self direct

Helping providers to change

Responding to the Challenges and Opportunities of Personalisation

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Publishing Information

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Contents

Statistics

About us

The co founders of **self direct**, Don Derrett, Jackie Lawley, Simon Cramp and Keith Wyatt started talking about the ideas they had for promoting changes in the social and health market-place in the autumn of 2007.

self direct was founded in March 2008 as a social enterprise, a not for profit company limited by guarantee.

self direct now has 7 staff members including; 2 Directors, a Family Carer expert, an Independent Living Expert, an Administrator, Finance Manager and a Marketing Officer. There are a growing number of associates working with **self direct** in various ways.

Associates

self direct is founded on the principle that people with personal experience of how social and health services affect lives are equal experts working alongside professionals and should drive the changes needed in the social and health market-place.

Associates work with **self direct**; supporting and informing planning and working at **self direct** events.

To find out more about **self direct** visit **www.selfdirect.org**

Our aims for the first year and why

An introduction to the 'Helping providers to change' events by ***Don Derrett****, co founder and director of* ***self direct****.*

"During my time working with in Control as their business manager and at Mencap as the Self-Directed Support National Officer, between 2005 and 2008, I attended many meetings, conferences and forums; facilitating, speaking and presenting at many of them. These meetings ranged from general awareness raising events about Self-Directed Support to specialist seminars and included representing Mencap's Chief Executive, at that time Dame Jo Williams DBE, on the Government's Individual Budgets Pilots[1] Steering group meetings. During this time I worked across England, Wales and Northern Ireland and the various meetings I attended involved 1000's of people who use services, family carers and professionals.

At the end of 2005 I became involved with the collection of evidence for the first evaluations of the In Control pilots.[2] During the collection of this evidence I met with several people whose lives had been transformed through Self-Directed Support. Included in the evidence I collected was the story of four men from Gateshead who had known each other for a number of years and had decided to pool some of their Individual Budgets to set up a home together; also I took evidence from the parents of Celia Bradford[3] (name changed) who described the transformation that had taken place not just for Celia but also for them all as a family; Clive Sneddon[4] told me enthusiastically about the changes he had been able to make in his life by using his Individual Budget, moving from a residential home and how he had been able now to set up in his own home with a friend. These stories and others used as evidence of the effectiveness of Self-Directed Support to achieve better outcomes for people were compelling and personal experiences like these should continue to be the driving force for the changes now happening in the way social and health support is provided.

Looking back, this time between 2005 and 2008 was a period of extensive 'market research' about the state of the social and health 'market-place'. During this time I also gained an insight into how the political lobbying taking place, much of which included people giving evidence of their personal experiences, was becoming more effective in driving forward the development of the personalisation[5] agenda.

But for all this progress, there was and continues to be many concerns and questions about how Self-Directed Support will work for everyone as effectively as it had been shown to work for the people who already had an Individual Budget. Many of these concerns and questions expressed at the meetings, conferences and events over those years could be summed up by 2 big questions:

1. "When people get their Individual Budgets, what is out there in the market-place for people to buy?"

2. "What does all this mean for existing providers of social and health services and how might they have to change what they do and how do they do it?"

Working with providers was one of the areas of work that we anticipated was needed to start to speed up the changes needed in the market-place.

Providers were in need of more information about what they could practically do to start making the changes needed to make services more personalised.

The ‘Helping providers to change’ events have always included someone with personal experience of how social and health services affect lives, people who have experience of using direct payments flexibly or Individual Budgets to have control of the support they or their family members need. These **self direct** associates have included representatives from user led organisations or individuals working in their own right as experts.

Our events have given us a real feel for the enthusiasm that many providers have to make the changes needed to the support they provide.

However, we have encountered a small number of people who are resistant to this new way of working; often this is because of a lack of understanding of the flexibility of the systems being developed and the checks and balances already being introduced by Local Authorities.

The events have given us a real insight into the concerns and issues providers have.

From the work done by the delegates from providers, Local Authorities and Health Authorities, often working together at these events with self direct associates, some practical ideas and possible solutions have been formulated. We have also gained an insight into the present state of the provider market-place but believe much more needs to be done in terms of researching this and monitoring the progress of the development of the market-place

We hope providers will find this book useful and that it will help them to start to get to grips with the practical issues of putting Self-Directed Support into action.

Three main messages gained from working in this way

1. If providers work together with people who use services and other professionals from the social and health care sector, including Local Authority officers, they can find solutions to the issues they face in putting Self-Directed Support into practice

2. Providers can take action now, they don’t need to wait for Local Authorities or Health Authorities to tell them what to do and when to do it

3. Providers need to start by working out how to put people they support in the driving seat of any changes they make

The suggested solutions in this book are only some of the possible ways forward. We believe they are a good starting point and we thank all those delegates who contributed to the ideas in this book.

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1 IBSEN (Individual Budgets Evaluation Network) reports, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505
2 in Control report 2003 – 2005, www.in-control.org.uk
3 Celia’s story, www.in-control.org.uk
4 Clive’s story, www.in-control.org.uk
5 Personalisation, www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/DH_079379
6 Putting People First Concordat, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

During the first year, 2008 - 2009, of running the event ‘Helping providers to change’, self direct worked with:

214 delegates

Delegates attending self direct events were from:

88 providers

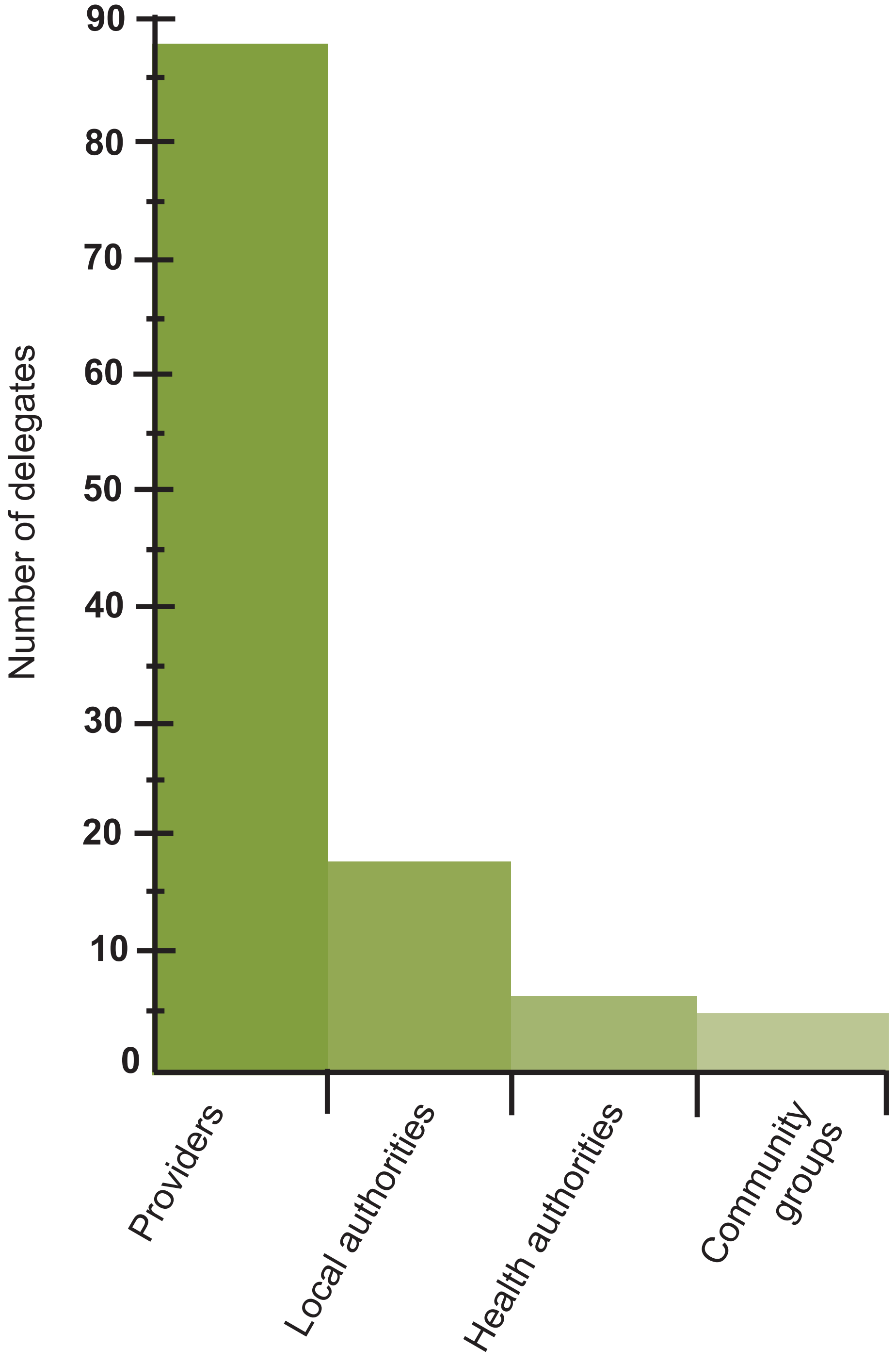
(from across the social and health sector, from small family run businesses to national organisations)

17 local authorities

6 health authorities

5 community groups

and representatives from the Association of Directors of Adult Social Services, the Department of Health and Skills for Care also attended the events


Number of delegates
90
80
70
60
50
40
30
20
10
0
Providers
Local authorities
Health authorities
Community groups

The delegates that attended the events were:

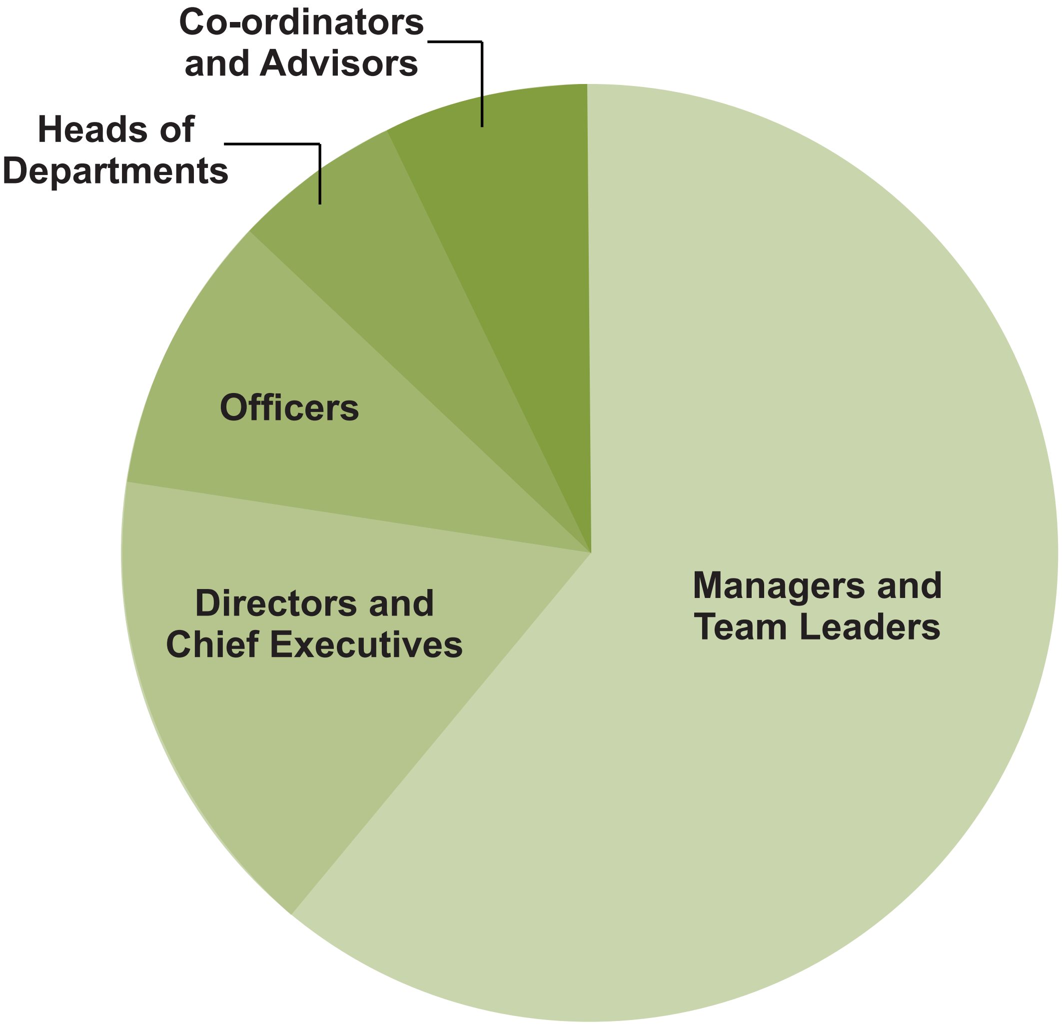
Managers and Team Leaders 61.2%

Directors and Chief Executives 16.5%

Officers 9.4%

Heads of Departments 5.9%

Co-ordinators and Advisors 7%


Co-ordinators
and Advisors
Heads of
Departments
Officers
Directors and
Chief Executives
Managers and
Team Leaders

