Better Lives

AN EVALUATION OF PERSONALISATION IN SOUTHWARK

by **Professor Roger Ellis, Professor David Sines**
and **Professor Elaine Hogard**

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PERSONALISATION PROGRAMME
FOR ADULTS WITH LEARNING DIFFICULTIES
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About the authors:

Professor Roger Ellis received his OBE in 2007 in recognition of a long and highly successful career in Higher Education. He is Emeritus Professor in Psychology at both the University of Ulster and the University of Chester. In particular he has established a number of contract research centres including, most recently, the Social and Health Evaluation Unit at the University of Chester which is now based at Bucks New University. This unit, over 12 years, has completed more than 70 externally funded programme evaluations in community development, social care, health care, education, regional development and community safety. It now has branches in England, Northern Ireland, Canada and Hungary and has been re-launched as SHEU International.

He brought to this evaluation internationally recognised expertise in programme evaluation including the development of innovative and effective methods and a capacity to conclude evaluations with recommendations that have impacted on practice and policy. He is proud to have contributed to an evaluation which has produced such significant results and to have an opportunity to continue this work over the next year on the broader topic of Personalisation.

Roger has published more than 60 evaluation reports, 10 books and over 200 articles in refereed journals in the broad area of Applied Psychology, Outcome Audit at interpersonal and organisational levels has been a particular interest of Roger's, and he brings these insights to the exploration of personalisation.

David Sines is currently Pro Vice Chancellor and Executive Dean and Professor of Community Health Care Nursing at the Faculty of Society and Health at Bucks New University. He was previously the Executive Dean for the Faculty of Health and Social Care at London South Bank University. David moved to Bucks New University in August 2009 to assume responsibility for the academic leadership of the Faculty of Society and Health and to lead the University's new health campus in Uxbridge.

David holds an Honorary Appointment with Imperial College Healthcare NHS Trust as Associate Director of Nursing. He is a member of the North West London Health and Innovation Education Cluster Partnership Board. David is a prolific author and his research has been included in the last 4 UK Research Assessment Exercises. He advises the Department of Health on clinical workforce issues.

David was awarded Fellowship of the Royal College of Nursing of the United Kingdom in 1989 for his pioneering work in advancing the art and science of nursing and community care. He was awarded the CBE in the 2010 Queen's Birthday Honours List for 'Services to Health Care'.

Following his research for this report David was appointed a Patron of Choice Support in May 2014.

Dr Elaine Hogard is Professor of Program Evaluation and Director of Assessment and Program Evaluation at the North Ontario School of Medicine. Elaine was previously Director of the Social and Health Evaluation Unit at the University of Chester. She is now the Director of the SHEU branch in Canada.

Elaine has completed more than 60 programme evaluations over the last 10 years, including several focusing on the quality of life of adults with severe learning disabilities. She is particularly gratified that the personalisation audit tool, which she played a part in developing, has demonstrated an improvement in the quality of life of adults with severe learning difficulties. She says 'I like to think the tool gave them a voice'.

Elaine is the author of more than 50 published evaluation reports and has published papers on her distinctive approaches to evaluation in all the top international journals. Her research interests within Program Evaluation include Professional Identity and Development; Organisational Communication; and Process Explication and Measurement.

Contents

Foreword (2nd Edition)

There is every sign that the re-publication of this report represents an important milestone. Eventually a simple, but powerful idea, that has been at the margins of health and social care, may now be coming into the mainstream. Put simply this idea is that service providers can be trusted to work flexibly with individuals to help them meet their own desired outcomes. This is what it means to use an Individual Service Fund (ISF) model.

This idea seems so simple and commonsensical. Why would we fund service providers for people with disabilities if we did not think that they could work in partnership with people to achieve the best possible? Why would we ever think that good support, something that is obviously highly personal, is best organised by complex regulations, contracts and controls from on high? Why would we not treat someone's budget as a flexible fund (an Individual Service Fund) and make sure that it was spent for the maximum benefit of the individual?

Nevertheless, despite these powerful arguments, the use of ISFs has remained at the margins - until now.

One small, but very encouraging sign, is that we have been forced to reprint and republish, in a second edition, this important report. One thousand copies were produced of the first edition (usually a sufficient print-run in these digital times) however demand has been so high that we have had to quickly print a further thousand.

Another positive sign was the award of the 2015 Platinum Medal of the European Society for Person-Centered Healthcare (ESPCH) to Steven Rose, Chief Executive of Choice Support, for his leadership in driving forward the use of ISFs by Choice Support. I have known Steven since 1991 and have witnessed his ongoing commitment to innovation and to the rights of people with learning disabilities. His determination to challenge injustice is inspiring and I am thankful that this award has brought him some well-deserved recognition.

Furthermore, just a few months after the publication of *Better Lives*, the government funded programme Think Local Act Personal backed the use of ISFs in its report *Individual Service Funds (ISFs) and Contracting for Flexible Support*. This best practice guidance for

commissioners and service providers makes clear that ISFs offer the best option, after direct payments, for advancing people's citizenship. The guide also makes clear that it is only with higher degree of trust and contractual flexibility that organisations can be liberated to work in this way.

Increasingly service providers and local authorities do seem to be waking up to the opportunities that can be created by the use of ISFs. However, as we go forward, we must remember that professionals (providers and commissioners) wouldn't have a job if the person didn't exist. It is the person who should choose their own service provider and be able to sack them if they wish. It is the person who should shape their own goals and define the purpose of their support. This new approach to health and social care only deserves to survive if it is built on and supports people's human rights and the goal of equal citizenship for all.

Dr Simon Duffy
Director, The Centre for Welfare Reform
September 2015

Foreword (1st Edition)

This report is the third in a series of publications by The Centre for Welfare Reform about the Personalisation Programme developed jointly by Southwark Adult Services and Choice Support, a learning disability provider in the London Borough of Southwark. The results speak for themselves:

1. A large traditional block contract, worth more than £6 million, was broken down into 83 Individual Service Funds (ISFs).

2. Over a period of four years a saving of £1.79 million (29.75%) was achieved.

Independent research, completed by the Social & Health Evaluation Unit at Bucks New University, verifies that the savings were achieved, but more importantly it identifies that there have been **on-going improvements in the quality of most people's lives**. This is an amazing achievement at a time when cuts to Local Government by Central Government have created serious problems for social care.

Personally it is also satisfying to see such a major advance take place in Southwark. This was where I began my own career in 1990, and where we pioneered early models of self-directed support and personalisation. However, 25 years later, it is also clear that achieving these kinds of changes is not always easy.

Building on my experiences in Southwark, I developed an organisation called Inclusion Glasgow in 1996. There we committed ourselves to work with each individual as an individual, and to create flexible and personalised support (Fitzpatrick, 2010). One of our key innovations was the idea of an **Individual Service Fund (ISF)** - treating each person's budget as if it were their own money and working with them to get the best possible value from it. This proved a highly successful innovation (Animate, 2014).

In 2003, while leading In Control, I took this idea and built it into our model of self-directed support, enabling service providers to also manage personal budgets. However, this model has only been rarely used. Currently only 1% of the money spent on personal budgets is managed via Individual Service Funds.

In my experience the critical obstacle to the development of provider-led initiatives, such as Individual Service Funds, is quite simple.

Commissioners do not trust service providers to act with integrity and to use money flexibly to help people meet their own needs. This lack of trust has crippled progress in personalisation.

This makes the achievement of change in Southwark all the more striking and encouraging. Here the original proposal was developed by the provider organisation, Choice Support; but, as the then learning disability commissioner, Chris Dorey said *"Choice Support was pushing at an open door when they suggested an Individual Service Fund approach for transforming their services in Southwark"* (Hoolahan, 2012). It was only the strong and sustained support of the commissioner, combined with significant levels of mutual trust, that made such positive change possible.

Quite rightly the independent evaluation team have recommended to Southwark and Choice Support that they share the lessons of their work with other commissioners and providers. They will need to persuade others to step away from old models of contracting, procurement, tendering and top-down control. Instead they will have to start with a focus on the individual, on what they really need, and to enable families, friends and professionals to work with them to achieve great citizenship and control.

Hopefully this report will mark the beginning of a sea change in social care in England: the end of an era of organisational mistrust and increased centralisation; the start of a greater focus on citizenship and community, with greater faith in the integrity of civil society to lead positive change from the grassroots up.

Dr Simon Duffy
Director, The Centre for Welfare Reform
November 2014

The
Report

1. Evaluation

This report is an evaluation of the Personalisation Programme of Choice Support in Southwark, undertaken by the Social and Health Evaluation Unit of Buckinghamshire New University

The evaluation was commissioned by Choice Support with the following objectives:

1. to assess the achievement of stated outcomes for the Programme which will include objectives for quality of life; and value for money;

2. to describe and analyse the process of delivery including the resources, activities and procedures of the Programme to compare with best practice and identify lessons learned;

3. to sample the views on the Programme of key stakeholders including care staff, parents/next of kin, and social services staff;

4. to prepare and present a report with conclusions and recommendations to inform practice and policy;

5. to disseminate the findings of the research.

The overall design of the evaluation employed our established Trident method which focuses evaluation questions on 3 main areas: outcomes, process and stakeholder perspectives.

For these 3 aspects we set the following questions:

- What were the key outcomes set by Choice Support and Southwark for their Personalisation Programme?
- What are the current best practice standards for Quality of Life for Learning Disability?
- How can these outcomes be reliably and validly measured?
- What processes were followed to plan and implement the Personalisation Programme?
- How can these be described and evaluated?
- How do they relate to best practice?
- What were the views of key stakeholders on the Programme?

The main new data gathered by the evaluators were from an audit of the quality of life of 70 individuals and from questionnaire surveys of the views of support staff, social services staff and parents, next of kin or friends. Improvement in quality of life was the key outcome anticipated for the Personalisation Programme. The audit therefore included questions covering a number of aspects of quality of life drawn from the partnership's objectives and from best practice. The practices and views of staff are recognised as the key element in the successful delivery of the Programme and a questionnaire survey explored these views. The views of parents and relatives provide a key external view on the Programme and its benefits to individuals and these views

13

were explored through a questionnaire survey. The views of the named social workers were also explored. These quantitative data were complemented with case studies of individuals.

We have been given access to a number of internal documents describing the approach taken to personalisation by Choice Support and the London Borough of Southwark. We also met the Choice Support Director and 2 managers to discuss aspects of the Programme. This enabled us to construct a description of the Programme's planning organisation and delivery and to compare this with best practice. We were given invaluable support in all this by Sian Hoolahan, Communications Manager, who was deployed by Choice Support as our key contact.

Chapter 1 summarises the challenges facing the implementation of a Personalisation Programme for those with learning disability and identifies some key elements of best practice in so doing. Chapter 2 summarises the processes through which Choice Support has implemented their Personalisation Programme and the ways these compare with best practice. The next 7 chapters are the central ones for the evaluation containing the new data we have gathered. These include the results of the *Quality of Life Audit*; the case studies of individuals, the details of savings, the results of the staff survey; the results of the survey of relatives and friends and the results of the survey of social work staff. The final chapter summarises our conclusions and recommendations.

14

2. Challenge

Personalisation has become a watchword for social services in the first decade of the 21st century. Originating in computing and adopted by social services and to some extent health care and education, the basic idea is that the person and their individual needs and choices should be at the centre of provision. This may be described as a fundamental shift in approach, requiring entirely different thinking about care and support services. It 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 is suggested that it requires a significant transformation of adult social care so that all systems, processes, staff and services are geared up to put people first.

One way of approaching personalisation has been to use a system known as Individual Service Funds (ISFs), whereby a sum, calculated on the basis of an assessment of their support needs, is assigned to each individual. This ISF is also sometimes treated as a mechanism for controlling a personal budget, from within an organisation. As such, it is funding which must be spent on the named individual, but which can be spent flexibly, in order to achieve the best possible outcomes for the person. In the past organisations often found that funding mechanisms were unduly restricting – controlling how funding was to be used and removing discretion and flexibility from service providers. However ISFs were developed at Inclusion Glasgow in 1996 and designed to overcome this problem and to put in place an individual funding mechanism that could be used with the necessary flexibility to provide personalised support to people with complex needs (Fitzpatrick, 2010; Animate, 2014). This same approach has also used been used by organisations such as Partners for Inclusion and C-Change for Inclusion.

Of course, personalisation, particularly when embraced by government (DoH, 2007) has been greeted with some scepticism. For it can certainly be argued that putting the person at the centre of care has always been a basic social work value. The current emphasis on personalisation may be no more than a rhetorical diversion from the hard reality of cost cutting. There is lack of hard evidence that personalisation generally, and ISFs in particular, actually improve the lives of individuals.

If personalisation is to transform care then there needs to be a clear understanding of exactly what is being done differently and what effect this is having on the quality of life of individuals. In that context this evaluation of Choice Support's response to the personalisation agenda and the impact of these changes on the quality of life of individuals and the views of staff and relatives and friends is timely.

It can't be denied that 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. It may start with, but 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 may be met and are able to access universal services such as transport, leisure, education, housing, health and opportunities for employment, regardless of age or disability.

If the personalisation agenda is a challenge for social services generally, there are particular problems in applying it to the provision for those with learning disabilities (SCIE, 2009). Evidence suggests that people with learning disabilities and high support needs are likely to be left behind in social care services provision while those who are more independent have more choice and control over social care services. The Social Care Institute for Excellence (SCIE) *Position Paper 6, Supporting self-advocacy* (Lawton, 2006a), indicated that a lack of skills, understanding and provision of advocacy for people with high support needs could mean this group missing out on opportunities to shape not just their individual support but also wider planning.

So a central idea in implementing the personalisation agenda is that individuals should have a say in what support they receive. This is obviously a challenge when the person has little or no language. If the person is unable to articulate a view then special steps must be taken to ensure that their needs and choices are identified and that there is advocacy on their behalf. Support staff have been brought up in particular systems and approaches and the shift to personalisation may require a shift in attitudes and dispositions with new skills and approaches being learned.

There is a plethora of advice and guidance regarding personalisation and ISFs as the attached reference list shows but a lack of research studies and evidence. We have tried to distil from this material some common recommendations. Using this distillation it is possible to set out requirements for a personalisation programme, such as that implemented by Choice Support.

These will include the following, which will act as standards or at least elements, against which Choice Support's Personalisation Programme can be evaluated:

1. The agency or provider should have a clearly articulated strategy for their approach to personalisation and ISFs and a focused agenda of initiatives that will express this strategy.

2. There should be a business plan relating the items in this agenda, particularly ISFs, to income and expenditure over a period. This will entail a valid and reliable approach to the calculation of support costs to meet the needs identified for each individual, and a strategy to secure contracts for this funding and contingency plans to work with what is attainable.

3. There should be a clear and feasible strategy and plan, with associated staff development, to ensure that the aspirations and choices of each individual are expressed, heeded and at the centre of provision. To achieve this there should be a valid, reliable and regular 'service user' voice. If individuals are unable to

16

articulate their views there should be staff and structures in place to ensure that they have a proxy voice.

4. There should be a partnership between a provider and a commissioner to pursue the personalisation agenda.

5. There should be an agreement through this partnership to follow a personalisation agenda through ISFs based on person centred plans (PCPs) as a basis for contracting in place of the conventional block grant.

6. Each individual should have a negotiated PCP which is based on an assessment of need, their preferences and the support needed to meet needs.

7. There should be a negotiated ISF for each individual based on the PCP and they or their proxy should play a central role in determining how this ISF is spent.

8. There should be a designated member of care staff supporting each individual.

9. There should be a clear staff development strategy and operational plan to ensure that staff are able to deliver the strategy including the support plans.

10. There should be regular liaison with stakeholders including relatives, friends, advocates, social services and commissioners with the quality of life of the individual as the central focus.

11. Residential accommodation provided for individualss should be deregistered to meet the standards of supported living.

12. Night support should be reviewed to move from Waking Nights to Sleep In and the effect of this on quality of life and risk management should be evaluated.

13. Each person's quality of life should be regularly monitored to ensure that the personalisation initiatives are achieving the intended outcomes.

14. There should be some form of external evaluation to assure commissioners and providers that objectives are being met efficiently and effectively.

17

This is not an exhaustive list, nor is it set out sequentially as a critical path, but it does provide some broad standards against which the Personalisation Programme of Choice Support in Southwark may be evaluated. This point by point evaluation is in the next chapter. The evaluation is preceded by a brief history of personalisation initiatives at Choice Support which will in itself exemplify the ways these standards have been met.

3. Response

We have been provided with a number of documents that chart Choice Support's response to the personalisation initiative ranging from the strategic to the operational.

In its Business Plan 2012-2015 Choice Support highlights personalisation as a strategic aim:

To deliver all Choice Support services on a personalised basis so that 60% of people supported will have individually-costed support plans by March 2015.

The strategic position of Choice Support regarding personalisation was summarised as follows in a paper by Chief Executive Steven Rose:

Notwithstanding support for personalisation from central government, progress on implementation across local authorities has been highly variable. Choice Support is committed to personalisation and to this end has developed a range of services and transformation strategies to maximise the impact of this policy initiative within the organisation. Over the next three years Choice Support intends to drive forward with these initiatives and has set itself the ambitious target of having 60% of its customers with individually-costed support plans.

In the Choice Support Business Plan for 2010-2015 an overview is given of the timing of Operational Objectives:

We will have discussions with all our existing commissioners to offer this personalised package.

Based on results of these discussions we will produce local project plans and start implementation.

These two references to personalisation highlight the developmental nature of the initiative and the intention to proceed to operational planning with those commissioners who are interested in a personalisation package.

These discussions were to be with 12 key customers. The proposal to 1 of these, the London Borough of Southwark, was produced by the Chief Executive, Steven Rose, in April 2010. This sets out the plan for ISFs for around 100 individuals within a reduced overall contract price.

In that paper the next 4 steps were identified as:

1. Choice Support will dedicate an experienced senior manager (Charan Singh) to deliver these proposals.
2. A joint Project Group consisting of representatives from the Southwark Council, Choice Support and other relevant organisations e.g. Housing Options, will be established to oversee this work and Charan Singh will present a project plan to the group at the end of June 2010.

3. All key managers in Southwark have already been briefed on these proposals and a planning/coaching day to be delivered by The Centre for Welfare Reform has been set up to take place at the beginning of June.

4. The creation of ISFs will be the first step for a number of people who will request/ be offered an Individual Budget.

The project plan referred to in the second step was produced by Director Charan Singh in July 2010.

Its objectives were:

- To agree criteria to allocate personal budgets to all individuals currently receiving 24 hour service from Choice Support within Registered Care and Supported Living Services.
- To ensure that all individuals received a personalised service by June 2013.
- To agree a process to assist individuals to recruit Personal Assistants to provide a service based on their Personal Budgets.

Recognising the substantial organisational change involved, the project plan included a SWOT analysis and a section on the management of change.

Weaknesses identified, realistically, in the SWOT analysis included the following:

- Systems & processes not fully developed for personalisation.
- Current staffing structures & terms do not reflect personalisation.
- Current services based on old model.
- Resources not being utilised effectively.
- Some people view personalisation as a cheap option and are concerned about Safeguarding issues.

Taking account of these the plan included five operational objectives, each linked with task/methods and outcomes.

These key objectives were

1. To devise a 'Needs Assessment' tool to calculate Individual budgets.
2. To agree individual budgets for 83 people currently receiving services from Choice Support in Southwark.
3. To liaise with families, friends, advocates and commissioners to support the project.
4. To develop flexible models of support, based on individual choices.
5. To achieve savings of £170k this financial year and a further saving of £200k next year.

These objectives were to be achieved by a Project Group together with staff teams and an internal working group.

19

Objective One

The development of a Needs Assessment Tool has been an iterative process starting with an imported tool which has been modified to suit circumstances.

The Needs Assessment Tool was crucial to determine ISFs. The Director described the development of the assessment tool as beginning with knowledge of people's existing support needs and then dividing the current budget on the basis of this. He felt it was not a very person-centred beginning. He then described the development of a matrix which was a way of dividing people up depending on their level of need. This was soon abandoned because it was felt to cause difficulties as it was based on needs rather than looking at the whole person. A template from the In Control website was then adopted and adapted. Together with the Commissioners and Social Services, Choice Support made a partnership agreement to take the lead in completing costed person-centred support plans.

An example of a completed template for calculating an ISF was submitted as part of this evaluation (see Appendices). This version was developed with input from the Commissioners and was used as a tool to negotiate the ISFs. It follows a similar format to the Outcome Based Assessments completed by social workers. The first column of the template is for the identified outcomes and the category within which these outcomes are assessed (i.e. moderate, substantial or critical). Based on these assessed needs, the appropriate level of support is agreed followed by cost calculations. These cost calculations are confidential at this point. The example also showed how the needs analysis and planning, including available finance, can be made meaningful to the individual.

