

Personalised Support

How to provide high quality support to people with complex and challenging needs - learning from Partners for Inclusion

by Julia Fitzpatrick



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About the author

Julia Fitzpatrick

Julia Fitzpatrick is an Independent Consultant and, since June 2010, Managing Director of Horizon Housing Association, a lead provider in Scotland of accessible and affordable housing and services with the aim of enabling disabled people to live in, remain in and contribute to their community. She is Chairperson of Thistle Foundation, a pioneering organisation helping people with disabilities or long-term health conditions to lead great, authentic lives where they are in control. She has been a member of Altrum since 2006.

As a consultant, trainer and advocate, Julia has worked with disabled people and their families, and supported new and existing organisations, in creating personalised support and housing models and expanding options. Over the last ten years she has authored a range of related publications, reports and articles.

Julia is a Fellow of the Chartered Institute of Housing and has previously held posts of Operations Director of Margaret Blackwood Housing Association; Director of Consultancy with Paradigm; Director of Ownership Options in Scotland, establishing this new agency to enable disabled people to become home owners; and Director of Housing and Care Services of Eildon Housing Association in the Scottish Borders.

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Foreword

“Life for people with major disabilities in good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.”

(Mansell Report, 1993 and 2007, paragraph 41)

The rhetoric of community living for people with learning disabilities emphasises ordinariness. The central message has been that people can be liberated by moving away from service-dominated structures and ideologies towards an approach founded on helping people to be valued and supported by their family and members of their local community. The subtleties and complexities of this message have often not been heard or understood, so that it has been assumed that providing staff support in a house or an apartment in the community is all that is needed to ensure people have a good quality of life.

This is not necessarily true, especially not for people with learning disabilities who have extra needs due to the severity of their intellectual impairment or the presence of other disabilities or problems. Although community living turns out to be, in general, better than institutional care it often falls far short of the quality that could be achieved. The most critical element in what makes the difference between exemplary and mediocre performance is the extent to which staff enable the people they support to live a good life: it is the quality of staff support that matters most.

What makes this account of the work of Partners for Inclusion special is that it begins to articulate the detail of how a person-centred service operates to support people with complex needs. Here the principle that everyone should have a good life in the community, whatever their level of disability or the nature of their problems, and the determination to make this a reality, are followed through by robust practical arrangements which illustrate how to do it. Here principles and commitment are backed up with a detailed way of working built around each person to enable them to realise the opportunities presented by home and community.

The account presented here illustrates two overarching principles of organisation in Partners for Inclusion. First, everything is referenced to and judged against its impact on the quality of life of the people the organisation supports; this means not only the way staff work, but how human resources, housing, finance and monitoring are carried out and how the organisation is designed. Instead of expecting people to fit in to arrangements designed for administrative ease, the organisation does its best to design arrangements around the people it supports. Second, there is a high level of attention to the detail of how people want to be supported. Instead of leaving staff to work things out for themselves, risking inconsistency and ineffectiveness, Partners for Inclusion pays attention to thinking through what each person needs and to continually adapting and refining the support provided.

Good descriptions like this are an important way of helping everyone understand what has to be done to support people well in the community. This booklet will be of relevance to people using services or their advocates and their families in working out what kind of help they want. It will be useful to people providing services to work out how to do a good job. It will be useful to commissioners in local authorities trying to move towards personalised services, and it will be useful to regulators in thinking about what really makes a difference to the quality of people's lives.

Jim Mansell

Director and Professor of the Applied Psychology of Learning Disability
University of Kent

Alison's Story

When Alison makes eye contact, her whole face lights up and it's wonderful. But since she was a couple of years old she's kept this for special occasions. For everyday situations, although she understands a lot of what you are saying, she relies on simple body language to let you know what she thinks. She takes your hands or she walks away, she smiles or she cries. Occasionally she will use her own hand signs.

If she had been born in a different family or a different time, this would have severely restricted her opportunities and experiences. Instead, her family have respected who she is now without assuming that she will never change.

Alison made a lot of demands on family life - as Astra, her mother, points out, now she's living in her own flat "there are five people doing the job I was doing". But her family was resilient enough not to get stuck in a siege mentality. Instead, they worked around Alison's preferences and habits when they reasonably could but made it clear what wasn't acceptable. This quiet sense of 'I'm OK, you're OK' has helped Alison grow up as a secure young woman.

The same approach has worked well with the service system. The family has been clear about the help they needed and asked for it without feeling dependent or aggrieved - and have been able to maintain a respectful partnership with professionals over many years.

This is a short story about Alison and her family.

Ken Fentie was born in Aberdeenshire, where the Fentie name originates, and moved down to Glasgow as a teenager with his parents. In secondary school he met Astra, and they have been together ever since. Ken's career has been with the Clydesdale Bank and Astra worked as a secondary school teacher for the first few years of their marriage.

Their children Stephen and Alison are at the centre of their life, but now they have both flown the nest Ken and Astra are starting to reorganise their own lives, with different part-time jobs, some voluntary commitments and more time for themselves.

When Alison was born in December 1985 Stephen was four years old and the family was living in Kilmarnock. They later moved to Troon and this was Alison's home until she moved to her own place in 2007.

Alison's nursery teacher Margaret Mair was a great influence on her and still keeps in touch with the family every Christmas.

Alison's first school specialised in teaching children with a hearing impairment but for Ken and Astra what was more important initially was the 'Ready Brek' factor – a warm glow they felt as soon as they walked into the school. By the end of primary school, though, she was falling behind because of low expectations from the staff.

Family life for Alison included the usual trips to museums and shops and cafes, though films and the theatre didn't do anything for her. It was on a trip to Disneyworld in Florida that Alison showed her determination to be part of the crew. When her brother and cousins reached the top of the queue to be photographed with Pluto, she wriggled out of her buggy and confidently made her way past the rest of the line to join them.

Ken and Astra were always determined that Stephen would be Alison's brother more than her carer – so much so that when Alison started spending a few days away from home every few weeks to give her mum a break from the caring they made a point of not doing much special with Stephen.

Alison's key teacher at secondary school was Catherine Brown who knew how to bring out the best in her, and Alison flourished with her determined support. Communication between school and home improved, she tried out all sorts of new activities and her confidence grew.

As school-leaving time approached, Alison's future was uncertain. Full-time education in college wasn't a viable option but through the Independent Living Fund Alison was given 15 hours individual support each week. Ken and Astra chose to use this to employ Partners for Inclusion to support Alison after school and on Saturdays, and Alison's horizons expanded further.

The young women from Partners for Inclusion gave Alison a crash course in being 18. The house filled with music, she got some decent clothes ("there's no way she's going out in that!"), tried some new foods, met Bacardi breezers, got her nails painted and listened to endless chat about TV and fashion. She went on holiday without her parents, and for someone supposed not to enjoy loud music and crowded places had a pretty good time at the ice rink.

Meanwhile, Astra had one of those light bulb moments when she went on a course and met a mum whose daughter had moved into her own flat. Her first reaction was 'you're telling me Alison could move out of here and we'd be lumbered with Stephen!' but as time went on the idea made more and more sense.

While it was great having the support staff and they were very respectful of the house rules, it was hard to combine a staff workplace with a family home. Astra felt restricted when the staff were there, but when they left it felt like Alison was restricted, and 'left alone with the wrinklies'.

So with support from social work and housing, and a great deal of financial creativity from Partners for Inclusion, a package was put together which would allow Alison to have her own flat. Alison could have had direct payments but for Astra and Ken having Partners for Inclusion manage the money was a weight taken off their shoulders.

Stephen helped Alison choose a flat near the shore with its own wee garden, and Alison spent the first six months trailing every visitor in and out of every room. She does still go back to her parents' house from time to time, but when she's had enough she takes her support worker to the front door to make it clear that she's going home.

Astra started as an unofficial team leader, training the staff and describing what works for Alison. Over time, the team trained new members, with Astra as an occasional coach.

Now Astra and Ken cheerfully admit that Alison's moved on and the team know more about her current likes and dislikes than they do (as they say, just like Stephen's wife knows today's Stephen better than they do).

Alison now has a few friends of her own that they have never met, friends of her support workers, and is doing things she would never have done at home – from washing up and making soup to choosing what to wear and eating by herself.

Astra, Ken and Stephen can be Alison's family but not her carers - and they remain her advocates. Over time, they hope that the business of looking out for Alison can be shared by a group of people. This group can hold Partners for Inclusion - or any other service provider - to account and, as people who have known Alison for years, can also provide the 'long view'.

Summary

Personalised Support is a new way of supporting people with complex and challenging needs to live their own life, on their own terms, but as active citizens.

Personalised Support was developed in Scotland, in 1996, to provide support to people who were leaving institutions and moving into their own homes. It is a radical step forward from the standardised and inflexible support that is often provided by Community Care services. In fact these early champions of Personalised Support were also the same people who went onto develop ideas like Individual Budgets and Self-Directed Support.

