known in advance what it was all about”</b></p>
<p>Users felt that there needed to be a greater awareness amongst the general public about what changes were going on in social care.</p>	<p><b>“I tell my friends about it and they don't know what I'm talking about. Not even my GP knew. They should have information at the surgery”</b></p>
<p>Several users mentioned that information should be distributed to 'mainstream' services such as local libraries and GP surgeries.</p>	<p><b>“Not many users read Community Care!” Joked one of the members of the Hampshire Personalisation Expert Panel</b></p>

In the focus groups, there was a fairly low awareness amongst users of what Personalisation was and what it really meant.

**“Cut out the gobbledegook”**

**“It's all just jargon to me”**

Another view expressed at the workshop was that Personalisation was just a new term for direct payments. This indicated users were not yet aware of the full meaning of Personalisation and current information and communication did not effectively communicate the difference.

**“Why don't they use terms that everyone understands..... resource allocation system means nothing to me”**

Users who were already accessing Direct Payments or Personal Budgets had a good awareness of Personalisation.

Users of Bedford House also had a good awareness of Personalisation, due to the proposed closure of services at Bedford house.

However, Users of Prospect House appeared to be less aware of Personalisation and how it may affect them or their services.

Even users attending the Hampshire Personalisation Expert Panel meeting reported that the over usage of jargon was sometimes bewildering.

**“All this new jargon is a way the workforce can keep control”**

Coupled with this, users reported that there was a lack of availability of information about what personalised services are available within the local community. It is clear that if users cannot access this information easily, it will be hard for them to make informed choices about what services may be best to achieve their desired outcomes.

**“They say day centres may close, but what else is there? I don't know”**

This was a particular concern for people who had used Bedford House.

**“Some people don’t want to approach professionals  
– the weekly group helps in this”**

**“I would prefer to be with others with  
similar problems”**

This illustrates a real need for users to be able to access peer support easily.

**“People without a voice cannot be heard  
which is why SCIL is so helpful”**

## **6.2.2 Communication and empathy barriers**

Surprisingly to the researchers, many users reported that one of the biggest barriers to Personalisation was that the social care workforce, particularly Care Managers, appeared to lack good communication skills in the way they engaged with users.

**“There was no attempt to build a rapport with  
me; he was just filling in a form.”**

**“If you do speak, it would be nice to have  
evidence that they have listened”**

Whilst there was some understanding from users that Care Managers were still learning the new way of working, users were less forgiving of the lack of preparation Care Managers appeared to have done before attending the appointment with the user.

Users reported this several times throughout the Workshops and it was obvious that this had had a really detrimental effect on the quality of the relationship between the user and the Care Manager.

**“She hadn't even read my notes or learnt anything about my condition so I had to go through it all again”**

**“If she can't be bothered to read my notes, why should I bother to answer her questions?”**

On a more positive note, users also reported that Care Managers seemed unfamiliar with the processes and procedures around Personalisation but this had to some extent levelled the playing field.

**“The Care Manager was very honest and said she had never done it this way before so we tried to work through it together”**

Users also reported positive interactions with workforce not directly employed by the council.

**“I spoke to Hayley at MIND and she explained it so I could understand”**

**“Talking to the broker from SCIL was like a breath of fresh air after being in a smoke filled room”**

Users valued the support of Brokers employed independently from the Council, for the following reasons:

- Users felt the Brokers knew more about the process and procedures so were able to explain it better
- The Brokers, through the nature of their employment, are seen by users as more empathetic of their situation and have wide experience of advising other users in similar situations and are able to bring the experiences and solutions of other users to use

This suggests that users value third sector organisations, seen as empathetic by users, may be ideally placed to provide high quality

advice, information and empathetic support that users value throughout the customer journey.

### 6.2.3 Structures and system barriers

Users understand that it will take time for Southampton City Council to make changes across the whole system to adapt to Personalisation. Users felt frustrated that on the one hand, an outcome based approach was adopted by the Care Manager and the Support Broker, but that the final agreement on funding appeared to users to be based on traditional criteria which have not yet been adapted to the needs of Personalisation.

**“We worked really hard on the support plan but it kept getting rejected. Eventually we gave up.”**

**“You need to enable people to meet their aspirations, whatever their needs”**

There appears to be a real tension between the aspirations to make support planning about outcomes and the need for the Local Authority to be clear and specific about what needs are met and any potential risks.

**“Provide realistic services; do not promise what you cannot deliver”**

Users often felt that Care Managers may understand their needs but that Team Managers and others who make the final decision do not see the 'whole person'

**“They [*the managers*] don't see me on a bad day. They just sit in their office”**

**“We need fewer managers and more people on the ground”**

There was also a concern regarding users seeing different Care Managers at each meeting or review because of the difficulties caused by this lack of continuity.

**“There's no consistency, and no handover”**

**“You have to start at the beginning every time”**

Encouragingly, users reported that long delays during the assessment process were now the exception, rather than the norm.

#### **6.2.4 Resource barriers**

The implementation of Personalisation is not happening within a vacuum. Many users mentioned the financial difficulties that the Local Authority was dealing with at the present time. Users found it hard to determine whether changes were related to Personalisation or to the difficult financial situation.

**“There's so much going on, it's hard to know what will be good and what will be bad”**

One user who got equipment from sensory services felt choice was more restrictive rather than less restrictive.

**“They used to offer choice but now you take it or leave it”**

#### **6.2.5 Cultural change and risk barriers**

Influential reports have already been written concerning the need for cultural change within the context of Personalisation. (*i.e. IBSEN 2008, 'Evaluation of the Individual Budgets Pilot Programme Final Report', Individual Budgets Evaluation Network*)

Users, as well as the Hampshire Personalisation Expert Panel, agreed that cultural change was probably the most important change which was necessary if Personalisation was to achieve its ambitions.

**“You can't just impose culture change on people. It evolves over time and that may be over a long time”**

**“There's too much emphasis on process. We need to win hearts and minds for things to change”**

Users felt comfortable with support from statutory organisations and also from third sector organisations (not only ULO's but also organisations like Citizens Advice Bureau (CAB) whose information provision was particularly valued). However, many users did not realise or welcome increased private sector service provision.

Mental health service users particularly valued community based health services (nurses, councillors etc) for the support they provided in helping to self manage and maintain their wellness.

Users generally felt that with the right support and information services they would not need much input from Care Managers or Care Coordinators, but that having them available as a safety net when needed was highly valued.

Users wanted a cultural change from an attitude which still exists of 'professional knows best' to one of service user choice and control over services which enabled users to look at their lives holistically.

**“No-one is qualified to understand me as well as I am”**

## **6.2.6 Attitudes of family and friends**

People with Learning Difficulties, in particular, voiced a concern that Family and Friends may not let them take control.

**“They need to know where I am. I can't go on the bus on my own”**

There was also a concern from these users that the Care Manager listened to the family more than the Disabled Person themselves.

These users wanted advocacy service availability and the choice of being able to meet the Care Manager away from where the Disabled People lived to enable them to say what they wanted.

### **6.3 Feedback re substance misuse service users**

Feedback, from the Broker, indicated that the workforce culture is, that social care professionals 'know what's best', and tell service users what they need and can have, (i.e. "Do to, rather than do with").

The workforce approach was felt to be 'Medical Model' and risk averse, with an unwillingness to change without substantial evidence of benefits from Personalisation.

The service focus is on high and urgent needs. "Usually service users coming into the system are in crisis" and due to staff shortages there is a backlog of service users awaiting a comprehensive assessment and service provision.

It was reported that a minority of service users can find, that having a personalised choice of services, bewildering or confusing and consequently prefer being offered traditional services. Our researchers considered this to be an issue of support needs being appropriate to the individual.

There was felt to be a lack of choice for peer support for alcohol and drug dependency. Service Users prefer peer support to be specific to their dependency.