20

Objective Two

ISFs have been achieved for the 70 individuals included in this evaluation.

Objective Three

We have not received records of liaison with stakeholders although we have no reason to doubt they will have taken place. It has been identified by the team that this liaison, particularly with relatives, is a point for development. It would be beneficial to record points from these liaisons and the follow up of the points.

The Director sent out letters to all key stakeholders (families, friends and advocates) informing them of the Personalisation Programme, which he explained was being run with the support of local commissioners. He invited stakeholders to a series of information days which included weekend and evenings to enable more people to attend. He also sent out the contact details and background information about key staff in the Personalisation Programme so that stakeholders were able to contact him and his team directly if they wanted to. The Director said: "*from the outset we communicated with people and we followed that through with contact details of named individuals whenever they wanted more information*".

A series of information days were held and a number of people attended them. However, due to the timing of the start of the project, which was close to the Coalition Government's Spending Review, the Personalisation Programme was seen by some families as a cost cutting exercise. So understandably there was a bit more resistance and reluctance by families who expressed concern at making any changes to current support arrangements.

The Director recalled having many conversations to reassure people. This approach was successful as there proved to be no major resistance from stakeholders. The Director said that there were not that many families involved, as a lot of people supported in Southwark were older, and their families were no longer alive or had moved on e.g. one family had moved up north. He said: *"We offered local Choice Support managers in the north that this family could speak to but they were happy with the information we sent them and said they were ok with the changes."*

A number of the families remained engaged and involved in the process. One family decided they wanted to move to another service provider. This was seen as a positive outcome achieved by the Personalisation Programme for the individual involved. One family raised concerns about the level of support and they made complaints to Choice Support and then to social services, referring to the level of support during the night time but this was worked through, and the complaint was resolved. This family has remained involved and continues to hold Choice Support to account if things don't work out.

There was another complaint from a friend/advocate of an individual who felt Choice Support had imposed an ISF on this person. He felt that this individual didn't have the capacity to make that decision. This again was resolved by talking to the friend and talking to the individual involved. In all 3 complaints were raised by families/friends or advocates and all were resolved satisfactorily.

Objective Four

The objective to develop flexible models of support has been achieved, including the production of PCPs for each individual; and these have determined, within achievable funds, how their ISFs would be used, following the method outlined above.

Objective Five

The savings achieved over the period are described in Chapter 6.

Meeting Standards for a Personalisation Programme

In the preceding chapter we distilled from the literature 14 elements that should be evident in a personalisation programme. These are listed below, with comments on the Choice Support and Southwark Programme. These comments should be read in conjunction with the information given above.

1. Personalisation Strategy

There is an explicit personalisation strategy in position papers and the Business Plan.

2. Business Plan

The Business Plan highlights personalisation as a key aim with 2 operational objectives.

3. Individual's voice

This standard is at the heart of personalisation. Although the advocacy project in Southwark had been phased out, Circles of Support were established by Choice Support to ensure that each person's views are either articulated directly or constructed on behalf of the user.

At the start of the project there was an independently funded advocate involved. She took an active part in all discussions on the project. She offered her support and read ISF support plans for many of the people on the former block contract. She made comments on them, which were found very useful to Choice Support and to Circles of Support held, when the advocate wasn't able to attend meetings. The advocate was also part of the Steering Group which had been set up. She attended the Steering Group together with some family members and senior social workers, including the commissioners, and Choice Support felt that they all had an advocacy role.

In 2012 the Camberwell advocacy project funding was reduced and the advocate was was made redundant from her position. She now works on the Choice Support bank pool as a support worker and continues advocating for people in a less formal way.

Managers thought that the timescales and deadlines were too tight at the beginning of the project. They felt that, had they been able to spend more time at the beginning with the people being supported they could have made things better. It would have allowed them to get more input from the people they supported in the planning but the timescales were 'out of our control and we were restricted with what we could do'.

Circles of Support have been an important innovation. To support the circles all managers underwent two days training and all staff had at least one day's training on personalisation and person centred support planning.

The people being supported were asked if they would like a circle of support. Family members were involved in circles of support and also staff members. The circles of support were named in the person's ISF support plan.

The circles have been considered successful, but not in all cases. Not every staff member can advocate independently and that is a weakness. Some staff have very good advocacy skills but they are in a difficult position as they are advocating for a person being supported by their own staff team. There will now be opportunities to refine this approach and establish standards and ensure compliance.

It was felt by Choice Support that there could be improvements for individuals with the most complex needs who are unable to communicate and where there was no external

input from family or friends. The advocate and some parents provided some advocacy on the Steering Group, however, where there was no family or official advocacy there was some weakness for these people.

4. Partnership between Commissioner and Provider

The Personalisation Programme is based on a partnership between Choice Support and Southwark LBC and there is the potential for such partnerships with a number of other commissioners with whom Choice Support works.

5. Agreed Personalisation Agenda through ISFs and PCPs

There is an agreed agenda set out in the July 2010 Planning Paper. Steps followed to implement the plan could be better documented.

6. Negotiated Person Centred Plans

There are PCPs for all seventy individuals in the Programme.

7. Individual Service Funds

There are ISFs for all 70 individuals in the Programme. The process for determining PCPs and ISFs is described above and demonstrates a sustained commitment to personalisation by the partnership of Choice Support and LBC Southwark.

8. Lead Support Staff: Personal Assistants

We believe each individual has a key worker although we have not seen documentation of this.

23

9. Staff Development Strategy and Operational Plan

Although we have not seen a strategy and plan, we have seen details of special study days and in the staff survey the support given for personalisation is acknowledged. In the survey of their views, Staff also indicate their need for further help to implement the agenda.

10. Stakeholder Liaison

While there is an objective to liaise regularly with relatives and commissioners we have not seen records of this. Accounts from Choice Support are provided above. Relatives in the survey indicated that they could be more involved.

   The Project Director said that the personalisation working group had intended to send out regular updates, but he felt he failed with this and had in fact only sent out one update. He didn't send up to date briefings and blamed this partly on the lack of capacity in administrative support. A key member of the administrative team supporting the Programme became seriously ill during this time. The Director acknowledged that this was a gap in the process.

   Choice Support has recognised that stakeholders could be more involved in developing their services and have asked the Foundation for People with Learning Disabilities (FPLD) to facilitate family forums.

11. Deregistration of residential accommodation

Accommodation for 66 individuals has been deregistered. 4 people are in 2 services that are still in the process of being de-registered. The Director said the delay in de-registering these services occurred because they were part of old campus provision. The PCT did not give permission to start on this work. The services have now been transferred over to Southwark Social Services. However, there was an added complication in that there were 2 people funded by Lambeth Social Services. Lambeth are now engaged in the process and are undertaking care assessments. Following this Choice Support will begin the de-registering application to the Care Quality Commission.

12. Review of Night Support

The shift from Waking Nights to Sleep In has been evaluated by the Social and Health Evaluation Unit (SHEU) and is the subject of a published report *Better Nights* in October 2012, which found successful outcomes in terms of quality of life, risk management and savings.

13. Quality of Life Monitor

Choice Support has commissioned quality of life audits, first for night support, and subsequently for personalisation.

14. External Evaluation

Choice Support has commissioned external evaluation from the Social and Health Evaluation Unit at Buckinghamshire New University.

It will be clear that Choice's Personalisation Programme stands up well against these criteria but with, as might be expected, points for development.

24

4. Quality of Life

The primary outcome anticipated for the personalisation initiatives of Choice Support was an improvement in the quality of life for individuals, albeit with an overall saving in expenditure. So the central focus of this evaluation is on the extent to which quality of life has improved over the three-year period of personalisation. In its objectives Choice Support spelled out further the improvements in choice, independence, privacy, communication, and activity which they hoped would contribute to quality of life. They also recognized that there might be risks that needed to managed. Choice Support also subscribed to Duffy's *Keys to Citizenship* (2003) as an analysis of topics that should be considered when helping someone with a learning difficulty to plan for their future. These considerations have contributed to the choice of questions in the *Quality of Life Audit*.

The outcome of an overall reduction in expenditure is addressed in Chapter 6. The various initiatives undertaken by Choice Support to implement their personalisation agenda are described in Chapter 3. In order to measure the impact of these initiatives on the quality of life of individuals a special audit tool was developed.

It consisted of 26 statements describing the life of the individual since the introduction of personalisation measures, drawn from the objectives of the Choice Support Personalisation Programme and from the *Keys to Citizenship* described by Simon Duffy (Duffy, 2006). A primary carer, close to the individual, was asked to make a judgement in relation to each statement. In each case the statement was phrased to invite a comparison of the individual now with their characteristics and behaviour before the introduction of personalisation. Respondents were able to agree or disagree with each of these statements on a five-point scale. After the audit was completed for each individual by their primary carer these judgements were verified by the carer's manager. The judgements could be taken as reflecting the views of the Circles of Support, of which the primary carer was a key member.

Audits were completed for 70 individuals. The audit was presented to the respondents, collected and analysed using Survey Monkey software. As will be seen below, overall the majority of the judgements were positive and suggested an improvement in the quality of life of individuals. However a significant minority of responses were less positive. There were also a number where the respondent wasn't sure. These may suggest relatively intractable problems for the individual, but would also indicate that there is still progress to be made.

The following is an analysis of responses for each of the 26 questions.

In response to **QUESTION ONE** the quality of life of the individual was considered to have improved for the large majority (62) but with 6 for whom improvement was not evident and 2 where the respondent wasn't sure.

1. The person's quality of life has improved
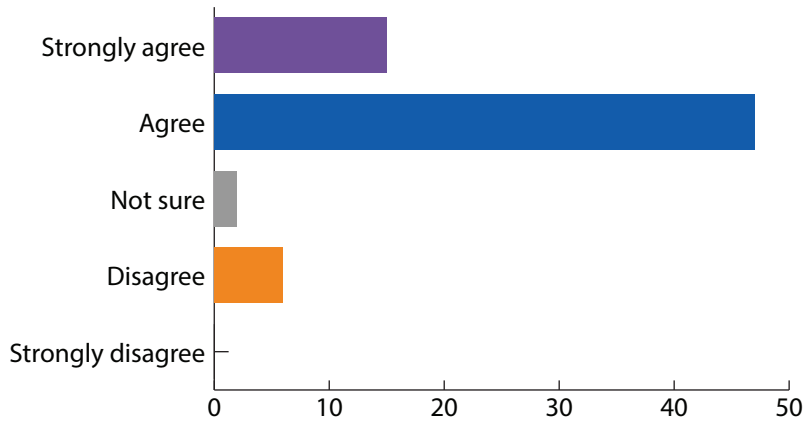
[People or representative: 70 completed question]

QUESTION TWO concerning the key innovation of ISFs revealed that it was considered that a majority of individuals (50) now had more control over their finances but 13 were thought not to have and 6 respondents were unsure. While the strongly agree category was used for 8 individuals, strongly disagree was used for 3. The question wasn't answered for 1 person. Given the importance of ISFs in the Personalisation Programme, the fact that 20 people were judged not to have more control over their finances is worrying.

26

2. The person has more control of their finances
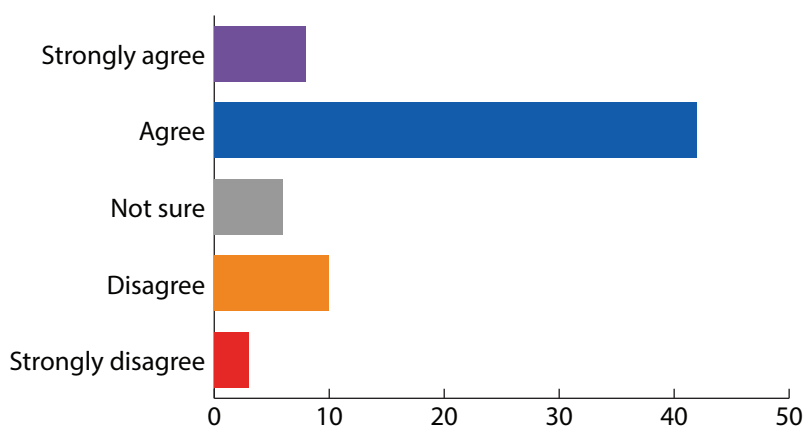
[People or representative: 69 completed question, 1 skipped question]

QUESTION THREE explored the wider issue of whether the person had more control over their life generally. Again a majority (57) thought they had but 4 didn't think they had and a relatively large number of 9 were not sure.

3. The person has more control over the direction of their life
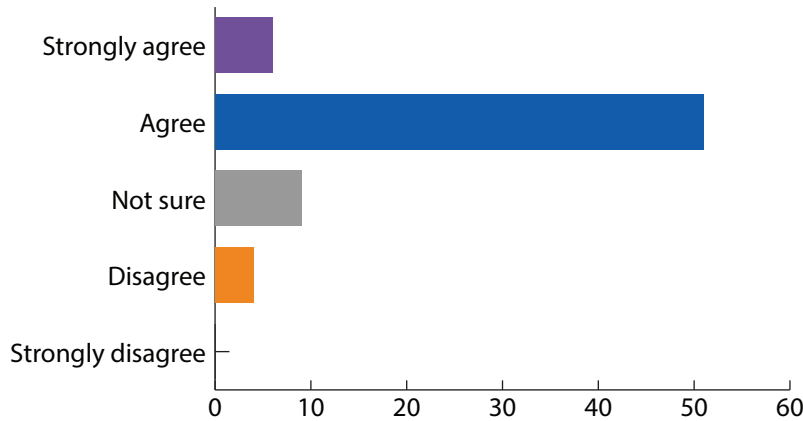
[People or representative: 70 completed question]

QUESTION FOUR was concerned with the extent to which individuals were living a life more like that of those without a learning disability. A majority of 41 thought they were, with 20 who thought they weren't, 8 undecided and 1 not answered. This question, perhaps not surprisingly given people's learning disabilities, has a higher number of unfavourable judgements (20) than the earlier questions. However it does raise the question of the extent to which normalization is a feasible goal for these individuals.

27

4. The person is leading a life more like people without a disability
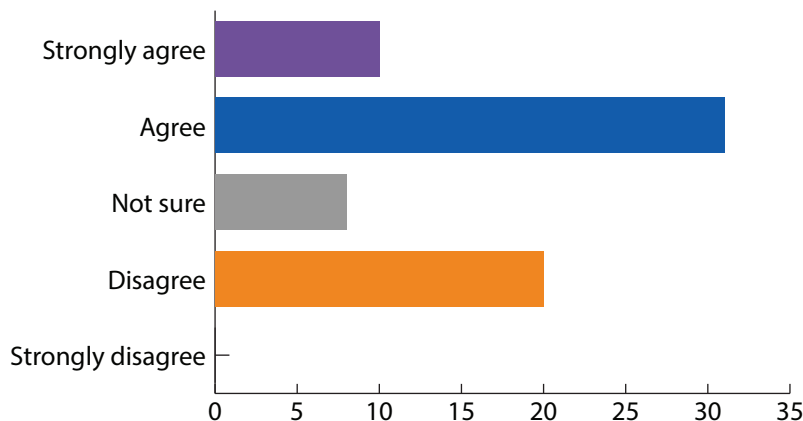
[People or representative: 69 completed question, 1 skipped question]

QUESTION FIVE required a view on whether the central personalisation measure of ISFs had definitely improved the quality of life of individuals. Typically a majority of 42 thought ISFs had brought about an improvement but 18 were not sure and 10 disagreed including 2 who strongly disagreed.

5. Having an ISF has definitely improved the quality of the person's life
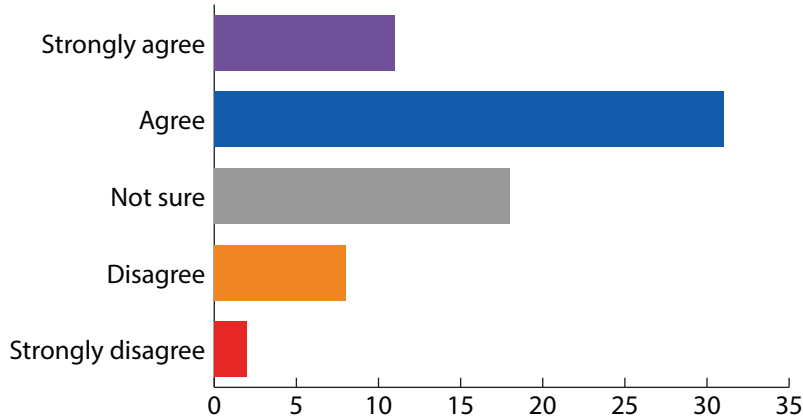
[People or representative: 70 completed question]

QUESTION SIX suggested that having an ISF meant little to the person. Views were divided on this with 29 disagreeing, that is suggesting having an ISF did mean something to the individual, 23 agreeing that ISFs meant little and 18 undecided.

6. Having an ISF means little to the person
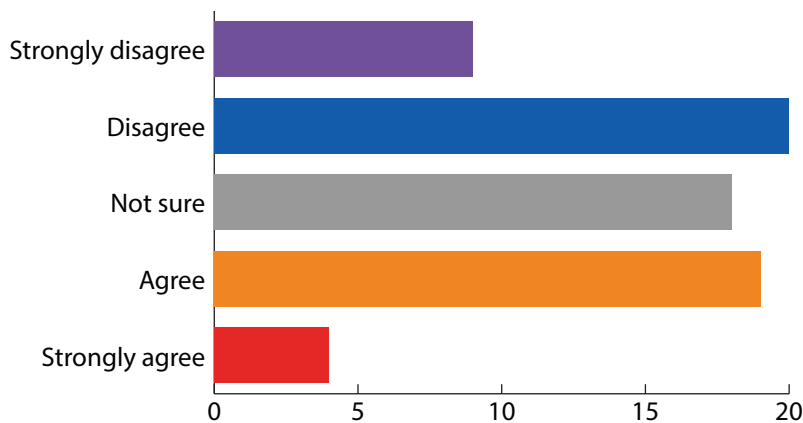
[People or representative: 70 completed question]

QUESTION SEVEN explored whether having an ISF had increased the person's range of choice. For a majority of 45 it was thought it had whereas for 14 this was thought not to be the case and there were 9 individuals where the respondent wasn't sure.

7. Having an ISF has increased the person's range of choice
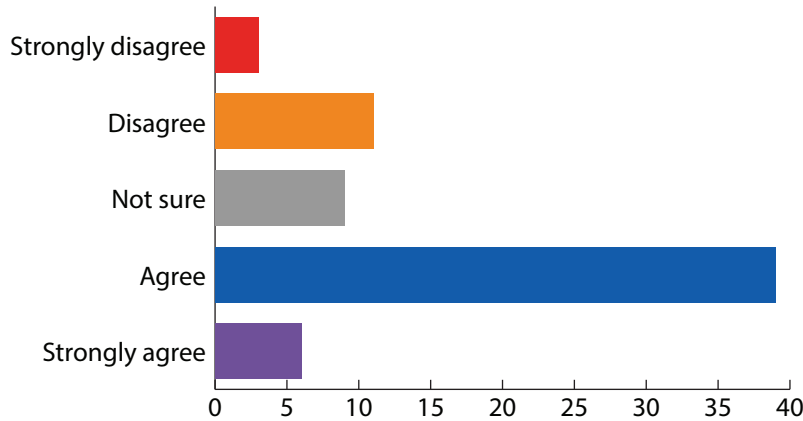
[People or representative: 68 completed question, 2 skipped question]

QUESTION EIGHT focused on the extent to which progress had been made in achieving the goals in each person's support plan. For a large majority (62) it was considered that progress had been made with only 4 disagreeing, 1 unsure and 1 not responding.