Personalised Support demands 7 key elements:

- 1. Commitment to Citizenship** - Above all else the organisation has to commit itself to seeing the people they support as full citizens, people with rights, people with potential, people with full lives to be led and supported. Without this vision and these values no practical systems will work.
- 2. Individual Service Design** - Each individual is unique, and so, each support service must be unique. This means helping the person to design support that reflects their individuality, their relationships, their neighbourhood and their future plans. Each design is different, but each design supports the person to express their citizenship - their way.
- 3. Individualised Policies** - Systems and rules need to be worked out, developed and reviewed at the level of the individual. Universal rules for the organisation are kept to a minimum and only set a framework within which individual policies are agreed. This is the only way of ensuring that people can maximise outcomes and manage risk effectively.
- 4. Individualised Support** - High quality personalised support demands that people get support from the people who are right for them. This is much more about values, personality and interests than it is to do with formal qualifications, although Partners for Inclusion do work to the rules defined by the Scottish Social Services Council and meets their requirements. This requires a radical change in personnel policy.
- 5. Individual Funding** - It is impossible to provide flexible support to individuals if their money is used to fund blocks of services. Personalised Support requires organisations to use Individual Service Funds to manage and protect people's individual budgets and ensure that money is used flexibly for the best possible outcome.
- 6. Power with the Person** - And each arrangement must ultimately be authorised by the person or those who can stand by the person and help them make the best decisions

for themselves. For the organisation this means involving the individual, their family or other representatives in all the critical decisions that concern their life.

- 7. Creative Community** - All these systems only come to life when they are used by a real community of people - both inside and outside the organisation -who can think creatively. This demands real value-based leadership and the development of trust based upon real understanding of needs and problems.

This is not a pipe-dream. Personalised Support has been working successfully in Scotland for 15 years, but only a few organisations have really taken up the challenge to work in this new way. In fact, even while personalisation has started to become recognised as one of the most important themes in reforming public services there have been few efforts to really change how support is offered on the ground.

Too often disabled people, older people or people with mental health problems are being asked to manage direct payments or take on other onerous responsibilities that are simply not necessary. Personalised Support offers a powerful and practical model for transforming the role of organisations that provide care and support, giving people the flexibility and control they value, without unnecessary complexity.

This book describes the work of one highly effective organisation; but it also provides a template which could be used by many others - to bring about real change.

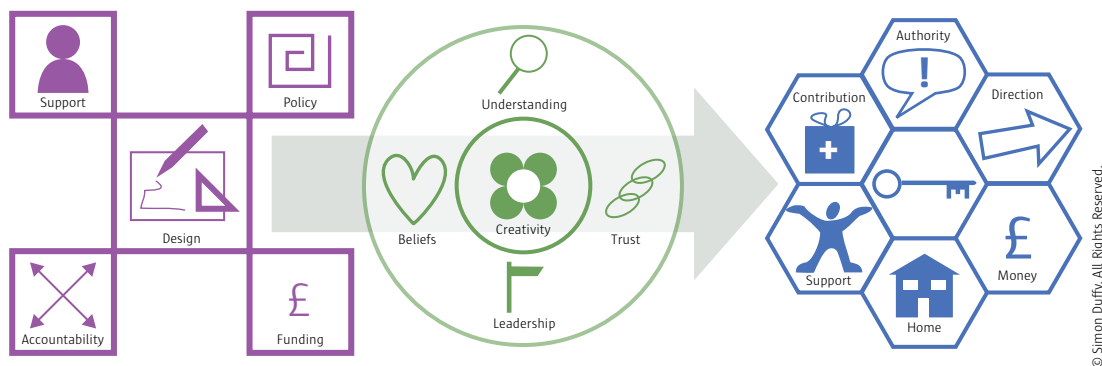


Figure 1 Personalised Support



7 key elements

1. Commitment to Citizenship

Personalised Support developed from the vision and values of those individuals, families and professionals who did not want to see people with complex and challenging needs offered limited, institutionalised solutions.

Over time we have discovered that when we give people the right kind of support:

- People do not need to be excluded or segregated
- Everyone can enjoy basic human rights
- Everyone has a positive contribution to make
- Everyone can be a full citizen

1.1 The start of Personalised Support

Partners for Inclusion provides Personalised Support to 45 people in South West Scotland. It has a strong reputation for its ability and effectiveness in working with people who are leaving institutionalised settings, such as hospitals and group homes, and those whose behaviour challenges existing services. Its expertise is in supporting people with highly complex needs to have a real life with real choices - their own home, job, friends and relationships.

Partners for Inclusion is not alone in working in this way. Scotland has developed a family of organisations who are working to this radical model of Personalised Support. The first of these organisations was Inclusion Glasgow, which was set up by Simon Duffy in 1996. In fact it was also here in Scotland that Simon first developed the concept of an individual budget - telling people what they are entitled to and supporting them to create their own personalised support with that budget. This idea has now become very influential in the UK, Australia and the USA, but it was first tested out in Scotland.

Instead of growing too large Inclusion Glasgow mentored and supported the development of Partners for Inclusion and its other sister organisation, C-Change for Inclusion. Partners for Inclusion started by working alongside two people who were leaving a long stay hospital in 2000 to return to Ayrshire, and became a separate organisation in 2004.

Partners for Inclusion is an organisation that succeeds in supporting people at significant risk of exclusion, to “live lives we dreamed of but had not thought possible”. It attracts labels like ‘creative’ and ‘inspired’.

But these labels do not help to explain its success. They may even give the misleading impression that its staff have unusual gifts and talents and that they can rise above the need for structure and compliance with legislation and regulation. The staff are, of course, wonderful but distinctly human - and the regulations in its areas of operation are no less rigorous than anywhere else in the UK.

Partners for Inclusion is an organisation designed for a very particular purpose. Its structure and culture would not suit a law firm or a train company. Partners for Inclusion was designed, like Inclusion Glasgow, to deliver Personalised Support. The organisational design is highly suited to provide high quality support and in a way which gives people power, control and flexibility, but which doesn't require people to manage direct payments or employ their own staff team. For the person it is personalisation made simple; but of course, behind the scenes these benefits can only be achieved by hard work and careful planning - at every level.

Of course Personalised Support did not develop in a vacuum. It was developed as a response to older models of support and their limitations. So it may be helpful to begin our exploration of Personalised Support by reflecting on the longer history of its development.

1.2 Earlier models

In the UK, USA and many European countries, the long-stay institution was the dominant social response to people with disabilities for all but the last few years of the 20th century. These institutions were often founded with idealism, but they became corrupted by eugenics, and finally they were overcome with inertia. Even today, as the institutions have been closed, these same institutions still shape our imagination and limit our appreciation of disability and difference.

Perhaps unsurprisingly the early models that were developed to support people outside the institution were also very limited and somewhat institutional in character. They also tended to focus their efforts on those who were deemed 'ready' for life in the community. Early models rarely focused on supporting those with the most complex or challenging needs.

Model 1 was the supported accommodation hostel. It was a dramatic improvement on the institutions it replaced. People had their own room, they lived in towns or cities rather than the middle of the countryside, they lived in a place that looked like ordinary housing, rather than a gothic castle or a prisoner of war camp, and they didn't 'get the needle' when someone decided they were out of line. But it **was** clunky. People had no security of tenure, no say in who came to live with them, often no choice of food or meal times. The system was staff-centred and built around staff rotas so, for example, bedtime was when the night shift started. The culture tended to be semi-authoritarian, parent-child, with sex and alcohol taboo.

Model 2 was the group home. This was a smaller place, less obtrusive, with more flexibility around food and activities. However it was still very much the organisation's place, with staffing determined by the needs of the group and the rules made by the organisation. This was true even when the size of group was reduced to 3 or 4 people.

Model 3 was core and cluster, with people having individual flats or houses but connected to the group home by an organisational umbilical cord. This could mean greater autonomy and a better use of staff time, but the flats or houses still belonged to the organisation providing support and there was a 'competence assumption' still at work: the less support you needed, the fewer strangers you had to share your home with. Staffing levels were still determined by the perceived average competence of the group.

Over time, custom and practice evolved and it became common for people, as a group, to have some say in the choice of staff. It became possible to discuss sex and alcohol, and people acquired more secure tenancies from the organisation, meaning they could not be simply moved if they became difficult for the organisation to support. But the organisation still tended

to create a glass wall between people and the community in which they lived. At best the culture was benevolent but paternalistic; at worst it was institutional and damaging.

Moreover the process of de-institutionalisation was painful and protracted, with budgets, professional status and power clinging to the rump of the hospital system. For a long time many people still assumed that there would still be a population of people whose needs were too complex to be met in the community.

1.3 Supported Living

In the mid-1990's the Supported Living movement developed in order to challenge these limited models of support provision, led by individuals like Peter Kinsella, Supported Living arose from dissatisfaction with the limitations of group homes, even 'group homes' for one person.

Supported Living called for a shift of perspective, from the service being at the centre, to the person being at the centre: from "doing to" to "doing with"; from "service-land" to the real world; from seeing the community as a physical location to seeing the community as a social context.