#### **"Service users with alcohol dependency do not identify or get on with drug dependency service users"**

The majority of service users were reported as uninterested in setting up and sustaining peer groups. The nature of substance misuse is being able to move on. People want to put these issues behind them and be independent and therefore tend not to want any more involvement than is necessary.

However there are still a minority of service users who would be keen to have involvement with peer support groups and developing service provision.

There is limited information of what services are available and how to access them and there needs to be more accessible information and publicity.

## **6.4 Recommendations: Barriers**

Recommendations have been grouped into the same 6 categories:

### **Information and jargon barriers**

**R6.1 Clear information for users:** Produce a brief introductory booklet, in a variety of accessible formats, (*Large print, Audio, Braille, easy read, alternative languages etc*) about how social care is changing and how it will affect users (new and existing). Include a glossary of jargon / unfamiliar terms. The booklet should be developed collaboratively with users and Carers

**R6.2 Reduce over-usage of jargon:** Reduce amount of jargon used in all materials, policy and procedures, and provide clear glossary explaining terms that are used

**R6.3 Community information:** Information regarding Personalisation and potential services on offer to be distributed to wide range of 'mainstream' services e.g. libraries, community centres, and social clubs. Information about Council Services, User Led Organisations, Social Clubs, Care Agencies and other Third Sector Organisations should be included

**R6.4 Timely communication:** Information about Personalisation should be provided to users in advance of an assessment or review to allow users time to consider Personalisation in their lives

**R6.5 Support for specific groups:** Consideration should be given on the best method of communicating and supporting users of day services and residential care, who may feel particularly threatened by Personalisation

**R6.6 Information technology:** The Council and User Led Organisations should be encouraged to work together on developing useful online resources to support users and front line staff in understanding Personalisation.

**R6.7 Maintain service directory:** Develop and maintain a 'bank' of available services or support groups which users can purchase with part of their personal budget. Encourage user input and evaluation

### **Communication and empathy barriers**

**R6.8 Training for workforce:** Refresher training offered to front line staff on core communication and listening skills, including preparation before visiting users to build rapport and awareness of user needs and situation. Training to be co-produced with users

**R6.9 Training for users:** Provide training for users about what Personalisation is and how they can use it to live independently and achieve goals. Provided by users experienced in Personalisation

**R6.10 Peer support:** Provide access and resources for peer support, one to one and in groups. For users to learn from each other's experiences of Personalisation. Peer support should also be available online through the use of moderated internet forums and social networking sites. Invest in setting up and sustaining peer support groups

### **Structures and system barriers**

**R6.11 Finance decisions to be Personalisation friendly:** Conduct an audit of financial decision making processes to ensure they are 'fit for purpose' and compatible with outcome focus of support plans to enable successful and timely delivery of Personalisation

**R6.12 Transparency with users:** Provide clarity with users over decision making procedures and appeal mechanisms. Clear information on complaints procedures

## **Resource barriers**

- R6.13 Empower front line staff:** Front line workforce to be supported to discuss issues of resources, when they may impact on decision making, in an honest and transparent way
- R6.14 Prevention:** Investigate with users, cost effective ways to provide preventative and lower level service provision to avoid crisis. Users are likely to have solutions

## **Cultural change and risk barriers**

- R6.15 Users to lead in culture change:** Users should be much more involved in training and supporting the workforce on what Personalisation achieves for the lives of users. This will assist in achieving culture change and to win hearts and minds
- R6.16 Discourage ‘professional knows best’ attitude:** Facilitate statutory and community based support, advice and information services which empower users to self manage their needs holistically, stay well and in control for longer; but with a statutory safety net when needed
- R6.17 Positive risk taking:** Front line workforce to receive training and support around positive risk taking and the importance of empowering and supporting users to take risks where appropriate to ensure Personalisation meets its potential. Increased support to be provided by managers to ensure workforce feel supported when taking decisions around risk

## **Attitudes of family and friends**

- R6.18 Supporting family and friends of users:** Provide appropriate information aimed at family and friends to reassure them and explain their role within the process of Personalisation to support the empowerment of the user
- R6.19 Space for people with learning difficulties to have a say:** Care managers should provide options to enable users to say what they want, rather than family members being in control

## 7. Role of users and carers in Personalisation

**This chapter presents our findings for roles that users feel they should have in Personalisation.**

Users identified three main roles which they felt would achieve more personalised solutions:

1. Peer support groups
2. Collective service provision
3. Training/supporting the workforce

### 7.1 Considering roles for users and carers

The questions we asked were:

Government policy recognises that service users are best placed to judge whether services meet their needs and enable them to live independently, not just ‘professionals’.

How can professionals and users work together to achieve good results?

Do you think that more power and resources being shared with people on the front line – service users, Carers and front line workers – will find solutions to living independently for service Users?

What roles should users and Carers have?

Users were enthusiastic about co-production and felt this should be the principle method for users and Carers to achieve change. Co-production is discussed in **chapter 8**.

At our workshops, users found it difficult to identify discrete roles, through lack of awareness of what functions they could have a productive role in. In the main, users felt that if they were in co-productive discussions with Adult Social Care, they would probably be able to identify roles for users and carers after they had built their awareness and confidence. Researchers understood users to be in a 'chicken and egg' situation.

Whilst users found it difficult to identify new roles, many did have experience of roles which they didn't find as useful as they had hoped:

**"I sit on the Citizen Leadership Group but I don't know how much we really get done"**

**"I would need a lot of help to understand what you were all talking about"**

## **7.2 Identification of roles for users and carers**

However, users did identify three roles which they did feel would work well for Personalisation, both collectively and individually:

1. Peer support and support groups
2. Collective service provision
3. Training/supporting the workforce to understand what Personalisation achieves for users; in the process effecting culture change

### **7.2.1 Peer support and support groups**

Users strongly identified that various forms of support groups were the most valuable method they had experienced of gaining mutual support, advice and empowerment, from the experiences of people in similar situations to themselves.

Users from Bedford House (Mental Health Service Users) most strongly identified the value of support groups.

**"What we miss most from closing of clubs is someone coming in once a month to help us with our problems"**

**“Some people don't want to approach professionals  
- the weekly group helps in this”**

**“You all feel in the same boat - with the same problems”**

**“I remember when you didn't get support and you really  
struggled, but now, it's really great”**

**“Having somewhere to go....an informal drop-in centre  
when you're well enough...this is our biggest need”**

**“Social Services offer support but is very much recovery  
based... whereas MIND runs services which are very  
good at supporting people who can be quite ill”**

## **7.2.2 Collective service provision**

Some users could see the opportunity of pooling their personal budgets to set up their own ULO's to provide services or to run peer support groups to meet their needs, and the needs of others.

However, users were adamant that whilst they would be able to run these services/groups when they felt well, they would need support from others when they had periods of being unwell.

**“If I wasn't very well, I wouldn't be able to cope and  
organising things would bring extra stress”**

**“Yes, if I could use the money...I would do this”  
[setting up self-help group with Direct Payments]**

**“You need a small multi-skilled committee to take over  
running it if you're not well”**

### **7.2.3 Training/supporting the workforce to understand what Personalisation achieves for users; in the process effecting culture change**

Users throughout this report have identified the need for improved communication with the workforce, collectively and at a personal level to help the workforce to understand user's situation, needs and expectations.

Communication is clearly a key issue.

Users felt they could have a role in working with, training or supporting the workforce to help them understand the issues of users, help them understand how their lives have changed through personalised services. Users felt this would be an important way of effecting culture change within the workforce.

## **7.3 Feedback re substance misuse service users**

Feedback, from the Broker, reinforced the need for more commitment to peer support and investment in setting up and sustaining peer support groups, these groups could provide low level social and emotional support.

In addition these groups could facilitate co-production in future service developments; develop and carry out service user audits.