Percentage of delegates from organisations supporting people:

Learning Disability
30.5%

Older People 29.5%

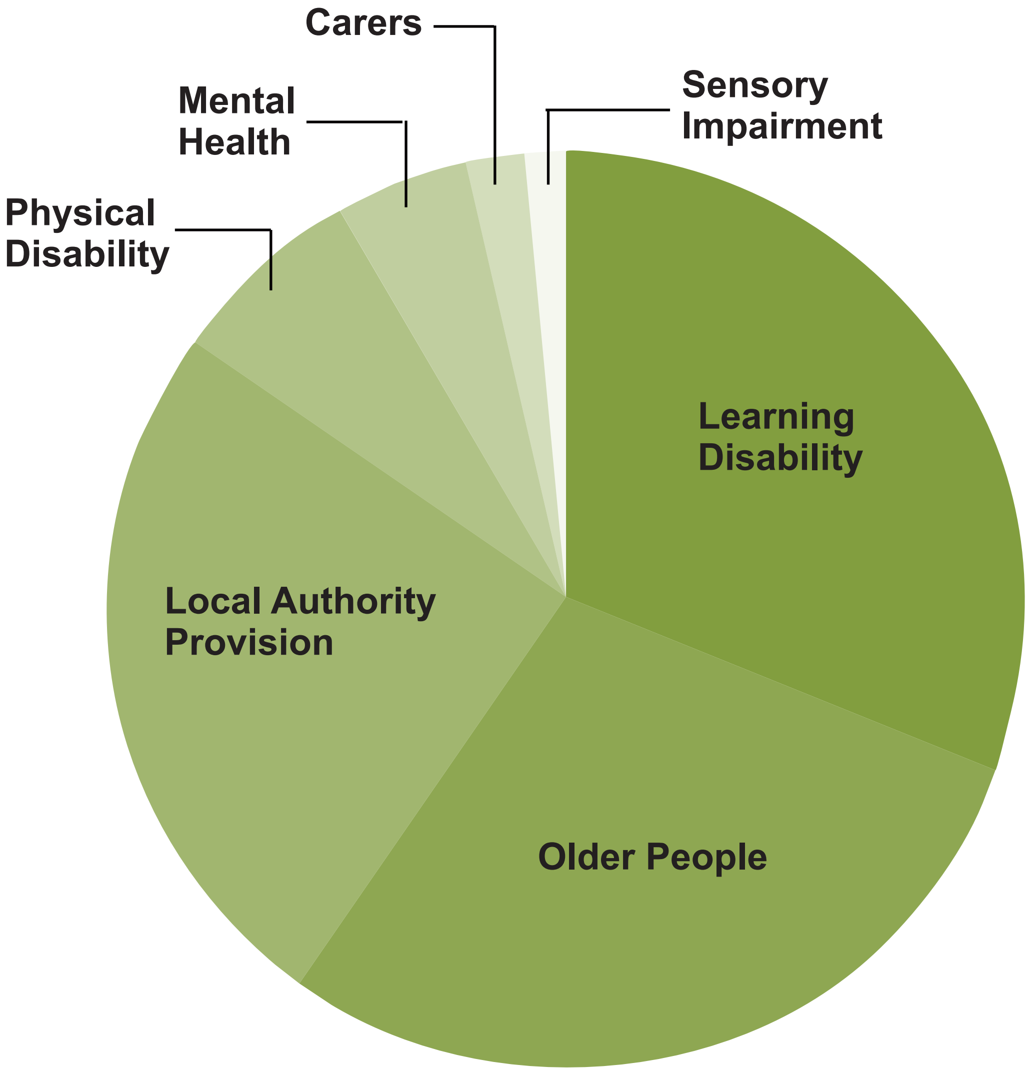
Local Authority Provision 24%

Physical Disability
7%

Mental Health 5.5%

Carers 2%

Sensory Impairment
1.5%


Carers
Sensory Impairment
Mental Health
Physical Disability
Learning Disability
Local Authority Provision
Older People

Delegate level of knowledge and understanding

We ask delegates to complete a pre event questionnaire to self assess their own individual level of knowledge and understanding of Self-Directed Support and also the present position of their organisation.

From the self assessment forms we found that:

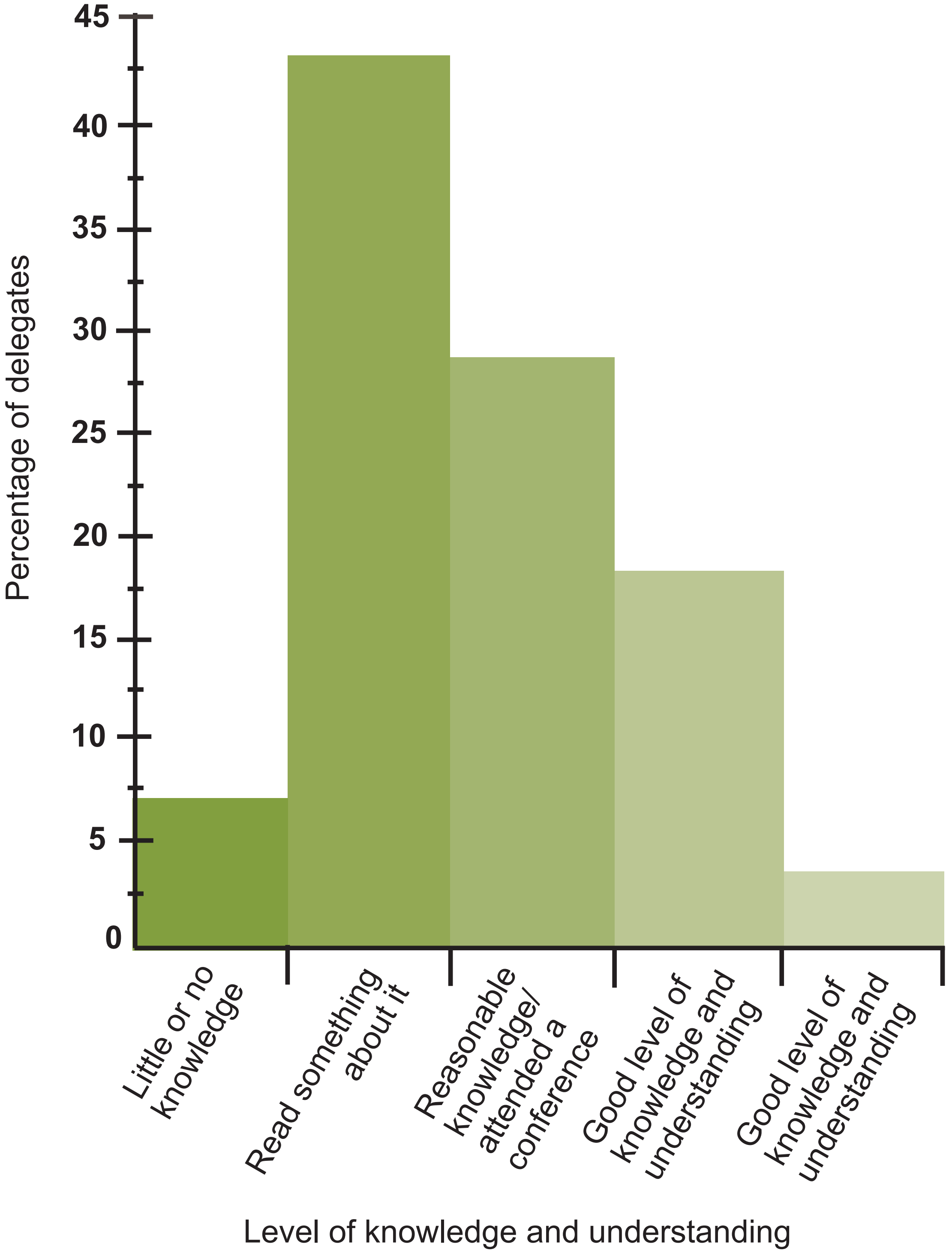
7% **of delegates had ‘little or no knowledge’ of Self-Directed Support**

43% **of delegates had ‘read something about it’**

28.5% **of delegates had ‘reasonable knowledge / had attended a conference’**

18% **of delegates had ‘good level of knowledge and understanding, having had a chance to discuss, explore and debate the issues’**

3.5% **of delegates had ‘already started to put their knowledge of Self-Directed Support into practice’**


45
40
35
30
25
20
15
10
5
0
Percentage of delegates
Little or no knowledge
Read something about it
Reasonable knowledge/ attended a conference
Good level of knowledge and understanding
Good level of knowledge and understanding
Level of knowledge and understanding

Organisation level of engagement

From the self assessment forms we found that:

3.5% of organisations 'didn't have enough information and hadn't started to think about their position and response to Self-Directed Support'