29

8. More progress has been made in achieving the goals in the person's support plan
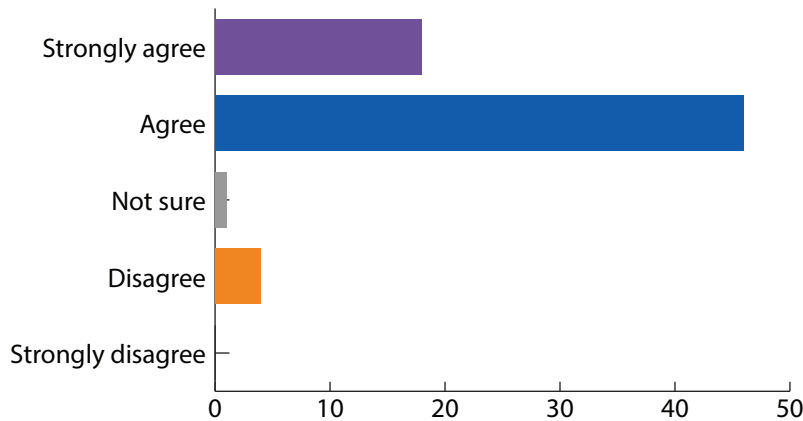
[People or representative: 69 completed question, 1 skipped question]

QUESTION NINE asked the extent to which personalisation had achieved savings for the person without detriment to their quality of life. This is a difficult question to answer on behalf of the individual since the respondent may not be aware of the exact savings that have been achieved, as opposed to the overall savings when ISFs are added together and compared with the block grant. They can however judge whether there has been a detriment in quality of life. Given the dual components in the statement it is not surprising that 27 respondents were not sure. However, of those who were able to make a judgement on behalf of an individual, a majority of 41 were thought to have achieved saving without detriment and only 2 not.

9. Personalisation has achieved savings for the person without detriment to their quality of life
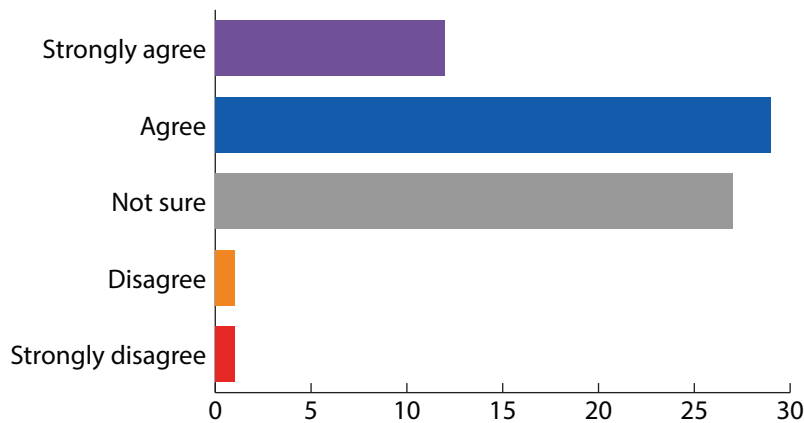
[People or representative: 70 completed question]

30

QUESTION TEN asked for a view on the extent to which individuals were now much more involved in their local community. A majority of 52 were considered to be more involved with 17 not and 1 about whom the respondent was not sure. These results complement the view expressed by several staff that with ISFs and an overall cut back, individuals sometimes had less activity in the community.

10. The person is now much more involved in their local community
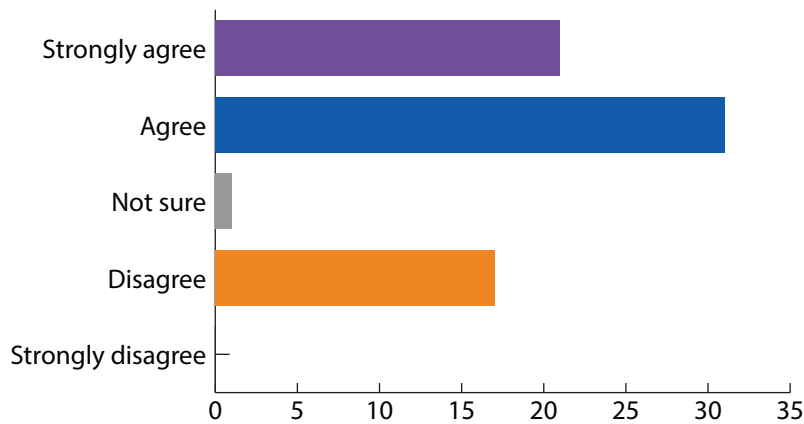
[People or representative: 70 completed question]

QUESTION ELEVEN asked whether support for the person was more effective following personalisation. Gratifyingly this was thought to be the case for a large majority of individuals (64). There were 4 about whom the respondent wasn't sure and only 2 where support was not judged to be more effective.

11. Support for the person is more effective
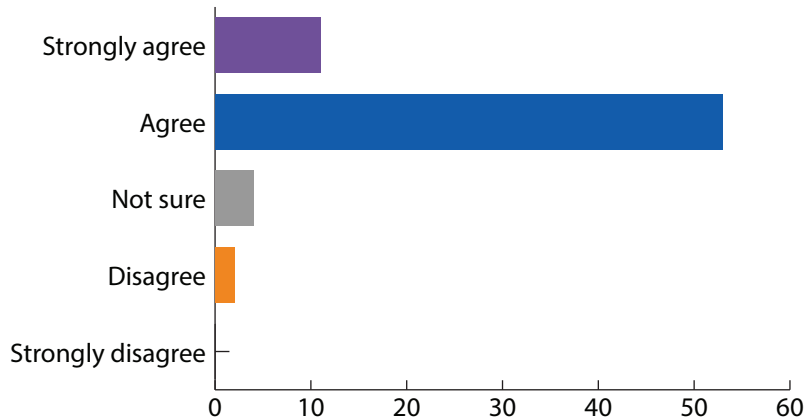
[People or representative: 70 completed question]

QUESTION TWELVE explored whether people were enjoying a fuller life. Again a majority was considered to be enjoying a fuller life (55) but a significant minority (12) were not. 2 respondents weren't sure and 1 didn't answer.

31

12. The person is enjoying a fuller life
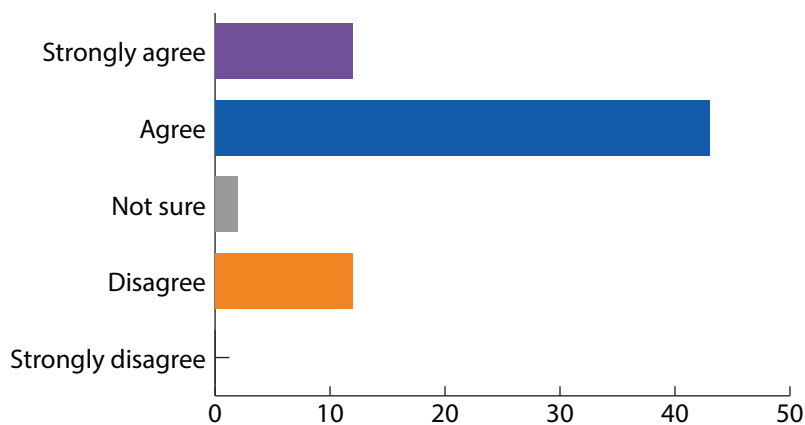
[People or representative: 69 completed question, 1 skipped question]

QUESTION THIRTEEN asked for a view on whether the person was communicating more effectively. The communication of a majority of 46 individuals was considered to be more effective whereas 12 had not improved and there was uncertainty regarding 9. 3 respondents did not answer this question.

13. The person is communicating more effectively
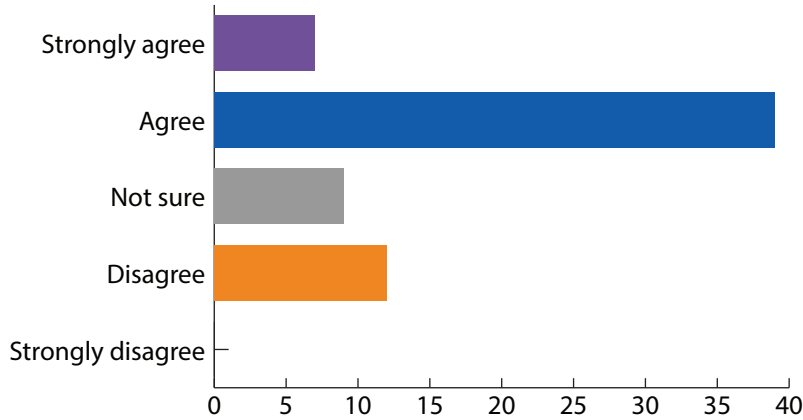
[People or representative: 67 completed question, 3 skipped question]

QUESTION FOURTEEN explored whether the person was able to act more independently. A majority of 48 could, whereas a significant minority of 16 couldn't. Respondents were unsure about 5 individuals and 1 auditor didn't complete this question.

14. The person is able to act more independently
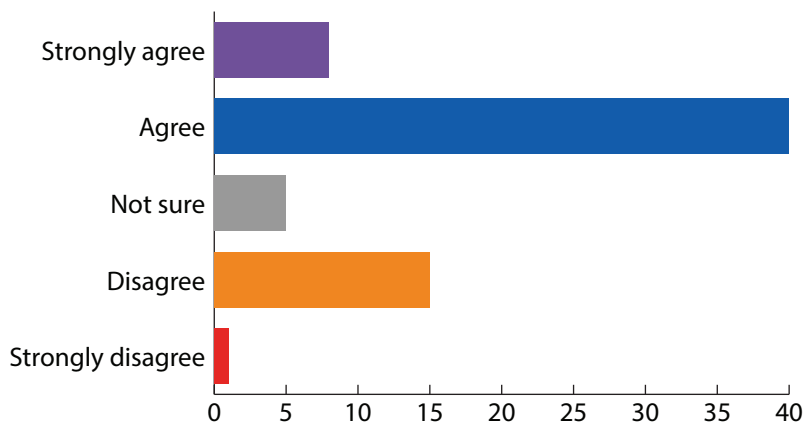
[People or representative: 69 completed question, 1 skipped question]

32

QUESTION FIFTEEN asked whether the person was enjoying better privacy. Consistent with our evaluation of night support where 'waking nights' had been replaced with the less intrusive and hence more private 'sleep in' system, a majority of individuals (51) were considered to be enjoying greater privacy. However, typically, a significant minority of 9 were not thought to be having more privacy and with respect to 10 individuals, respondents were not sure.

15. The person enjoys better privacy
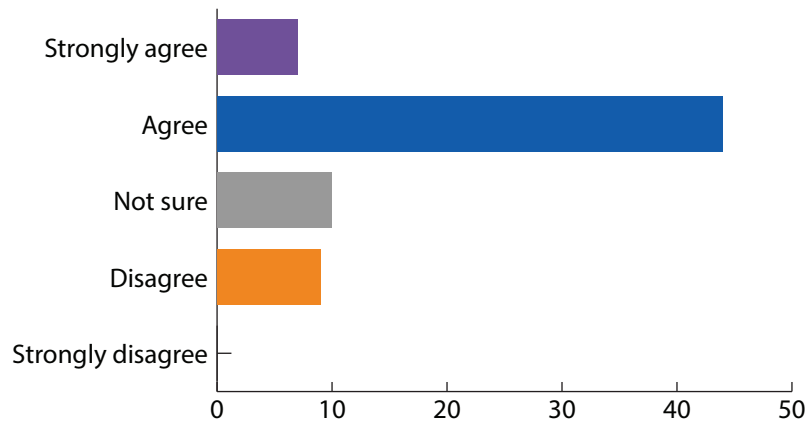
[People or representative: 70 completed question]

QUESTION SIXTEEN addresses a possible negative consequence of the greater freedom and independence associated with personalisation: that the person is at greater risk. A minority of 8 individuals were considered to be at greater risk whereas for the majority of 50 this was not considered to be the case. Within the 50 who were not considered to be at greater risk, 15 responses strongly disagreed with the statement. There were 11 respondents who weren't sure and 1 who didn't complete the question. These responses are consistent with our findings regarding night care, where possible increased risk was an important factor but found to be well managed.

16. The person is at greater risk
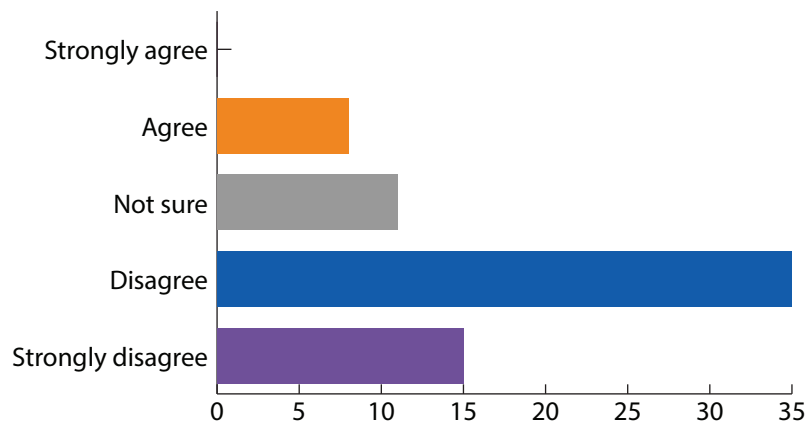
[People or representative: 69 completed question, 1 skipped question]

33

QUESTION SEVENTEEN explored whether the person's life had more sense of direction as a consequence of personalisation measures. In a majority of cases (45) this was thought to be the case, but for a small minority of 6 this was not so. For a relatively large number of 19 individuals the respondents were not sure.

17. The person's life has more sense of direction

[People or representative: 70 completed question]

QUESTION EIGHTEEN posed the central question of whether the individual had developed as a person. Gratifyingly a large majority of individuals (59) were seen as having developed as a person and this included 7 for whom there was strong agreement. Nevertheless development was not seen as having taken place for 8 people including 1 where there was strong disagreement. For a small number of 3 the respondents were not sure.

18. The person has developed as an individual

[People or representative: 70 completed question]

34
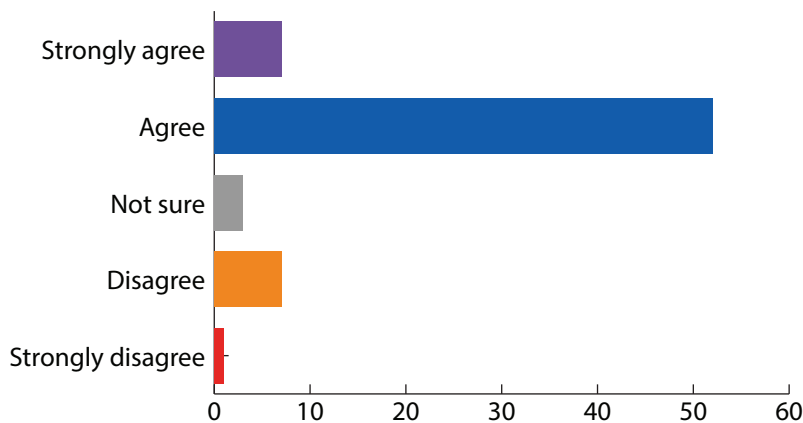
QUESTION NINETEEN explored whether the person was considered to have developed more skills for daily living. A majority of 49 was considered to have developed new skills and in 9 cases the respondents strongly agreed that this was the case. 8 individuals were considered not to have developed new skills and there was uncertainty in 11 cases.
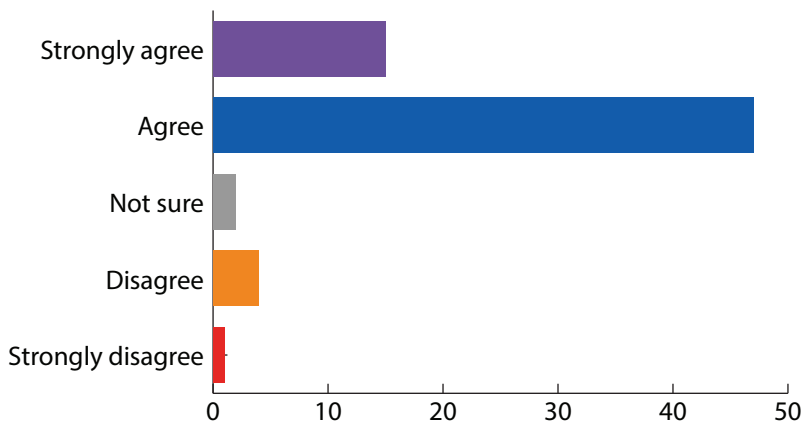
19. The person has developed more skills for daily living
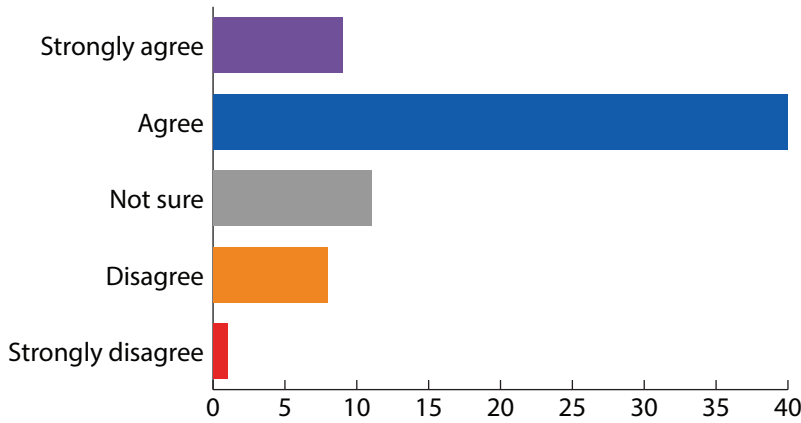
[People or representative: 69 completed question, 1 skipped question]

QUESTION TWENTY explored whether the person had more opportunities to do what they wanted to do, a central tenet of personalisation. In a large majority of cases (62) individuals were considered to have more opportunities to exercise choice and this included 15 persons where the judges strongly agreed. A small minority of 5 was not considered to have had opportunities and in 3 cases respondents were not sure. 1 audit was not completed for this question.

35

20. The person has more opportunities to do what they want to do

[People or representative: 69 completed question, 1 skipped question]

QUESTION TWENTY-ONE invited a broad view on whether the person appeared generally happier. For the majority of individuals (51) it was considered that they were happier with 16 respondents strongly agreeing this was the case. 10 individuals were not considered to be happier and in 7 cases respondents were not sure.

21. The person appears generally happier

[People or representative: 68 completed question, 2 skipped question]

QUESTION TWENTY-TWO explored whether the person had more friends since personalisation measures had been introduced. This might be seen as a desirable outcome but not necessarily so and obviously depends on the extent of friendships prior to personalisation. Given the somewhat ambivalent nature of this outcome it is not surprising that judgements were more divided than usual with 41 individuals seen as having more friendships and 21 not. In 7 cases the respondents weren't sure and 1 audit was not completed for this question.

22. The person has more friends

[People or representative: 69 completed question, 1 skipped question]

36
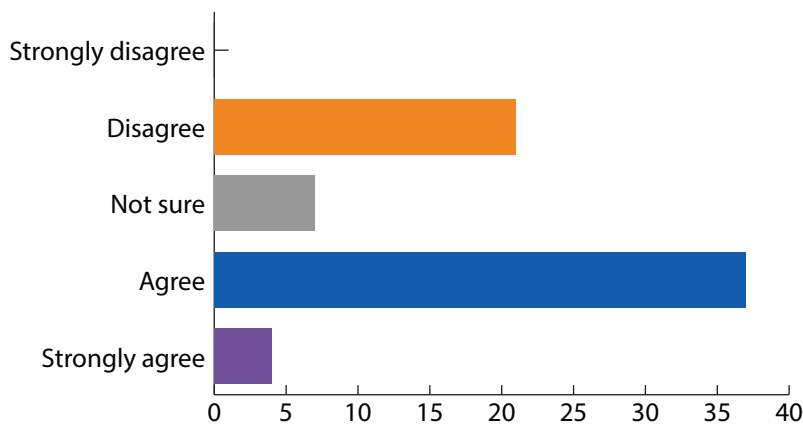
QUESTION TWENTY-THREE asks whether the person is more aware of having money to spend. Awareness obviously depends on cognitive capabilities so not surprisingly this statement also elicited more of a balance in responses with 32 individuals, still a majority, judged to have greater awareness and 23 not. In 12 cases the respondents were not sure and 3 skipped the question.

23. The person is more aware of having money to spend
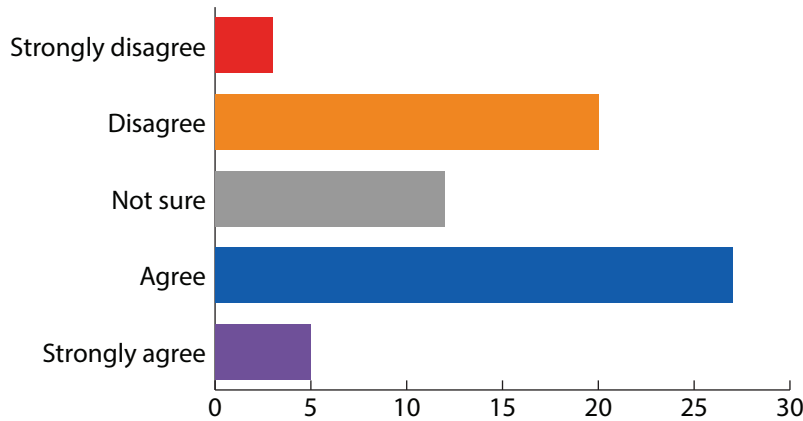
[People or representative: 67 completed question, 3 skipped question]

QUESTION TWENTY-FOUR explores the ambitious and, perhaps, in many cases, unrealistic goal of whether the person has developed skills for employment. Despite the challenge 14 individuals are judged to have developed skills but in the majority of cases (43), predictably this is not so. Respondents were not sure in 9 cases and 4 skipped the question.