Peer support groups could also provide a mechanism for service user feedback and recommendations about:

- Quality of domiciliary support
- Quality of residential rehabilitation stays
- Customer journey
- Quality of life questionnaire

## **7.4 Recommendations: Role of users and carers in Personalisation**

**R7.1 Co-production will enable users to identify roles:** Development of co-production will encourage users to get involved, gain

confidence, knowledge and empowerment; thereby enabling users to develop into new roles to support Personalisation developments

**R7.2 Facilitate and support development of peer support and general support groups:**

Develop a strategy to encourage development of user controlled support groups which work from a self-help principle to enable users to support each other and find empowering solutions to their lives. The strategy will need the availability of specialist support when users need it

**R7.3 Facilitate and support development of collective support provision:**

Develop a strategy to enable and support small groups of users to pool budgets to meet their collective needs, and to compliment individual solutions

**R7.4 Provide opportunities for users to train and support the workforce:**

Users have a valuable role working with the workforce to improve the understanding of how Personalisation changes lives and therefore effect culture change in service provision

## 8. Role of co-production

**This chapter presents our findings concerning users understanding of, and enthusiasm for, co-production.**

We present recommendations to enable Southampton City Council to develop a strategic implementation of co-production, based on the views and preferences of users.

### 8.1 Considering Co-production

For the purposes of this project we adopted the following definition of co-production (*see section 4.3*):

**“The co-production model of care and support recognises people who use services and carers have assets and expertise that should be valued. Co-production means moving away from “doing the same thing, only trying to do it more cheaply” towards sustainable public services that meets needs and provides better outcomes. Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered”**

Users generally welcomed use of the term ‘co-production’, as they felt it did accurately focus on the need for Adult Social Care to work in a meaningful partnership with users.

Users highlighted the need for joint working to be embedded within the work of Adult Social Care.

**“We could tell them what works well and what doesn't”**

**“*[Co-production is]* A bit like you are doing today”**

**“I don't just want to give my opinion; I would like to be involved with what they do next”**

However, some of those we spoke to felt that a new term would not have been necessary if terms like ‘consultation’ had not been misused in the past.

**“It’s a lot more than consultation”**

From this user feedback, it is felt important, that if Adult Social Care does use co-production in the future, then it will be important that all involved develop a proper understanding of the meaning of co-production, and only use it when the function is co-production, rather than a substitute for consulting or simply informing.

The Hampshire Personalisation Expert Panel, from their experiences of co-production expressed their view that “co-production needed to be demonstrated and evidenced in a very concrete way”:

**“Co-production is often overused or wrongly used”**

**“There needs to be real evidence that joint working between staff, users and carers is regularly happening, with specific aims and outcomes in mind”**

Users felt that co-production presented many opportunities for empowering users and assisting the workforce to adapt to the Personalisation agenda.

By harnessing the expertise of both the workforce and users themselves, users felt that co-production had the potential to share their issues and ideas with the workforce and develop a better understanding of the needs of users. Users welcomed the opportunity to work together to develop better services as a result of co-production.

It was felt by users that some types of work may lend themselves more easily to working in co-production with users. Discrete pieces of work with a clear start and end date, with clearly defined objectives may enable both the workforce and users to identify their role within the process, and very importantly demonstrate how their involvement made a difference.

## **8.2 Co-production case studies**

In order to understand the difference between co-production and other forms of involvement, users found it useful to see examples of co-production in action, rather than simply discussing concepts by way of a definition.

We focused our usage of examples on the Hampshire Personalisation Expert Panel (PEP) and the national development of the Independent Living Strategy (ILS).

**NB: Co-production Case Studies: Appendix C**

We asked users at the workshop focus groups about these models of co-production and they were broadly supportive of the PEP approach to co-production.

**“I like the idea of setting our own agendas and being involved”**

A senior manager from Hampshire Adult Services was very positive about the effect the Personalisation Expert Panel had on their department:

- *“It's really helped officers think about things from a different perspective.” “We've seen a real change in attitudes around user involvement over the last 18 months”*

Some Workshop members felt co-production should not just be restricted to issues to do with social care:

**“Service Users should be involved across all council services”**

### **8.3 Feedback re substance misuse service users**

Feedback, from the Broker, indicated that, at an individual level, co-production is already a well practiced principle.

For instance, personal health budgets for alcohol dependency, is a collaborative process where the service user is involved with support planning, choosing the services they have identified that will meet their stated outcomes.

**“The focus is on the abilities and how these can help with recovery”**

### **8.4 Recommendations: Role of co-production**

**R8.1 Define and use co-production with care:** Southampton City Council should agree a shared definition of co-production and develop a strategy for when it would and would not be appropriate to co-produce results with users. This recommendation will stop co-production as a term from being misused which users find disempowering and de-motivating

**R8.2 Develop a Southampton PEP:** Users welcome the establishment of a Personalisation Expert Panel for local users and Carers to work jointly with officers from Southampton City Council to monitor and review workforce developments to ensure they are aligned to the Personalisation agenda and meet agreed outcomes

**R8.3 Co-production focus:** Co-production is felt by users to be particularly effective for designing and delivery of training, and future service developments

## 9. Training and support needs of service users

**This chapter presents users views of how they feel about their training and support needs, to enable them to use Personalisation effectively to meet their needs.**

Users discussed what training they needed, and how this training could be most effectively provided.

### 9.1 Considering training and support for users

Training and support is routinely provided to the social care workforce, and is considered essential to meet the professional expectations of their roles.

However, there is far less acceptance of the need to provide empowering training and support to users. For Personalisation, involvement and co-production to be most effective, users and carers obviously need to be trained and supported. This means users must have skills, knowledge, understanding of their rights, as well as having confidence in their selves.

Without training, users will not be well equipped to make the best of Personalisation or to get involved in helping the Council through involvement and co-production.

The questions the research team asked the Workshop were:

What 'formal' training do you feel you need to enable you to take full advantage of the Personalisation agenda, if any? Core roles of recruiting; managing; being an employer; budgeting; sourcing and negotiating with providers etc.

What 'personal development' training do you feel you need to enable you to take full advantage of the Personalisation agenda, if any? Empowerment, Personal Development, peer support training?

How would you like this training provided?

## **9.2 Evidence gained**

Users were clear that training and support for users would be essential for users to make the most of Personalisation.

Despite concerns from some users about 'being thrown in at the deep end' by being moved from a service where they did not have to make decisions to a service where they did.

However, most of these users did want to have choice and control, particularly if they knew they would be supported.

**"We're not all used to making choices and thinking about consequences. It's exciting and scary at the same time"**

**"Now I know about SCIL, I would take anything on, as I know I could ask you if I got stuck"**

## **9.3 Skills based training needs**

For users to be able to make the best of Personalisation, training topics that were identified by users included:

- What Personalisation is
- Writing support plans
- Keeping safe
- How to find out about services they could use
- Managing money
- Finding good staff
- What to do if it all goes wrong

## **9.4 How to meet users training needs**

Some users felt they received this training from their broker, on a one-to-one basis; others felt a workshop or training session would be more useful for them:

**“You could meet other people who were nervous too. Then I wouldn't feel you were the only one”**

**“People with mental health problems may have difficulty absorbing information....something tailor-made....a CD Rom followed by a talk”**

**“The whole environment, including access, is important”**

**I'm finding out how difficult it is to find out about training and where to go, If you're not internet literate, it's doubly difficult”**

**“We tried a computer course at a local technical college but it was out of our league....we couldn't get the help we needed”**

**“Support is needed to help you and to encourage you”**

The majority of users believed that peer support was needed and they should have a choice of who provides support and training.

Key support needs identified, were:

- The assessment process
- Support planning
- Ongoing support

Users said they felt more comfortable, confident and more trusting in someone with whom they could empathise. A peer who had direct experience of the barriers, issues and concerns they faced as users and could relate and understand the user's circumstances.

Users also believed that any support mechanism whether peer-based, independent, commercial or statutory should have experience, specialist knowledge and skills for particular service user groups.