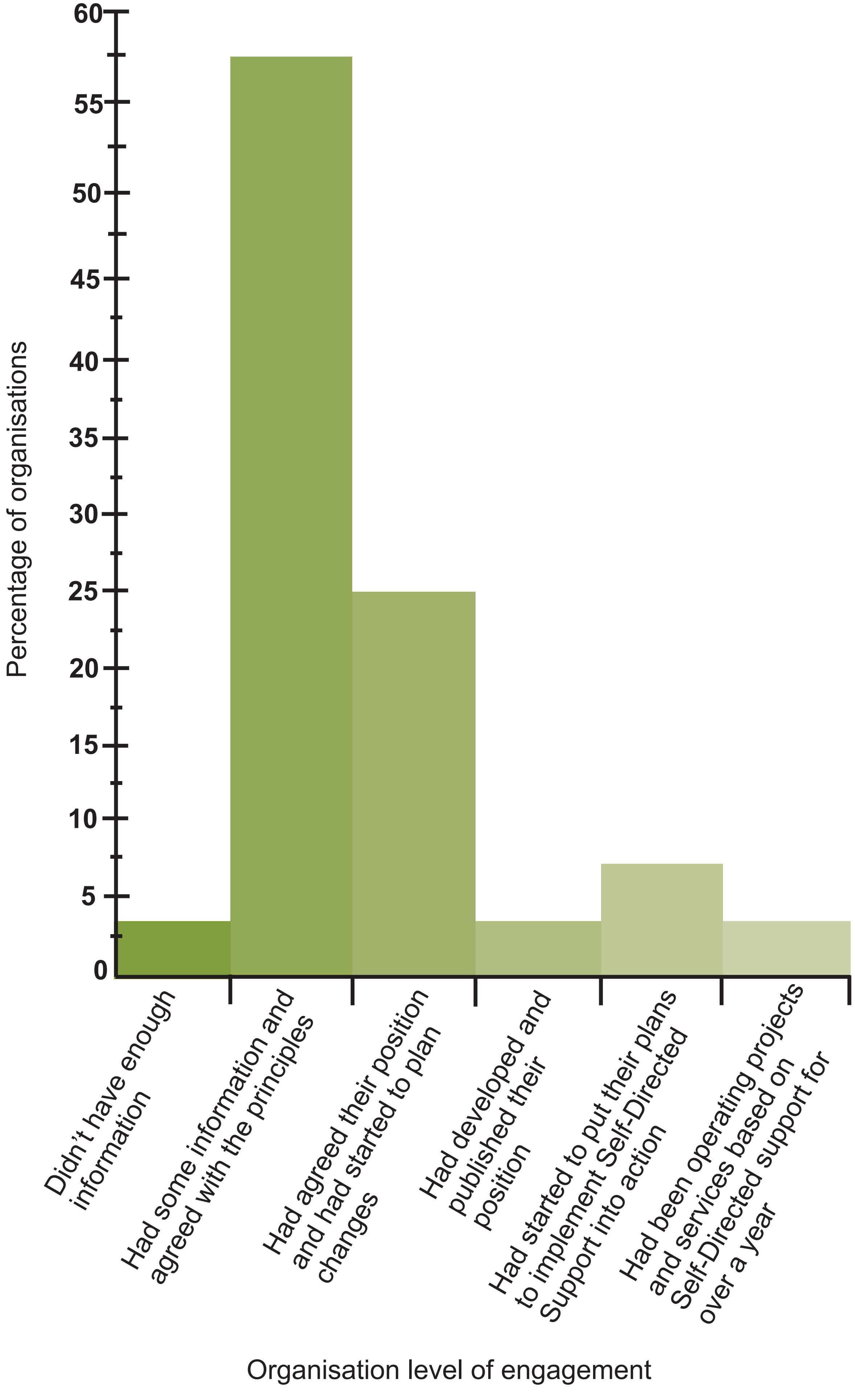
57.5% of organisations 'had some information and agreed with the principles but needed to gain a better understanding before they developed their position'

25% of organisations 'had agreed their position and had started to plan changes'

3.5% of organisations 'had developed and published their position, had agreed measureable aims and objectives'

7% of organisations 'had started to put their plans to implement Self-Directed Support into action'

3.5% of organisations 'had been operating projects and services based on Self-Directed Support for over a year'


Percentage of organisations
60
55
50
45
40
35
30
25
20
15
10
5
0
Didn't have enough information
Had some information and agreed with the principles
Had agreed their position and had started to plan changes
Had developed and published their position
Had started to put their plans to implement Self-Directed Support into action
Had been operating projects and services based on Self-Directed support for over a year
Organisation level of engagement

Evolution or Revolution?

We start our events by sharing each others background and experience. We found that most of the delegates had many years of experience in the social and health sector, mainly in a professional capacity but a number of delegates had personal experience as well.

On average delegates had 21 years of experience of the social and health sector; a few delegates were relatively new to the sector but a large number of people had over 30 years experience. Over the year we have worked with people with a combined 4,494 years of experience of the social and health sector.

Most people had a good understanding of Person Centred Planning, Supporting People and Direct Payments. A good number of delegates had direct experience of the changes that had taken place during the 1980s and 1990s to close the large institutions and of moving people into the community. And many delegates remembered the introduction of Normalisation and Social Role Valorisation.

Many people had experienced the campaigning for Independent Living driven by disabled people.

We believe that these years of experience need to be acknowledged and used in the co-production of the new ways of working needed to put Self-Directed Support into practice.

We also ask delegates to share their thoughts about what the future may hold and we have included here a number of the hopes and concerns that many of them share.

Hopes and Concerns

Overview of organisation’s Hopes and Concerns

The delegates from each of the provider organisation’s were given the opportunity to share their concerns and hopes about the introduction of Self-Directed Support.

Their hopes and concerns have been brought together under the headings below.

It should be noted that these are the delegates concerns and hopes, not those of **self direct.**

Concerns Delegates expressed concerns about their organisation’s future

Finances

Losing block contracts that have in the past been a guarantee of income for the length of the contract.

Credit control of a large number of small individual contracts, concern that there may be a greater debtor problem for the organisation.

High cost ‘out of county’ placements are simply seen as an ‘easy target’ or ‘quick win’.

TUPE arrangements will leave organisations with high liabilities if people decide they no longer want to be supported by the people who have moved from another organisation with TUPE terms and conditions.

Money being clawed back if targets for achieving outcomes are met.

The cost of regulated services will not be competitive with small unregulated service providers, i.e. neighbours and friends.

Restructure of organisation and services	How organisations can totally restructure the way they deliver all the services they provide and at the same time maintain financial stability.
People choose other providers or become employers themselves	Once people have the power to choose a different provider then they will. People will choose to employ Person Assistants directly because of cost alone. Their hourly rate will not include company overheads and they will be able to charge a lower hourly rate than the organisation has to charge to fully recover its costs. Different providers working alongside each other in the same ‘service’, i.e. where a group of people live together but each chose a different provider to support them.
Staff recruitment and retention	Difficulty recruiting and retaining staff in an uncertain employment situation where people they are supporting are able to pick and choose who supports them. If Personal Assistants are expected to be totally flexible them the need they have to strike a balance between work and home life will not be seen as important. Human Resources staff then worries about people not being able to recruit properly, i.e. asking inappropriate questions.
Providing information to people who have Individual or Personal Budgets	The responsibility that the organisation or people providing information and advice have to people with an Individual or Personal Budget.
Working with families	An increased need and expectation for organisations to work more closely with family members as well as the people they are supporting. There has been experience of some families taking advantage of peoples’ finances, i.e. acting as appointees and using people’s benefits to the benefit of other family members and not necessarily the person in receipt of the benefit. If people don’t have the support of family and friends they may not be empowered to take

	control. Families are really in control and not the individual who needs support.
The way people’s money is allocated	Whether someone’s allocation will cover sickness, holiday pay and redundancy? Whether there will be enough money in the allocation to meet fluctuating and changing health needs? Money being moved from social care management to be managed by individuals.
Use of the person’s money	People’s use of their money not being monitored closely enough. People being exposed to financial abuse from others, for instance their families.
Safety and well being of the person	People choosing providers that are cheaper and those organisations possibly having less well trained staff and therefore perhaps putting people more at risk. People not using Criminal Record Bureau Checks or other methods of checking the background of staff, increasing the likelihood of abuse. People not having enough support from families and friends to take control themselves. People with high and complex needs not having a voice and dogma dictating the way things change for them.
Future policy direction and leadership from the Government	Personalisation not being seen as a priority in the future under pressure from competing political and social pressures.
Direction and leadership from Local Authorities	Fear of putting Self-Directed Support into practice in case people do it ‘wrong’ becomes a barrier in itself and there isn’t the training or support in place to give people the tools they need and the leadership for people to be brave enough to make the changes needed. Risk aversion and a blame culture continue to be a barrier to progress.

Or conversely, things change too much and too quickly without the proper structures being in place to make it sustainable.

Primarily seen as a way of saving money.

Local Authorities putting Self-Directed Support into practice

Different Local Authorities are implementing Self-Directed Support in different ways and are at different stages of changing their systems.

Some Local Authorities seeing this as a way of ‘washing their hands’ of ‘difficult’ people.

‘Old way’ of thinking is carried into ‘new way’ of working and people still have professionals dictating how their support money is used.

Local Authorities keeping people ‘hidden’ and refer people one at a time; providers don’t know who has an Individual Budget and what they are looking for.

Commissioners holding onto power and control.

Providers on approved lists continue to be the only service providers used and are imposed on people, giving them a limited choice.

Will information be shared with providers about the real level of support someone needs?

This reinforces risk averse behaviour as Care Managers are reluctant to sign off support plans that contain risks.

People getting enough support to complete assessments realistically.

Approach to change

The larger institutionally based organisations decide to ‘fight’ the changes.

Some social workers seeing this as a threat to their role and will be resistant to promoting this as a positive change for people.

Fear becomes a barrier; training and support needs to be in place.

Health

There is going to need to be a bigger shift in the culture within Primary Care Trusts.

Hopes Delegates hopes for the organisation’s future

Finances

There is an opportunity for organisations to start to ring-fence money around individuals they support in the form of Individual Service Funds ahead of Local Authorities introducing Self-Directed Support.

There is an opportunity to start to gain a better understanding of the real cost of the services that are provided for each person that an organisation supports, including identifying all the on-costs and were cross subsidised services exist.

A move towards lighter touch monitoring will reduce paperwork and bureaucracy.

Restructure of organisation and services

Opportunity to diversify and expand by developing extra / ancillary services.

Smaller organisations will be able to adapt and change quicker.

Services will expand and become more creative in delivering support.

Brokerage develops and is available to anyone who needs this type of support.

People choose other providers or become employers themselves

People will be supported and empowered to choose between good and bad service providers.

Staff recruitment and retention

An opportunity to introduce more personalised recruitment.

More flexible and rewarding roles for Personal Assistants.

Personal Assistants able to have a say in how their role should change to better suit the life style of the person they are supporting.

Good people will be encouraged to support people to have a life that’s right for them.

There will be an opportunity to better match staff skills and qualities to people being supported.

People will get the support they need and want.

Individuals will be as involved as they wish to be in the recruitment of personal assistants.

Providing information to people who have Individual or Personal Budgets

There is an opportunity for organisations to offer information and advice, for example with employment issues and managing money.

Organisations led by service users will continue to play a key role in providing information and advice.

Working with families

Families will be encouraged to have a better life for themselves as well and have better relationships with the member of their family that needs support.

Use of the person's money

There is an opportunity to build on the way that Direct Payments have been used flexibly.

People having the control to choose how they are supported may lead to greater recovery.

Person-centred funding giving people more power and greater choices.

There will be fewer restrictions on what people can use their individual budgets for.

That families get the support needed where their family member requires very high levels of support.

Closer working with local authorities and family members are for the benefit of the customer.

Safety and well being of the person

There will be a less risk averse culture that enables people to achieve their dreams and ambitions.

There will be creative ways developed to improve safeguarding.

Local Authorities putting Self-Directed Support into practice

There is a real opportunity to work in partnership with and learn with Local Authorities.

The transparency involved in identifying costs leads to an acknowledgement by Local Government of what services actually cost to provide.

There will be more and better preventative services.

That person-centred approaches apply to all people that need support and are acted upon.

That Self-Directed Support is rolled out across the country in an equitable way.

Approach to change

There is an opportunity for organisations to become early adopters and be seen as taking a lead by offering new and imaginative ways of supporting people.

There will be a growing body of evidence through good stories that help to move the change along quicker.

To have choice and control, to be equal citizens, is what most disabled people have been asking for and many people have actively campaigned for; this is the best opportunity yet to make this happen.

Customer expertise and skills will be used to drive the changes.

Aspirations of people who need support

That peoples' expected outcomes will be achieved.

Tables will have turned - "professionals won't be telling me what's going to happen".

That all service users become empowered by service providers.

More integration of mainstream; organisations and companies outside the usual social and health care sector are fully accessible to all.

Where do we start?

All the concerns, fears and hopes that people and organisations have can seem overwhelming. Where do providers make a start with this large scale change?