24. The person has developed skills for employment
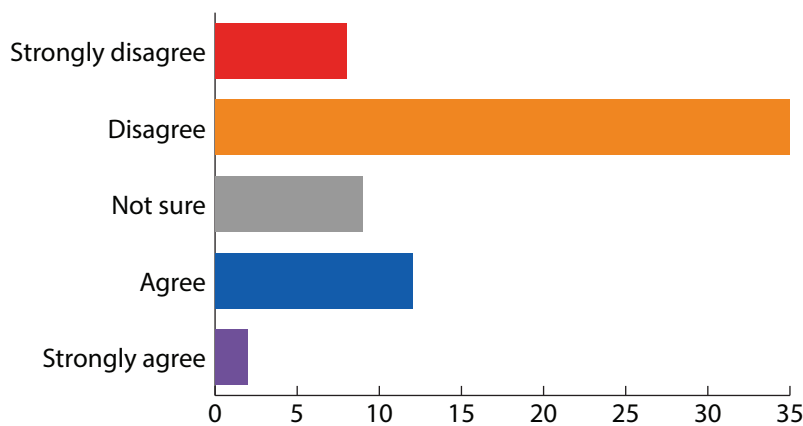
[People or representative: 66 completed question, 4 skipped question]

37

QUESTION TWENTY-FIVE invites a response to a negative expression of the outcomes of the programme suggesting that the person's quality of life may have deteriorated as a consequence of personalisation. Encouragingly this statement was rejected in the vast majority of cases (66) with 26 respondents strongly disagreeing. Nevertheless and surprisingly 4 individuals were judged to have suffered a deterioration in quality of life perhaps due to factors outside the Personalisation Programme.

25. The person's quality of life has deteriorated
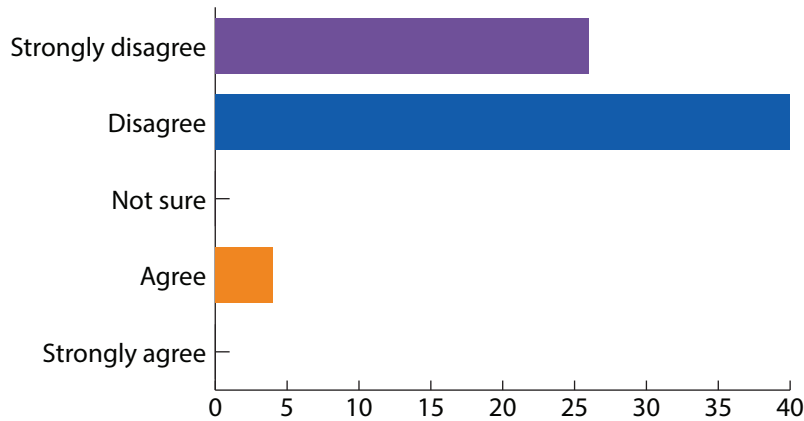
[People or representative: 70 completed question]

38

QUESTION TWENTY-SIX again expressed outcomes in more negative terms suggesting that personalisation may have made little difference to the person's life. This elicited a more mixed response with respondents agreeing with the statement for 21 individuals but disagreeing for 29. In disagreeing 10 used the strong category whereas those who agreed used the strong category once only (1). In 17 cases the respondents weren't sure and 3 skipped the question.

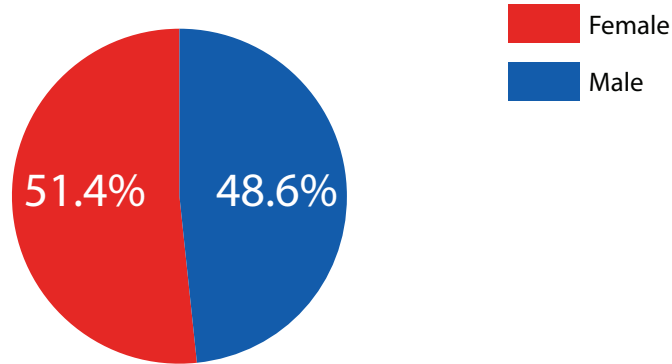## 26. Personalisation made little difference to the person's life
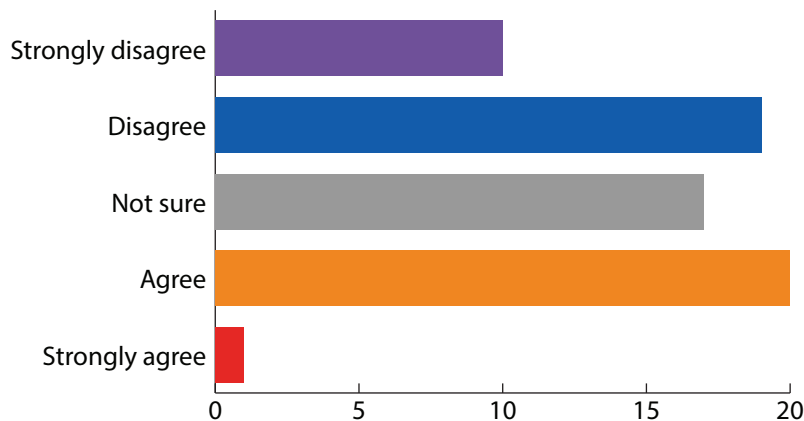
[People or representative: 67 completed question, 3 skipped question]

QUESTION TWENTY-SEVEN identifies that 34 individuals are male and 36 female, a division close to the population gender balance.
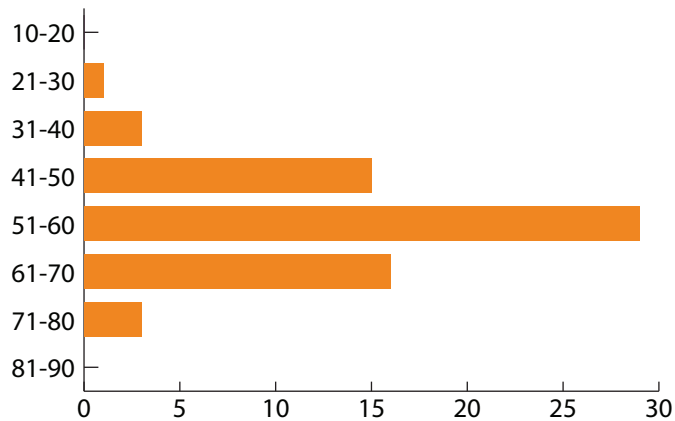
27. What is the person's gender?

[People or representative: 70 completed question]

QUESTION TWENTY-EIGHT shows the age profile of the individuals which is predominantly middle aged to elderly with 41% between 51 and 60 and 84% between 41 and 70.

39

28. What is the person's age?

[People or representative: 70 completed question]

The encouraging message from this audit is that overall the majority of people are considered to be enjoying a better quality of life following the introduction of the personalisation measures. However this should not obscure the judgements that for an appreciable minority of individuals, varying from question to question, quality of life has not improved. There is also a significant element of uncertainty shown by a number of respondents.

It will be important to follow up these audits in the review of the PCP plans for individuals and ask, particularly, why life has not improved for some and what can be done about this.

40

5. Case Studies

To complement the *Quality of Life Audit* data, we produced case studies telling the stories of individuals and the ways in which personalisation generally and ISFs specifically have affected their lives. The following is a selection of five from these case studies. These case studies are consistent with the generally positive results of both the *Quality of Life Audit* and the surveys of views of support staff, social workers and relatives.

The five people featured were selected on the grounds of their support needs, ethnic background, age and sex in order to reflect the diversity of the people being supported in Southwark. Wherever possible the people themselves were interviewed and they told their own stories. If the person was unable to speak those people closest to them, either their friends, family or staff told their story. There were no set questions apart from asking people to reflect on how their lives had changed during personalisation.

John

John with his support worker

In 1995 John slipped over in the kitchen of his family home. Unfortunately, although the doctor said he was not badly hurt, John would not stand up again.

John was very over weight and had lost his confidence in walking which meant he did everything while sitting on the floor. John was also nervous of having any health care treatment

John's mother became exhausted caring for him at home and due to ill health. John's brother said *"It was with a heavy heart that John had to leave his loving family."*

Choice Support started supporting John in 1995 in a registered care home. His support is now provided through an ISF. John's staff thought that John would enjoy life more if he could be supported to leave his home. John is not able to speak and his staff started using pictures to help explain to him what was going to happen next. It proved difficult at first because John would sit on the ground and refuse to move. He is now walking and is happy to go out to do his own shopping and can choose what he wants.

John has also had blood tests taken for the first time in his life. Twenty people and professionals were involved to help make this happen together with an ambulance

in case there were any emergencies. After his blood test John was diagnosed with a thyroid problem and he now has treatment for this.

Today John has learnt many new skills from his staff. He will ask to go out for a drive and has lost a lot of weight. John goes out for lunch in restaurants, goes to parties, has friends who he visits and socialises with and is enjoying his life. John's brother and sister are very much involved and visit him regularly. They are very happy with how things are going.

Janette

Janette with Zig and Zag

"I have my own staff now. They are on my person centred plan. I chose the ones I like to support me. I get 21 hours of support a week from Choice Support and this is enough for what I want. Therese is my Personal Assistant; I pay for her from my support money. I like Therese because we are like friends really and she helps me a lot. She has supported me for a long time.

"I think things are better than they used to be. I do a lot of different things now. I go out shopping on my own. I used to go with staff, but now I go alone. I like knitting. I am making a baby's matinee jacket for my nephew and his wife. I've got two budgies called Zig and Zag. I went on the Undateables programme on Channel 4 and I am still seeing my date Ray as a friend. I've worked as a receptionist for five years in the same job only three days a week. I like my job very much. I used to work in a café. I was offered work experience and because I did so well they gave me the job.

"My plan is to go to Australia to visit my great cousins who live there because I don't get to see them often. I'm saving all my silver in a jar for the trip. I've found money lying around the house, underneath the sofa. I found a load down there! My family are happy with how things are going. I had a gastric bypass one year ago and I'm still losing weight. I feel much better. I can walk everywhere now. I saw a programme about big women and I thought "no, I can't be hacking this no more."

"I've moved to a new flat. I like it, the neighbours are a bit noisy but it is alright. I get the support I need. It is my second flat and I moved because I didn't have a separate door. I wanted my own space. I wanted my own life. Yes, I've got that now. I have my own pets, my own space."

42

Kathy

Kathy travelling

In 2011 Kathy became the first person in Southwark to have an ISF. Kathy has support for 14 hours a day which is the highest ISF of all the people supported in Southwark. Kathy can't share sleep-in staff because of her complex needs but despite initial anxiety that she would go over, she has kept within her budget.

Kathy used to live in a registered care home. She doesn't like women and would become aggressive towards them. Kathy's manager needed to change her staff teams regularly. In an emergency there were no temporary staff who could support her.

Since having her ISF Kathy has moved to her own supported living flat with a garden and hasn't presented any challenges to her support. Now she will tolerate the occasional need for new staff and will accept being supported by women.

Kathy's manager attended Choice Support training and realised Kathy didn't know what was going to happen next. She needed to learn how to sequence things. Staff started a visual planner with pictures so Kathy knows exactly what to expect every day.

Staff have also been supporting Kathy to learn coping and tolerance skills and have used stories to help her interact and talk. She can now accept being in new situations and meeting new people. Unfortunately Kathy has developed rheumatism and arthritis. In the past Kathy wouldn't have allowed the health tests she needed but she has now had all the necessary medical scans.

Every Friday Kathy has a meeting and she talks about what has happened during the week. Kathy says:

> "Kathy doesn't do those things anymore. She hasn't banged her head since she moved here."

Kathy is being supported by staff that she likes and has chosen; staff who also care about her. Kathy's support worker says:

> "Working with Kathy has made me happy. We have come a long way, and I really understand her."

When Kathy met with the Care Quality Commission (CQC) inspector during a recent inspection she was able to talk with them and answer their questions for the first time.

43

Cookie

Cookie (right) with her housemate Alison

Although Cookie doesn't look her age she is going to be sixty soon. Cookie has lived in the UK for many years but her family originally came from Spain. Cookie is a lively person who loves going out; but this hasn't always been the case.

Cookie used to be reluctant to leave her home after having a few falls. Cookie is now using the stairs again. She has learnt how to hold the rail and asks for support if she needs to carry things up and down.

Cookie now gets on the bus and is always ready to go out. Her Choice Support staff have found more activities for her to try and she says she doesn't like to be indoors. Cookie's doctor has been able to reduce her medication so Cookie is fitter to walk. Cookie attends a local college where she is studying art and pottery. She says:

"I like art. I like doing drawings and pictures of faces."

Cookie stays in touch with her Spanish roots. She goes to a mainstream nightclub for people with a Spanish background. She has many friends at the club who talk to her in Spanish and she really likes this. Cookie says:

"I like going out. I like going to the Spanish group. I go around 10pm and stay to 3am. I like drinking shandy. I meet my friends there for the dancing."

"I went to Spain last year. I went clubbing and to the beach, a lot of places."

"I like going out with my sister Rosa, looking around, we stop at the café. Rosa is my big sister. She comes every week. I'm going to my sisters at Christmas."

Cookie's Choice Support staff are shared with her three other house mates:

"I am happy here. We go out together to Helping Hands club and drama on Friday night. With my seven hours one to one support, I go to the bank, shopping and cinema."

"I like to watch Spanish films. I have a DVD player and my friends give me DVD's to watch. I go to a Spanish hairdresser on the Green. She speaks Spanish to me, Anna, she does my hair."

44

Paul

Paul (left) at a football match with his support worker

Paul has been supported for many years by Choice Support in Southwark. Paul is 43 years old and has an unassuming and gentle personality. He gets on very well with the two other men he lives with. Paul isn't able to speak but he lets people know what he wants through his body language and simple hand signs called Makaton.

The ISF budget has enabled Choice Support staff to plan a new range of activities for Paul to try. Paul's care manager from Southwark Council commented after a recent meeting:

"Paul is one of the people most affected by the modernisation of day services, he was attending five days a week and the new plan removed this completely. Clearly this was a huge change for Paul."

"I am really pleased with the outcomes. The plan has surpassed expectations and Paul has experienced a huge range of activities, now he is actively being supported to find employment opportunities. This is something new to Paul which he clearly enjoys. In September he was supported by staff on a holiday to Cyprus with his mother which meant a lot to her."

Paul's support worker said:

"Things are much better now. Paul is going out more and he has more confidence. We have helped him to learn to travel on the bus."

"Paul had never flown before. We went on a day trip to Biggin Hill and went to the airport three times before we tried the flight. The holiday to Cyprus went well and he got on the plane fine."

"He is so busy there is no space for him to get bored. Paul and his housemates go out together on Saturday afternoons and always have Sunday roast together in the house. There is a good balance between work and play."

45

6. Savings

The financial plan included immediate savings in December 2010 and further savings made over subsequent years. The savings were achieved by reducing Choice Support's local and central overhead costs to 15% of ISFs, reducing the costs of their hourly support rate and only providing support based on each individual's PCP. Southwark agreed for a percentage of these savings to be used by Choice Support as a transitional fund.

Choice Support achieved the savings in a number of ways including changing their existing staff terms and conditions, revising their management structure, reducing overheads and closing the local office. They also deregistered all care homes on the former block contract. This work has been recognised by the National Development Team for Inclusion (NDTi) in their *Feeling Settled Report* (2011) and the *Feeling Settled Toolkit* (2013). This Toolkit aimed to improve housing rights and security of tenure for disabled and older people.

Other savings were achieved by reducing the amount of direct support hours and with increased use of Assistive Technology (AT). A previous SHEU report *Better Nights* (2012) evaluated the provision of sleep-in night time support in place of waking night cover.

The following table describes the savings made:

FINANCIAL YEAR	PER ANNUM	CUMULATIVE
2010-11	£324,250	£324,250
2011-12	£310,750	£635,000
2012-13	£260,314	£895,314
2013-14	£250,041	£1,145,355
2014-15	£649,718	£1,179,073

Choice Support are saving £1.79 million over 4 years which is a 29.75% saving on the cost of the former block contract for Southwark Adult Services (Source: ISFs in Action, Hoolahan, 2012).

7. Care Staff

Care staff are obviously central to the delivery of the personalisation agenda. It was therefore decided to survey their views on the Personalisation Programme through a specially devised anonymous questionnaire. In the questionnaire respondents could agree or disagree (on a five point scale) with statements regarding their position and views in relation to personalisation. At the conclusion of the twelve structured questions respondents were given a chance to identify the best and worst things about personalisation.

All staff were given an opportunity to complete the questionnaire if they wished. In fact 36 took this opportunity. The questionnaires were constructed, administered, collected and analysed using Survey Monkey software. As will be seen from the following charts, the majority views of staff were positive or highly positive on all the topics with a minority unsure or negative. On the free response questions 21 staff identified a strength and a smaller number some weaknesses. These responses are summarised after the following question-by-question analysis.

QUESTION ONE explored staff familiarity with the idea of personalisation. 35 staff claimed familiarity, with a small number (3) moderating their claim to 'some' familiarity and 1 saying they knew little about it.
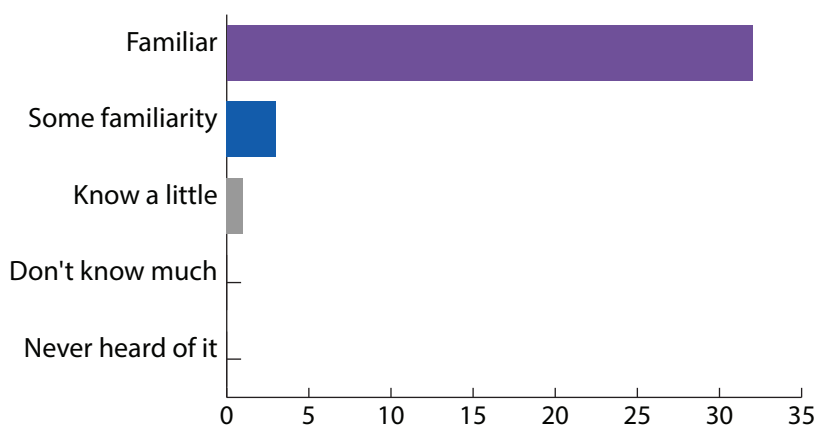
47

1. Familiarity with the idea of Personalisation (including ISFs)

[Supporters: 36 completed question]

QUESTION TWO asked for views on the effectiveness of personalisation on the lives of individuals. 15 staff thought it had a considerable effect; 17 that it had some effect; 1 person wasn't sure; and 3 didn't think it had much effect. No one thought it had no effect.
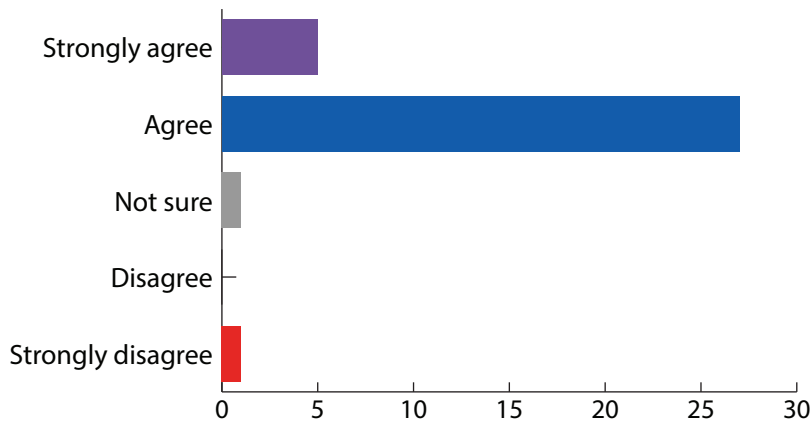
2. Effects of Personalisation (including ISFs)
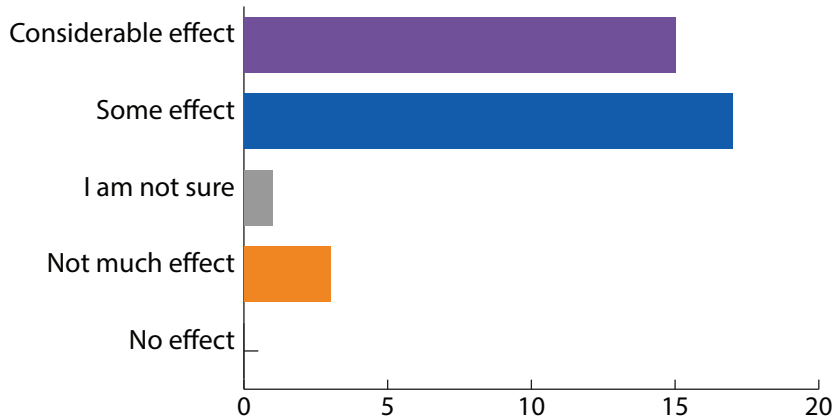
[Supporters: 36 completed question]

QUESTION THREE offered a statement that 'Personalisation (including ISFs) has been a key factor in the lives of individuals' with which respondents could agree or disagree. 5 strongly agreed; 27 agreed; 1 wasn't sure; and 1 strongly disagreed that it had been a key factor in people's lives.