Users felt training should be provided free of charge and delivered by a combination of public and voluntary organisations. (e.g. Charities; peer support groups, ULO's, colleges)

Users felt it important to have training delivered by people who understand and have experience of impairment.

Users said training opportunities must be accessible and tailored to people's needs. Users understood many of the different methods for training, and were keen to try them out (e.g. distance learning, web based training, DVD, or training held in small groups at accessible local venues such as libraries, colleges, community centres, peer support, self-help or informal drop in sessions)

## **9.5 Role of personal development**

Some users reported higher levels of disempowerment than others, some were enthusiastic about Personalisation, whilst other saw it as a threat or for people 'other than them'.

However, whilst most of the users agreed that personal development was probably important, many of them didn't really understand the term or what it would involve. Some of the users for instance didn't understand what the Social Model of Disability or Independent Living meant or how an understanding of it could change their lives.

It was clear to the researchers therefore that the importance of personal development was accepted by users, but that until users had experience of personal development training, they would not be able to assess how beneficial it could be.

Many users were a long way from understanding of how to manage their impairment, develop an understanding of the principles underpinning Personalisation and how society treats Disabled People. Researchers experience is that skills based training often highlights user awareness of the need for personal development.

## **9.6 Feedback re substance misuse service users**

Feedback, from the Broker, highlighted service users need for training to help identify, understand and manage risk, and to make Wellness Recovery Action Plans (WRAP)

## **9.7 Recommendations: Training and support needs of users**

**R9.1 Develop training programme for users:** Users should be provided with appropriate skills based training to enable effective use of Personalisation. The following skills were identified:

- What Personalisation is
- Writing support plans
- Keeping safe
- How to find out about services they could use
- Managing money
- Finding good staff
- What to do if it all goes wrong

**R9.2 Modular training:** Modular training for users should be developed (in conjunction with users), to enable users to choose appropriate modules for their needs and chosen services

**R9.3 Personal development:** Investigate provision of personal development training to meet user needs for confidence building, self-worth, assertiveness, understanding of empowering models such as the Social Model of Disability and Independent Living

**R9.4 Role of peers:** Consider development of a training, support and mentoring scheme where more confident users can support less confident users, using the principles of peer-support

**R9.5 Flexible training options:** Employ a range of training methods to maximise user engagement and collaboration

**R9.6 Risk management training:** Provide training to enable users to make positive risk assessments

## 10. Functions of Adult Social Care in Personalisation

**This chapter records the views of users concerning how Adult Social Care functions should be focused.**

Users were very aware of the difficult financial settlement imposed on Southampton City Council and the need of the Council to decide what it was and was not able to provide in the future

We encouraged users to say what they felt were the most important functions, which should be preserved.

Users did consider there to be broad areas of responsibility which Adult Social Care should retain. However, users were less concerned over the detail of which organisation did what, so long as the role was done well and with the user empowered and in control.

### 10.1 Considering the context of Adult Social Care

Users agreed that Personalisation will require a review not only of the systems underpinning Adult Social Care, but also the Adult Social Care workforce and its culture.

The financial context presents a challenging environment for these changes. (*“A minimum 25% Government budget reduction, which could mean as much as an 11% reduction in staff resources”*: Project specification, Appendix A(1))

Additionally, Southampton City Council has a policy position that Direct Payments will be the default position for all service users, which provides a top level policy commitment, which the Personalisation agenda will need to take account of.

Within this context, users understood the importance of reassessing what roles should Adult Social Care be doing and what roles might best be done by other organisations, or users themselves.

The project specification asked us to obtain user views about what the functions of Adult Social Care should be to enable users to realise the person centred goals of Putting People First (PPF), which are:

“ that all people irrespective of illness or impairment are supported to:

- Live independently
- Stay healthy and recover quickly from illness
- Exercise maximum control over their own life and where appropriate the life of their family members
- Sustain a family unit which avoids children being required to take on inappropriate caring roles
- Participate as active and equal citizens both economically and socially
- Have the best possible quality of life irrespective of illness or disability
- Retain maximum dignity and respect”

## **10.2 Evidence Gained**

Users had some knowledge of how Adult Social Care functions within the context of Personalisation. Users knew it was important to remember that the Local Authority have statutory duties in relation to:

- Assessment
- Safeguarding
- Duty of care

### **10.2.1 Functions**

After discussing these issues, users concluded that the Local Authority’s main functions in delivering Personalisation should be:

- Transparent allocation of resources according to needs (*i.e. the body that decides how to allocate available resources*)
- To provide monitoring proportionate to risk, and service user demands. (*i.e. monitor and meet duty of care*)
- To provide a safety net for when things went wrong. (*users wanted control and choices, but recognised that impairment fluctuation or other factors may result in the need for someone to take over*)
- To monitor quality of care provider services, and facilitate a feedback mechanism to ensure service providers are more accountable to both the Local Authority and the user
- To provide a safeguarding mechanism, where concerns could easily be reported, and dealt with

## **10.2.2 Delivery agents**

However whilst users felt that the Local Authority should retain responsibility for ensuring the functions listed above were delivered, some aspects of the delivery of these roles could be performed equally well, if not better by other organisations.

We should be clear to state that whilst some users were familiar with third sector delivery, (and liked how they were treated and empowered by these organisations), most users did not know about other organisations, other than those who provided the services they used.

Our researchers felt that users understood and were comfortable with what they knew worked for them, and did not have familiarity with other sector providers and therefore could not express an opinion.

However, our main finding, which surprised the researchers, was that users by and large did not care who provided services and support. What mattered to users was that they wanted whoever provided their services or support to have direct experience of impairment, appropriate skills and to be well prepared and empathic/empowering and to communicate well.

Our other important finding in this discussion, was that users kept saying Adult Social Care should go 'back to basics' with what they called 'old style social worker skills'. Users wanted social workers who helped them

find solutions in their lives, whereas now-a-days they felt Care Managers were principally resource gatekeepers and no longer 'on our side'.

Users wanted access to high quality on-going support, when required, but not for it to be intrusive.

Finally in this section, users wanted consistency, people they knew and trusted (and who knew the user), particularly brokerage, information and on going-support, but wherever possible for the whole customer journey. Time and again, users complained about never seeing the same person twice, which resulted in lack of consistency, knowledge and understanding.

**"Someone who knows what they are talking about"**

**"[someone with] Information on self-help"**

**"Someone who understands disability"**

**"Independent advocate, the Disabled  
Person decides who this is"**

**"Service user choice so they do not  
become restricted"**

### **10.3 Feedback re substance misuse service users**

No specific feedback was received for this section.

### **10.4 Recommendations: Functions of Adult Social Care**

- R10.1 Main roles for Adult Social Care in Personalisation:**  
Should be focused on: transparent allocation of resources, monitoring risk, provision of safety net, quality monitoring, and safeguarding.

- R10.2 Internal or external service provision decisions:** Commissioning of services should be based on skills and competencies required, as valued by the user.
- R10.3 Users value old fashioned social work skills:** Users want support from individuals who help them find solutions in their lives, with knowledge of what works for other users. This role is not considered by users to be compatible with finance based decision making
- R10.4 Consistent application of human resources:** Users want consistency of workforce provision from those supporting users during the customer journey. Staff changes result in poor quality contact, lack of consistency and communication

## **11. Skills and competencies required in the workforce**

**This chapter provides a user perspective on what skills and competencies they considered most important.**

Users identified a number of skills and competencies which researchers analysed for this chapter to fit within the Putting People First (PPF) standards.

Users considered these issues were fundamentally important if Personalisation was to be successful. However, users felt the skills and competencies were the important factor. Who the provider was, was less important.

### **11.1 Considering skills and competencies**

Government has said it wants to see a continued increase in the scale of services procured from non-statutory sectors, which have traditionally been provided by Local Authorities. Government also wants Local Authorities and third sector organisations to work together in delivering Personalisation in Adult Social Care.

In order to facilitate a better understanding of how this might work, the research team wanted to identify what users felt the key skills and competencies needed by the workforce were.