The different approaches providers have chosen to take can be summed up in the following 4 ways:

1. Watch to see what other providers are doing and wait to be told by commissioners what the changes will be and when and how the changes will affect them.
See 'Watch, wait and see' case study for example

2. Small scale 'pilot' projects to test how personalised services could be delivered.
See 'Threedom' case study for example

3. Take a strategic approach; form a guiding coalition of leaders, agree the direction and set targets to introduce personalisation across different areas of operation over a period of time.
See 'Choice Support' case study for example

4. Complete change of all services as quickly as possible.
See 'Castle Supported Living' Case Study for example

Watch, wait and see

A case study provider by North Lincolnshire Council

Where service providers have taken the ‘watch, wait and see’ approach, many Local Authorities have taken a pro active approach to engage with provider organisations and have facilitated the formation of provider forums.

A good example of this is North Lincolnshire, where the Local Authority decided to organise a ‘show-case’ event for providers.

Engagement by providers with the personalisation agenda in North Lincolnshire up to this point had been minimal, particularly from providers of services for older people.

The officers involved in organising the event included some of the providers in the development of the structure of the day and clearly set out the aims, objectives and expected outcomes. One of the hoped-for outcomes by North Lincolnshire was that a number of providers would ‘sign up’ to become champion organisations in the area; taking forward the agenda with small pilot projects,supported by the Local Authority.

Important elements of the event were:

- Explain the national agenda, particularly in relation to services for older people
- Describe what was happening in North Lincolnshire to take forward personalisation
- Include real life examples of people who had experience of using funds flexibly to buy the support they need
- Include examples of organisational change
- Have a series of workshops that were directly related to what people had heard in the presentations
- Include people with real life experience as co facilitators of the workshops

After the event a number of organisations ‘signed up’ to work more closely with North Lincolnshire and the next steps will include further engagement events, including looking at work force development issues with the providers.

Contacts: Rani Kaur and Gill Powell

Threedom

A Case Study provided by SummerCare

We currently support three individuals in a supported living scheme all of whom have Individual Budgets. In partnership with Gateway housing (a local social housing provider) we built a bespoke house for the individuals to live in so it best suited their needs and requirements. Their support has been tailored around them as individuals so they are not restricted in any way by their fellow house mates. It is always staffed with one to one support, with detailed outcome-based support plans. They share their sleep-in hours which allows them to free up support hours to be used elsewhere for more productive and effective support. Support has been designed to be as flexible and structured where needed to make sure individuality and choice is secured at all times for the individuals. We worked closely with several different departments in social care occupational therapy being just one of them to ensure that everything was tailor made for the individuals. We also drew upon our existing working partnerships within the local community to offer and guarantee a wide range of choice and knowledge was available for all.

During the set up period there were numerous meetings where the individuals met along with parents so they got to know each other first and to discuss how they wanted to decorate and furnish their house. The individuals took an active part in recruiting their own staff team ensuring they were being supported by people they wanted. There were then meetings with the new staff team and the new staff team and the individuals themselves to get to know each other before they moved in. This worked exceptionally well as there was no awkward moments. It was more like old friends meeting up on moving day.

The Individuals named their house with a play on the word freedom they named it Threedom as they strongly felt that this new personalised support in which they played a major part in designing gave them the freedom, opportunity, choice and enrichment in life that they fully deserved.

This scheme was the pilot for Southend Borough Council in regards to individual budgets and it took a lot of hard work in the background by senior social workers and management and staff at Summercare to make it happen. It has been such a success that Southend Borough Council have filmed a best practice DVD there on the ways Individualised Budgets should work within a supported living environment.

Case Study information provided by SummerCare
38/40 Ceylon Road, Westcliff on Sea, Essex, SS0 7HP,
T – 01702 343 062, F – 07092 039 258,
E – contact@summercare.org, www.summercare.org

Choice Support

A Case Study provided by Choice Support

Choice Support decided over 3 years ago to take a strategic approach to changing their business model in a way that incorporated the introduction of Self-Directed Support across the organisation, whilst at the same time recognising the need to trade in a mixed market of old style commissioning and Self-Directed commissioning. They developed new structures, new roles and new jobs to reflect this gradual change in their business model.

New Structures included a new directorate

Development Directorate:
The portfolio of this new directorate included elements of the old / present system and the new emerging system of Self-Directed Support: Brokerage, Individualised service development, Self-Directed support development, Tenders

New roles included developing and changing existing operating systems

Finance Department:
The finance department developed a 'menu of services' to offer people who had a personal budget and wanted to have control of the recruitment of their own teams but may chose to use Choice Support infrastructure services in a selective way. The menu included: payroll services for individual employers of Personal Assistants, budget management and accountancy services

New jobs included the development of the skills and roles of team members

Service manager's roles developed into: Domiciliary care co-ordinators; Person centred thinking co-ordinators

Team manager's roles developed into: Coaches; Best Practice mentors; Person centred planners, thinkers and facilitators

Other specialist jobs were developed and created including:
Brokers; Community connectors; Personal assistants; Coaches; Domiciliary care agency workers; Advocates; involvement managers

Partnerships with families

"New partnerships have been developed as we have created individual services, particularly with users and their families. In some cases we have employed parents and family friends as managers and personal assistants because it made sense to do so – although doing so brings with it its own share of difficulties to overcome!"

David Helm

Complete change of all services as quickly as possible

A Case Study provided by Castle Supported Living

Where we started

- We are a family led organisation
- Services are designed around peoples' plans
- People own or rent their homes
- Support teams are selected by the tenant and/or their families
- Funding for support was varied and inconsistent - private funding, social services, supporting people, direct payments and Independent Living Fund - also Lancashire County Council contributions from tenants
- Support was delivered flexibly - and liberally. Core responsibilities were not defined

What we needed

- We wanted to preserve our values and provide quality individual support
- We wanted to support people to have more control and be able to plan their lives more flexibly
- People wanted to continue to live on their own or with one other person
- We wanted a fair and equal cost for our service that allowed us to continue our business
- We needed clarity about what we were responsible for in peoples' lives and what was not our paid business

What we did – planning support

- Made sure that peoples' support plans included support in the areas of the Resource Allocation System (RAS) where points were scored
- The RAS covered health, communication, staying safe, work and leisure, essential living tasks and personal care needs
- We included all the things that were important to people or important for people - this included dreams
- There were clear outcomes identified for their plans - what would it look like if things were working: what would it look like if they were not

What we did – organise support

- Agreed with people involved what our key responsibilities were
- Agreed how the plan would be delivered and monitored and reviewed
- Applied for Independent Living Fund for some individuals
- Supported the organisation to plan rotas and make change e.g to planning, supervision, policies

What is different for the organisation?

- People supported understand and feel the control
- Any hours not used can be banked or saved, emergencies can be responded to more flexibly - without need for authorisation
- We have to monitor very carefully. We

have developed an IT system with in Control and Valueworks

- Staff feel a greater sense of accountability to the people they support rather than the organisation and have clearer roles
- The people we support and others in their lives are clear about our support and how it can be delivered
- People use their funds to buy different things

Challenges, threats and opportunities

- Monitoring and maintaining quality
- Pressures to expand to make 10% increase to give a bigger pot of money – could result in watering down of successful model - overstretching of resources
- Refining person centred practices - fitting it all together, using reviews to make a difference

Learning and work in progress

- Finding more natural supports and real community connections - good jobs, volunteering, a great social life
- Look into measuring success - person centred reviews and work with reach standards and “quality checkers”
- Supporting people to take more control over their life plans and also the risks they face
- Support those people who want to be their own brokers

Claire Sherliker
castle_supported@btconnect.com

Working through the changes needed

Area of service / business	**What might need to change?**	**Who would need to be involved?**	**What issues does this raise for you and your organisation?**
Human Resources / Personnel	For example: Contracts of employment that name the person someone is working for		
Finance	For example: Accounting for individuals and reporting to them in a clear and easy to understand way		
Training, learning and development	For example: Core training and targeted training needed to meet the needs of people being supported		
Marketing	For example: Where and how services are advertised and who they are targeted at		

Whichever approach or stage an organisation is at in making changes, the delegates that attended the **self direct** events ‘Helping providers to change’ found it useful to use the Framework provided here.

With this Framework, delegates worked through the issues for their own organisations with colleagues or, in the case of Local Authority officers, with provider organisations they knew well and had a good working relationship with. Having completed their notes from these discussions, the delegates then came back together to discuss the issues raised for their organisations and started to work together to develop solutions to these issues. The following pages give some insight into the issues providers have and to the solutions the delegates started to develop; providers, Local Authority officers, including commissioners, and people with real life experience of how services affect lives worked together to explore potential solutions.

Area of service / business	What might need to change?	Who would need to be involved?	What issues does this raise for you and your organisation?
Contracting	For example: Contracts may no longer just be with Local Authorities / Health Authorities		
Management Structure	For example: Management decisions now made at a distance from the individual that affect a person’s life		
Front line delivery	For example: Personal Assistants may have to support people to manage the resources they have to provide the support they need		
Partnerships / joint working	For example: People being supported by you sharing accommodation with someone being supported by another organisation		
Governance / Planning for the future	For example: Customers being involved in a way that drives any future changes of your organisation		

Potential Issues	What might need to change
Individual ‘named’ contracts	Person being supported named on employees contract - i.e. employed by ‘Jim’
Team member not needed – dismissed? Moved?	Terms and conditions that name the person being supported, different for each person’s team Easy to understand explanation of employment law for the individual and explanations of why certain decisions are made Training provided for individuals in how to be good employers
Team member unable to change and be redeployed to support someone else within the organisation	Contract – between the purchasers, i.e. the individual, and the provider that states that the purchaser can pick the person supporting them and have the right to change these people and this is reflected in the employees contract of employment
Operating within several contracts – existing and ‘new’ customers?	Existing contracts may need to change
Providers take on staff under TUPE transfer arrangements	Transitional agreements with the Local Authority and / or Health Authority that support the provider taking on this responsibility

Human Resources /

Possible solutions / actions that could be taken

Individualised job description and person specification

2 part job description, part 1 what is expected by the organisation, i.e. standards, values, skills etc. and part 2 what is expected by the individual

Employee’s contract needs to include what would happen in these different situations, i.e. redeployment if possible, option of redundancy

Need robust and appropriate recruitment, i.e. matching of potential team members with individual being supported, and performance management ‘system’ that includes the individual being supported, to avoid possible ‘breakdown of relationship’

Part 1 of contract of employment is the provider section of the contract
Part 2 of the contract of employment names the person being supported

2 part recruitment process to meet organisation’s standards and also matching with the person and meeting the individual’s requirements

Renegotiate existing contracts over time, work with staff to identify what is important to them as well as to the people they support / will be supporting in the future

Future short to medium term potential problems underwritten by the Local Authority or Health Authority

Learning and development process to bring staff attitudes up to date and also to gain an understanding of entitlements under TUPE, i.e. redundancy

Involve staff and union representatives from an early stage in any negotiations

Potential Issues	What might need to change
Existing contracts (TUPE) may specify the hours/times that people work between and where they work	Renogotiating contracts with staff, including the unions where appropriate
Cultural issues may limit when people can work	Awareness of / early identification of and an acknowledgement of any cultural issues that may affect working practice This becomes part of the training for individuals in how to be good employers
Need to have a more flexible workforce	Start employing staff on more flexible contracts, i.e. minimum or zero hours contracts
Support / supervision / management of Personal Assistants employed directly by individuals	Offering support, supervision and management of individual Personal Assistants or teams of Personal Assistants that are not employed by the organisation
Recruitment of staff for individuals rather than generically for the organisation	Matching people by personality and interests as well as values, skills and experience

Possible solutions / actions that could be taken

Working through the issues with staff, identify who would want to have a contract based on ‘office hours’ and who would be willing to have a contract based on more unsocial hours / weekends. Also change contracts from building based to person based

Open and honest negotiation about the times someone is needed and when the Personal Assistant can work needs to take place between the purchaser and the employee

Recognise that custom and practice needs to be taken into account; staff working hours need to be monitored closely to ensure people’s entitlements are recognised

Have 2 types of teams, those working just for one or two individuals and a team of floating peripatetic Personal Assistants

Price what this would cost your organisation to do and offer it to individuals for their Personal Assistants

Organise Personal Assistant forums to raise issues in a safe environment and to provide peer support

Carry out an audit of your existing staff team. This should include their interests, skills and experience outside of their existing role as a member of your organisation’s support staff

When drawing up a person specification for an individual’s Personal Assistant ask the individual what they are looking for; who is a person that you like / admire / would want to spend time with? What is it about that person that is important to you?