The principles of Supported Living were:

- **Real housing rights** - It's your home and you can't be moved out to suit the convenience of the organisation.
- **Choice of support** - It's your support and you can choose who supports, you when and how.
- **Person-centred planning** - It's your life and plans need to be based upon your perspective, interests and relationships.
- **Community life** - It's your community and support should enable you to be a full member of your community.
- **Inclusion for all** - Nobody should be excluded from these basic entitlements, no matter how complex their needs.

Supported Living marked an important step forward in thinking about support for people with complex needs. It is a human-rights perspective, which starts with the assumption that people have the same rights as everyone else. It demands a radical change in thinking and practice. But it has proved very difficult to achieve.

There has been some real progress; changes in funding systems and regulation have led to an increased numbers of people leaving residential care and moving into their own homes. Many organisations have tried to help people do their own person-centred plans, moving away from institutionally driven care plans. Some people have managed to live better and more interesting lives.

But even where organisations have wanted to make the change towards providing more appropriate support they have found that they have faced many challenges:

- **Model-first designs** - Organisations are used to thinking in terms of standard models of support. The model comes first, then people need to fit within that model. New

ways of working were difficult to adopt, especially when funders are nervous of change.

- **Generic staffing** - Organisations primarily employ staff and then assign them to work with different people. Giving people choice over their staff often runs contrary to established personnel systems.
- **Universal policies & procedures** - Organisations put in place policies and procedures which are not sensitive to differences in need or context. Often sensible changes are impossible because of policies that are applied too simplistically.
- **Block funding** - Many services are funded in blocks and the person cannot shape or control how their funding is used. Even when individual funding is used the person would often not be given any discretion in how it was used - it was treated as the organisation's money.
- **Hierarchical accountability** - Bureaucratic and hierarchical systems of control are highly valued by the wider system. Organisations are expected to be accountable to statutory funders, but not to individuals or their families.

Perhaps more importantly than any of these factors was the fact that Supported Living, and the focus on achieving real citizenship, demanded a complete change in culture and belief. Institutional thinking and practices are in fact rooted in widespread negative assumptions about people with complex needs:

- People with complex needs or 'challenging behaviour' don't have gifts that they can bring to the wider community.
- The family and friends of people with complex needs are likely to be bad or exploitative.
- Communities are hostile to people with complex needs and will never welcome them.
- People with complex needs and their families can't be trusted to exercise choice and control.

These negative beliefs are highly prevalent in society as a whole, even if they are not usually expressed as strongly as this. But it is very hard to build the radically new ways of working demanded by the principles of Supported Living into your organisation when these beliefs are active.

1.4 Personalisation

Today we are entering a new phase in thinking and practice, which has become known as Personalisation. Personalisation is an attempt to radically rethink the principles upon which the whole welfare state has been designed, and it starts from beliefs and values which are the complete opposite of those which still corrode society today:

- Every individual is unique, and has their own unique set of gifts and capacities which we should welcome.
- Love, family and friends are vital to our existence and we must organise things so we can build and sustain these vital relationships.

- Communities will become better and more vital when they welcome and include the gifts of all their members.
- Everyone has both the right and the responsibility to control and shape their own life, with help from those they value.

One way to think of this new approach is to recognise that each of us builds a life and meaning for ourselves using our real wealth (Duffy, 2010b). This is not just about money, its about combining and growing these four capabilities:

- **Gifts** - our skills, strengths and needs
- **Relationships** - our family, friends and peers
- **Community** - all our community offers us
- **Resources** - our means to set our own path and achieve our goals

Furthermore, at the heart of real wealth must be the personal resilience or spirit which enables us to see and use all that we can make use of - in their various forms.

In Scotland in 1996 a group of professionals and families gathered together to try and do something different. They were frustrated by the slow pace of change and wanted to see real progress. Inspired by the ideals of citizenship, inclusion and a commitment to human rights they wanted to design organisations that would properly respect and support people with complex and challenging needs.

For this group of leaders the ideal of helping people achieve real citizenship had become increasingly important and they were convinced that they could develop approaches which

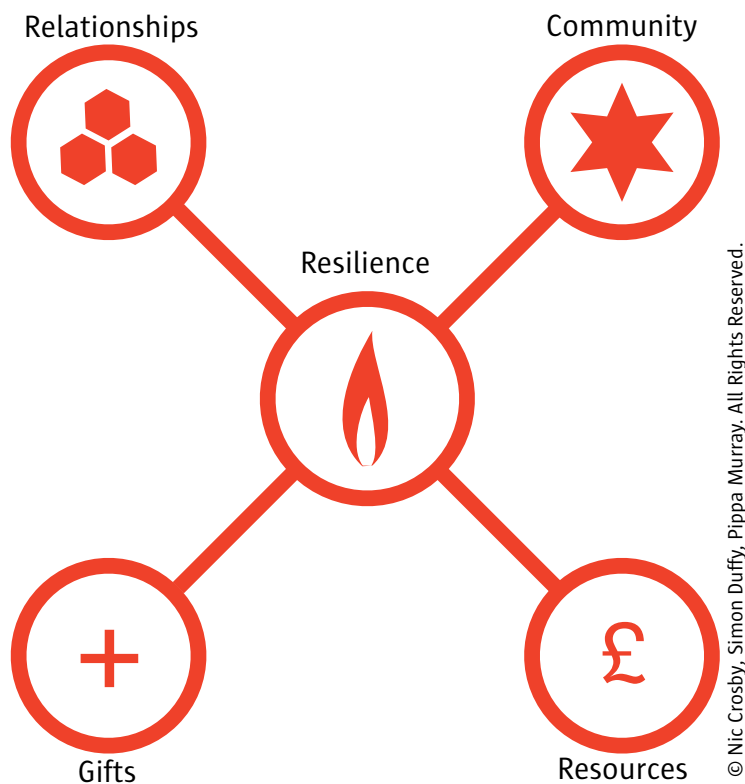


Figure 2 Real Wealth

made a real difference and could genuinely shift power and control to disabled people - even people with the most complex needs.

This community included Simon Duffy and Frances Brown of Inclusion Glasgow, John Dalrymple and Gina Hagan of Support for Ordinary Living, Sam Smith of C-Change and, Doreen Kelly, founder of Partners for Inclusion and many more people and organisations, including Altrum, Diversity Matters and Scottish Human Services. This book focuses on Partners for Inclusion and the work of Doreen Kelly in particular, but it is rooted in a whole community of people who were and are committed to developing Personalised Support.

They realised that they would have to move beyond an idealistic commitment to citizenship. Instead they had to develop the real systems that could offer flexible and personalised support. They also found that, in order to bring these principles and systems to life took real leadership and required the development of a genuinely creative community (see Figure 3).

Importantly these leaders focused their efforts particularly on those people whom others had struggled to support in the community. Instead of treating Personalised Support as only being relevant for those who were easiest to support they wanted to demonstrate that citizenship could be real for everyone - however challenging or complex their needs.

This meant focusing on key groups:

- People with challenging behaviour who were living in institutional settings
- People experiencing severe mental health problems
- People with complex and multiple impairments
- People in danger of being sent to live away from their home communities in to special units, homes or residential colleges

This does not mean Personalised Support is just for people with these levels of need. But learning how to support people with these needs is invaluable for understanding how Personalised Support can really be achieved for everyone.

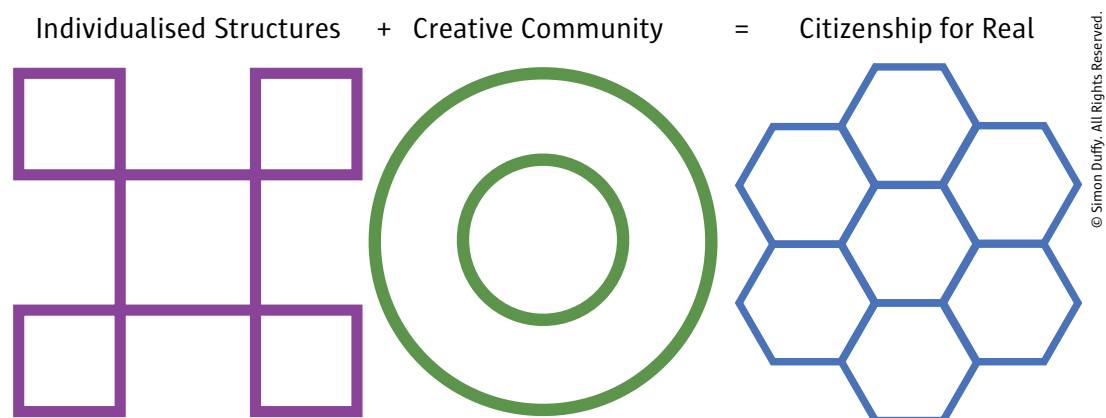


Figure 3 Making Citizenship Real

2. Individual Service Design

Personalised Support requires that every service is designed, from scratch, with only that person in mind, and modified in the light of experience and as things change. Individual Service Design is rooted in the organisation's commitment to help everyone achieve citizenship for themselves.