We wanted users to consider what skills and competencies would be needed to deliver the seven PPF standards, which we explained are to:

1. Live independently
2. Stay healthy and recover quickly from illness
3. Exercise maximum control over their own life and where appropriate the life of their family members
4. Sustain a family unit which avoids children being required to take on inappropriate caring roles

5. Participate as active and equal citizens both economically and socially
6. Have the best possible quality of life irrespective of illness or disability
7. Retain maximum dignity and respect

Users were asked the following questions:

Users know that front-line workers should focus on people's abilities rather than seeing them as problems and they should have the right skills to do this.

What are the right skills in your opinion for the social care workforce to have?

It has also said that developing social care staff confidence is very important so they can support service users, how should this be achieved but still putting service users first?

## **11.2 Evidence gained**

From the workshop, users identified a number of key skills and competencies that they felt were required for the future Personalisation focused workforce.

These are explored in detail:

### **11.2.1 Ability to communicate with a diverse range of service users, service providers, and statutory agencies**

**Communication skills:** As previously discussed in the 'Barriers' chapter, communication was a key theme throughout. User experiences of individual workforce staff's quality of communication skills varied. Users found this variance to be unacceptable for such a basic and essential skill, and felt that training and support systems should ensure consistent communication standards.

**Listening skills:** It was clear that the majority of users felt the ability to communicate with a diverse range of people was an essential core skill of any one providing support. A clear consensus believed more emphasis should be placed on the workforce listening to what the service user has to say and that they are empowered to speak freely by providing sufficient time and an empathetic approach.

**Empathy:** Furthermore users felt the workforce should be less judgemental and their approach should be one of working with and for the service user to empower, inform and advise.

**Power:** Users wanted a more equal partnership with the workforce, where users had more power, choice and control.

**“It is important to have support  
and to build up trust”**

**“I find Social services people who come  
round to be insensitive, even hostile”**

**“They must listen to the service User”**

**“Open dialogue with Social Services, Service user and  
Social Services staff should have an equal relationship”**

**“Recognise [my] needs and accept them”**

**“They should be easily contactable and responsive”**

## **11.2.2 Ability to support users with self assessment and person centred planning**

### **Support with self assessment:**

Workshop responses were inconclusive about the necessity for assistance with the Supported Self Assessment Questionnaire (SSAQ); though the general view was the majority of users would either like,

prefer; or need support, and that they felt they should have a choice of who supported them with their SSAQ.

Some users felt it was important to have peer support provided by Disabled People during the self assessment.

A few of the users felt they may need some support but that this was best achieved with family members, existing Carers, or close friends. However others felt they would not know where to start, or did not want the additional burden of doing this unsupported, or would not be confident to tackle this alone.

**“Not being able to participate fully  
in the assessment process”**

**“I’m not being assessed as a priority case”**

**“It would be nice to have a letter  
to clarify the situation”**

**“Some of them might have set ideas on how you are”**

**“Have understanding of individual so  
that they are not just a number”**

**“Need a properly trained Care Manager  
to help self assessment”**

### **Knowledge of person centred planning approaches:**

The majority of users felt that they would either like, prefer, or absolutely require support with drawing up and implementing their support plan.

Some users felt they would not need assistance with planning. Some users felt they may need some support but that this was best achieved with family members, existing carers, or close friends.

However others felt they would not know where to start, or did not want the additional burden of doing this unsupported, or would not be confident to tackle this alone.

This group felt having independent advice from a Third Sector organisation or ULO would be highly valuable.

**“More peer support is needed”**

**“Easier if more person centred/better continuity”**

**“More time needed to be spent at the beginning”**

**“Spend more time in the beginning  
giving power and knowledge”**

**“We need more knowledge of what is available  
and signposting and packages of ideas”**

### **11.2.3 Knowledge of statutory, community and voluntary resources within Southampton**

The majority of users lacked awareness and understanding of Personalisation before attending the workshops; however, following on from the information they received during our research, the majority of users stated they now had their own ideas of how best to meet their needs.

Some users believed they could find services or resources to meet these needs from their existing knowledge. However, there were others who felt they would need advice and information about the services and providers available in the: commercial domiciliary care market; the voluntary sector; the local community; leisure and educational opportunities and recruiting and employing their own Personal Assistants, as well as finding out about suppliers of equipment, aids and adaptations.

**“I’m not always aware of the services available and therefore need people to support me”**

**“It’s nice to be able to choose what you’d like in the way of services”**

**“The person supporting me needs to be knowledgeable, and have the ability to be able to sign post”**

**“It would be nice if they said these are the services and you can choose what’s best for you”**

**“Services that are available need to improve – more types and specialist services”**

**“Offer more advice and information”**

**“Have a directory of services”**

#### **11.2.4 Ability to support users with financial and budget management**

Many users felt they would need support with planning and budgets for their Personal Budget.

A few users also expressed the view that they would need assistance to manage the budget, and would prefer a representative to do this for them. The majority of users felt they would be able to do it themselves without any support; or would be able to with initial support and some training.

Users accepted that planning and budgeting was an essential skill and good basic knowledge of support costs is required to assist users to achieve maximum value from their budget.

**'It will cause you a lot of stress, managing your own finances, keeping receipts and a book'**

**"The system for accounting for Direct Payments expenditure is over bureaucratic"**

### **11.2.5 Ability to provide advice and information (social care legislation, knowledge of disability benefits, employment support and advice)**

**Knowledge of social care legislation regulations and guidance:**

**"Care Managers need more training they need to be more informed and knowledgeable about [PPF]"**

**Knowledge of disability benefits and understanding of the criteria and application processes for these benefits:**

The majority of users believed that the workforce supporting them should have a working knowledge and be able to advise users on types of state benefits and tax credits that may be available to them.

A minority of users believed that they should also have the necessary skills to assist with completing benefit application forms; but there was no clear consensus from users as to whether this should be an essential competency.

**"Just helping me to fill in forms... they are a nightmare"**

**Employment support and advice: employment regulations, and Pay as You Earn (PAYE):**

Some users stated they would consider employing their own Personal Assistants (PA's). However, most stated they would need support with

all aspects of recruitment, employment, and PAYE. They would also prefer one to one support, and that the person supporting them should have this knowledge and ability to advise as well as train and empower them to be independent in the future.

**“Wouldn't want responsibility for employing somebody without support”**

### **11.2.6 Ability to support users with risk assessment, risk management and safeguarding**

#### **Risk assessment and risk management:**

The consensus of users was that users should decide and define what risk meant for them and that they should be allowed to decide on which risks to take; or that people who knew them well should support them in making decisions about risk. A common view was that users should not be viewed any differently to the general population when it came to making choices and decisions about risk.

The majority of users believed that information and advice coupled with an open dialogue about risk would empower and equip users to make decisions and reduce risk; that risk applied not just to themselves, but others (e.g. Personal Assistants, family, friends or others in the community).

The majority believed that there was a risk adverse culture with the Local Authority (and NHS). *(Some believed this was driven by the need to avoid making the “Headlines”)*. However, the consensus was that the root cause was a paternalistic culture within the Local Authority (and NHS); where the feeling given to users was still that **‘professionals know best’**

Users felt there needed to be a change not only in the culture of Adult Social Care but also in the ‘Public’ perception about them. Users said they should be encouraged to take risks to promote independence, as well as for promoting their personal development.

Many recognised that users have varying degrees of 'capacity' and where Service Users 'lacked capacity' under the Mental Capacity Act 2005 that family should be involved, and where there is no family; other statutory bodies would need to be involved.