Use vacancies as they arise to look at outcomes identified in someone’s support plan and align these to the skills, interests, experience that a Personal Assistant would need, rather than recruiting to replace a generic support worker for the organisation

Develop a policy and procedure that accounts for the possibility of recruiting family members as team members

Offer training to individuals who want to be involved in recruitment

Design adverts that are aimed at recruiting Personal Assistants for an individual rather than generic job adverts

Potential Issues	What might need to change
Cultural change needed in Human Resource Teams	Moving from a ‘blame’ culture that creates restrictive policies and procedures to a imaginative ‘risk taking’ culture that allows for the potential to have varied and fulfilling lives within a ‘risk enablement’ framework
Personal Assistants being asked to work in a way that they are not comfortable with because it is soley based on what suits the person they are supporting and does not take into account the Personal Assistant, i.e. their need to plan ahead for family holidays etc.	Need to train the individual being supported to be a good employer
People wanting to do social activities outside normal shift times, i.e. staying out late on a night out	Staff working hours or shift patterns

Possible solutions / actions that could be taken

Work closely with the Local Authority or Health Authority and help to co produce ‘risk enablement’ policies and procedures, i.e. the Oldham ‘risk enablement’ process is designed to be available not only for individuals but also provider organisations that identify situations that arise that need to be reassessed

Co production of rotas that work for both the individual and the Personal Assistant

Ensure there is an on call system for times when team members are not available and that the person being supported understands how this works and why it is there

Within existing shift patterns start by looking at the possibility of ‘handing over’ shifts in the place were someone is having a night out

Match staff members with people being supported that is mutually acceptable to both, i.e. both enjoy the same social activities and the times these take place

Contract staff who are willing to have an unsocial hours contract

Potential Issues	What might need to change
Breaking down block contracts	Moving emphasis from cost per hour to identifying what it costs to support an individual
Debt management	Move emphasis from chasing Local Authorities finance departments for payment to ensuring invoicing to individuals is clear and understandable
Unexpected voids due to people deciding to move on with little or no notice	Change arrangements with Local Authorities
Building in acceptable administration charges into cost of support	Need to be upfront and transparent about the costs

Finance

Possible solutions / actions that could be taken

Identify individual hours and shared hours, i.e. sleep overs. Then negotiate with the Local Authority about what continued amount of funding would be needed to make the service viable if someone decided to move

Convert hours to money or other resources, i.e. hoist

Keep ongoing records of hours used and not used / owed, i.e. 'Noah West Community Services' use a system which produces an ongoing statement of 'credits'

Use the Individual Service Fund model for each person. Refer to Helen Sanderson Associates papers for useful guidance; 'From a support plan to an Individual Service Fund' and 'What we are learning about Individual Service Funds'

Ensure you have a system that is able to take payment from cards 'loaded' with Individual Budgets, i.e. Royal Bank of Scotland have developed a pre loaded card that is being used in Kent

Negotiate at the support planning stage with the Local Authority to set up an Individual Service Fund, i.e. money held by the Provider on behalf of the individual, for people that are at a known higher risk due to difficulties they may have in managing their money themselves

Ask your Local Authority for the option of being able to use a 'Risk enablement panel' process quickly if people default on payment, i.e. if the service is at risk of being withdrawn because of bad debt

Ensure there are contingency amounts built into contracts with individuals where appropriate, i.e. known risk, to 'protect' the provider from people moving on at short notice

Carry out full cost recovery exercise. Then if necessary, explore alternative means of covering / subsidising the cost of Administration, i.e. offer a menu of finance support services for individuals who do not receive any other services from the organisation or micro providers to buy:

- Payroll
- Budget management
- Contract management

In Oldham an organisation called In Stream has been set up to offer these and other services, i.e. a P.A. register

Choice Support, a provider organisation has started to offer this menu of services

Potential Issues	What might need to change
Increase administration costs moving from a system of a few contracts to many	Need to explore present suitability of systems to handle numerous accounts and to report to individuals in an easy to understand way
In house services unable to compete on price if all the infrastructure costs are included in costing of the service	There will need to be a recognition that costing and pricing are two different things and that subsidising of in house services may be necessary
Higher costs of providing higher staff to people being supported ratio, i.e. more one to one support	Finding new ways to off set the cost Where support money is being spent at the moment may need to change

Possible solutions / actions that could be taken

Explore existing and developing ‘off the shelf’ systems:
- ‘Care management 3’
- ‘CM2000’
- Inclusion Glasgow’s ‘Budgeter’
- you2choose
- shop4support

Skill up individual staff team members so that they are able to manage or support someone with their Individual Service Fund; to manage a person’s budget and the accounting / reporting for that budget in a way that is open, transparent and easy to understand for person being supported

Move responsibility for the administration / management of the Individual Service Fund to the team supporting the person being supported and use light touch monitoring of this, i.e. quarterly checks that pick up on variances and plan to resolve these

Commissioners need to identify where there are gaps in services that are not being provided by the private sector and the third sector, possibly because they are not able to provide them in a way that is economically sustainable. Having identified gaps in services needed, decide which in house services need to be subsidised, i.e. priced in such a way that makes them accessible for people with Individual Budgets and comparable / competitive on price with third sector / private organisations

Support people to develop connections in the community and move towards using more ‘natural’ support when and as this becomes appropriate

Use assistive technology were possible and if appropriate, i.e. Telecare

As front line staff take on more responsiblity and accountability, review the role of middle management and if possible and appropriate strip out these roles

Potential Issues	What might need to change
Moving from training that is primarily driven by organisational generic standards and regulation to training that meets the needs of the individual	Need to re examine what it essential core training, what is needed and what is not needed, and then identify what, if any, other training is needed to meet the individual's needs
New roles / imaginative alternatives	Develop new skills to support community involvement and development Encourage autonomy of teams and the development and use of creative / entrepreneurial skills
Career / personal development of Personal Assistants	Personal Assistants need to be given more autonomy in order for them to work out with the person they support what their own training / learning and development needs are
Who will deliver individualised training?	Recognition of the person who needs support as the expert in how they want to be supported
What training will individuals need to be good employers?	Recognition that people shouldn't be left to be employers without the appropriate information and support with that information

Training, Learning and

Possible solutions / actions that could be taken

Work with Local Authorities and regulatory bodies to identify and agree common areas of core training; values, cultural - shift of power, safeguarding, basic health and safety, moving and handling

Work with other organisations to see when it would be possible to offer joint training across the workforce of different organisations

Redesign existing roles to include these new skills

Make use of free ‘business’ advice and training from:
- Business Link
- HMRC
- Chamber of commerce

Allocate Personal Assistants an Individual Budget for their own training / learning and development needs

Offer training the trainer courses to individual’s that wish to train their own Personal Assistants

Training in being a good employer should include:
- Basic understanding of employment law
- Legal responsibilities of employers
- Effective supervision
- Negotiation skills
- Assertiveness training
- Keeping safe
- Resolving disputes and dealing with things when they go wrong
- Basic record keeping

Potential Issues	What might need to change
Providers are not used to ‘selling’ themselves and what they do	Will need to identify what you are good at, what you do differently compared to other organisations and what specialist services you offer May need to change the language you use for a different audience, i.e. people seeking services will not be used to the jargon that is so often used in tenders for Local Authority contracts
Identifying gaps in the market	Commissioners collecting and sharing generic intelligence about services used and unmet need with providers Providers willing and able to change quickly to meet unmet need You may need to think about diversifying and offer services to a wider range of people
Changing target audience	Recognition that for a number of years there will continue to be a mixed market and whilst Local Authority and Health Authority commissioners continue to be potential customers, at the same time there will increasing be a need to market to individuals, families and groups of people who decide to pool their individual budgets Reaching self funding customers

Possible solutions / actions that could be taken

Ask existing customers to tell you what you are good at, customer satisfaction checks etc. Start to use the language they are using to describe what you do. Where possible and appropriate in any promotional work you undertake use endorsements and good stories, i.e. supporting people to achieve their outcomes

Identify what is different about what you do from what is already on offer by other providers; what is your 'unique selling point'? Then be clear about what you have to offer and how much that will cost

Develop your identifiable 'brand', what you stand for, what your values / standards are and why people should use your services?

Invest in a branding / logo redesign that appeals on a personal level and represents what you are about

Commissioners should be encouraged to actively collect and share generic information with providers to help to shape the market; aggregated market need information collected and collated from Person Centred Plans what people are wanting to spend their money on and from support plans what they are spending their money on. They should also be encouraged to use the review process to collect generic information to share about what has worked well, i.e. what people want more of, and what hasn't worked so well, i.e. what needs to change or stop being offered. Also intelligence about the existing 'market place' should be collected through the work of 'community facilitators' / 'community bridge builders' / 'local area coordinators' and should be shared openly with providers as well as people looking for activities to do in the community

Work with commissioners, community facilitators / connectors and brokers to gain an understanding of the market mix now and how it will change over the next few years, what competition there exists for what you are offering

Find out where people who do not have contact with social services or are not eligible for social care support go to find out about what is on offer for people who need support but are self funders

Potential Issues	What might need to change
How do you tell people what you do in a cost effective way	Recognition that the best form of marketing is word of mouth, i.e. other people who have received a good service recommending your organisation
	There may be a need to increase the amount of networking you do
	Take more opportunities to show people what you do and to be more up front about what you charge for the services you provide

Possible solutions / actions that could be taken

Use staff to spread the word and ensure they are aware that the way they work with the people they support, i.e. treating people with dignity and respect, is the best form of 'marketing', what they do is a significant part of the 'brand' of the organisation. And the people who presently are supported by your organisation also need to know what you can offer them, i.e. how flexibly you can work with them and support them to achieve their aspirations and get the outcomes that are important to them

Ensure when you have done a good piece of work that there is some recognition of this

Use the local press to run good news stories about people achieving their outcomes

Keep commissioners and community facilitators / connectors informed of the good work you and your team are doing

Some Local Authorities are setting up or already have running the equivalent of the 'one stop shop', in Oldham they use the Link Centre for this purpose. An organisation providing brokerage services, In Stream, is based there. All Local Authorities should be looking to set up similar arrangements, i.e. Centres for Independent Living (C.I.L.s), make contact with the people involved in these and offer to provide information about the services you offer

Use existing local forums and community group meetings

Run open days if appropriate to the service you offer

Use the emerging market development web sites:
- you2choose
- shop4support
- slivers of time

The Local Authority you operate in may have already developed a website were you can promote your services or be in the process of developing one

There are an increasing number of 'market-place' events taking place across the country, use these not as a way to give away 'freebies' but as a way to really engage with potential customers. Make sure the information you produce for these events is in an easy to understand format and free from jargon

Potential Issues	What might need to change
Need to have contracts that focus on outcomes not ‘inputs and outputs’	Move away from ‘task and time based’ contracting between Local Authorities / Health Authorities and providers to ‘outcome focused’ contracts between the individual and the provider
New forms of contracts are needed that are reasonable, agreeable and legal	Some contracts will need to be between the individual, the Local Authority / Health Authority and the provider
Quality assurance and monitoring	Acknowledgement of the person receiving the support as usually the best placed person to quality assure and monitor the contractual agreement or with independent support if needed

Contracting

Possible solutions / actions that could be taken

Monitoring of outcomes achieved moves from the Local Authority / Health Authority to individuals. The Local Authority monitors customer satisfaction at reviews.