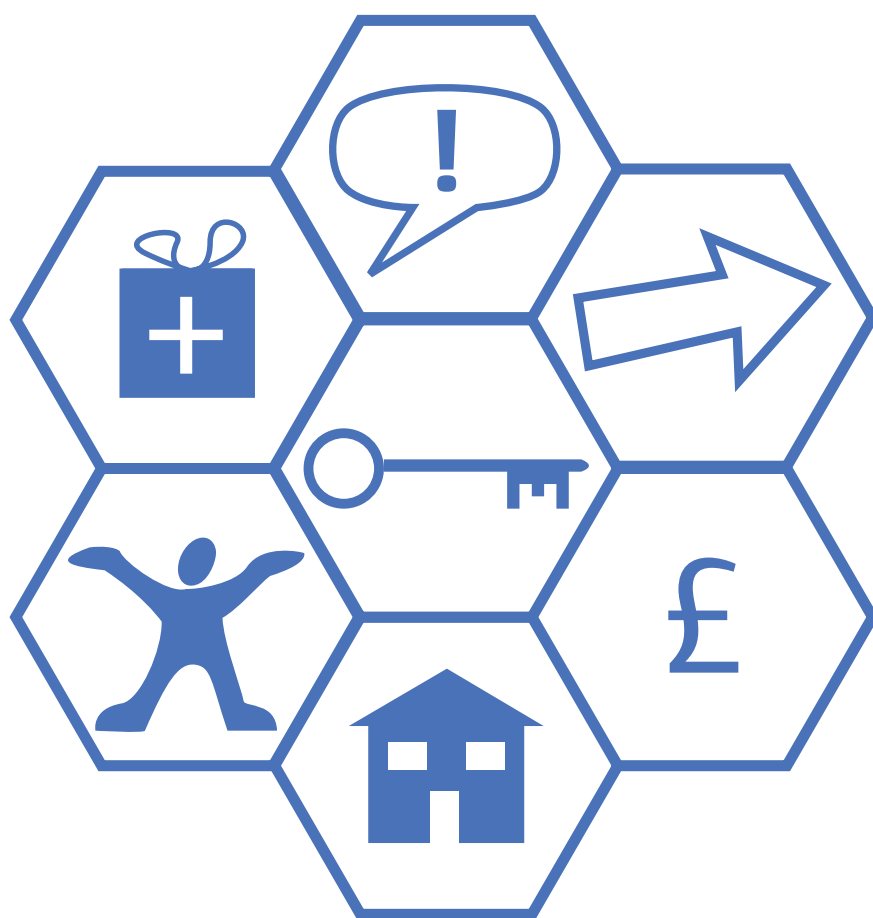
2.1 The elements of Individual Service Design

Individual Service Design is the practical consequence of a commitment to citizenship. Each individual should be enabled to organise their life, and any necessary support, in a way that suits them as an individual and supports them to achieve active citizenship.

The key elements of the individual service design are:

1. **Authority** - Every person is entitled to make their own decisions, but some people, especially those with complex needs or communication difficulties, need some support or even representation over key decisions.
2. **Direction** - Each of us must be able to shape the course of our life to fit our particular values, aspirations or preferences. For people with complex needs this often means finding effective and engaging forms of planning to help identify opportunities and take action.
3. **Money** - We need money in order to take control over important aspects of our life and to exercise a reasonable degree of independence from others. It is important that people can maximise their income and take control of that income.
4. **Home** - People need a place of their own, where they can be safe and secure. It is important that people only live with people that they really want to live with and that they can exercise as much control as possible over who comes into their own home.
5. **Support** - We all need support, but we need support that fits our personality, our interests, our community and our values. It is important that the people who support people with complex needs are the right people for them.
6. **Contribution** - We all have something to give back to others in love, work, voluntary action, friendship and all the other ways that we can express our own unique gifts. It is vital to our well-being and our citizenship that everyone gets the chance to give of themselves.

This framework, the Keys to Citizenship framework (Duffy, 2002) is what shapes the Individual Service Design. In respect of each key Partners for Inclusion will work with the individual to help them get the right support arrangement, to suit their life and their community.



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Figure 4 Citizenship as the Key to Individual Service Design

2.2 The result of individual design

If we then look at the kinds of support services offered by Partners for Inclusion we can see that individually designed services can lead to much greater levels of creativity and much more appropriate support.

Patrick has very challenging behaviour, autism, a visual impairment and a significant cognitive disability. When Patrick was leaving hospital his support needed to be carefully designed to keep him safe with a range of innovative elements:

- His home, ideal for his needs, in an area close to his sister, was purchased for him by a trust, using an imaginative funding system.
- His support team included two live in flatmates who were able to provide extra support when needed and a feeling of normality in his home.
- Patrick's family oversee the service and often stay over in his home.

Sometimes, when Mary-Jane's mental health was poor she would set fire to her own home. She needed very specific housing, which would not put other people at risk but which also suited her own needs and preferences. But although she needed a very specific home she did not want to own that home (partly because she was more likely to damage something that she felt was

her property when she was feeling bad about herself). So Partners for Inclusion, after finding a suitable home worked with a housing association who purchased the home and then rented it back to Mary-Jane.

Jonathan wanted his independence from hospital but in the past he had stayed up at night and played loud music and this led to lots of neighbour complaints which eventually led to him being admitted to hospital. He was also insistent that he did not want anyone sleeping over in his house and did not accept that this had been a problem in the past. So Partners for Inclusion worked with the local authority and organised renting a second flat in the block where Jonathan was to live. They then organised for someone to live in that flat as a 'supportive neighbour' able to help Jonathan connect to his neighbours and intervene if problems started to arise. In time, with the success of the arrangement, the tenancy was eventually given to the supportive neighbour directly.

Perhaps even more important than these examples of creativity is the creativity that goes into developing detailed and thoughtful Working Policies (we will explore this in section 3).

“No problem is too big, no needs too complex, for an individualised service - in fact it is the in-built flexibility of the individual service that allows change as necessary.”

.....
Doreen Kelly, Partners for Inclusion

2.3 Planning for Individual Service Design

When Partners for Inclusion is invited to support a person, because everyone is different it knows that the answers to these questions will be different. Its approach to finding out the answers then leads to unique service propositions - ranging from how and by whom the person will be supported to finding a suitable home.

The planning processes for devising the Individual Service Design and Working Policy is based on the values that underlie person-centred planning and often specific tools like Essential Lifestyle Plans, Paths, Maps and others provide to be useful ways of gathering information.

The key points are:

- There are no shortcuts, and the process cannot be substituted by just reading what others have written.
- This work has to be done before the organisation starts to support someone with complex needs. Partners for Inclusion's experience is that where they had deferred this first step, they were far more likely to fail the person in their effort to respond to the needs of others for a quick solution.
- The organisation needs to have strong facilitators within its staff to do this well in partnership with the important people in the person's life.
- The process involved is as important as the information that emerges. It is the process that deepens the support provider's understanding about the debates and emotions that these important people bring to the person's life. The process will reflect and affect how the relationships and support need to be developed thereafter.

- The Individual Service Design needs to be reviewed at least once a year, as part of an individual planning day, and that other structures - meeting time, support and supervision - are essential for keeping its momentum.

2.4 Organising a planning day

In fact, with the right preparation, much of the individual design work can be completed in a planning day. To begin with, one of the organisation's team who is a good facilitator needs to meet and spend some time getting to know the person and their family or significant people in their life.

Together with the person and their family they need to agree who should be at the planning day. Where people have been institutionalised or have limited communication skills, it is essential to make use of the full range of people who know and care about the person. This could include family members, neighbours, care managers, advocates, support workers and anyone else known to have a strong relationship with the person.

It is also important to make sure the person will be comfortable at the meeting. Decide, with the person or their family, where the planning day should be held. It is vital that the person is present. However they may not want to stay in the room all the time.

The first half of the planning day is taken up with hearing the person's story and unpicking this. It is important to capture this in great detail: when they were born, where they lived, what schools they went to, what people they had in their life, what they enjoyed, what support they got and how they responded to this and so on. Start with wide questions and drill deeper and deeper.

The information you gather here is the evidence for how the person needs to be and wants to be supported, and how they do not. Partners for Inclusion have found this to be fundamental to developing the right service design.

Some person-centred planning tools may help to find out, for example:

- **Essential Lifestyle Planning** (Smull & Harrison, 1992) - helps you understand preferences and needs by a detailed examination of behaviour
- **MAPS** (Falvey et al. 1997) - helps you understand the whole of someone's life and get a sense of direction from the past
- **PATH** (Pearpoint et al. 1993) - helps people articulate hopes for the future and get practical next steps for action
- **Personal Futures Planning** (Mount, 1987) - helps people examine all their resources, community, relationships and build upon these
- **Individual Service Design** (Duffy, 2010a) - helps people to develop appropriate support using the six keys to citizenship

Any of these questions and approaches can be useful, so it is a matter of finding an intelligent and balanced approach to exploring what will be the right set of questions in the light of the priorities and understanding of those involved.