48

3. Personalisation (including ISFs) has been a key factor in people's lives

[Supporters: 34 completed question, 2 skipped question]

QUESTION FOUR gave the statement 'The Personalisation Programme (including ISFs) has improved the quality of life of individuals.' 10 strongly agreed with this fundamental statement on the key outcome; 20 agreed; and 5 weren't sure. No one disagreed.

4. The Personalisation Programme (including ISFs) has improved the quality of people's lives
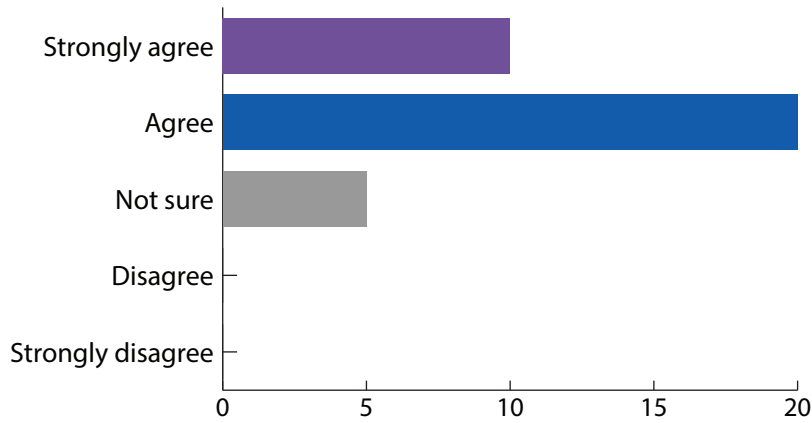
[Supporters: 35 completed question, 1 skipped question]

The statement in **QUESTION FIVE** was 'I have been fully informed regarding the Personalisation Programme.' 34 staff agreed with this statement with 4 strongly agreeing. Two skipped the question.

49

5. I have been fully informed regarding the Personalisation Programme
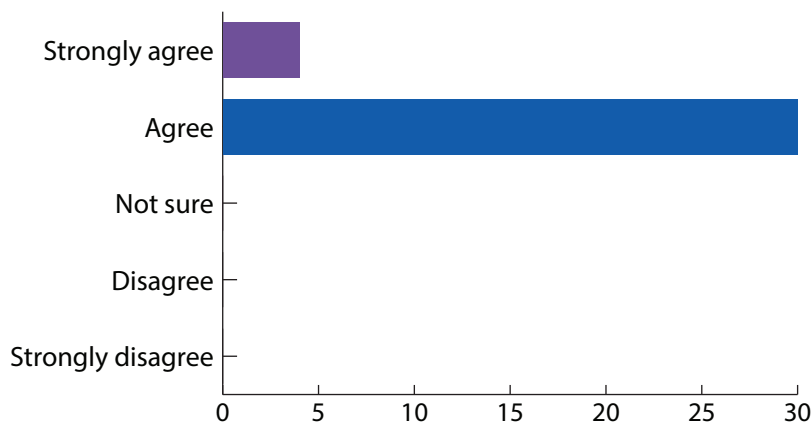
[Supporters: 34 completed question, 2 skipped question]

The statement in **QUESTION SIX** was that 'I have been given training to prepare me for the Personalisation Programme.' The response to this was very positive from all respondents with 10 strongly agreeing and 26 agreeing.

6. I have been given training to prepare me for the Personalisation Programme
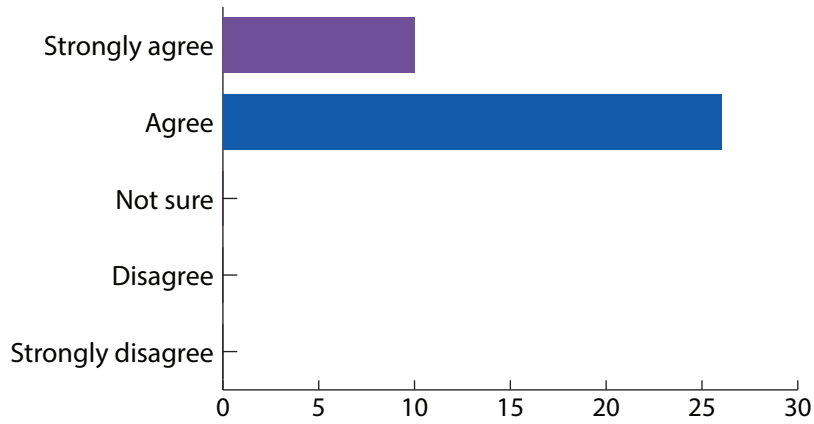
[Supporters: 36 completed question]

QUESTION SEVEN suggested that 'the Personalisation Programme has had a significant effect on my working practices.' Again this elicited a mainly positive response with 6 strongly agreeing and 21 agreeing. However 8 weren't sure, which might be a concern.

7. The Personalisation Programme has had a significant effect on my working practices
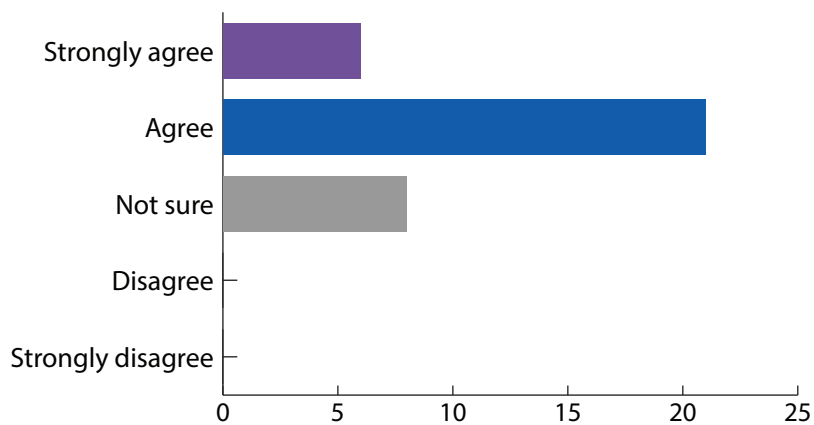
[Supporters: 35 completed question, 1 skipped question]

50

QUESTION EIGHT put forward a negative statement that 'The Personalisation Programme is irrelevant to my working practices.' This elicited a somewhat mixed response with a relatively narrow majority of 20 disagreeing, including 2 who strongly disagreed, 10 who weren't sure and five who agreed including 1 who strongly agreed. 1 respondent skipped the question.
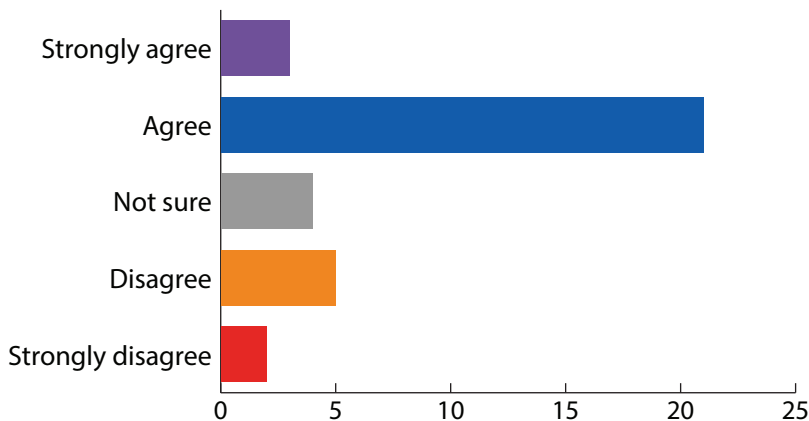
8. The Personalisation Programme is irrelevant to my working practices
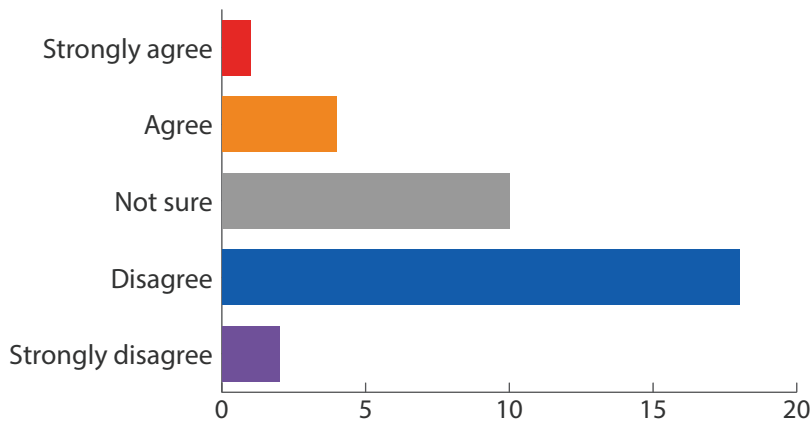
[Supporters: 35 completed question, 1 skipped question]

QUESTION NINE suggested 'I need help to implement the Personalisation Programme' a proposition with which a majority of 24 agreed, including 3 who strongly agreed. 7 disagreed including 2 who strongly disagreed and 4 were not sure. 1 person skipped the question.
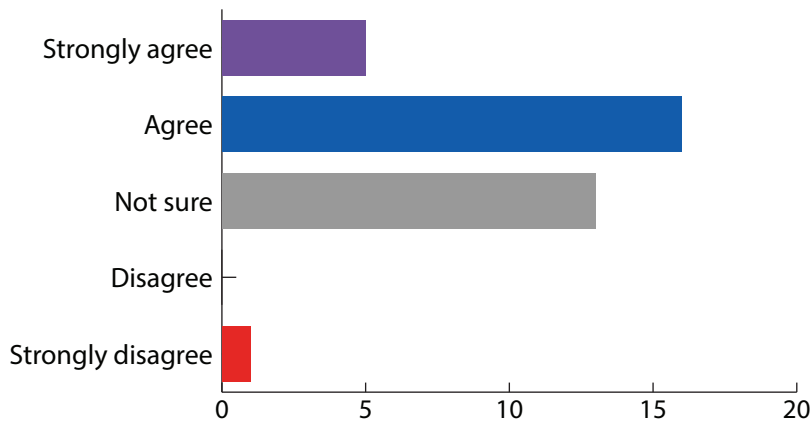
51

9. I need help to implement the Personalisation Programme

[Supporters: 35 completed question, 1 skipped question]

In **QUESTION TEN** the strongly positive statement 'The Personalisation Programme is the most significant initiative I have experienced in my working life' was put forward for consideration. A majority of 21 agreed with the statement including 5 who strongly agreed. However 13 were not sure. 1 person disagreed strongly. 1 person skipped the question.

10. The Personalisation Programme is the most significant initiative I have experienced in my working life

[Supporters: 35 completed question, 1 skipped question]

The statement in **QUESTION ELEVEN** was a counterbalance to that in Question 10 and was 'The Personalisation Programme is just management jargon.' A majority of 25 disagreed with the statement including 6 who disagreed strongly. However a small number (5) agreed and another 5 were unsure. 1 person skipped the question.
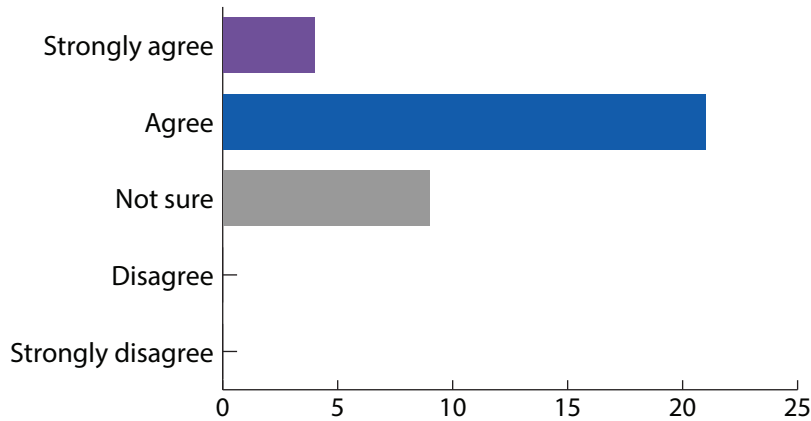
11. The Personalisation Programme is just management jargon
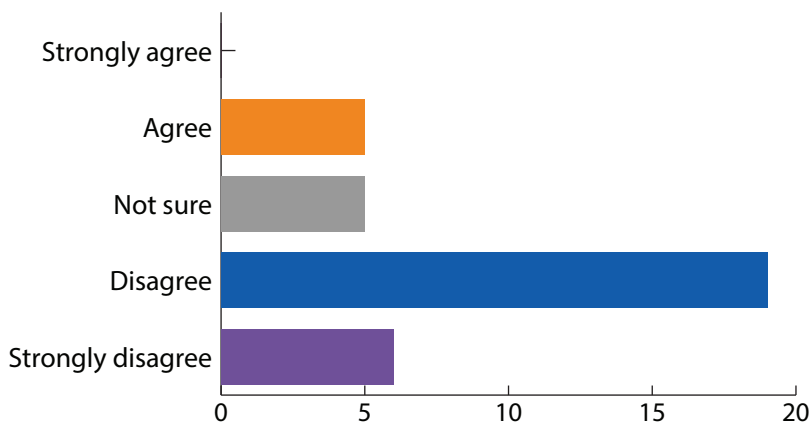
[Supporters: 35 completed question, 1 skipped question]

QUESTION TWELVE put forward the proposition that 'Personalisation has achieved savings for the individual without detriment to his her quality of life.' A majority of 25 agreed with this including 4 who strongly agreed but 9 were not sure. No one disagreed but 2 skipped the question.

12. Personalisation has achieved savings for the person without detriment to their quality of life

[Supporters: 34 completed question, 2 skipped question]

OPEN-ENDED QUESTIONS

The final two questions were more open ended with question 13 inviting a response to 'The best thing about the Personalisation Programme is' and question 14 inviting a completion of 'The worst thing about the Personalisation Programme is' 21 respondents out of 36 possible chose to address one or both of the open ended questions. In the 21 responses, 4 were left blank, one was incomplete, one wrote N/A, and 4 had no negative points to make. All 21 respondents completed question 13 and a smaller number question 14.

- **Personal independence** - 7 out of 21 respondents stressed that personal independence was an important outcome. Offering opportunities for individual activities rather than group activities was regarded as a positive step by five respondents – e.g. 'People have more control over their lives – they make their own decisions'.
- **Choice** - 6 respondents emphasised that freedom to choose and having the flexibility to choose were important e.g. 'People now do what they will like and don't go to activities they don't want to go or agree to.' 'It's flexible'.
- **Control** - 7 respondents stated that having control over one's life and specifically having financial control were very positive improvements e.g. 'Individual is more in control of their allocated ISF money and can choose services that are suitable for their needs'.
- **Staff working patterns** - 2 respondents stated that staff working patterns were affected, presumably adversely.
- **People missing out on group activities and visits** - 3 respondents felt that group visits to the Day Centre and group activities and outings were now limited.
- **Funding inadequate to meet people's needs** - 1 respondent regarded funding to be inadequate to fully meet the needs of people being supported.

53

The balance of these comments mirrored the generally positive responses to the earlier questions and elaborated positive views with reference to independence, choice and control. The perceived disadvantages of the Programme included some comments that were not otherwise available including adverse effects on work patterns, limitation on certain activities, and funding not meeting expectations.

Overall the results of this survey mirrored those of the *Quality of Life Audit* in that the majority were favourable but a significant minority, varying by question, were not. The unfavourable responses could be addressed in staff development sessions at the same time as the generally positive quality of life results.

Views of Managers

We were able to spend time with the Director and two service managers to highlight aspects of personalisation from their point of view. Their points included the following.

- Personalisation was driven by the aim to make the individual and their choices and control over their lives the centre of provision.
- Managers conceived the Personalisation Programme as an agenda with a number of items including ISFs and PCPs; deregistration; changes in night care from waking nights to sleep in; and overall increased attention to individual needs and wishes.
- This agenda had to be achieved in a short time scale and in the context of economies and associated staff cuts.
- Personalisation entailed a significant change to a strongly established work and support culture with resistance from advocates, trade unions and families, all of whom had to be persuaded.
- Communication was vital for such an organisational and cultural change and was made more challenging by the cuts in staff, including managers, and the abbreviated time scale of introduction.
- Planning for and delivery of the agenda was through a partnership between Choice Support and London Borough of Southwark with challenging discussions about individual need, PCPs and ISFs.
- With the phasing out of the advocacy service, which had special time limited funding, the Circles of Support were an important innovation involving key workers, advocates and families.
- The new way of working, with reduced but individually focused funding, had encouraged creativity and new ways of solving problems.
- Partnership with the commissioner to assess and determine needs, PCPs and ISFs was a strength. Personalisation gives a focus for optimal engagement of commissioner, provider, staff and relatives with the individual at the centre and an enhanced awareness of available funding and possibilities.
- The restructuring consequent on reduced funding and personalisation placed additional tasks on a smaller number of managers who had been reduced from 22 to 15.
- Strengths of personalisation were the more personalised support for individuals including, for example, holidays and the goodwill from staff.

54

8. Social Services Staff

The London Borough of Southwark has the statutory responsibility for those assessed as having learning difficulties. On a day-to-day basis they discharge this mainly through support commissioned from Choice Support although social workers may be involved in determining PCPs and ISFs and when there are individual difficulties. It was therefore important to sample the views of social service staff on the personalisation initiative.

While the direct support for these individuals is provided by Choice Support on contract from Southwark, the care managers from Southwark social services are involved in the review of ISFs on an annual basis. They verify if the funds are being spent in line with what has been agreed and they work with individuals, families, circles of support and providers to review and suggest changes in the way the ISF is being implemented. They work to ensure that the individual is receiving the optimal support for the package that they receive.

Each care manager has a case load of approximately 40 people. Individuals may be either on a normal 'duty' rota or have a special 'allocated' status. Those who are 'allocated' have a 'named' social worker. Allocated people tend to be individuals with some significant issues. They may for example have safeguarding issues, health issues or be chronically at high risk. Other individuals have a 'duty' social worker. There is a rota where each care manager takes their turn at covering duty. Most of the individuals (when the ISFs were devised) had a duty care manager and were on the duty system.

Most of the individuals in this evaluation, being settled, would have only a passing acquaintance with a care manager or other social service staff). If there were problems for an individual the care manager would arrange case conferences and social services would be more involved. When problems are resolved the individual's case is closed and they return to 'duty' status.

It was decided to survey the views of care managers on the Personalisation Programme through a specially devised anonymous questionnaire. In the questionnaire respondents could agree or disagree (on a five point scale) with statements regarding their position and views in relation to the programme. The questionnaire was identical to that given to Choice Support staff which allowed for comparison. We were told that the number of social services care managers involved would be around 15. In fact responses were received from 17 persons. Two additional responses were received in error and had no data. The questionnaires were constructed, administered, collected and analysed using Survey Monkey software.

55

In general the views of care managers regarding personalisation were positive and comparable with the views of Choice Support staff. As will be seen from the following charts, the majority views of staff shown through their responses to all 12 questions were positive or highly positive on all the topics with only a minority unsure or negative. It is interesting that when there are differences the Southwark social services staff tend to be more positive or less negative as can be seen by comparing the graphs for the two groups.

QUESTION ONE explored staff familiarity with the idea of personalisation. 16 stated they were familiar, with 1 moderating that to some familiarity.