Cheshire have developed a ‘lite’ monitoring of Direct Payments

Barnsley Metropolitan Borough Council has developed a 3 way contract that is legal and works for the Local Authority, the individual and the provider. They are willing to share this example contract with others; it can be found on the in Control website and the self direct website

Have robust monitoring systems that put people in the driving seat of monitoring their own services

Encourage customer feedback and publish these, i.e. on websites

Link people with independent support, i.e. advocates / brokers, if needed to give constructive and objective feedback

Potential Issues	What might need to change
More autonomy for staff teams supporting individuals, move to self managing teams	Devolving more power, responsibility and accountability from higher in the hierarchy of the organisation to team leaders and team members so that quality decisions are made as close to the person being supported as possible
What infrastructure support is needed for self managing teams?	Infrastructure costs need to be clearly understood and priced in such a way that contributions from Individual Service Funds are clear
Board directorate remits may need to change	Finance directorates need to look outwards at potential customers who may buy from a menu of services Brokerage / community involvement and development may need to be included in a directorate's remit Human Resources directorates may need to re focus the support they provide to external customers

Management

Possible solutions / actions that could be taken

Review the structure of the organisation and make changes if needed, this could mean taking out a layer of middle management

Review what needs to be devolved to team leaders and teams so that more quality decisions are made as close as possible to the person being supported, i.e. budget setting and management, rota / sickness management, safeguarding, co produced individual service design

Assess what training and support structures are needed before devolving responsibility and accountability to team leaders and teams

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Treat individual services or groups of services, whether this is one person or a number of people living / being supported together, as autonomous services that ‘buy’ infrastructure support from the ‘parent’ organisation as needed

Explore the potential of groups of services becoming independent organisations

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Develop a menu of infrastructure support for internal ‘customers’ and external customers, clearly priced

Potential Issues	What might need to change
Workforce - Allowed to take on responsibility - Willing to take on responsibility - Able to take on responsibility	Changing roles & responsibilities, i.e. more autonomy
Possible conflicts of interest	Increased use of advocates if a team leader and members of a team are seen as not being objective in the support they provide to develop support plans
Team members that are well matched to individuals may lead to some team members becoming too close to the people they support	The way the working relationship between the person being supported and their team member is viewed and managed

Front line delivery

Possible solutions / actions that could be taken

Be clear who can make decisions and at what level and what type of decisions. For instance; sick monitoring / leave / covering for absent staff; the staff team need to be given the ‘permission’ to take on this responsibility

The team leaders need to be multi skilled and take responsibility and accountability for decisions that were previously made by middle managers not directly involved in supporting individuals

‘Lone working’ policies may need to be reviewed

‘Permission’ for team members to be able to recommend / sign post to services other than services only provided by the organisation they work for

Produce a positive ‘friendship’ policy that supports the develop of friendships in a safe way where these occur naturally and for the right reasons, i.e. Inclusion Glasgow developed a ‘friendship’ policy because when people are matched well in terms of personality and shared interests, friendships are more likely to occur naturally between people being supported and the person providing the support

Potential Issues	What might need to change
Staff working alongside people from other organisations, for instance with no training, i.e. Health &Safety, use of a hoist – moving & handling, behavioural management	Working in partnership with other provider organisations to either provide support in the same residence or for the same person Reassessing the level of training that is needed
Individuals choosing to live together and have pooled budgets but choosing different providers	Working collaboratively with ‘competitors’
Smaller organisations may not have the infrastructure needed to support larger numbers of small contracts or to market what they do to a wider audience	Smaller organisations may need to find support from outside their own organisation

Partnerships /

Possible solutions / actions that could be taken

Clear lines of responsibilities need to be agreed and appropriate but not restrictive protocols need to be developed

Agree data protection / sharing information issues

Be clear about insurance issues

Need to have clear, open and honest lines of communication

Have regular cross organisational meetings to discuss issues and resolve these, these could take the form of forums or action learning sets

Build on relationships with families

Be honest about what's possible

Acknowledge possible conflicts and put out 'small fires' on an ongoing basis

Develop 'house rules' and review regularly how these are working

Develop contracts that are clear about what is individualised support and what is provided jointly and what this costs and how it is paid for

Proactively seek out like-minded organisations and start to explore with them partnership arrangements, this could be as simple as buying in the extra infrastructure support an organisation needs or it could involve more joined up working such as setting up a consortium with a number of other smaller organisations

Joint Working

Potential issues	What might need to change
More decisions being made by staff on the ‘front line’ may mean that the organisation’s risk of liability will change	Having a clearer understanding of who makes what decisions and who is responsible and accountable for the consequences of those decisions Your organisation’s insurance cover may need to be changed
Board members continue to make decisions that affect people’s lives	Board members become facilitators of the service, helping to shape the development of the service and not acting as managers of managers of the services provided

Governance /

Possible solutions / actions that could be taken

Ensure you have a clear decision making ‘map’ and that this clearly shows how decisions that directly affect the person being supported are made by them or as close to them as possible, i.e. by the team members supporting them if appropriate or their circle of support or an independent advocate

Ensure you have a process for assessing the risk involved in decisions being made in this way and that this process is understood and is being used in a way that ensures unnecessary risks are not being taken but that it is not unnecessarily restricting what people are able to do

Keep your insurer informed of the steps you are taking to ensure that risk is assessed appropriately and that staff are trained to assess risk

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Move the focus of the board members; run training sessions that include people who already or are wishing to, manage their own staff teams

Include people being supported in board meetings in an appropriate and meaningful way, i.e. in a way that their evidence is heard, actively listened to, has an influence on the decisions being taken and action is taken on this evidence. Make meetings accessible; brief people before the meeting, meet at mutually agreeable venues and at times that suit the person being supported, make sure that the ‘rules’ of the meeting are easy to understand, i.e. how and why decisions are made in the way they are.

Planning for the future

First Steps

Each organisation will have to decide which areas of their business need to be tackled first and which are dependent on the other for success. However there are clearly some things thatproviders need to do and if your organisation is trying to decide when the best time to do these would be, we would suggest that this is it, the time to start planning for change is now.

Get sign up from Directors / Trustees

Agree Approach

Involve people you support

Identify learning and development

Identify resources that each person has

Ring fence money around individuals

Start with people who want to change

Identify what else is available for people

Match people supported with people supporting

Diversify

Start to collect stories as peoples' lives change

Share learning / tell people what you do

Strategies

Establish a guiding coalition of leaders and develop a communication strategy; internal and external

Develop a plan to take action; pilots, new directorates or complete change of all services / policies and procedures

Move the decision making process, i.e. decisions that affect the lives of the people that you support, to them or as close to them as possible if they need support with decision making

Start a learning and development programme to skill up staff teams and to empower the people you support

Break down blocks of money into management costs, core / shared hours and money only used to support each person you support and seek agreement on a transitional phase with the Local Authority to maintain business during these changes

Develop Individual Service Funds for everyone you support and explain to them clearly what money they have and how you can support them to use this flexibly

Develop new person centred support plans based on what peoples' aspirations and expectations are; what's important to people and what's important for people. Carry out individual service designing with all the people you support

Carry out a 'skills and interests audit' of existing staff so that people can be supported in different ways by staff who can help them get a job, learn new skills and do new activities in the community that they enjoy and value

Match Personal Assistants with the people they are recruited to support, support people needing Personal Assistants in this process as much as they wish to be, and offer this to people who don't want to employ people themselves but want to be fully involved in the recruitment of the people that support them

Develop new ways of doing things, i.e. develop new social enterprises and provide support in different ways and for people with different / more complex support needs than you do presently

Collect information in a variety of formats about peoples' lives, as they are now and as they start to change to achieve peoples' identified outcomes; what helped and what got in the way

Work collaboratively with like-minded organisations and individuals, Local Authorities / Health Authorities and community groups / organisations. Market what you do well, using different ways to do this that are appropriate to you and your customers

What the experts say to providers

“Just listen to what people are telling you”
Andy Pollin

“Think outside the box, my life is for living not existing”
Vivienne Gilman

“Be flexible”
Virginia Webster

“My life, my way”
Keith Webster

“A good quality service doesn’t necessarily mean a good life”
Sarah Wood

“How accountable are you to the people you support and how do you demonstrate that you are?”
Andrea Broadway-Parkinson

self direct believes that any changes in the social and health 'market-place' should be driven by people with real life experience of how services affects lives. Therefore, we always have people working with us at our events that have that expertise.

Sarah Wood starting working with **self direct** in this way last year as an associate, Sarah is now employed by **self direct** as a Family Carer Expert. She has worked with many providers over the last year, describing the affect services have had on her family's life. Sarah has also worked with the Department of Health on behalf of **self direct** as a 'citizen leader', working with them and others to develop the National Common Resource Allocation System framework.

This is Sarah's story

I guessed Adam was going to have a few problems as soon as he arrived in June 1989. His delivery had been rushed and traumatic, for the pair of us. He needed to be resuscitated and then he was handed to me.

We took him home to his big sister, Cori, then twenty one months old. My daughter was beginning to display the typical signs of jealousy at the new arrival. My husband was not particularly supportive; frequently losing his patience with Adams crying and Cori's age appropriate behaviour. I had a massive post delivery haemorrhage and before long, after struggling with my own ill health, a toddler and a poorly baby, I sank into a pit of post natal depression. My, already fragile, marriage dissolved before Adam was two years old.

From that moment on, none of my anxieties about my baby seemed to be listened to. Now I had the label of "over anxious mum" on top of everything else.

It was only when he failed his 15 month check that any of my concerns were taken seriously. The Health Visitor recommended that he be seen by a paediatrician. He was making no verbal sounds, he did not point at things, he seemed deaf, he could not feed properly, he was always vomiting, and he woke up frequently during the night struggling for breath. He seemed totally disinterested in the world around him. Yet he would sit happily for hours, spinning a single wheel on a toy car.

The paediatric appointment led to either us attending appointments or people visiting us at home. We saw a clinical psychologist, a psychiatrist, a learning disability nurse, a preschool teacher, a speech therapist, a physiotherapist, a play therapist, a family centre, a dietician, an ENT surgeon, a genetic counsellor, an educational psychologist. Although all these appointments and visitors were a massive intrusion into an already busy and stressful time, I held out hope with each and every one. I pinned hope that the therapist would have Adam speaking, I was secure in the knowledge that the paediatrician would come up with a diagnosis which I could research and understand, find families in the same position and become an expert on my sons condition, I hoped that the ENT surgeons suggestion of removing Adam's tonsils and adenoids and insertion of grommets would result in a healthy little boy who would miraculously begin eating a variety of foods instead of the bland puree which he seemed to prefer. I thought the psychologist would give me insight into his bizarre behaviours and help me to understand the weird rituals that were starting to become a huge part of our daily functioning. In short I was desperate and truly grateful for anything the professionals could offer us.