Only when there is a sufficient level of shared understanding about the person, their needs and their desires, is it possible to move on to the actual process of developing a service design. However it is often the case that, by the second half of the day people are ready to look at some of the key questions:

- 1. Authority** - How will the person remain in control of their life? What support is required with communication? Is any representation required?
- 2. Direction** - What are the person's desires and hopes for the future? How can they be best supported to plan and achieve their goals?
- 3. Money** - How much money is available?
- 4. Home** - What kind of home do they want or need? Where does it make sense for them to live? Would they like to share their home with anyone? Would any equipment, adaptation or IT be useful?
- 5. Support** - What kind of support is required? How often and when is help needed? What kind of person should provide help?
- 6. Contribution** - How will the person live? What relationships need to be maintained or strengthened? What interests or jobs do they want to pursue?

By understanding the answers to these questions and by thinking through what can be achieved for real, the facilitator helps the whole group, and the person in particular, think through their options and balance different considerations.

In the light of this it is often useful to end by looking at the big themes from the day, and developing aims and objectives for the service so that the service provider knows what their job is – what is expected of them and what they should be trying to achieve. After the meeting a detailed Individual Service Design can then be written up and examined in more detail after the day.

On the following two pages we have included many of the critical questions that have proved useful when developing Individual Service Designs.

Useful questions for service design

Who am I?

- ☐ What do people say about the person?
- ☐ What does she like and dislike?
- ☐ What are her hobbies or interests?
- ☐ What are her gifts and talents?
- ☐ What else is important to, for and about the person?
- ☐ What are the person's hopes and dreams? (Be as imaginative as possible.)

What would make an ideal home for this person?

- ☐ Town/city/village?
- ☐ What would it be like? (Based on who the person is and their likes and dislikes)?
- ☐ What sort of community would it be in?
- ☐ What would the immediate neighbourhood be like?
- ☐ What would be in the street or not in the street?
- ☐ Would the person have a garden? What would it be like?
- ☐ Is it a flat/detached/semi-detached house?
- ☐ How many rooms need to be in the house? What rooms?
- ☐ What about the furniture/fixtures/fittings.

What sort of people are needed?

- ☐ Who worked well in the past and who didn't?
- ☐ What kind of people are needed - what would be their likes and dislikes; Will they be quiet or noisy, busy lively people or calm, peaceful people?
- ☐ What knowledge, skills and experience would they have?
- ☐ What contacts would they have?
- ☐ What leadership skills are needed?
- ☐ What hobbies or interests should they have?
- ☐ Does the person prefer to be supported by a man or a woman, or either?
- ☐ Age range?

How will the staff team need to work together?

- ☐ What would the team need to consider?
- ☐ How would the team do its rotas?
- ☐ Where would leadership sit?
- ☐ What roles do team members need to play i.e. responsible, friendly, rule keeper, parental?

What should support look like?

- ☐ What does the person do now with his/her time (routines)?
- ☐ What should we keep doing?
- ☐ What should stop happening?
- ☐ What should they and we start doing?

What does this mean in terms of?

- ☐ What hours of paid support does the person need?
- ☐ What will happen in those hours?
- ☐ What support could help the person to become more independent or to have more natural support?
- ☐ What do we need to do to keep the person safe and to keep other people safe?
- ☐ (Risk mapping and enabling is a natural by-product of this process.)

What is the big picture?

- ☐ What are the aims and objectives of this service?
- ☐ What are the big themes from the day?
- ☐ Why are we involved in this person's life?
- ☐ What does the person/their family expect of us?
- ☐ And how can we achieve this?

3. Individualised Policies

In order to provide Personalised Support it is not good enough to work to standardised systems. Each person needs policies that make sense for them. This means developing an Individual Working Policy. This is a policy which is not only individual to the person, it is also a policy which is actively reviewed and amended in the light of experience - a Working Policy.

3.1 Attention to detail

The working policy is the 'how' - how, in great detail, does the person like to be and need to be supported. The information is drawn from past experiences, information gathered at the planning day, and from other discussions and sources. This is translated into the fine detail of how the person is to be supported in all aspects of their life, what Partners for Inclusion, and others, will do to support them and how they will respond when the person is finding life difficult. There should be no gaps about important aspects of the person's life - when something goes wrong, it is often because there was a gap and this highlights the aspect of the person's life where more thought and detail is needed.

Everyone involved in the person's support has to know about, sign up to, and follow the Working Policy. However the person themselves and their family members may choose not to be involved in developing the detail. Some families opt out because the Working Policy is often about responding to difficulties and this can be too painful to discuss. But others choose to be involved and this is also true for people who get support.

Understanding and learning how to put the Working Policy into practice is a core part of the induction and continued training of the person's staff team. A systematic review at least every year means that new learning and changes can be incorporated. It is also reviewed after any incident - as this may have revealed a gap or some element of the policy that had not been emphasised strongly enough.

An example of the kind of detailed work required in order to develop a Working Policy is provided by John. John does not want to be admitted to hospital, but this is where he can end up if a self-destructive episode is allowed to escalate. John knows and fully accepts that for him to stay out of hospital, other people need to make decisions for him when he feels bad and when he asks, verbally or by his behaviour, to be admitted.

All members of the multi-agency team agreed that John wants to, and is able to, live outside a hospital environment. But in order to do this he needs clear boundaries, tight communication between those involved in his life and a consistent approach from members of his team. Together with John the team developed a Working Policy that sets out clearly how to manage when things start to go wrong. A large section of this Working Policy is set out below (p. 26).

The Working Policy gives his team clarity in how to respond in difficult situations, which will allow them to feel supported by the organisation, Social Work and health care professionals.

It also gives John the clear boundaries he needs and the security of knowing these will not be changed by anything he does.

3.2 Managing risk together

Even when people are living full lives and directing their own support, they may also need support with decision-making, learning to take risks and understanding consequences. Partners for Inclusion has to comply with the same legislation, regulations and contract terms as any other support provider - and has an equally important requirement not to compromise the rights of the person they support in the process.

So while Partners for Inclusion staff must follow general health and safety policies, each person they support also has individual activity and environmental safety assessments. For instance the Working Policy may need to be expanded if, for example, the person is going away on holiday. Both the Individual Service Design and the Working Policy provide the information that leads to individualised, and legitimate, employment decisions.

The approach to the Individual Service Design and Working Policy involves all the main partners - commissioners, care managers, allied health professionals - in thinking about risks and how to enable the person to take them. The roles and responsibilities of external health and social care professionals in this are, where possible, agreed and incorporated into the Working Policy. As a minimum, their role and care plan for the person is appended to the Working Policy so that support staff and the person can be clear about what can be expected.

Most of the people Partners for Inclusion works with have suffered years of exclusion, sometimes years of neglect or abuse within institutional settings. Individual Service Designs and Working Policies are the foundation for truly individualised working, but they are not a quick fix. Partners for Inclusion needs on-going support from other professionals; and the working policy may set out additional supports that the person will need during periods of transition, and while relationships are developing between the person and their team.

John gave permission for copies of his Working Policy to be given to professionals who are part of his life, for them to follow in the event of a difficult situation. So, for example, the local Accident & Emergency Department holds a copy of the Working Policy to refer to when he presents himself for treatment. All agencies are asked to consult first with Partners for Inclusion before making any decision to admit John to hospital.

For John, and for Partners for Inclusion, this Working Policy achieves two objectives: it protects John from being denied the right to make his own mistakes and deal with the consequences; and it is essential for ensuring that Partners for Inclusion can satisfy regulators that it is supporting John in a very careful and considered way, within the legislation. Risk is being managed sensitively and in partnership.

John's Working Policy (an extract)

Introduction

John wishes it to be known that he does not really want to be admitted to hospital even though he may be saying he does, literally or with his behaviour.

John's difficult times will manifest in: being very angry and/or emotionally distressed; self-harming - cutting and alleged overdose; threatening to and setting small fires in his home.

Communication between key people must be tight and effective to minimise the possibility of John playing one agency off against another.

John will test our ability to maintain a consistent approach by continually challenging us to reassess his ability to live outside hospital. He will do this by increasing the frequency/ severity of his behaviour.

John, his care manager (Social Work), community nurse, his psychologist, consultant psychiatrist, hospital staff and his Partners for Inclusion support staff have been fully involved in the design of this

Working Policy via the Care Programme Approach.

These people believe the risks associated with John's behaviour can be managed if we do not over-react to the challenges he presents us with when he is feeling bad.

Over recent years John has shown us it is possible to support him in a way that greatly reduces his need to self-harm and increases his motivation to live in his own home.

This document is written to help the Partners For Inclusion team to support John through difficult times by helping them recognise such times, and respond in a way that is useful.

It is important to remember John also has good times when he is good company, witty, keen to be active and good fun. Often the difficult times come around as a result of his belief that he is not worthy of a nice life. At these times he is unhappy with himself rather than with others, but this is not always clear.

In Difficult Times

How John shows he's having a bad time:

- He'll argue a lot and be confrontational about minor issues.
- He gets angry.
- He cries.
- He cuts himself.
- He looks and is grumpy.
- He is short tempered.
- He buys lots of over the counter medicines, especially aspirin.
- He takes too many aspirin.
- He says he feels frightened.
- He says he has nightmares/ isn't sleeping well.
- He wakens early.