1. Familiarity with the idea of Personalisation (including ISFs)
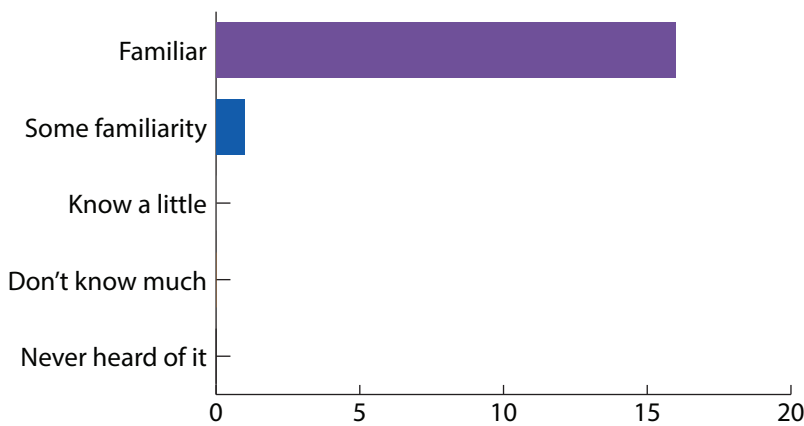
[Social Service Staff: 17 answered question]

QUESTION TWO asked for views on the effectiveness of personalisation on the lives of individuals. 10 thought it had considerable effect; 6 thought it had some effect and 1 thought it hadn't had much effect.
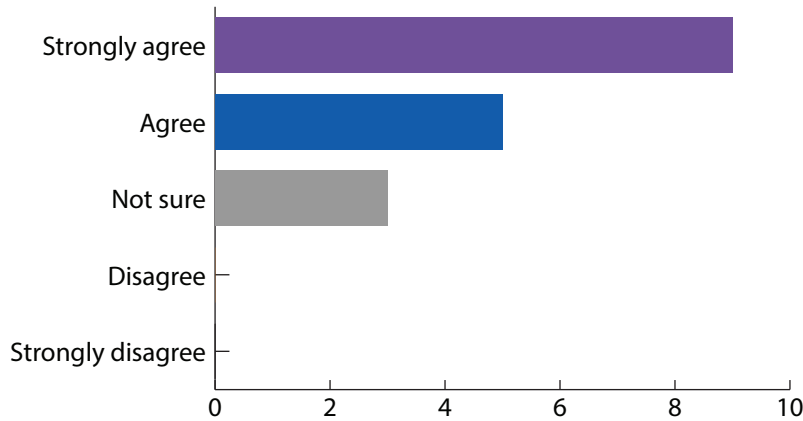
2. Effects of Personalisation (including ISFs)
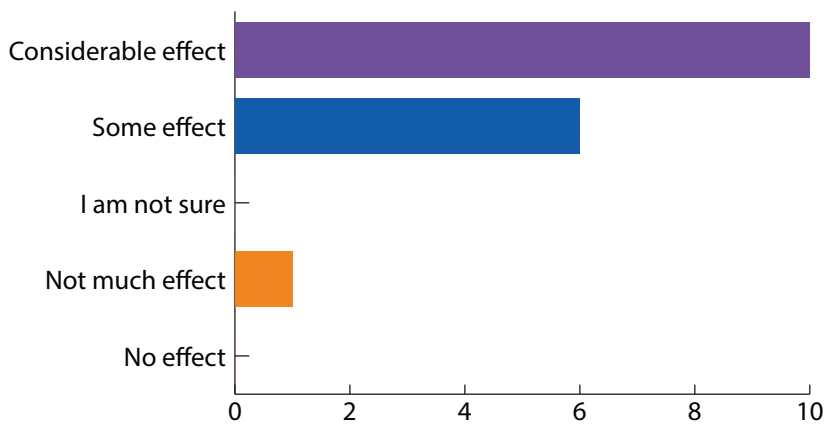
[Social Service Staff: 17 answered question]

QUESTION THREE offered a statement that 'Personalisation (including ISFs) has been a key factor in the lives of individuals' with which respondents could agree or disagree. 9 strongly agreed; 5 agreed and 3 weren't sure. No one disagreed.

3. Personalisation (including ISFs) has been a key factor in people's lives

[Social Service Staff: 17 answered question]

QUESTION FOUR gave the statement 'The Personalisation Programme (including ISFs) has improved the quality of life of individuals.' 5 strongly agreed; 10 agreed; and 2 weren't sure. Again, no one disagreed.

57

4. The Personalisation Programme (including ISFs) has improved the quality of people's lives
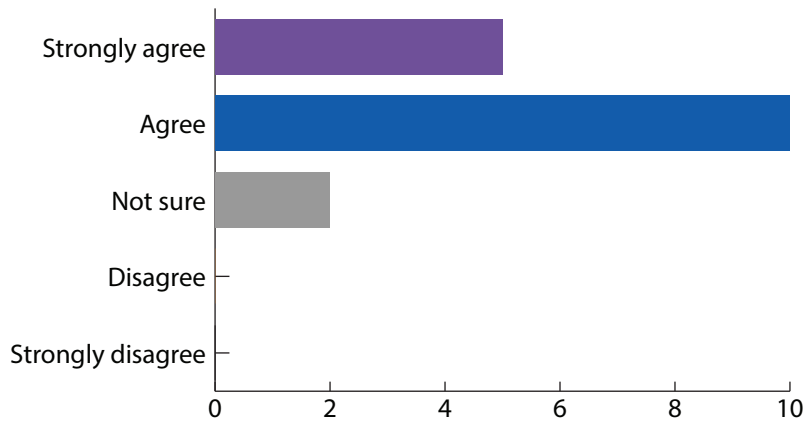
[Social Service Staff: 17 answered question]

The statement in **QUESTION FIVE** was 'I have been fully informed regarding the Personalisation Programme.' 12 strongly agreed and 5 agreed.

5. I have been fully informed regarding the Personalisation Programme
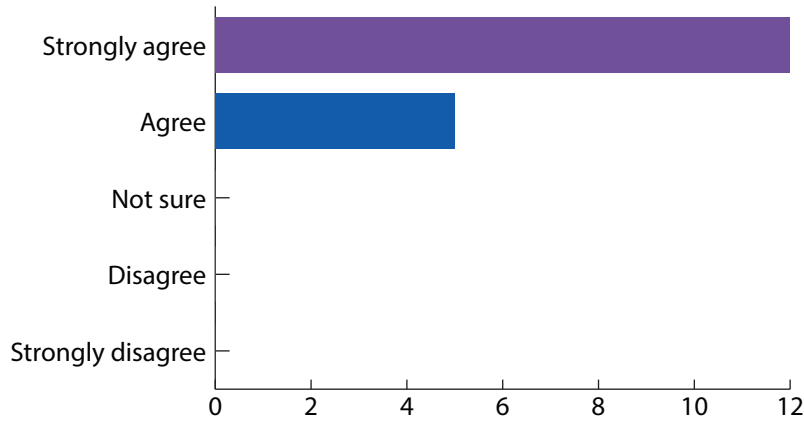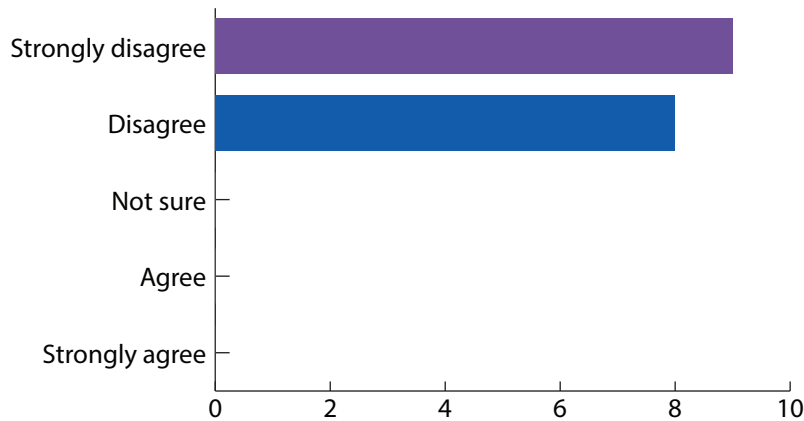

[Social Service Staff: 17 answered question]

The statement in **QUESTION SIX** was that 'I have been given training to prepare me for the Personalisation Programme.' 9 strongly agreed and 8 agreed.
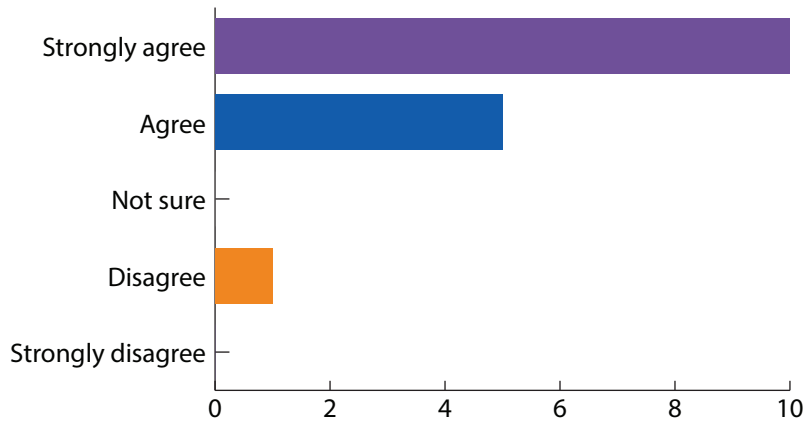
58

6. I have been given training to prepare me for the Personalisation Programme

[Social Service Staff: 17 answered question]

QUESTION SEVEN suggested that 'the Personalisation Programme has had a significant effect on my working practices.' While there was a majority positive response with 10 strongly agreeing and 5 agreeing there was 1 who disagreed.
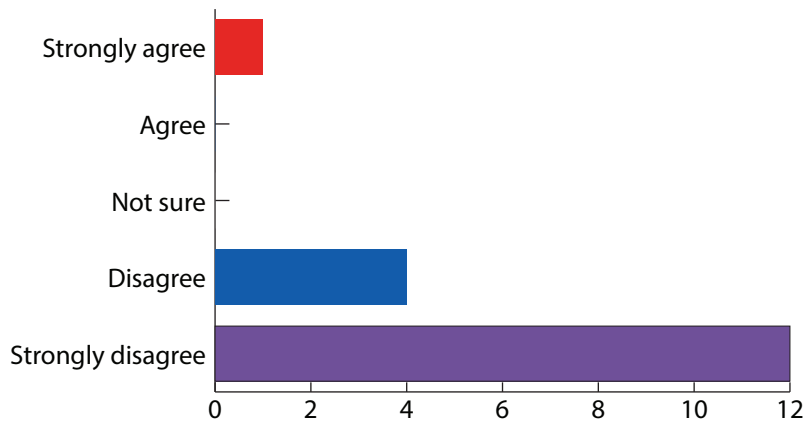
7. The Personalisation Programme has had a significant effect on my working practices

[Social Service Staff: 16 answered question, 1 skipped question]

QUESTION EIGHT put forward a negative statement that 'The Personalisation Programme is irrelevant to my working practices.' The majority disagreed with this statement with 12 disagreeing strongly and 4 disagreeing but again as in the previous question there was 1 dissident voice who strongly agreed with the statement.

59

8. The Personalisation Programme is irrelevant to my working practices

[Social Service Staff: 17 answered question]

QUESTION NINE suggested 'I need help to implement the Personalisation Programme' a proposition with which a majority of 13 agreed including 5 strongly. However 4 disagreed and felt they didn't need help.

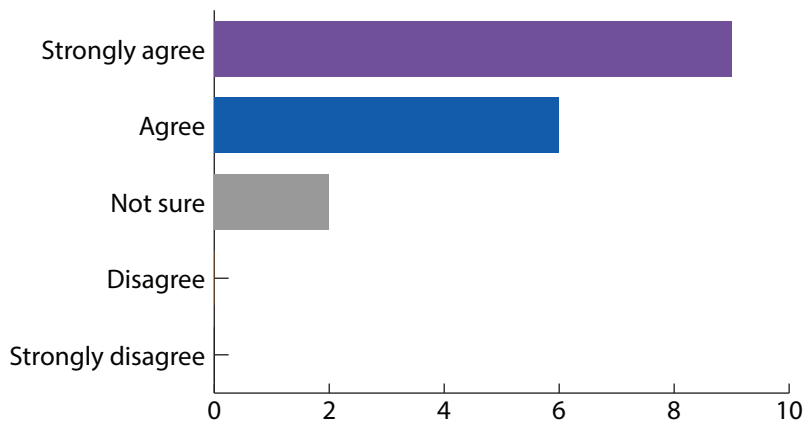## 9. I need help to implement the Personalisation Programme
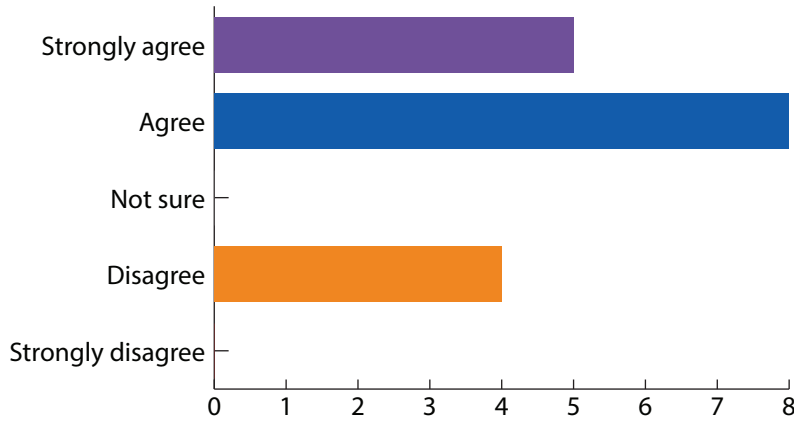
[Social Service Staff: 17 answered question]

In **QUESTION TEN** the strongly positive statement 'The Personalisation Programme is the most significant initiative I have experienced in my working life' was put forward for consideration. 15 agreed with this statement, 9 strongly but 2 weren't sure. Nobody disagreed.

60

10. The Personalisation Programme is the most significant initiative I have experienced in my working life

[Social Service Staff: 17 answered question]

The statement in **QUESTION ELEVEN** was a counterbalance to that in Question 10 and was 'The Personalisation Programme is just management jargon.' A majority of 14 disagreed with the statement, 6 strongly. However, two weren't sure and 1 actually agreed.
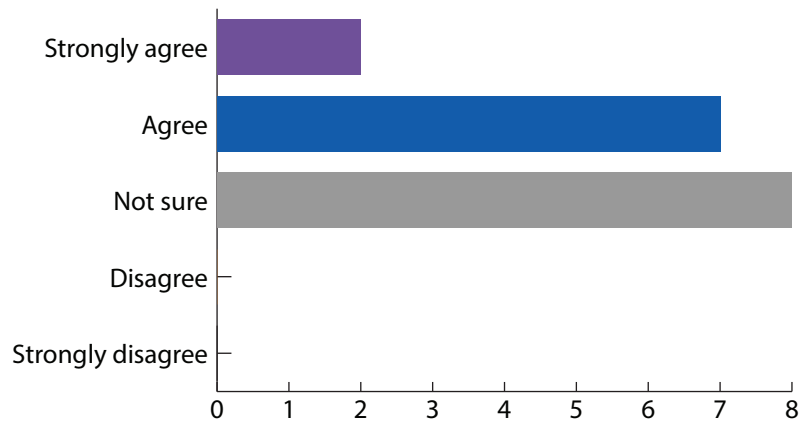
11. The Personalisation Programme is just management jargon
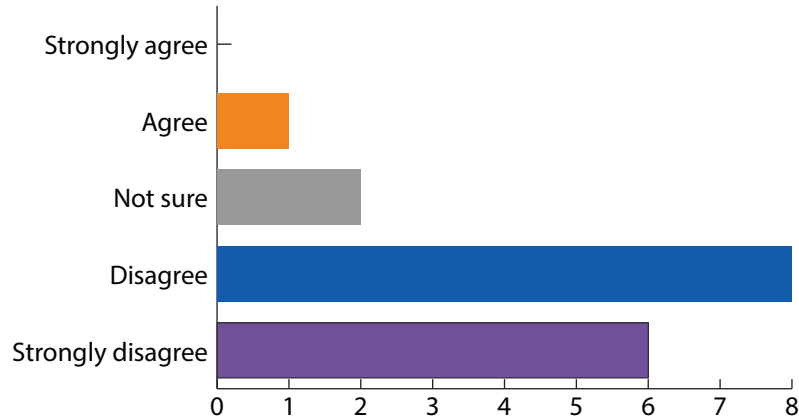
[Social Service Staff: 17 answered question]

QUESTION TWELVE put forward the central proposition that personalisation has achieved savings for the individual without detriment to their quality of life.' There was some uncertainty here with only 9 agreeing, 2 strongly, but 8 not sure. However, no one disagreed.

61

12. Personalisation has achieved savings for the person without detriment to their quality of life

[Social Service Staff: 17 answered question]

9. Relatives and Friends

The parents, next of kin or close friends of each person are key stakeholders in relation to the Personalisation Programme. They represent a distinctive external view of the success of the Programme and can be an important and insightful proxy voice for individuals. It was therefore decided to survey their views on the Personalisation Programme and its effects on their relative or friend. A special survey questionnaire was constructed consisting of twenty questions which, so far as feasible, triangulated with the questions in the *Quality of Life Audit*, the Staff Survey and the Social Services Survey. The questionnaire consisted of twenty statements with which respondents could agree or disagree on a five-point scale.

Choice Support staff facilitated the completion of the survey questionnaires by 19 relatives or friends. Whilst this may seem a small figure for 70 individuals it nevertheless compares favourably with other similar surveys in which we have been involved including the one undertaken in relation to the Waking Nights/Sleep In Evaluation published as *Better Nights* (2012). The completed questionnaires were input to and analysed by Survey Monkey software.

Responses were mixed but with a preponderance of positive views alongside a consistent proportion of negative views. There were a persistent couple of respondents whose views were generally negative. These would clearly merit investigating further. With a small sample it is difficult to be sure of the significance of the minority negative views but they are consistent with the minority negative views in both the *Quality of Life Audit and the Staff Survey* and are discussed in the conclusion.

A question-by-question analysis follows.

QUESTION ONE explored familiarity with the Personalisation Programme, inviting agreement or disagreement with the statement: 'I have an idea what is involved in personalisation and ISFs.' The majority agreed with this (16) with 2 agreeing strongly. A small minority were either unsure (2) or disagreed (1). Given that the 19 respondents were self-selecting it is of some concern that 3 did not feel they had an idea of what was involved in the Programme.

1. I have an idea what is involved in Personalisation and ISFs
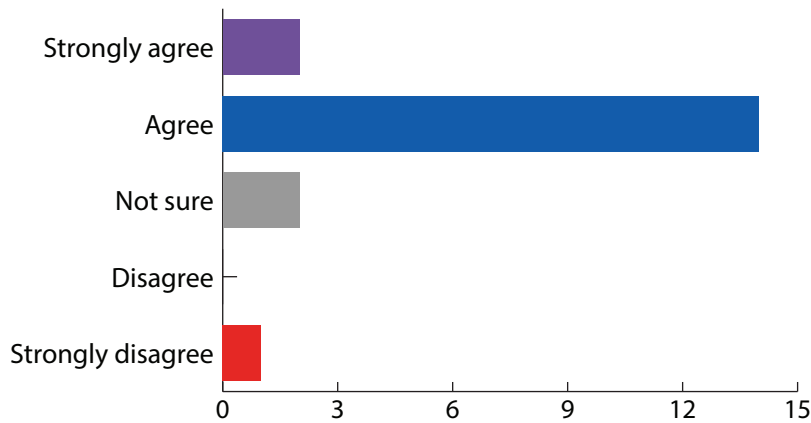
[Family: 19 completed question]

QUESTION TWO explored the information that respondents felt they had about the Programme and invited agreement/disagreement with the statement 'I have been informed about personalisation and ISFs.' The large majority (16) agreed that they had been informed although none strongly agreed. 2 strongly disagreed which is worrying and 1 wasn't sure.