**"Encourage individuals; if things don't go to plan provide a safety net"**

**"Individuals should be judged on their own merit"**

**"It is impossible to take into account every eventuality"**

**"I want explanation of what the risks are and how the Care Manager can help avoid the risks"**

**"It's the Service Users prerogative to make decisions"**

**"Not being able to take risks takes away development to learn"**

**"Need advice and information on the risk"**

**"It's down to the individual"**

**"Equip the service user with knowledge of the risks"**

**"Empower individuals to make own choices"**

**"If Care Manager says no to package due to concerns; where does the line stop"**

**"No family and unable to make choice who should help them? Care Managers/Social services become responsible for individual. Possibly the police?"**

**Safeguarding:**

**“Focus on monitoring individuals”**

**“Increased and better monitoring”**

**“Remove barriers/red tape when reporting concerns”**

**“Clarification of whom concerns should be reported to”**

**“Society needs to play a bigger part  
within the community”**

**“Another independent channel such as SCIL”**

### **11.2.7 Advocacy skills**

A majority of users believed that advocacy skills would be an essential requirement for anyone supporting a service user who was managing their own support; particularly where individuals were assessed as “vulnerable” or had no family or informal support network.

**“My previous Care Manager used to  
write letters for me”**

### **11.3 Feedback re substance misuse service users**

The following comments were received from the substance misuse Broker:

- **Counselling services:** More are needed
- **Continuity of social and emotional support:** Service users want continuity of support, i.e. the same home support workers to provide intensive 1 to 1 home support. The same key worker while engaged with services.

- **Community domiciliary provider staff should be non-judgemental:** Understanding of substance misuse issues and needs; good communicators; supportive and be good listeners. Crisis home support can be intensive and service users can feel lost or isolated when it ends and there needs to be ongoing lower level support provided.
- **Key Workers need a thorough knowledge and understanding of the issues and difficulties faced by service users,** to be responsive, to be good communicators and listeners, able to provide advocacy, have a good knowledge of and be able to provide information and advice on a range of issues e.g. income and benefits, housing, money management and what services are available.

## **11.4 Recommendations: Skills and competencies in the workforce**

- R11.1 Skills and competencies which users felt to be most important:** Southampton City Council should consider how best to ensure the workforce has consistent skills and competencies as follows:
- i. Ability to communicate with a diverse range of service users, service providers, and statutory agencies
  - j. Ability to support users with self assessment and person centred planning
  - k. Knowledge of statutory, community and voluntary resources within Southampton
  - l. Ability to support users with financial and budget management
  - m. Ability to provide advice and information (social care legislation, knowledge of disability benefits, employment support and advice)
  - n. Ability to support users with risk assessment and positive risk management (including safeguarding)
  - o. Advocacy skills
  - p. Training on philosophy and values of Personalisation, including case studies and success stories

## **12. Training and support needs of staff**

**This chapter provides a user perspective of the factors which users feel should be taken into account when making decisions about the training and support needs of the workforce.**

Users concluded that training for Personalisation should be about:

- Developing a more equal relationship between users and the workforce
- Working together to achieve better outcomes and objectives for users
- Relinquishing power to users.

This chapter highlights that users feel training should fit skills and competencies that users valued, in addition to formal qualification (which users valued as less important).

### **12.1 Co-production in training and support**

A key theme that emerged from the workshops was that users felt they should be involved in the design, delivery and evaluation of training for the workforce.

Users felt that this would help staff to better understand user's perspectives and expectations, which would contribute to breaking down staffing barriers already identified in this report.

Greater user involvement in training **and support** would provide greater insight and understanding for both the workforce and user.

Users felt there was enormous potential in developing a co-productive approach to the design and delivery of training for the workforce.

### **12.2 Communication and interpersonal skills**

The workshop responses on quality of individual workforce staff's one to one communication skills varied. However it was clear that the majority

of users felt the ability to communicate with a diverse range of people was an essential core skill for anyone providing support.

**“They need to understand the different mental health problems and how different approaches can help or aggravate the problem”**

**“A lot of users and carers have had personal experience and have a better insight”**

**“There is competitiveness when what we need is uniformity of approach”**

**“I think floating support is excellent.....they do all sorts of things (provided by MIND)”**

## **12.3 Person centred planning**

Users who had experience of support planning felt it was an important tool to assist the workforce and users to think about which services best met their needs. Users wanted the workforce to work more in partnership with the user and relinquish the power they currently held over users; to encourage and support the user to take control of their own lives.

Users valued person centred planning because it involved listening to the views of the service user and working with them to empower and inform how aspirations and goals can be achieved, with support from people with empathy and experience of similar experiences.

This central principle of Personalisation, users felt to require a cultural change. Therefore, whoever was supporting a service user with support planning, whether it was a ‘Support Broker’, a Care Manager; a Care Co-ordinator or a Community Psychiatric Nurse, should have mandatory training on the principles of Personalisation.

Users felt strongly and that cultural training of this nature would only be effective if it was co-produced with service users.

## **12.4 Safeguarding and Positive Risk Taking**

Users felt that it was important that the Local Authority needed to maintain overall responsibility for Safeguarding and liaising with other statutory bodies.

Users however did feel they were often capable of assessing risks for themselves and should be supported and empowered to take bigger roles in these decisions.

## **12.5 Feedback re substance misuse service users**

No specific feedback was received for this section.

## **12.6 Recommendations: Training and support needs of staff**

**R12.1 Co-production of training and support:** Users should co-produce the design, delivery and evaluation of all training regarding Personalisation

**R12.2 Training external partners:** Southampton City Council should consider the viability of providing training or information to external partner organisations on Personalisation and how they need to change to meet the expectations of users

**R12.3 Communication & interpersonal skills:** Users are clear that this is the most important skill for any member of the workforce, particularly in respect to how they engage and empower users.

These skills should be given a higher priority for future training provision

**R12.4 Co-produced workforce culture change:** Training and support to enable the workforce to understand the culture change needed for Personalisation should be developed and delivered in co-production with users

**R12.5 Safeguarding:** Training on safeguarding should provide more emphasis on empowering the user to recognise risk with respect to safeguarding issues, and support the user to manage these risks with the support of workforce staff, rather than being excluded from responsibility and involvement

## **13. Evaluation/ measures to evidence change and more effective outcomes for users**

**This chapter details the opinions of users about how the impact of Personalisation on users should be evaluated.**

Users recommended use of:

- Quality of life questionnaire
- Service user feedback forms
- Web-based feedback
- Personalisation Expert Panels

Although guided by user evidence, the researchers undertook a secondary evidence review to identify Personalisation monitoring methods used by other organisations.

### **13.1 Considering evaluating and measuring success**

The research team wanted to know how Personalisation success should be evaluated to measure the impact on users, by way of life opportunities, quality of life, and more effective outcomes.

We asked users:

- How can Adult Social Care know they are getting it right?

### **13.2 Evidence gained**

Users were clear that any redesign of the workforce should only be done if there were clear advantages that could be demonstrated in terms of

user satisfaction. Many users emphasised again that qualities such as empathy, communication, and clarity were important measures, but felt these were very hard to judge in an objective way.

Users also felt it was important to recognise that there were positive aspects of the current Adult Social Care system and the Local Authority needed to ensure it did not 'throw the baby out with the bathwater'.

**"New is not always better"**

Users recognised that the following methods would be useful in measuring the impact of Personalisation:

- **Quality of life questionnaire:** With baseline measurement at initial assessment and annually thereafter to measure impact. *(A similar based-line and review model was adopted the Office of Disability Issues (ODI) with their recent Support Advocacy & Brokerage demonstration project which Southampton Adult Social Care participated in)*

**"Send questionnaires to service users"**

**"Service user able to state what would like, what worked and what didn't"**

- **Service User feedback forms for customer satisfaction:** Initial Contact and Care Manager/Care Co-ordinator assessment and review processes and Occupational Therapy assessment and equipment delivery

**"Care Manager should leave feedback forms about quality of service – publish results"**

**"Service users appraising Care Managers standards"**

- **Web-based feedback forum on quality of care providers:** Users could provide feedback on how effective service providers were at

enabling users to achieve personalised outcomes. This feedback would help inform other users considering different providers. (User review sites such as [www.tripadvisor.co.uk](http://www.tripadvisor.co.uk) could provide a template)

**“Care provider feedback – web based”**

**“Set up information and feedback services dedicated to Service User – and publicise it!”**

- **Use of Personalisation Expert Panels:** Co-production forums such as those used by Hampshire County Council and the ODI are felt by users to provide effective methods for evaluation

**“Service User Forum to establish what they want –opens up awareness”**

### **13.3 Feedback re substance misuse service users**

No specific feedback was received for this section.