- He needs to talk about the past.
 - He sets small fires.
 - He says he's stopped taking his prescribed medication.
 - He takes too much of his prescribed medication.
 - He threatens to 'walk into the sea'.
 - He goes to the Accident & Emergency departments demanding to be admitted.
 - He demands medical/psychiatric interventions.
 - He'll say he doesn't want to live in his house.
 - He doesn't want to do things he usually enjoys.
- He'll rearrange his furniture lots.
 - He'll miss appointments/make excessive appointments with GP.
 - He takes more risks with his diabetes e.g. skips meals or eats large amounts, especially sweets and cakes.
 - He goes back to bed in the morning or goes to bed early at night (8pm'ish).
 - He'll want to be alone but not want you to leave completely.
 - He threatens to harm himself.
 - He gets emotionally distressed.
 - He drinks more alcohol than he's agreed is reasonable for him (2 glasses wine).

How to support John effectively - with his medication

When looking at issues around medication, John feels that although he currently uses the medibox system effectively, he would need assistance from someone to do a daily check of his medication. However we have learned that if we monitor too closely if/when he takes his medication this leads to increases in conflict and self-harm. He has also shown us that he finds the responsibility of having more than a day's supply of medication at a time too stressful. John having access to 'as required' medication at home has also proved to be counter productive.

1. John will be accompanied to collect his medication on a weekly basis and we will give him a day's supply of this at a time.
2. The day's supply should be left on his kitchen worktop for him. We do not stand with him as he takes his medication. At the end of the day he will either hand back to you the empty (or otherwise) box or leave it on the kitchen worktop.
3. Regardless of whether or not the strip is empty, do not comment or be drawn into discussing why he has/ hasn't taken his tablets.
4. Whether he takes it or not, this will be recorded in the team's daily diary, noting which tablets he does not take e.g. Lunch, Dinner.
5. Any discussions he wants to have about medication and its efficacy will be directed to his community nurse in the first instance and then his psychiatrist.
6. No 'as required' medication will be prescribed.
7. John will not be given a repeat prescription directly, this will be held at the pharmacy. John should not be given ad hoc prescriptions (e.g. antibiotics). John's community nurse will ask the surgery to 'flag' John's notes to alert the General Practitioner.
8. Any unused medication will be returned to the pharmacy by staff. We will ask the pharmacist to sign a check sheet for us; this will not be done in the time spent directly supporting John.

4. Individualised Support

Although an Individual Service Design can include many elements it is always the case that getting the staff, the people, right will make the most difference to the success of any arrangement. This makes individualised support an essential part of Personalised Support, because if it is impossible to put in place the right people, offering the right support, then problems are bound to arise.

4.1 Staff Structure

The Individual Service Design will provide a lot of information that will shape the support service:

- How many paid people are needed?
- What kind of things do people need help with?
- What kind of person would be best?
- What kind of training might be needed?
- Would live-in support be helpful?

As an organisation, Partners for Inclusion's structure and staff roles come primarily from thinking about what one person needs to get good support, and working from there. Usually this means that each person has their own staff team. This does not mean that the organisation employs people and then appoints them to work with the individual - instead each person has his or her own staff team, selected just for them.

Staff are picked for, with and, wherever possible, by that person and their representative. Recruitment information and processes are tailored to that person. Staff members are mostly recruited only to work with one person. If someone is also recruited for another person's team, that role will be different, and may involve different skills, responsibilities and a higher or lower rate of pay. The worker would then have 2 contracts of employment.

Most, but not all, also have a Team Leader who is part of their support team with additional responsibilities for co-ordinating and supporting staff. This team also needs support, guidance and coaching - hence there is also an important role for a Service Leader who offers support and coaching for between 6 and 8 staff teams. The Service Leader also manages and maintains the relationships and contractual requirements associated with each person's support.

Finally, Service Leaders need a couple of things to do their job. They need administration, recruitment, staff development and financial services, which are provided by Partners for Inclusion's central service staff. They also need organisational leadership and governance. The small senior leadership team is expected to nurture organisational values, culture and learning, hold the roof up over people's heads at difficult times, represent and account for the organisation in the wider world, maintain organisational memory and provide a space and framework for reflection and judgement.

4.2 Staff Recruitment

The individuals or their families decide which people they want to work with them, with the advice of their Service Leader who facilitates the staff recruitment process. We cover some of the approaches that support this in the following text.

During the planning and service design processes, time is invested in finding out what sort of person is needed to work successfully with the person. “Usually someone will remember one person that worked well with or really understands the person, so we’ll find out more about that person’s qualities, but we’ll also say “so where is she now, and does she want a job?”

Every job description and person specification is unique - as defined by the Service Design and Working Policy. A statement of the core duties of a support worker is supplemented with a statement of duties related to staff working with that individual person; and there may be a further ‘additional duties’ statement applying to the particular post.

The employment contract names the person who the post-holder will be supporting and specifies the person’s home as the place, or base, of work.

Staff are recruited for qualities, not qualifications, to match the needs, personality and interests of the person they support and the life they want to lead. There is, of course, emphasis placed on ensuring these staff get the appropriate qualifications and meet the National Standards. Partners for Inclusion believes that the first step is to get the right people and then, if necessary, support them to achieve required qualifications.

The application form is simple and focuses on finding out about the interests, gifts and qualities a person can bring to someone’s life. It asks for information that helps in matching staff with a person whom Partners for Inclusion supports. For example: How would your friends describe you? What resources do you have to bring to the person you may support e.g. knowledge of places to go and things to do, useful contacts?

Good staff do not necessarily perform well in a formal interview setting, and this is not usually the person’s preferred way of getting to know a prospective support worker. So alternative ways of interviewing and appointing staff are also considered as part of the Individual Service Design, for example, sharing an activity with the person, going for a coffee with them in a local café. If the person does not speak, the other ways they communicate choice are recorded in the Working Policy and used in the recruitment process.

When recruiting for staff, the Working Policy will also often shape the characteristics that will be important for staff. For example, John who’s behaviour becomes more distressed and extreme if he sees someone panic therefore needs staff who are capable of staying calm and know how not to overreact.

4.3 The employment contract

Partners for Inclusion is the legal employer of all the staff, offering a contract of employment that specifies that the place of work for the person is the home of a named individual.

Partners for Inclusion prefers that staff only work with one person, but if a good match is achieved it will offer two concurrent employment contracts (two is the maximum). This means that a staff member may be, for example, a part-time Team Leader for one person, and a part-time Support Worker for another.

Partners for Inclusion has developed contractual terms and conditions to support the appointment of staff in a way which makes most sense for the person and their support plan.

There are 3 types of employment contract in use:

- Contract hours: for staff employed to work for a fixed number of hours - full or part time.
- Variable hours: which does not guarantee the hours for the staff member but will set a minimum amount.
- Ad-hoc hours: staff recruited to work with the person from time to time, but where there is no guaranteed or minimum hours of work.

4.4 Terms and conditions

Partners for Inclusion tries to tailor the contractual arrangement for the staff member so that it maximises their ability to employ, and keep, the right person for the job as well as making the best use of fixed funds. This means that salary, annual holiday entitlement, pension contribution levels, and hours worked may be varied on an individual basis.

Effectively each person supported has their own micro-business, and is supported to make this work financially. Pay rates can be set within the team and may vary across teams, because no two people are the same and the best way of spending the budget will be unique to that person.

At the same time, in practice there is not a huge variation. Partners for Inclusion is bound by the same employment and equal opportunities legislation as any other employer, so its decisions cannot be arbitrary. There is central guidance on appropriate salaries and the organisation does have to bear in mind comparability of salaries for equivalent work.

Part of the 'back office' or central support is to protect people and the organisation from making decisions that might not be legal or making them in a way that could not be explained and justified. Therefore in helping people to choose staff who can offer support tailored to very specific and personal needs, the detailed support planning and working policies are essential. These provide the evidence for selection on gender or age grounds in particular circumstances; and provide the explanation for decisions made on remuneration and other employment terms.

John's support team provides a good example of the kind of flexibility inherent to Personalised Support. John spent most of his life in hospital. When stressed his behaviour can put himself and the community at risk. Partners for Inclusion supports John with an average 60 hours support a week. His Individual Service Fund is around £62,000 per annum.

However the level of support that John needs is not consistent from week to week – it needs to be arranged flexibly to respond to how John is feeling so that, for example, John can be supported to take regular breaks away to reduce his stress. The team works out a staffing arrangement to achieve a balance of certainty, consistency and flexibility, within the budget.

This is achieved by employing staff on different contracts so that he has:

- A team leader contracted to work 35 hours each week.
- A support worker contracted to work 10 hours each week.
- A support worker contracted to work 15 hours each week.
- A support worker on a variable hours contract, with guaranteed payment for 20 hours a month.
- An ad-hoc Support Worker to cover holidays, sickness etc.

The Individual Service Design details particular skills and qualities needed for the support workers to support John in managing his stress levels, and to respond when he is distressed. The budgeting process and staff retention strategy worked out by the team with John and his family, means that the terms and conditions for staff include an above average annual leave entitlement, and John's budget also includes a sum for his own counsellor and staff time for a regular meeting with a team counsellor.