I then spent years fighting for everything, I fought for a diagnosis (which was a battle not won until Adam was nineteen), I fought for nappies beyond the age of infancy (anyone having been subjected to a continence assessment will have full empathy for that appointment!), I fought for a school place in our local language unit (and lost), I fought for respite so my daughter could have some normality in her life, I fought for speech and language therapy, I fought for meaningful activities for Adam, I fought for all the disability related benefits, Carers Allowance, Disability Living Allowance, the offer of a free washing machine, the occasional organised day trip and the provision of a wheelchair.

The thing that I never really questioned was the fact that all these battles ended in either losing or winning something that did not actually enhance our life. I was always frightened of complaining and suggesting things that would really help, like a bit of help with the cleaning or an extra pair of hands to make family outings a reality.

He was placed in expensive respite which he found distressing, he was taken everywhere by mini bus or taxi, he was visited by lovely women who turned up, wearing tabards, to take him out for a toasted tea cake, he was managed and what we received in the way of services, helped us to manage and cope. Nothing really fitted with our family routine or our personalities. Nothing actually made our lives any happier.

When Adam was eleven and settled into his special school, I went to university for three years to undertake nurse training. It was in my second year that disaster struck. Our house had a fire and we had to move out. Due to problems with the builders we ended up being out of our own home for over four years. During this time we lived in a cramped and totally unsuitable house. We had belongings everywhere and boxes piled high. Many of our familiar items were in storage and this all had a massive negative impact on Adam, resulting in behaviour and sleep disturbances.

We continued life as best as we could and I did well at university despite becoming weak and exhausted, which I put down to studying long hours, working shifts at the hospital and caring for Adam.

We took the decision in 2004 to remove Adam from his respite facility because it was actually causing him more distress than staying at home and I could not handle the added pressure of the problems we faced before and after he went. The building was beautiful and the staff were great and hard working but it was just not suitable for Adam. We were now managing alone. We were told around this time that Adam was to have a new care manager as he was now in 'transition'. We waited to see what new services were open to us as he headed into his teenage years.

Adam has a passion for cars and keeping them clean and tidy; he spent hours with my friend's husband washing his car and looking at cars on the internet and helping him with his car maintenance. Whenever Adam went to stay with his new friends, he was enthusiastic and eager to leave us. This is priceless, it meant I could truly relax and hardly give him another thought while he was away. I could concentrate on getting better and sleep peacefully rather than waiting for the telephone to ring for him to be brought home. Or feeling guilty knowing he was terribly unhappy.

I didn't realise it at the time but we had actually started our journey of Self Directed support. At Adam's annual review the care managers celebrated the link, between Adam and his sharing carers but I remember thinking, "We did it, not you!", "We found the right people, not you", "We made it happen, not you."

When I was invited to attend a five day course about planning with people, I had a vague idea about person centred planning as I had recently completed an assignment about it as part of my nurse training, but had no idea how to make it happen for Adam. The course really did change our lives. We were talked through the planning process; looking particularly at PATH and MAP planning tools. We learned how to facilitate these meetings for people and how to uncover seeds of dreams and how to identify gifts, talents and passions of people rather than just caring for them.

I went home and tried a little bit of what I had learned with Adam. I played some relaxing music and got our pens and paper out. I asked him to draw a picture. He spent a long time drawing a picture of two boys in a school classroom. One of the boys was dressed from head to toe in blue.

"Who's this?" I asked.
"It's Pete"
"Why is he in blue?"
"It's his favourite colour."
"Why have you drawn Pete?"
"He's my friend."
"But Pete is older than you; he has left your school now."
"I know."
"Do you want to see more of Pete?"
"Yes."
"Shall I ring Pete's mum and try and sort something out for him to come for tea one night?"
"Yes please."

I had not realised that Pete and his friendship had meant so much to Adam. It was a massive insight to discover that just because Adam did not have the skills to maintain a friendship, this did not mean that he did not want or need a friendship. From that day on we have kept regular contact with Pete and his parents. Pete and Adam enjoy a fulfilling and longstanding friendship, they have been on holiday together, socialised together, shared personal assistants and are hoping to live together in the future. This took about half an hour to find out and only a telephone call to make happen. All I had done was learn, after fourteen years, to listen.

We then went on and organised a PATH meeting.

I invited mainly friends of my own as Adams circle of friends was still very small. We had a great day and it was fantastic to hear all the positive things that people had noticed over the years about Adam, things I had not known.

Instead of ‘obsessive’ he became ‘neat and tidy’, instead of ‘painfully shy’ or ‘mute’, he became ‘quiet and conscientious’, instead of being ‘repetitive and boring’ he became ‘brilliant at retaining factual knowledge’. To hear him being described in positive ways, to see his life being looked at in a hopeful way, to see people giving him ideas on how his future could look and all the brilliant things he can do, can achieve, can become. All his choices and aspirations came out in the open; all his hopes and dreams were looked at, celebrated and encouraged.

We started the ball rolling by looking at him getting out and about. He was allowed three hours a week of Direct Payments. One of my daughters friends became his personal assistant, she also happened to be a model. So Adams first outing to the pub to play pool was with a model. It’s a story I love to tell. From: Being transported around in a taxi to somewhere he did want to go. To: Going out on the bus, for an orange juice and a good night on the town with a gorgeous stunner! Life was starting to look brighter.

Adam desperately wanted to go everywhere under his own steam by cycling. We were not aware of this until he drew a tiny little picture of a bike on his PATH plan. This led to further exploration; a dream of getting himself to school each morning, instead of being picked up in a taxi, emerged. We decided to make it happen. His school was about seven miles from home and meant journeying right through the city centre, not a journey I would be prepared to undertake. We enlisted the help of the Independent Travel Coordinator. He helped Adam find a safe (but lot longer) route to school. Adam has always despised public transport but was persuaded by the travel trainer to ‘give the bus a go.’

When it came to Adam’s annual reviews, we had previously been seated in his Headmasters office, around a table, with various people, some of whom we knew and some whom we had never met before. The Chairperson was often someone who had not previously been introduced to us or Adam. We decided (as a result of reading the Valuing People white paper) that Adam should have a review in which he was represented as the person he is and who he wants to be seen as. Historically, Adam had found his annual reviews a traumatic event. After one in particular he said he had to nip his bottom as he felt he “Was going to poo myself with fear.” We made Adam’s next review accessible to him. We insisted it was held in a place and in a style that Adam was comfortable with. So from then on, Adam’s reviews followed a set of guidelines that he had decided upon: No-one was to wear a suit, the review had to take place in Adam’s home, we had Christmas carols playing in the background despite it being July, we graphically recorded the meeting in bright colours on a huge paper table cover, we had balloons that were patted back and forward between people, we had sweets and individual cartons of juice instead of the teas and coffees that were usually offered. Adam spoke up at these meetings and some care staff, who had been involved with Adam for years, heard him speak for the first time.

As a birthday treat to myself, I hired a hot tub for the weekend and invited some girlfriends around for a few drinks and to relax in the tub. The night before it was due to go back we persuaded Adam to try it. Once he was in he started talking more freely than he had ever done and that night had his best sleep for years.

When Adam received a full Personal Budget, initially we used some of the money to buy a hot tub for our back yard, having completed a rationale for the expected outcomes for Adam.

When Adam sits in the warm water at the end of each day, he becomes relaxed and communicates well. He then sleeps right through the night which was something that was also new to us; eight hours, straight through. After seventeen years of interrupted sleep, believe me, it was money well spent.

Instead of taking up the offer of a residential, out- of- county, college placement when Adam left school (at an estimated cost of £150,000 a year), we decided to use Adams budget to employ a personal assistant for thirty two hours a week (Adam's Personal Budget is about £20,000 a year). Adam now has days each week when he buys his own food and toiletries, he changes his own bed, he pre-cooks some of his own meals for the week ahead, he works one day a week valeting the cars of our local learning disability staff team, he attends a gym, he cycles regularly, long distance which in turn keeps him fit, relaxed and known to the neighbourhood.

It came up in one of Adam's friendship meetings that he loves listening to stories from the past. So we thought about all the elderly people who live in isolation, who would be happy to spend some time each week chatting to Adam. He became a regular visitor to an elderly gentleman who lived up our street and this continued after the gentleman was admitted to residential care.

The Individual Budget allows me to pay for some domestic help which frees me up to oversee the planning and organising of his budget and also makes the day to day, full time personal care of Adam a lot easier.

Then my partner walked out. That's right; he said he could not handle life in this weird, wonderful world of Autism so he left. Choosing to go and live a life with no ritualistic behaviours, no appointments with the clinical psychologist, no having to stay in when he would rather be out, no disturbed hang over's and basically being able to create his own life choices, from that moment on.

I did what most women would do in those circumstances, I collapsed in a heap on the floor and cried and cried and then cried some more. Nothing unusual about that, I hear you say, and I suppose you are right. There is nothing at all unusual about that.

Life consistently throws events at us that we do not expect, people get ill, people split up and people die. Of course there is never a great time for this to happen.

When life throws events at a carer though, things are very different. The only thing I can compare it too, is the feeling when you have very young children and become ill. You long to stay in bed and be ill in peace but that is impossible due to needing to safeguard and feed your child, well that's what it's like for carers too. Always needing to be there, sorting out medication, appointments, money, food, social life etc; there is no time off for good behaviour or illness.

When crisis has hit us before, like the time I needed 5 months of chemotherapy or the time our house burnt down (never good time for that to happen!) we relied heavily on the mercy of social services and what they could offer to help out with the care of Adam.

This time it was different. Adam was already away at his adult placement, a scheme where carers look after him in their own home. A telephone call was made to the family who happened to be hosting Adam's best friend that week, they were more than happy for him to stay where he was for the rest of the week. So instead of arriving home to see his mother in a catatonic state of grief, or being shunted off to an emergency bed somewhere unknown, or having late night conversations with the emergency duty social worker; we experienced a natural run of support that was seamless, effortless and brought entire peace of mind to both of us. Not to mention a week away with his best pal.

Because the carers know Adam very well and understand the anxiety associated with Autism, they were able to discuss the events with him. This meant that when he returned home, he knew exactly what to expect and had already accepted that from now on, it was just going to be the two of us.

A telephone call was then made by a friend on my behalf to alter the hours of Adam's personal assistant. So he had a couple of days off and then repaid us by collecting my son a week later and running me to the supermarket. He then picked up prescriptions and arranged a night out for them so there was something pleasant to look forward to for the week ahead.

I doubt that the old system would have provided the appropriate response and I also feel sure that if we had chosen that route, the cost to the tax payer would have been higher than the cost of two telephone calls and three extra nights at his adult placement scheme. (We paid for the three nights from Adam's Personal Budget.)

In the future we plan to help Adam secure his own home and live with who he chooses to and be supported by people he can trust and who have his absolute best interest at heart.

And what's more, in the not too distant future, Adam will have a job. Adam went for an interview at Morrison's recently. When he was asked what he would like to do, he mentioned the trolleys outside. At this time of the year, the manager said most people didn't want to be out in the cold weather to sort the trolleys out. Adam said he wouldn't want to be outside when the hot sunny weather comes, it's then he would prefer to be working inside. He is going to be very popular with his fellow workers come summer!

Although the Personal Budget has helped immensely (albeit a fraction of the cost of the unsuitable services) I have to add that most of the changes that directly benefit Adam and our family are the changes in the way we think. I had to be taught (I am ashamed to say) to see Adam as a citizen and a true member of our community, so it's hardly any wonder that others did not see him positively. Our neighbours used to see Adam getting picked up in mini buses or taxis and taken to mysterious places. Now they see him waiting at the bus stop, going out on his bike, washing cars on the garage forecourt, using our local shops and visiting his mates.

It's taken many years and lots of hard work, it still does. The gaps in the system put an awful lot of pressure on family members. We are all still learning and we have a long way to go. For Adam, his life has changed beyond all recognition. He determines himself, his day and his future with the support of those he loves and trusts. For me, I no longer have a deep seated fear of leaving him alone in the world, so I can get on and live my life too.