### **13.4 Secondary evidence review**

SCIL’s researchers felt it would be valuable to undertake additional research into how Adult Social Care might construct Personalisation evaluation methods and to fill in the basic ideas of users in section 13.2 above.

The following evaluation tools appeared to provide quality evaluation which our researchers felt had potential to be adapted by Adult Social Care in Southampton to meet the ambitions of Southampton’s service users:

- **POET Personal Budget Evaluation:** (National Personal Budget Survey by the Putting People First consortium, In Control, and Lancaster University:  
<http://puttingpeoplefirst.limeask.com/83472/lang-en>

- **ASCOT (Adult Social Care Outcomes Toolkit):** By the Personal Social Services Research Unit (PSSRU):  
<http://www.pssru.ac.uk/ascot/scrqol.php>

## **13.5 Recommendations: Evaluating Personalisation**

**R13.1 Develop evaluation methods which measure how Personalisation has benefited service users:** Users valued the following four methods:

- e. Quality of life questionnaire:** With baseline measurement at initial assessment and annually thereafter to measure impact
- f. Service User feedback forms for customer satisfaction:** Initial Contact and Care Manager/Care Co-ordinator assessment and review processes and Occupational Therapy assessment and equipment delivery
- g. Web-based feedback forum on quality of care providers:** Users providing feedback on how effective service providers were at enabling users to achieve personalised outcomes. This feedback would help inform other users considering different providers. (User review sites such as [www.tripadvisor.co.uk](http://www.tripadvisor.co.uk) could provide a template)
- h. Use of Personalisation Expert Panels:** Co-production forums such as those used by Hampshire County Council and the ODI are felt by users to provide effective methods for evaluation

**R13.2 Establish base-line and comparative measures:** In order to measure success of Personalisation, Adult Social Care should conduct a baseline measure before users receive Personalised services, and if possible provide a comparative measure for users not receiving Personalised services

**R13.3 Consider POET and ASCOT evaluation tools:** Adult Social Care may find these pre-existing web-tools a useful pro-forma for evaluating Personalisation in Southampton

## **14. Conclusion**

This report details the views of service users on how the Adult Social Care workforce in Southampton should be redesigned to meet the challenge of Personalisation.

Personalisation is about giving users control, with support if needed, to manage which services they use to meet their social care needs.

It follows that the views of users should be taken fully into account in ensuring Southampton City Council's Adult Social Care is redesigned to better meet the expectations, experiences and needs of the user.

SCIL hopes this report will be a valuable insight of the views of users, and when considered alongside parallel studies of the views of the workforce, and other relevant resources, will enable Southampton City Council to develop a strategy, co-produced with users, to ensure that the Personalisation agenda revolutionises the provision of Adult Social Care.

A summary of this report will be provided to all service users who participated in our research and will include Southampton City Council Adult Social Care's formal response to this report.

SCIL, April 2011

## List of appendices

- A. Feedback re users of substance misuse services ..... i
- B. SCIE definition of Personalisation ..... v
- C. Co-production case studies ..... vii

# Appendix A

## **Feedback re users of substance misuse services**

### **1. Introduction**

There were no responses to the invitations to participate in the Workshops; consequently the Solent Healthcare Personal Health Budgets Lead for Alcohol Dependency was contacted. The same Workshop questions were asked, asking for responses based on their experience; Service User experience and the development of a Personalised Service for Substance Misuse.

The service provision for Alcohol Dependency does not offer cash payments in lieu of services, there are similarities to PPF in the approach being holistic and offering a greater choice and range of services.

### **2. Customer Pathway for Personal Health Budget**

1. Initial Contact: GP, No Limits, Options, Community Mental Health Team
2. Referral to New Road Centre Community Drug Service, Drugs Alcohol Support Health (DASH)
3. Service user scored questionnaire to prioritise need
4. Comprehensive Assessment
5. Severity of Alcohol Dependency Assessment Questionnaire (SADQ) or Substance Dependency Severity Scale (SDSS)
6. **Traditional Pathway:**  
Service user given block contracted service: Priory, Home Detox, or Outreach Community Support

**In the new Pathway:**

7. Scores from SADQ and SDSS calculate budget
8. Service User given menu of service options, or can find and suggest alternatives provided they are safe and meet outcomes
9. Wrap around services.

### **3. Co-Production**

Personal Health Budgets for Alcohol Dependency is a collaborative process where the Service User is involved with Support Planning, choosing the services they have identified that will meet their stated outcomes. “The focus is on the abilities and how these can help with recovery.” New services have been created by Third Sector organisations to meet the service users identified needs, and provide more flexible and tailored services. A private commercial service provider reacted to Service User pressure by lowering their costs.

#### **3.1 Recommendations: Co-production**

Service User co-production in training design and provision for Key Workers

Service User co-production in future service developments

Provide a mechanism for Service User feedback and recommendations about:

- Quality of Domiciliary support
- Quality of Residential Rehabilitation stays
- Customer Journey
- Quality of Life questionnaire

There needs to be more commitment to Peer Support and investment in setting up and sustaining Peer Support Groups, these groups could provide low level social and emotional support. In addition these groups could facilitate co-production in future service developments; develop and carry out service user audits.

## **4. Barriers**

Workforce culture is social care professionals know what's best, and tell service users what they need and can have, i.e. "Do to rather than do with." The workforce approach is 'Medical Model' and risk averse; they are unwilling to change without substantial evidence of benefits from Personalisation, personalised services. The service focus is on high and urgent needs "Usually service users coming into the system are in crisis" and due to staff shortages there is a backlog of service users awaiting a comprehensive assessment and service provision. It is reported that a minority of service users can find, that having a choice of services is bewildering or confusing and prefer being offered traditional services.

There is a lack of choice for Peer Support for Alcohol Dependency, and Drug Dependency. Service Users prefer Peer support to be specific to their dependency, "Service users with Alcohol Dependency do not identify or get on with Drug Dependency Service Users." The majority of Service users are uninterested in setting up and sustaining Peer groups, "The nature of substance misuse is being able to move on." People want to put these issues behind them and be independent and do not want any more involvement than is necessary. However there are a minority of service users who would be keen have involvement with Peer Support Groups and developing service provision. There is limited information of what services are available and how to access them and there needs to be more accessible information and publicity.

### **4.1 Recommendations: Barriers**

- More information and publicity about service provision.
- A greater variety of Peer Support opportunities.
- Staff training with focus on cultural change and positive risk management.
- Invest in setting up and sustaining Peer Support Groups
- Provide Preventative and lower level service provision to avoid Crisis
- Trust the service user

## **5. Training for Service Users**

Service users need training to:

- Help identify, understand and manage risk.
- To make Wellness Recovery Action Plans (WRAP)

## **6. Workforce Skills and Competencies and Training**

More Counselling Services are needed

Social and emotional Support: Service users want continuity of support, i.e. the same home support workers to provide intensive 1 to 1 home support. The same key worker while engaged with services.

Community domiciliary provider staff should be non-judgemental; understanding of substance misuse issues and needs; good communicators; supportive and be good listeners. Crisis home support can be intensive and service users can feel lost or isolated when it ends and there needs to be ongoing lower level support provided.

Key Workers need a thorough knowledge and understanding of the issues and difficulties faced by service users, to be responsive, to be good communicators and listeners, able to provide advocacy, have a good knowledge of and be able to provide information and advice on a range of issues e.g. income and DWP Benefits, housing, money management and what services are available.