If John did not receive this kind of flexible Personalised Support it is highly likely that he would be living in a specialist medium secure unit, which typically costs between £120,000 and £150,000.

5. Individual Funding

Personalised Support is impossible without individual funding. For if you cannot take your funding, transfer it to another organisation, or use it to reshape your support you are effectively tied into arrangements that suit other people - but will only partially suit you. The systems developed in Scotland to give the necessary flexibility to support are highly innovative and were critical to the later development of individual budgets.

5.1 Individual Service Funds

Each of the 45 people supported has a uniquely tailored, costed and funded service. Each service operates as a cost centre with the income for that person's service being set against the costs of providing it - mostly direct support costs, but also specific amounts for shared services such as staff training and financial management.

Each person's Individual Service Fund (ISF) is expected to stack up financially: the very different ways in which people's services are funded may mean this requires internal financial transfers on a temporary or recurrent basis to manage cash flow. However, financial transparency has great benefits - and not just for the person being supported and her advocates, who can see exactly where 'her' money is going. The person and her staff team are also empowered by this to make decisions about how to use the Individual Service Fund creatively, and organise themselves accordingly.

This is very different from having to put in a request to Head Office for more hours, or money for a holiday - which leaves the person and her team in a dependent relationship.

It is easier in a small organisation than in a large company to have a clear understanding of the organisational finances, and for this to be shared openly with staff and others. Partners for Inclusion is committed to being transparent with the people on whose behalf they manage the money, and with staff, about the financial situation of each person's service which are, in effect, micro- businesses. This includes the contributions made by the Individual Service Fund to the cost of central services, and clarity about what these services are.

It is only by sharing the budget information, and supporting staff to take responsibility for this, that staff can understand how they contribute to making the money work for the person - how they can support the person to get the best value for money from services provided or offered centrally; how too much paid support can adversely affect the person's participation in the community.

5.2 General principles

Partners for Inclusion's approach to the money received by the organisation to support people starts from some basic principles:

1. Everyone should have their own Individual Service Fund, with spending decisions made by and for that person.
2. This should be treated as the person's money and respected as a restricted fund.
3. Decisions need to be made as close to the person as possible.
4. How money is spent should be clear and transparently reported.
5. Most of the individual budget should be spent directly on the person.
6. People need to manage within their budget - if they haven't got the money, they cannot spend it; if they do, they choose how to spend it.

The majority of Partners for Inclusion's income is 'Restricted Funding' - that is income which must only be used for the benefit of the person. This is allocated to an Individual Service Fund to meet all the direct and indirect costs associated with supporting that person.

The internal financial policies permit only some of this individual income to be transferred from the ISF into unrestricted Central Management and Service Co-ordination cost centres to meet the pooled, or shared, costs of administration, overheads, training and recruitment, service co-ordination and development.

The Service co-ordination fee meets the costs of service planning, quality assurance and monitoring, support and supervision of the teams, team building, problem solving and individual service development. Each person and their staff team need and benefit from this input.

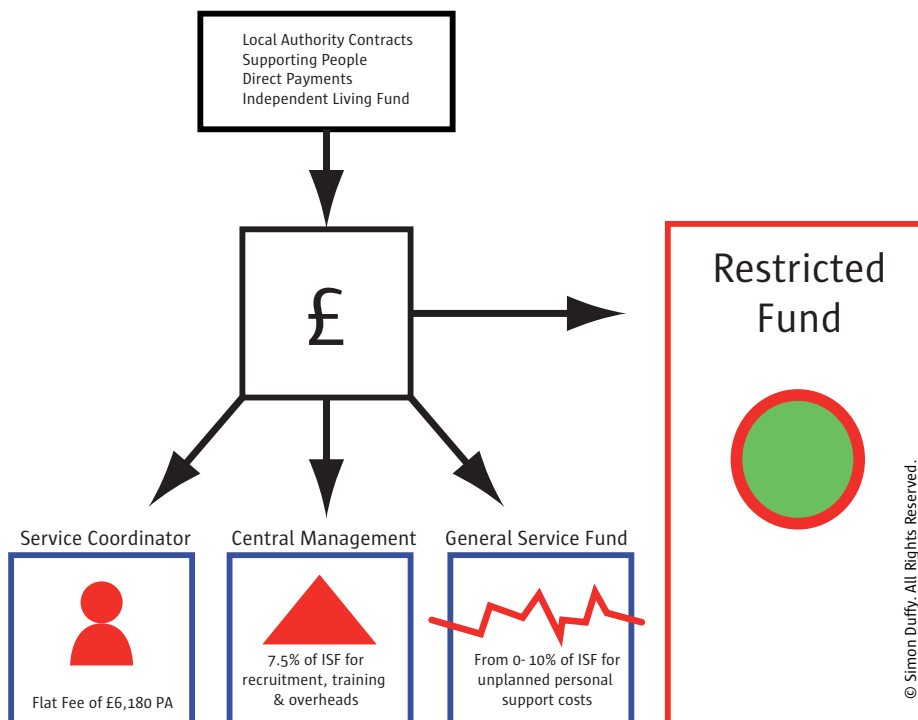


Figure 5 Individual Service Fund

Partners for Inclusion has found that people whose needs are complex but who need less paid support, still need as much service leadership and co-ordination than those who have a higher level of direct support. At the moment therefore this is a fixed fee. This does present dilemmas and a challenge: on the surface it makes an expensive service for someone who may not need intensive support on a daily basis, but the local authorities have recognised the benefits of the more developmental and preventative approach it supports. For the most part Partners for Inclusion is supporting people with a high level of support needs, who have previously challenged services leading to a history of exclusion. However it may have to rethink this calculation as individuals achieve direct purchasing power.

Each Individual Service Fund also makes an individually negotiated annual contribution towards a General Service Fund (GSF). This is a designated fund used for any person that may need additional resources that have not been included in their budget. For example a person may unexpectedly need a significant increase for a temporary period to cope with a big change in their life, or the staff team may have unexpectedly high absence. Effectively the GSF acts as an internal insurance system.

Conceptually this approach has been very important – that while each individual has their own funds, there is a value in paying into a ‘common good’ fund, from which people will derive different benefits depending on their needs. The payments are not ring fenced for that person. In practice, Partners for Inclusion’s experience has been that personally designed support within an individual budget, and creative approaches by teams has meant fewer calls on the GSF than budgeted. The Fund is therefore currently at a level which can sustain demands on it without further contributions, and so individual service funds do not currently include contributions to the GSF.

The balance remaining in the ISF is then ring fenced for the person and is used only for direct support costs such as support workers’ salaries, travel and other expenses.

This structure and associated accounting systems adapt to different contractual arrangements:

- **Spot purchase contracts** - where the contract sum becomes an Individual Service Fund.
- **Block contracts** - which are split, according to people’s needs, into Individual Service Funds for each person included in the contract.
- **Direct Payments** - where the agreed payment becomes an Individual Service Fund.

Obviously in England, which is now allocating people individual budgets, this structure would also allow people to ask the service provider to manage the budget for them.

The person may also have other streams for funding, such as the Independent Living Fund (ILF) which they can add into their fund. In the block contract arrangement, it is clearly agreed with the local authority that this should not be used to deny the person the right to change support provider if they wish to do so, or to elect to take and manage the money in a different way such as a direct payment.

In addition to these over-arching rules and systems there a number of other tools and processes that are used to underpin this way of working and to ensure financial safeguards and thorough audit trails.

5.3 The Budgeter

Each person's annual budget is developed using an accessible Excel-based budgeting tool called The Budgeter. The finance team presets fixed financial assumptions, for example levels of national insurance required, service co-ordination and central administration or management fees.

The Service Leader is responsible for preparing the individual annual budget, in conjunction with the Team Leader and staff team, and with the person and their family as far as they are able or wish to be involved.

They make decisions on support staff hours, rates of pay and other expenses, relating this to the person's individual support plan. If the projected staff hours and salary levels result in a deficit budget, then the team has to look at alternative ways of managing or delivering the support needed and adjust the budget accordingly.

5.4 Quarterly individual budget meetings

The finance team prepare a quarterly report of expenditure against budget for each ISF, and highlight variances for discussion. The budget management is devolved to the staff team, and the person or their family where they wish to be involved, with structured support from the finance team and Director or Depute Director who meet with the team quarterly.

All people supported and family, friends or advocates can if they wish be involved in budgeting. In reality as long as people have control over their lives and the service they get to support this, several people have declined to take on this responsibility. This is likely to change in the future when people become more familiar with the responsibilities of having an individual budget.

The group discusses the budget, finance report and bank accounts associated with the service. This aims to:

- Keep the senior staff directly in touch with the realities of the person's life and the support that is being provided.
- Facilitate discussion about how money is being spent (or not spent) leading to insight into the whole way the service is working.
- Develop the staff members' ability to relate what they do and how they do it, to the money available for the service.
- Give an opportunity for reflection and problem solving.

The process imposes a discipline on all involved to manage within the means available, and to plan for contingencies. If there are budget savings during the year, for example because there has been no staff sickness, the team decides how to reallocate the funds with reference to the support plan. If the budget is overspent in one quarter, the team has to decide how to deal with this.