Adam finally got a diagnosis last year of Autism, but it hardly seems important now. Adam is Adam. He is who he is. He's my son and I am so proud of the way he lives his life. I have had challenges over the years but when I see the challenges Adam faces every day; it makes me so proud to call myself his mum. Like the time he was consistently and maliciously bullied whilst using the bus; a group of boys were reported as spitting on him and laughing at him, before photographing him on their mobile phones and sharing the joke. This went on for weeks until a member of the public made someone aware. Adam had not complained or let anyone know that this was happening. His Autism makes it difficult for him to share anything, including information. My gut instinct was keep him safe by returning to taxis for his transport.

“No way!” he laughed when I suggested this to him.

“But then you won’t have to worry about the boys spitting on you again” I offered trying to achieve some peace of mind.

“I don’t want taxis. I love my life now.”

And the next day he was back out there waiting for his bus.

I have often heard carers say that they want just a ’little bit of life’ of their own; I have met mums who have never managed to read a book or who have lost touch socially due to the restraints of being a carer. Self directed support can mean an end to that: families can take the opportunity to exercise control over their lives, as we have done with ours.

These days I speak in public frequently about how our lives have been transformed, so when I was asked to speak at the National Children and Adults Conference I was excited about being asked and felt very privileged to be trusted with such a task......

“This is where you will be speaking Sarah” said my colleague, as he held open one of the huge black doors.

In front of me was a vast arena. Raised seating like a theatre. I found out afterwards that there are one thousand two hundred seats in total. On the stage was a panel of six chairs each with its own microphone, which looked like little black matchsticks from where I was standing. To one side of the stage was a podium with its own microphone and behind the stage, a huge screen.

“Well I wasn’t scared before but, suddenly, now I am!” I laughed, “It’s like something from Prime Minister’s Question Time!”

“Come on, we’ve got about fifteen minutes to go through it and grab a sandwich.”I didn’t feel like it would be right, given the circumstances, to mention that I was trying to stick to a wheat free diet.

It had been two weeks since I had received a telephone call asking me to do this; present the Common RAS (resource allocation system) Framework at the annual National Children and Adults Conference.

The first stage of the hard work was over. For the last nine months, 18 local authorities and 8 citizen leaders (me being one of them) had worked together on the development of the Common RAS Framework. The fact we had worked together is why I had been asked to present it. Coproduction is the key word. Local authorities have been given benchmarks by the government to meet in this area and the Department of Health were keen to show authorities how it could be done and indeed that it had been done. The development of the Common RAS Framework is an example of true coproduction.

We hurried along to the main conference exhibition hall where we weaved between stand after stand of chocolate fountains surrounded by marshmallows on sticks, free gifts of mugs, post it notes, reusable hessian shopping bags and pens galore. There was no time for us to hover or network. Eventually we found somewhere to sit and with sweating, shaking hands, I made some last minute notes on the back of a draft copy of the RAS paper.

Five minutes to go, luckily, I did not have to explain my wheat free diet or the fact my stomach had now joined my tonsils physiologically; there was no time to eat. The place was packed and the people around us all seemed to know where they were going.

We were advised to, “Take the lift that’s to left of the man with the bald head.” by a friendly conference host, who had noticed our blank expressions when we were faced with stairs, turnings, and numerous escalators.

Arriving back in the main arena, it was now spot lit and buzzing with activity. People had started to take their seats and the entire panel were seated. Our presentation slides were now visible to the world on the big screen.

I speak in public frequently; being nervous about public speaking is something other people suffer from, not me. Not until today, that is.

I kept telling myself that in about an hour, this would all be over. I needed to spend a penny. Yet I could not need to, I had just been. My face was red; my hands had a cold yet sticky feel to them. My legs were so wobbly that I considered asking to be allowed to speak from the safety of the panel; I was unsure if I could trust them to carry me, along with high heels, along to the podium, in full view of hundreds of directors.

It was difficult to make out individual faces, as the audience were in a shadow. I could feel the heat of the spot lights making my face even hotter and redder. I wanted to take my cardigan off but being forty two, I was also aware of the wobble in my upper arms, knowing that I would feel even more self conscious whilst flashing ‘bingo wings’, I decided to go with the hot flush instead.

The grey leather seat was comfortable and as I attempted to sit right back (in an effort to appear relaxed) I realised it was a swivel and a rocking chair, oh what fun I could have had, under different circumstances. My mind drifted ever- so- briefly, back to being a child; spinning my little brother around so fast on our parents’ seventies swivel chair that he could not walk straight for ages after.

I remembered a book I had read, ‘Feel the fear and do it anyway’ (Susan Jefferson.) I practised some of the non- attachment that Susan suggests. I repeated positive affirmations in my head; I deserve to be here, people want to hear what I have to say, I deserve to be here, people want to hear what I have to say.

At best, in the past, people who have met me, and know my story tended to feel sorry for me.

I was waving a friend off the other day and she shouted,
“See ya.”
I replied,”Wouldn’t want to be ya.”
She got in her car and shouted back,
“Yeah but I wouldn’t mind being YOU!”

For someone to feel envious of our life was unimaginable a few years ago. Through making our own decisions and honouring who we really are, we not only ‘have a life’ but have, at last, created a great one.

Sarah's Evaluation

What's worked well throughout

- The families and friends that have stood by us throughout the whole process: our peers
- The input we have received by way of our own and extended networking i.e. training and conferences offered by Inclusion North, Partners in policy making and Paradigm. It's within these circles of "not having to explain ourselves" that the encouragement happens.
- Our own personal tenacity and ongoing commitment

Outcomes

- Have met all outcomes identified in Adams plan
- Have exercised choice and control despite a feeling of "going against the grain"
- Have the help in a way that suits our family and our routine rather than fitting into a service

Personal cost

- It's been a long and arduous process that has impacted massively on my life. At times I have felt unsupported, intimidated, misunderstood, misinformed and the culture of the service provision has led me to feeling like I am some kind of rebel
- I have felt very alone in this process, as if our providers are not really sure of how and why we do the things we do, it's been like we are following two different agendas
- I have been unable to entrust any of the process to our providers, which has meant everything has landed on my own shoulders from learning, recruiting, planning, implementing and sustaining the process. This responsibility comes on top of usual life stresses and my caring role so has led to exhaustion and an additional barrier to socialising, working, studying and generally enjoying my life.

What would have helped me

- It would have helped massively to have had someone to go through the process with me, someone who saw things the way that we do and genuinely valued Adams life choices
- Some practical help with the organising of planning meetings and the development of a support plan would have helped hugely
- The biggest help would have been for the professionals involved with Adam, to really understand where we are coming from instead of a feeling of negativity and obvious lack of enthusiasm for the self directed nature of our support

Word Of

We asked delegates who attended our events to tell us what they thought about them. Here's what they had to say...

"Every aspect of the day was useful for me. it made all the background reading I have done re Individual Budgets more real to me
- Nicola Barnes, Vitalise, Derby"

"Gave me confidence to realise we're thinking along the right lines and that we won't get answers and how to, we just need to try things and be creative. It was inspiring
- Harriet Michael-Phillin, Service Manager, Support for Living"

"**Very useful to focus thoughts and begin to plan a way forward**
- Jackie Carré, CARE (Cottage and Rural Enterprises Ltd), North Yorkshire"

"**Will be advising people at Regional Service Development Network to attend your future events**
- Jamie Anderson, Age Concern, Wirral"

"Massively helps people understand personalisation in a very user friendly way which is much needed
- Mark Finch, Choice Support and Transport, Oldham"

"As well as being informative and uncompromisingly positive, to listen to people and their life experiences was invaluable
- Biba Boele, Rochdale Council"

"Made good links and have come away with some good ideas
- Lisa Cole, Mental Health Matters, Middlesborough"

"Very informative. Time to think things through, along with open discussions. Good learning
- Tracy Sims, Deputy Head of Operations, IAS"

“Very informative and makes you want to change things quicker so peoples’ lives improve
- Emma Daffey, Registered Manager, New Directions”

“Thankyou for a well structured, informative and exceptionally useful 2 days!
- Jamie Anderson, Age Concern, Wirral”

“**Thanks for a great 2 days, really valuable and lots to think about**
- Neil Ternent, Area Manager, Mental Health Matters”

“**Pretty much planned 2 years of my project work!**
- Anonymous”

“Allows real in depth discussions to enable you to get a good understanding of what your organisation needs to be doing
- Philip Carpenter, NORSACA”

“**Good knowledge, knowledgeable trainers**
- Lydia Jones, Service Director, HAIL”

“Great mix of formal and informal methods
- Ruth Cartwright, Head of quality and improvement, Metropolitan Support Trust”

“**I attended your two day ‘Helping Providers Change’ event. I found it really informative and will impact on my practice in my role as a Contracts Manager**
- Lynn Mounfield, Contracts Manager (Adult Social Care) Brighton, Hove”

“I left the workshop feeling much more positive
- Dan Davies, Director, integracare”

Mouth

Next Steps

We have noticed over the last 6 to 12 months more confidence and higher levels of knowledge and understanding among a growing number of provider organisations in England and Wales.

Many providers and more importantly the people they support are now benefiting from the learning and development events provided by Local Authorities in England and the Social Services Improvement Agency and the Citizen Directed Support Alliance in Wales.

The social and health market-place is developing and not just through the work **self direct** has done but also from the work of the increasing number of providers of learning and development who are turning their focus to the personalisation agenda and we welcome this.

We are increasing being asked by Local Authorities and Health Authorities if **self direct** can work with providers, both in house and external, and by individual provider organisations themselves to develop their plans for the future. This has led to a number of commissioned **self direct** events, each tailored to the specific needs of the organisation requesting our support.

After our events we always ask what other support we could provide to take forward the personalisation agenda and have had many requests from Local Authorities and providers to work with them to develop practical ways to achieve personalised outcome focused support and services.

Keeping the momentum going so that more people can benefit from the improvements this whole agenda can deliver is important to us and we welcome the opportunities arising to work in more depth with organisations across the UK.

Acknowledgements

We wouldn’t have been able to produce this book before we started working with the delegates who have attended our events over the last 18 months. So we owe them thanks for taking part and helping us to co produce this book. The delegates came from providers across the social and health sector, from small and large provider organisations in England and Wales, from Local Authorities and Health authorities and from voluntary and community groups. We are also grateful for the input into these events from the Association of Directors of Adult Social Services, Skills for Care and the Department of Health.

The providers that attended our events are not named individually in this book but we have included comments from a selection of delegates from some of those organisations under the heading ‘Word of Mouth’.

We would also like to thank the organisations and Individuals that have allowed us to use their resources during the events to help the delegates think through the issues and develop solutions to these. Resources were provided by in Control, Inclusion Glasgow, Partners for Inclusion, Helen Sanderson Associates, Choice Support, Castle Supported Living, you2choose, shop4support, Barnsley Metropolitan Borough Council, Oldham Metropolitan Council, the City of York Council, SCIE, the Department of Health, and Simon Duffy, Director of The Centre for Welfare Reform.

Of course the events would not have had the impact they have had if not for the involvement of people with real life experience and we would like to thank them; particularly for the expertise they brought to the events in sharing their experience of using direct payments and Individual Budgets. We will not name them all here, you can find more details of our associates on our website, however we would like to mention the organisation York People First; a number of their members have worked with us at many of our events over the last 18 months.

Sarah Wood, self direct’s family carer expert, has contributed greatly to these events. Her family’s story is one of great success against the odds and is a testament to the difference that self direction can make. You can read more about Sarah’s family’s experience on the self direct website, where Sarah regularly writes her blogs.

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