### **6.1 Recommendations: Workforce skills, competencies and training**

- Training on philosophy and values of Personalisation and Personal Budgets, including case studies and success stories
- Training on Positive Risk Management

## **Appendix B**

### **SCIE Definition of Personalisation**

The Social Care Institute of Excellence (SCIE) 2010 publication: 'Personalisation: a rough guide' provides an admirable, but lengthy definition, which SCIL's researchers feel is valuable for policy makers/implementers:

Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives.

It requires a significant transformation of Adult Social Care so that all systems, processes, staff and services are geared up to put people first.

The traditional service-led approach has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives and goes well beyond simply giving personal budgets to people eligible for council funding.

Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing, health and opportunities for employment, regardless of age or disability.

Personalisation means:

- tailoring support to people's individual needs
- ensuring that people have access to information, advocacy and advice to make informed decisions about their care and support

- finding new collaborative ways of working (sometimes known as co-production) that support people to actively engage in the design, delivery and evaluation of services
- developing local partnerships to co-produce a range of services for people to choose from and opportunities for social inclusion and community development
- developing the right leadership and organisational systems to enable staff to work in creative, person-centred ways
- embedding early intervention, re-ablement and prevention so that people are supported early on and in a way that's right for them
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities
- ensuring all citizens have access to universal community

## Appendix C

### Co-production case studies

- 1) Hampshire Personalisation Expert Panel
- 2) Independent Living Strategy

#### Case study 1:

##### Hampshire Personalisation Expert Panel (PEP)

Following Hampshire County Council's Commission on Personalisation in 2008; 2 ULO's (SCIL and Hampshire Centre for Independent Living (HCIL)) proposed to Hampshire County Council Adult Services that a group of users and carers who were 'Experts by Experience' should meet alongside Senior Managers and Commissioners from Hampshire Adult Services to help guide Hampshire's transformation of Adult Social Care services. The 2 ULO's felt that the PEP should be developed as a true partnership of users and Council staff, to enable issues to be raised and discussed in a positive and constructive environment, and solutions co-produced which meet the needs of both user and the Council.

Hampshire was broadly supportive of the concept and asked for a costed proposal, to include payment of both time and expenses of participants as the experts they were. First meeting were held in 2009.

The PEP **Terms of Reference** are:

- To ensure that Service Users and their organisations are at the forefront of all aspects of the implementation of the recommendations of HCC Personalisation Commission.
- To ensure that the experiences gained from Self Operated Care, Direct Payments and other Independent Living schemes informs the future development of Adult Social Care in Hampshire and ensure that wheels are not unnecessarily reinvented
- To ensure that reform of Adult Social Care in Hampshire is developed to meet the needs and aspirations of all potential

Service Users based on the principle of equality i.e. regardless of age, impairment, race, gender, sexuality etc.

- To ensure that marginalised groups and people who do not have a voice can have their views represented in this discussion
- To ensure that the priorities of Disabled People are fully taken into account and at the forefront in terms of setting the agenda for PEP
- To ensure that reforms develop in line with other Government agendas, with respect to Independent Living
- To ensure that 'Self Directed Support' develops to enable it to meet all the needs of Service Users (health, housing, employment, leisure and other County Council services etc.)

Membership of the PEP is drawn from a range of ULO's covering, all Disabled People, Carers, Older People, and day service users as well as a number of individual users. Council workforce membership comprises of a small number of senior managers supportive of the PEP's aims, and other officers that come and go dependent on the issues being discussed.

The PEP is chaired by users and finances managed by one of the ULO's.

Agenda items are decided in partnership with the Council and users, and comprise of a range of subjects felt important to either party. Agenda items are usually scheduled to co-incide with Council decision making processes.

The PEP enjoys the active support of Hampshire Adult Services Departmental Management Team, with whom they meet on a 6 monthly basis to discuss progress.

The Hampshire PEP has been involved in a variety of work streams that have influenced the workforce redesign agenda. These include:

- Co-production of training for Care Managers around Self Directed Support
- Developing training for Personal Assistants who will be employed by Disabled People
- Jointly delivering presentations to Local Authority staff on personalised practice
- Day service redesign

After 2 years of operation, the PEP is seen by both users and the Council and a valuable contribution to Personalisation.

The PEP is now expanding and developing a 'hub and spoke' model of working to enable it to engage with and bring forward the input of many other groups who are keen to be involved.

## **Case study 2:**

### **The Independent Living Strategy (ILS)**

The Independent Living Review was set up in July 2006 to make progress on the government's aim that all Disabled People (including older Disabled People) should be able to live autonomous lives, and have the same choice, freedom, dignity and control over their lives as non-Disabled People. The Review followed the commitment in "Improving the Life Chances of Disabled People" which was published in 2005, to deliver Independent Living for all Disabled People.

The Review was given the task of developing a five year Strategy to deliver Independent Living.

The Review took a case study approach to developing evidence-based policy commitments so that the Strategy is grounded in the lived experiences of Disabled People.

A key starting point for the Review was that policies should be co-produced with the people whose lives they affect.

Consultation happens once policy proposals have been developed; co-production means involving Disabled People at all stages of policy development, implementation and delivery.

The Review used a variety of methods to involve Disabled People and other stakeholders in the development of the Strategy.

An Expert Panel was set up to give expert advice to the Review. Members contributed their direct experience as Disabled People, family carers, as well as their experiences of commissioning, providing, regulating and inspecting local services. The Expert Panel was chaired

by Baroness Jane Campbell.

The Review started, at a series of regional events, by asking Disabled People:

- What does Independent Living mean to you?
- What are the barriers that get in the way of Independent Living?
- How might those barriers be removed?

The government has adopted Disabled People's own definition and vision of Independent Living (see previous page).

As well as regional workshops events were held to focus on specific policy areas, for example:

- Transition to adulthood for young Disabled People
- Older People and Independent Living
- Support, advocacy and brokerage services

Emerging proposals were then tested with groups of Disabled People as part of the ongoing co-production.

There was no one single action that Disabled People felt would deliver Independent Living; rather it was a combination of things that, together, would bring about change.

Working with Disabled People, the Expert Panel and colleagues from across Government the many suggestion from Disabled People were prioritised into a series of commitments that formed the Independent Living Strategy.

The Strategy takes a themed approach (e.g. health, housing, transport and mobility) and brings together, for the first time, policies from across government that contribute towards delivering Independent Living for Disabled People.

The Strategy contains over 50 commitments (things that the government was committed to doing – as opposed to recommendations or options). For each of the commitments the Strategy sets out what will happen, what we expect to see change as a result of this and details of how this will be measured. Commitments include:

- Action and Learning sites to demonstrate the effectiveness of user-

led support , advocacy and brokerage to ensure people get the right support to make decisions for themselves.

- A national strategy to enable people to remain in employment when they acquire an impairment or their condition worsens.
- An awareness campaign aimed at practitioners (in social work, the NHS and elsewhere )and Disabled People themselves to ensure that health, social care and other services are delivered in ways which enable Disabled People to have choice and control over how their needs are met.

The Review was asked to consider whether legislative change was needed to address the barriers to Independent Living. The Expert Panel expressed strong concerns that the Strategy would have a limited impact and would fail to meet the aspirations of Disabled People without a legislative framework.

The government (at that time) acknowledged the Expert Panel's views but decided that there was not a need for changes to primary legislation. However, the Strategy does contain a commitment that states that the Government will review the need for legislation if sufficient progress has not been made against the outcomes by 2013.

The Strategy was launched in March 2008. At the same time a consultation was started to seek views on how best to involve Disabled People in the implementation and monitoring of the Strategy.

Following the consultation we have set up the Independent Living Scrutiny Group – a small group of influential experts in Independent Living, which is chaired by Baroness Jane Campbell. This group provides, directly to Ministers, a disabled persons' perspective on progress being made to deliver the Independent Living Strategy.