63

2. I have been informed about Personalisation and ISFs
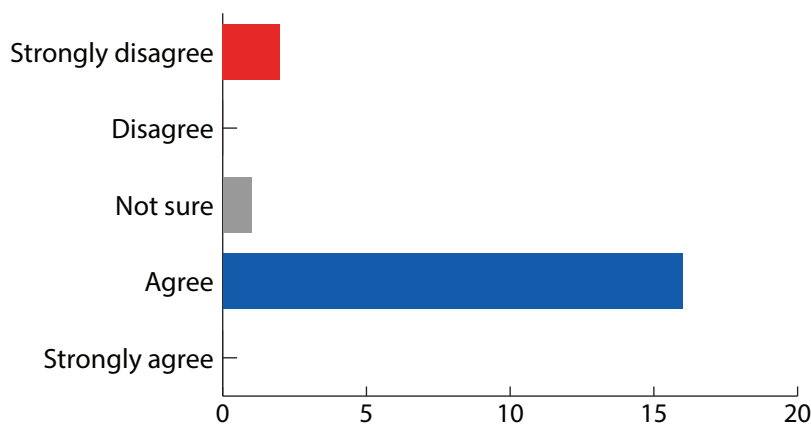
[Family: 19 completed question]

QUESTION THREE focused on the key outcome of improvement of quality of life for the person with the statement 'My relative's quality of life has improved as a result of personalisation and ISFs.' 15 out of 19 respondents agreed with this statement with 3 agreeing strongly. However, a minority of 3 disagreed with 2 disagreeing strongly. 1 respondent was unsure.
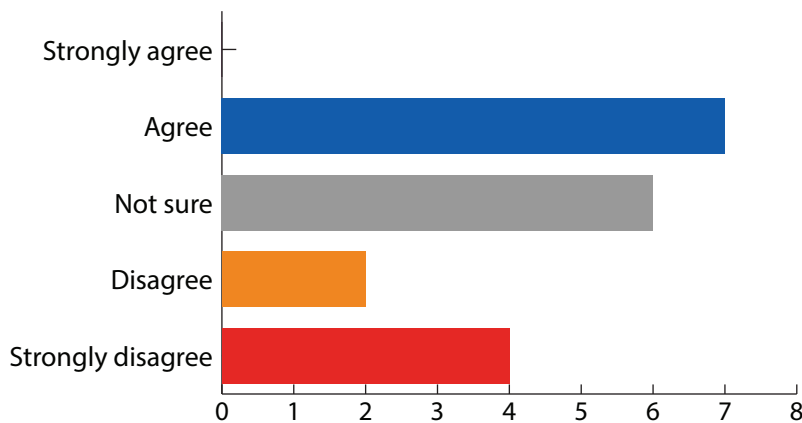
3. My relative's quality of life has improved as a result of Personalisation and ISFs
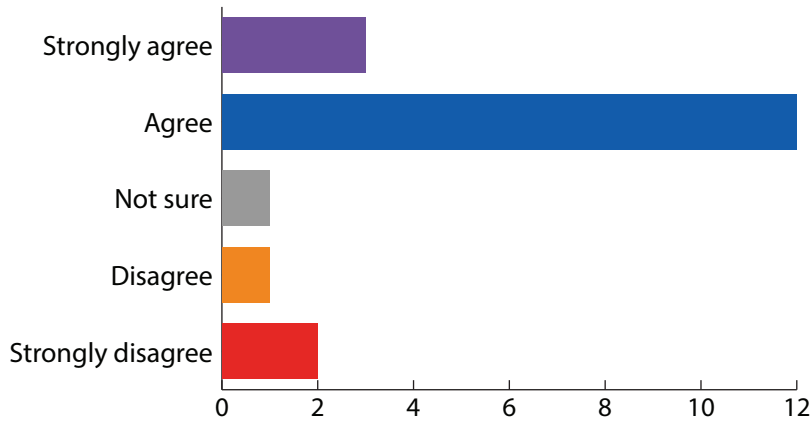
[Family: 19 completed question]

QUESTION FOUR suggested that 'My relative has more control of their finances as a result of personalisation and ISFs.' 7 agreed with the statement whereas 6 disagreed and 6 weren't sure. This is a disappointing result given the importance of control and choice for individuals following the introduction of ISFs. However it may be that the individuals concerned would be unlikely to understand control of finances. This would need to be checked against completed questionnaires to track the relative.

4. Personalisation has given more control of finances

[Family: 19 completed question]

64

QUESTION FIVE explored the issue of the individual controlling their own life, a key aim for personalisation. The statement 'My relative has more control over the direction of his/her life as a result of personalisation and ISFs' was agreed with by a majority of 12 with 2 agreeing strongly but disagreed with by 4 including 2 strongly. 3 were not sure.

5. My relative has more control over the direction of their life as a result of Personalisation and ISFs
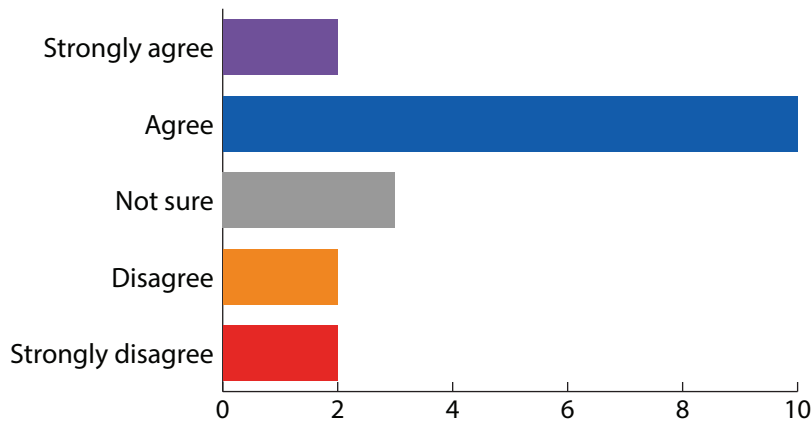
[Family: 19 completed question]

QUESTION SIX asked if 'As a result of personalisation and ISFs my relative is leading a life more like people without a disability.' Responses were similar to the previous question with 12 agreeing including 4 strongly; 4 disagreeing, including 2 strongly; and 1 not sure. 2 skipped the question.

65

6. As a result of Personalisation and ISFs my relative is now leading a life more like people without a disability
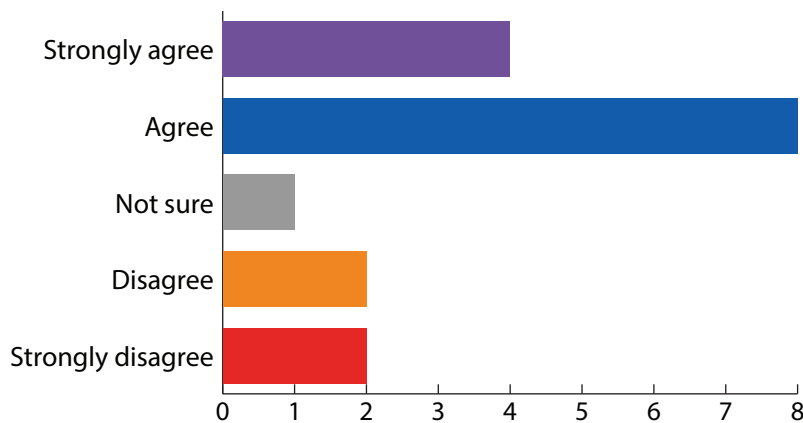
[Family: 17 completed question, 2 skipped question]

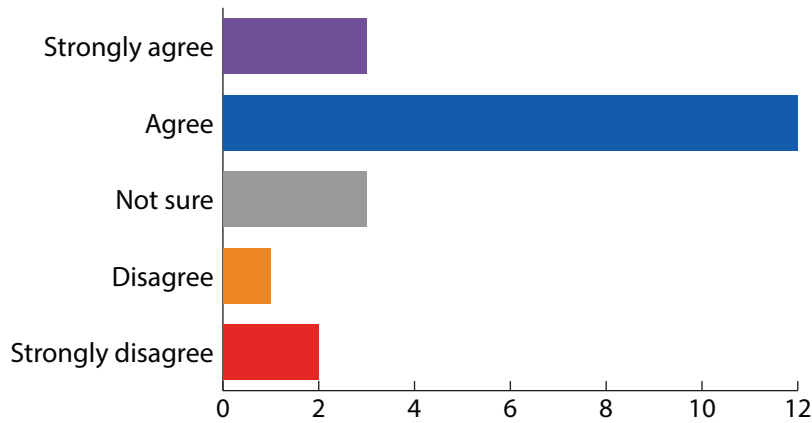**QUESTION SEVEN** proposed that 'Having an ISF has definitely improved the quality of my relative's life.' A majority of 15 agreed with this including 3 strongly. A minority of 3 disagreed with 2 strongly disagreeing. 3 were unsure.

7. Having an ISF has definitely improved the quality of my relative's life
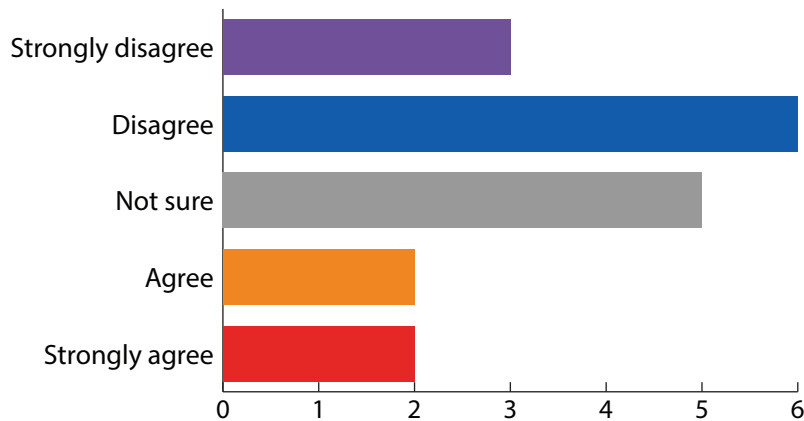

[Family: 19 completed question]

QUESTION EIGHT offered the negative statement that 'Having an ISF means little to my relative.' Responses were mixed with 4 agreeing, 2 strongly; 9 disagreeing, 3 strongly; and 5 unsure.

66

8. Having an ISF means little to my relative

[Family: 18 completed question, 1 skipped question]

QUESTION NINE stated that 'Having an ISF has increased my relative's range of choice.' This statement elicited the strongest positive response from the relatives with 16 agreeing, including 1 strongly, but 3 disagreeing strongly. This is the most polarized response.

9. Having an ISF has increased my relative's range of options

[Family: 19 completed question]
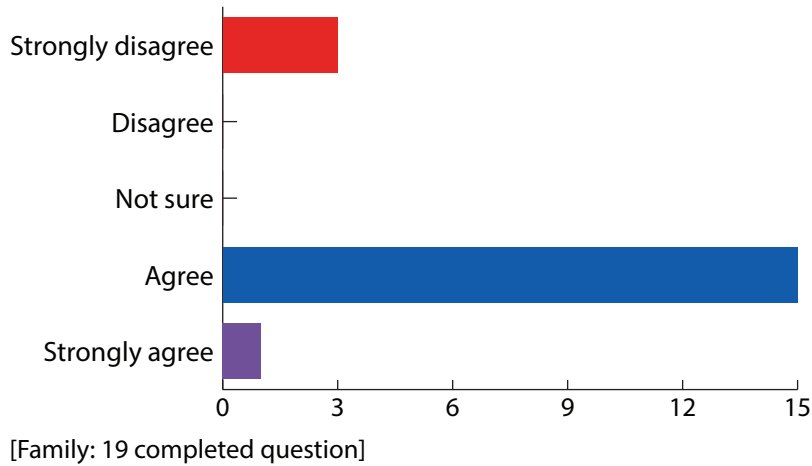
QUESTION TEN explored the extent to which individuals were more involved in the local community as a result of personalisation. The statement 'My relative is now much more involved in their local community as a result of personalisation and ISFs' was agreed with by a majority of 12, with 1 strong agreement; but disagreed with by 3 with 2 strong disagreements. 3 relatives weren't sure.

67

10. My relative is now much more involved in their local community as a result of Personalisation and ISFs

[Family: 18 completed question, 1 skipped question]
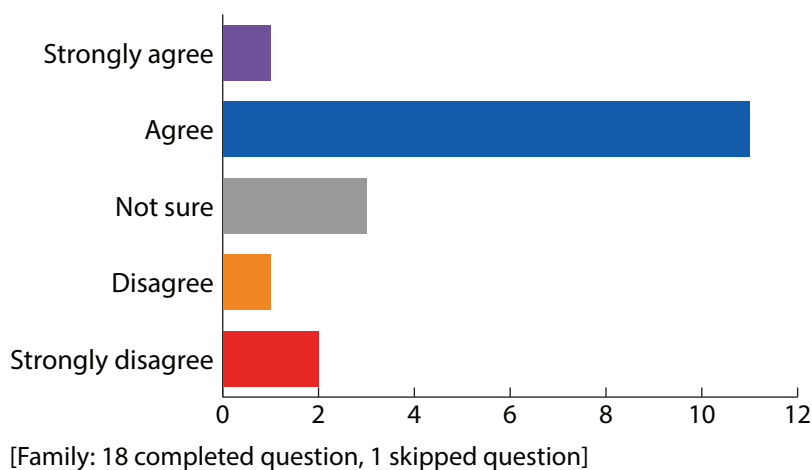
The statement in **QUESTION ELEVEN** was the positive one that 'Support for my relative is more effective as a result of personalisation and ISFs.' Again a majority (12) agreed with this 3 strongly. 2 disagreed with 1 strongly. A relatively large number of 5 were not sure.

11. Support for my relative is more effective as a result of Personalisation and ISFs
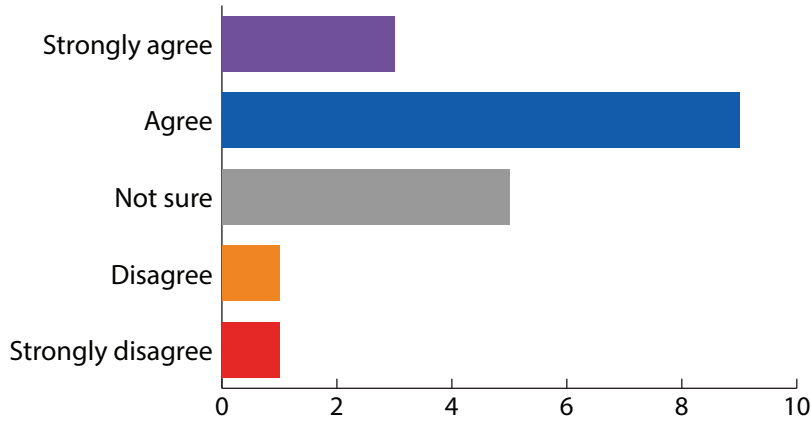
[Family: 19 completed question]

QUESTION TWELVE explored the general quality of the individuals' life with the statement 'My relative is enjoying a fuller life as a result of personalisation and ISFs.' A large majority of 15 agreed with this statement with 3 agreeing strongly. Nevertheless 3 disagreed, 2 strongly. 1 respondent wasn't sure.

68

12. My relative is enjoying a fuller life as a result of Personalisation and ISFs
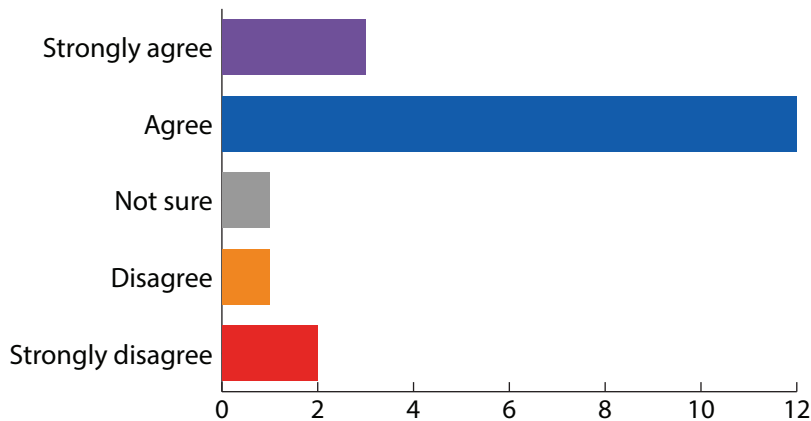
[Family: 19 completed question]

QUESTION THIRTEEN explored the important area of communication with the statement 'My relative is communicating more effectively as a result of personalisation and ISFs.' This statement produced the most mixed response of all with 8 respondents not sure; 6 agreeing with 1 strongly; and 6 disagreeing with 2 strongly. This question focuses on an area with the clearest behavioural reference separate from although arguably related to personalisation. Assuming that communication is a key facet of personalisation this result gives a modestly positive and perhaps more realistic indication of outcomes.

13. My relative is communicating more effectively as a result of Personalisation and ISFs

[Family: 19 completed question]

69
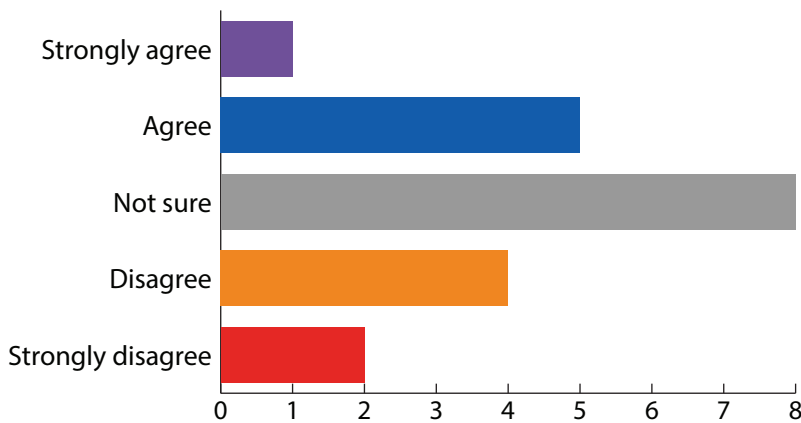
QUESTION FOURTEEN focuses on the important aim of increased independence with the statement 'My relative is able to act more independently as a result of personalisation and ISFs.' 9 agreed that this aim had been achieved including 2 who agreed strongly. 5 disagreed, 2 strongly and 5 were unsure.

14. My relative is able to act more independently as a result of Personalisation and ISFs
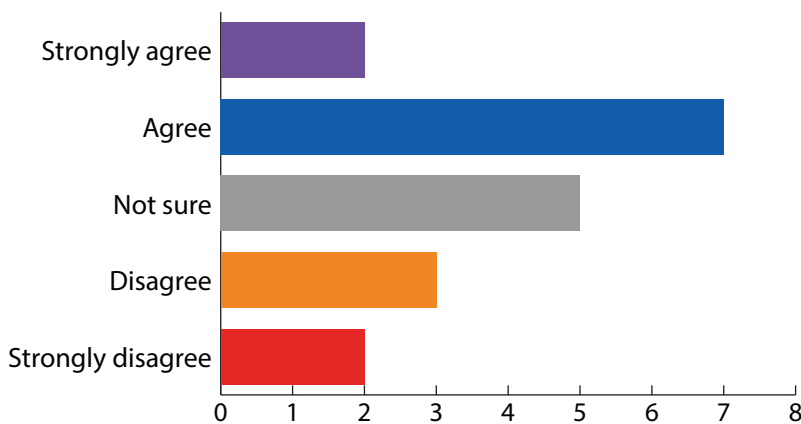
[Family: 19 completed question]

QUESTION FIFTEEN asked about privacy, an important feature of personalisation for these individuals. The statement was 'My relative enjoys better privacy as a result of personalisation and ISFs.' A majority of 14 agreed with this statement including 2 who agreed strongly. 2 disagreed, 1 strongly, and 2 weren't sure. 2 relatives skipped this question.

15. My relative now enjoys better privacy as a result of Personalisation and ISFs
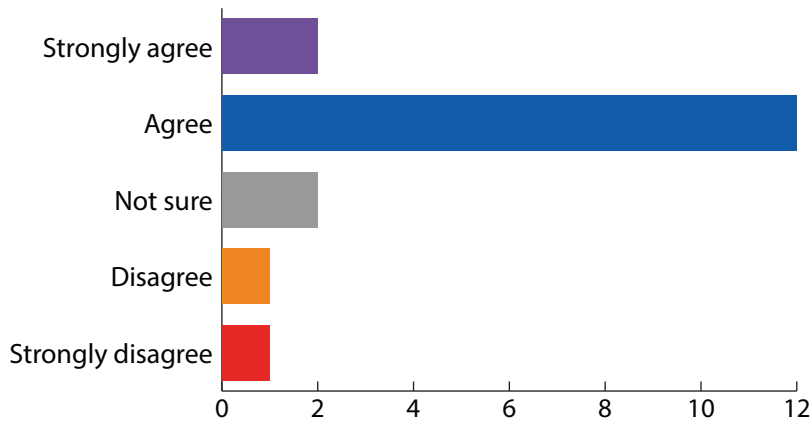
[Family: 18 completed question, 1 skipped question]

QUESTION SIXTEEN offered the proposition that 'My relative has developed as a person as a result of personalisation and ISFs.' 11 agreed with this key statement, 2 strongly but 3 disagreed with 2 strongly and 5 were unsure.

16. My relative has developed as a person as a result of Personalisation and ISFs
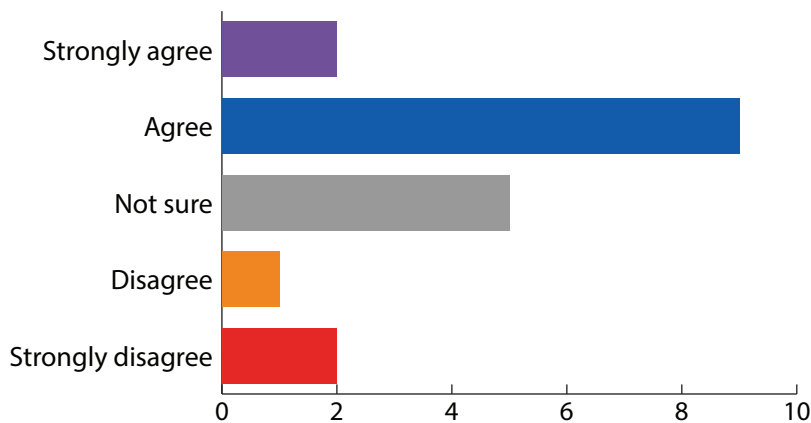
[Family: 19 completed question]

QUESTION SEVENTEEN explored individual choice with the statement 'As a result of personalisation/ISFs my relative has more opportunities to do what they want to do.' A large majority of 16 agreed with this statement, 2 strongly. 2 disagreed, 1 strongly, and 1 wasn't sure.

17. As a result of Personalisation or ISFs my relative now has more opportunities to do what they want to do
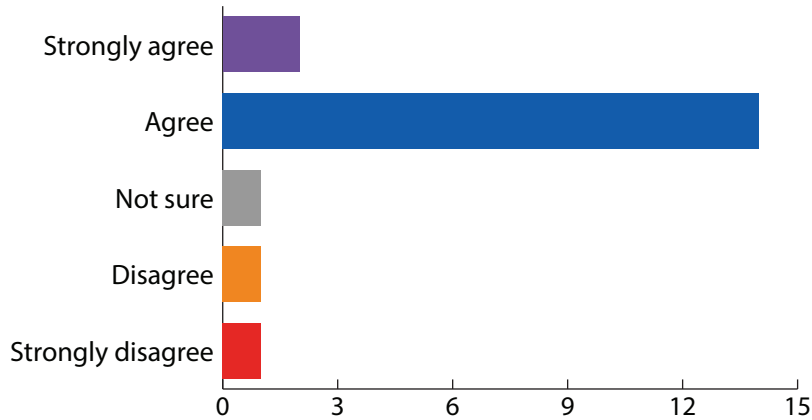
[Family: 19 completed question]

QUESTION EIGHTEEN investigated views on the affective status of each individual with the statement 'My relative appears generally happier as a result of personalisation and ISFs.' 10 respondents agreed that their relative was happier with 1 agreeing strongly. 2 disagreed, 1 strongly, 4 were unsure and 3 skipped the question.

71

18. My relative appears generally happier because of Personalisation and ISFs
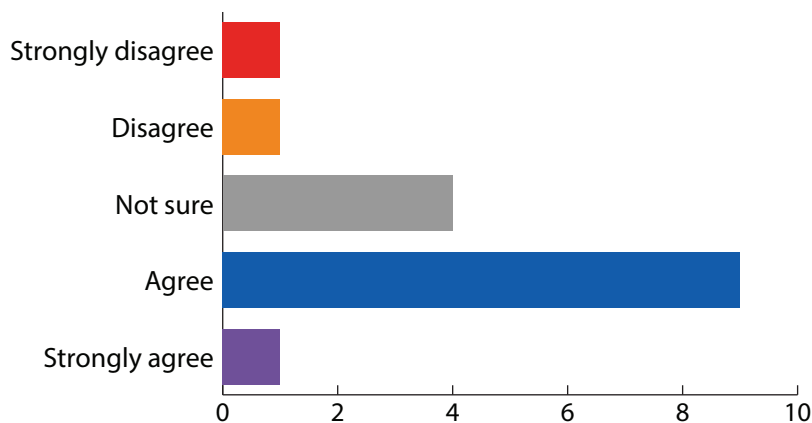
[Family: 16 completed question, 3 skipped question]

QUESTION NINETEEN offered the negative statement that 'Personalisation including ISFs has made little difference to my relative's life.' Only 3 agreed with the statement whereas 11 disagreed with 2 strongly. 5 weren't sure.

19. Personalisation including ISFs have made little difference to my relative's life
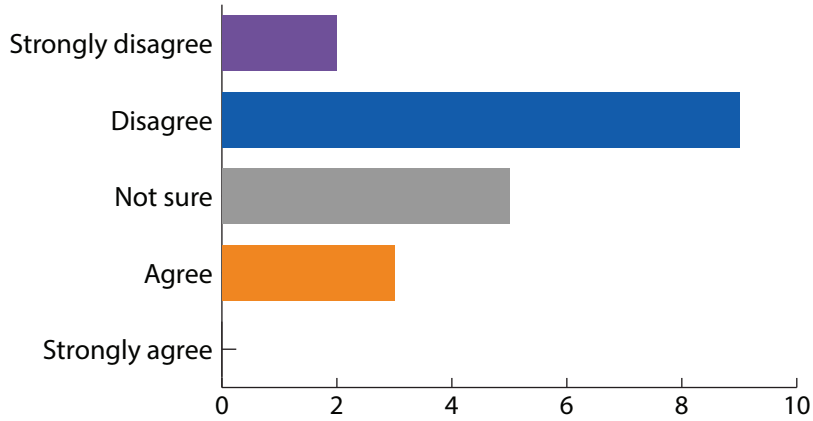
[Family: 19 completed question]

QUESTION TWENTY, explored whether relatives felt they could have played more part in the Personalisation Programme. The statement 'I could have been more involved in implementing personalisation and ISFs' elicited 10 who agreed, 5 strongly, and 3 who disagreed. 6 were unsure. This does suggest that there is a resource here to develop.

20. I could have been more involved in implementing Personalisation and ISFs
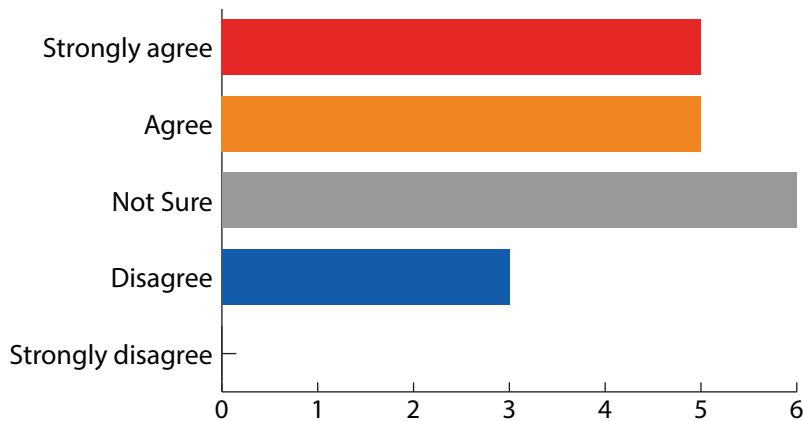
[Family: 19 completed question]

Overall these survey results mirror those in the *Quality of Life Audit, the Survey of Staff and the Survey of Social Services Staff* in that there is a majority of favourable responses. However the appreciable minority where responses are less favourable do provide an agenda for sustained liaison with relatives. It is recognized that this poses problems particularly with the profiles of individuals but a good starting point would be the positive responses to the last question where half the respondents felt they could be more involved in the Personalisation Programme.

73

10. Recommendations

There is no doubt that the Personalisation Programme introduced by Choice Support in partnership with the London Borough of Southwark can be judged a success. For the majority of the 70 individuals the introduction of ISFs linked with PCPs has improved their quality of life. This has been achieved with a substantial net saving over the previous block grant scheme. There have been no increased risks that we could find and both staff and relatives have a generally positive view of the Programme and its impact on individuals.

An audit of the 70 individuals against quality of life outcomes agreed by the partnership and reflecting best practice in personalisation and citizenship showed an improvement for the majority. This quantitative evidence was matched by case studies of individuals showing improvements in choice and control of their own lives. The savings required for the new scheme were achieved despite significant reductions in staff needed to achieve the savings.

The process of delivery showed a principled, determined and focussed approach to strategic and operational planning and delivery which has been justified by the outcomes. An evaluation of the approach against elements of best practice distilled from the literature confirmed the quality of Choice Support's approach. Surveys of support staff, social services staff and relatives of individuals showed largely favourable views of the Programme and its effects.

However, in all the data gathered there was a significant if small minority of around 12 individuals who apparently had not enjoyed an improvement in quality of life and this was reflected in minority unfavourable views of the Programme from both staff and relatives.

Our two major recommendations are first that Choice Support should roll this Programme out to other commissioners in order to improve the quality of life of individuals and achieve savings. At the same time our second recommendation is that every effort should be made to follow up the unfavourable audits and the adverse views of staff and relatives. There will undoubtedly be lessons to be learned and improvements to be made from the analysis of negative results.

74

The following are more detailed recommendations relating to the two above based on the impressions we have formed from the evidence available.

- It is recommended that a summary of our findings should be used to promote a roll out of personalisation to other commissioners for the undoubted benefit of individuals.

- It is recommended that the unfavourable quality of life audits, should be identified using the first question from the collector list and particular attention given to the individuals concerned in reviewing their PCPs and ISFs. It may be that these audits are for individuals with profound learning difficulties and multiple disabilities where progress will be difficult to measure. They may be the individuals where it has been acknowledged that identifying their needs and views is a particular challenge.

- It is recommended that case studies should be produced for those individuals where personalisation has not yet been successful in improving their quality of life. These case studies could be a good basis for discussion of how personalisation might become more meaningful and effective for these individuals including the identification of indices for quality of life improvement.

- In the context of Choice Support's commitment to being a Learning Organisation, it is recommended that attention should be given to the minority of staff returns which show unfavourable views of personalisation and the views expressed in these should provide an agenda for group staff development sessions. The views, received anonymously, could be contrasted with majority good results in the audit but related to the case studies of the minority who have not benefited with a view to developing new approaches. Similar attention should be given to the negative views of the minority of relatives and friends.

- It is recommended that special efforts should be made to involve relatives more fully in the Personalisation Programme. It is recognised that relatives can be difficult to reach or not available given the age profile of the individuals. However a starting point would be the expressed views of a number of relatives who stated that they could have been more involved in the Programme.

- It is recommended, in the context of much excellent documentation, that better records should be kept of the steps taken to implement the Programme including, for example the establishment and operation of Circles of Support and the liaison meetings with relatives and other stakeholders. This should not be seen as unnecessary bureaucratisation but as an opportunity to profile achievements and facilitate communication and development.

- It is recommended that Choice Support should respond to the recommendations in an Action Plan indicating how, by whom, and on what time scale the responses might be implemented.

75

An Action Plan from Choice Support developed from the recommendations in this report is included in the Appendices.

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Appendices

Completed Template for Calculating ISF

1. MAKING DECISIONS AND ORGANISING MY LIFE	
NEED	Substantial
PLAN	To try new activities during the day To continue to attend the project 3 days a week
CONTINGENCY	To continue to go to the project
ACTION	Support staff to get me information Support staff to give me the opportunity to try new activities
MANAGEMENT	Pay with my personal budget which will be managed by ISF provider
WEEKLY COST	3 x £37.31 = £111.93
ANNUAL COST	£111.93 x 52 = **£5820.36** membership = **£1514**

2. KEEPING SAFE IN AND OUT OF THE HOME	
NEED	Substantial/Critical
PLAN	To put an alarm on the front door to alert staff whenever the door is opened To support me to learn how to travel safely to my mum's (cost included in Table 5)
CONTINGENCY	To look in to alternative technology to keep me safe
ACTION	Continue to employ sleep in supporter Ask staff to help get telecare to install an alarm at house

2. KEEPING SAFE IN AND OUT OF THE HOME	
MANAGEMENT	Share the sleep cost with 2 other housemates Pay with my personal budget which will be managed by ISF provider
WEEKLY COST	7 x £38 = £266 ÷ 3 = £88.67
ANNUAL COST	£88.67 x 52.142 = **£4623.43**

3. MEALS	
NEED	Critical
PLAN	Staff to continue to enable me to prepare meals
CONTINGENCY	To have support in buying healthy foods
ACTION	Staff to encourage and help me to purchase and cook healthy food
MANAGEMENT	Pay with my personal budget which will be managed by ISF provider
WEEKLY COST	8.5 hours x £14.31 = £121.64
ANNUAL COST	£121.64 x 52.142 = **£6342.55**

78

4. MANAGING MY HOME	
NEED	Critical
PLAN	To be more involved in my finances and access extra money
CONTINGENCY	
ACTION	Ask social worker to work with staff to support me to be more involved in my finances (Ensuring I have the right amount of benefits paid to me. To go and choose and buy my own clothes and to go on more trips out)
MANAGEMENT	Pay with my personal budget which will be managed by ISF provder (cost included in Tables 2 and 3)
WEEKLY COST	£0.00
ANNUAL COST	£0.00

5. BEING PART OF MY COMMUNITY	
NEED	Critical
PLAN	Opportunities to meet new people and broaden outlook Continue to go to Helping Hands, Newsagent, Pub, Drama, Meals, Cinema and parties
CONTINGENCY	
ACTION	Ask for support to join Southwark resource centre and look for other options in the community
MANAGEMENT	Pay with my personal budget which will be managed by ISF provder
WEEKLY COST	4 hours x £14.31 = £57.24 (1:2) 11 hours ÷ 2 = 5.5 x £14.31 = £78.71 (1:3) 19 hours ÷ 3 = 6.33 x £14.31 = £90.58 (1:4) 23 hours ÷ 4 = 5.75 x £14.31 = £82.28
ANNUAL COST	£57.24 x 52.142 = £2984.60 £78.71 x 52.142 = £4104.10 £90.58 x 52.142 = £4723.02 £82.28 x 52.142 = £4290.24

79

6. WORK AND LEARNING	
NEED	Substantial
PLAN	To enrol in college for basic reading and writing To go to college twice a week on Tuesday and Wednesday
CONTINGENCY	Staff will encourage me to read simple books and to write
ACTION	Ask staff to support and help me to enrol in college
MANAGEMENT	
WEEKLY COST	15 hours x £14.31 = £214.63 (3 months) 3 hours x £14.31 = £42.93
ANNUAL COST	£214.65 x 52.142 = £11192.28 ÷ 2 = £2798.07 (3 months) £42.93 x 52.142 = £2238.46 ÷ 4 = £559.61 (3 months) Total cost is £559.61 + £2798.07 = **£3357.68**

7. TOTAL COSTS	
TABLE 1	£5820.36
TABLE 2	£4623.43
TABLE 3	£6342.55
TABLE 4	£0.00
TABLE 5	£2984.60
	£4104.10
	£4723.02
	£4290.24
TABLE 6	£3357.68
MANAGEMENT (15%)	£4536.84
MEMBERSHIP	£1514.00
DAY CENTRE	£5820.36
TOTAL	**£42296.82**

80

Example Budget Plan

Name:		Care First Number:	
DOB:		Address:	

ABOUT ME AND MY LIFE

I have a good sense of humour and care about the people who are important to me. I believe I am a people person; I am interested in everything that goes on in my house and the lives of staff that is not work related. I like it when I am involved in day to day matters especially handovers, where I inform my support staff of my future plans and my plan for the day as this makes me feel valued and important.

WHAT IS IMPORTANT TO ME?

My family are very important to me. I visit my family every weekend, I go every Saturday morning, after I clean my bedroom, hoover the passage, lounge and do my laundry and I return back to my home on Sunday evening after I have had my dinner at my parent's home.

My project is important to me and I attend Monday-Fridays and every two weeks I go to Riverside for my art therapy and this helps me with my feelings. I enjoy going to the project. I would like to try lots of new activities as I get bored easily. I love listening to music, dancing, singing and performing. I go to Helping Hands on Wednesday evenings and Stepping Stones on Friday evenings where we work towards a performance that we show at the end of the year.

It's important to me that I eat some form of chocolate every day. I always bring home a chocolate treat for myself to have after my dinner or late evening. I love football, Chelsea football club is the best, I will watch the match when they are playing and I sometimes get upset if they lost the match. My friends and flat mates are important to me; I like to keep in touch by phone, visits and meeting up for coffee. I also enjoy buying presents for friends. Keeping my tenancy is important to me as I love my home and where I live. I love being independent and it is important that staff support me to keep my independence, most of all - I like to be treated with respect.

Things that would make my life better – what do I want to change/achieve?

I would like to get more access to my money so I can go out to new places and do other activities at the spare of the moment, like everyone else. Also I would like to have a birthday party as I have attended everyone else's party but have not been able to plan one for myself

I would like to be able to see my boyfriend more often, he has moved out to Kent and so it is difficult for me to see him.

81

I would like to go and spend a weekend close to where he lives so we can spend some time together. I would like to visit my friends' homes and meet the people that they talk about - their loved ones. I would like to learn to use the phone at my house so I can phone my friends without any help. I will like to be able to buy my own clothes, and then I would buy the fashion I like.

How will I stay as healthy, safe and well as I can?

I have support with my money from my parents. I do not know what benefits I receive. My parents support me to the bank to collect my money. When I visit at the weekend they give me a weekly amount of £120. At present if my activities change I will let my parents know. My parents may adjust my weekly money. If I need anything extra I will work out with staff support, a mini invoice letting my parents know how much I need. My parents ensure that they give my money to the staff who then put it into my safe which is in my bedroom and is checked with me daily. My staff help me to budget my money daily, £5 in coins for spending money. I do it this way because I find it hard to manage large amounts of money. I like coins, not notes. I use my daily amount to buy my lunch and paper and chocolate. I need support to ensure that I give the correct money and receive the right amount of change. I have been known to throw away 5p and 2p coins

I'm usually a happy and positive person but sometimes things get on top of me. When I become bored I have been prone to engage in negative behaviours. I know the consequences of my behaviour especially at the project and I need support to manage my challenging behaviour at times.

I need support to travel around. I have a very good knowledge of my local area. I can be very trusting of new people I meet and people around me think that sometimes I can put myself and other people around me at risk. I would like to know more about keeping myself safe.

I am fortunate that my health is good at the moment and I am not taking any medication but I am prone to ear infections. If I need to see the doctor, staff will support me to phone the surgery to make an appointment and staff will support me to the appointment and support me to understand any treatment I might need. At my age I need to think about well woman checks and my staff will support me with information around these. I need regular prompting and encouragement to attend the dentist regularly to look after my teeth. Staff also prompt me to brush my teeth regularly. Very occasionally I will suffer with migraine headaches and back ache. If this is the case, staff will support me to take medication PRN.

As I was born with one leg slightly longer than the other, I have a slight limp which has caused me backache over the years. The orthopaedic department have made special shoes for me to correct this, but I find them uncomfortable to wear and so I rarely wear them. I will continue to need support in this area.

82

How will I stay in control of my life? How will decisions about my support be made?

I will use the information from my support plan and from other sources so I can l write a person centred job description with my manager for both paid and voluntary staff. I will be employing my staff. In the future as I gain more independence I will hopefully need less support

In the event of my needs changing I will discuss this with Choice Support managers. If they cannot help me with extra hours then they will then help me to approach the Learning Disability Team so that my needs can be reassessed by going through the assessment process

I have reviewed and agreed to the above:

Signature .... Date ....

Support Planner (Name, Organisation):

Signature .... Date ....

Choice Support Action Plan

1. Choice Support to have discussions with all our existing commissioners to offer this personalised package. The evaluation report to be used as evidence to demonstrate the improvements to quality of life to individuals and savings achieved.

2. Choice Support has set up an Organisational Learning Working Group (OLGA) who will be asked to review this evaluation report and recommend learning across the whole of Choice Support.

3. Choice Support has recognised that family stakeholders could be more involved in developing our services and have asked the Foundation for People with Learning Disabilities (FPLD) to facilitate family forums. Choice Support will welcome feedback from these family forums and attention will be given to the negative views of the minority of relatives and friends in the audits.

4. Choice Support will identify the individuals in the audit whose quality of life was not improved. Case studies will be produced for those individuals where personalisation has not yet been successful in order to identify and resolve any issues.

5. Southwark managers to organise group staff development sessions, part of which will focus on the minority of case studies who have not benefited with a view to developing new approaches.

6. Choice Support to review their documentation in order to ensure better records are kept in the future to ensure communication and evidence outcomes.

November 2013

83