For example, Harriet had not had a holiday for two years and was very keen to take a trip abroad. In discussion with her family, the team proposed a budget that reduced her variable staff hours for 6 months to create funding which will cover the travel and accommodation costs

for the staff support that she will need to go on holiday. To support this the team worked to support Harriet in doing some voluntary work at a local business centre. This slowly developed so that she built up to two hours at a time twice a week when she is supported by the Centre's administrator rather than Partners for Inclusion. The team demonstrated very low levels of sickness absence and this allowed a further £1132 to be added to the support expenses budget.

5.5 Annual budget setting

One of these quarterly meetings is used to plan the budget for the year ahead. Senior staff support and challenge the team - with questions focused on the budget in relation to the person's plans, checking out that people are not being over-supported, and making sure that the proposals are not putting the person or the organisation at risk. Family members are invited to the budget meetings and to see the detailed ISF accounts and it is quite possible that they might take on higher levels of control or oversight.

For example, Alison's parents initially decided that they wanted to manage their daughter's Individual Service Fund. They received and were responsible for budget setting and decisions, and took the lead in all appointments to their daughter's staff team. After a short time, they found that this required a higher level of involvement, time and responsibility than they wanted. They also felt that their daughter was successfully being supported to develop her own life, and it was more appropriate that she and her staff team took on the responsibility. They have now opted to be less involved in the ongoing management of the Individual Service Fund. However they still have an oversight role, are involved in budget setting and receiving accounts. Alison, and her parents, are still young, but as she grows up the family are also thinking about the role a Circle of Support could play in supporting her to control her Individual Service Fund and to make decisions about the support she receives.

5.6 Staff induction and training

The recruitment process for staff looks for people who are confident in managing their own money and those of others; or who are willing to learn and be trained on this. Staff induction includes training from the Finance Team on 'good money management', and supports an expectation that everyone is responsible for and accountable for the money. Training is provided on the simple procedures for recording and monitoring spend. It also introduces staff to the organisation's auditing mechanisms and whistle blowing policy - so that people know that if they see something which concerns them, they have to tell someone and that it does not have to be the Team Leader.

5.7 The Number Two account

The person's individual budget for their Individual Service Fund includes amounts for support expenses. The budgeted amounts for staff support and sundry expenses are transferred to a separate Partners for Inclusion bank account, known as the 'number 2 (or 'team') account'. This is managed directly by the staff team on a weekly basis and is subject to regular audits.

John's Individual Service Fund Budget

Contract Staff

Team Leader (35 hours per week)	23,205.20
Support worker (10 hours)	5,428.80
Support worker (15 hours)	8,143.20
Training time	1,292.80
Management/meeting time	1,002.24
Annual Leave time	3,272.44
Contractual sick pay	522.00

Variable Staff 3,062.40

Shift hours (20 hours per month)
Training time
Annual leave time
Variable sick pay

Other staff costs 1,403.60

Ad hoc staff costs (n/a)
Support expenses
Mobiles

Other support costs

Sundry expenses	1,500.00
Service co-ordination Fee	6,180.00
General Service Fund	0.00

Central Services 5,196.00

Administration Fee
Training
Recruitment
Accreditation
Insurance

Total £60,208.68

5.8 The Number Three account

The Individual Service Design and Working Policy include details of how the person wants to be, and can be supported with making decisions about money. This will lead to one of two approaches:

1. Where possible, people have their own independent bank account for their personal money (benefits, money from family, earnings), and have varying need for support with managing this. The Working Policy will detail what support is needed from the team and how this will be provided, including regular checks and other protections that may be needed for the person, staff and organisation.
2. For those people who require full support with managing their finances, Partners for Inclusion holds an individual 'client' account (number 3 account) on behalf of the person, and into which their benefits and any other personal income is paid. The staff team then supports the person to manage this money for their ordinary living expenses, subject to the appropriate checks and balances.

Sometimes it makes sense for the person to operate a mix of these approaches, and then this too is detailed in the person's Working Policy.

5.9 Spot checks and internal audit

Partners for Inclusion believes that the closer money is to the person, the more effectively it will be used to support them in the way that makes sense for them. But they are not naive about the need to build in checks that money is being used appropriately and accounts are accurate. The Service Leaders carry out spot checks. An internal audit group, made up of selected team leaders, service leaders and finance staff carries out a detailed twice yearly audit of every account. The team is given notice when the audit is going to be carried out; during the audit any discrepancies are immediately highlighted; and an audit report is written noting any areas where attention is needed.

6. Power with the Person

Partners for Inclusion has built in several safeguards to help it stay true to its values and mission. This means welcoming accountability and ensuring that the organisation is accountable both to formal statutory bodies, and even more so, that it gives power to people, their families or representatives.

6.1 Regulation and accountability

Partners for Inclusion and its staff are legally accountable to:

- The purchasers of their services - at the moment, mostly local authorities.
- The care standards regulator - the Care Commission.
- The charities regulator - the Office of Scottish Charities Regulator
- The company regulator - Companies House.

But in addition they also hold themselves accountable to:

- The people who get support, and their families.
- The communities they work in.
- Their peers, particularly the organisations who are members of Altrum.

Partners for Inclusion is subject to the same inspection and reporting cycles as any other support provider which contracts with a local authority and is registered with the Care Commission. The Care Commission inspections of Partners for Inclusion's services have resulted in grades of 5 (very good) or 6 (excellent). In other words, it is recognised as a quality service provider even though its approaches may challenge older models of support for people with complex needs.

What regulators or contract compliance units cannot do though, is hold the organisation - through its Board and staff - to account for how well Partners for Inclusion is doing in achieving its core purpose and goals, and where it can learn to do better.

- Are people living the life they want - with home, friends, relationships, job, making a meaningful community contribution?
- Are they supported to do this safely in ways that protects their rights, health and wellbeing?
- Do we have highly committed and skilled staff doing this job?
- Are we fostering and spreading leadership - in our staff, and in the people we support?
- Are we in right relationship with the people we support?
- How effectively are we transferring power to the people we support?
- How resilient and full are the lives of the people we support, when we are not there?

“We have learned that some processes are useful and support us in exercising good judgement, where before we might have rejected this idea. If there was a staff vacancy, we might have found an ideal match in the uncle of one of the person’s other support workers. Because there was already a link, there was much less formality about, for example, obtaining references from the right sources. This was poor judgement - and it took a combination of an incident and a question from a family member to make us think about this in the round; and decide that a more structured process for employing people was needed to keep people safe.”

Doreen Kelly, Partners for Inclusion

An operating system designed to support citizenship and control has to give as strong, or stronger, weight to these questions as it does to the questions asked by external stakeholders and regulators. Partners for Inclusion staff still maintain a heightened awareness of the risk that systems and processes and regulatory requirements get in the way of people having real lives. They commissioned an independent consultant to put this under the microscope - asking support workers what they do on a daily basis, asking people about their lives. The findings were positive, that systems and paperwork do not, at the moment, get in the way of the real work. This external review will become a regular check that the balance does not, inadvertently, lead to the organisation’s needs taking priority over the needs of people.

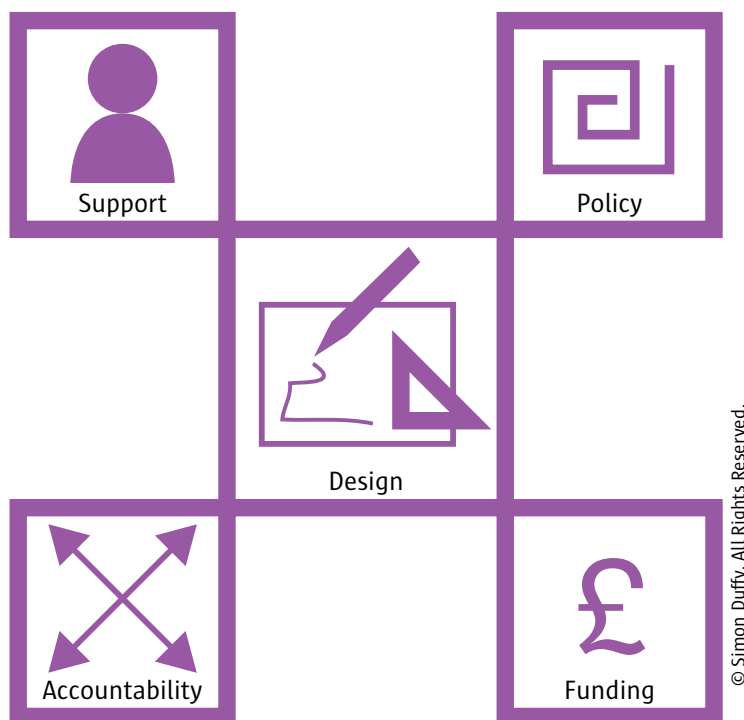


Figure 6 Organisational Structures for Personalised Support

6.2 Governance

Partners for Inclusion started its corporate life with a very small Board of 3 people who were closely involved in its development and understood in some detail the needs of the people supported. This has recently grown to 7 people, bringing different perspectives and knowledge to the task of strengthening its effectiveness and sustaining what it does well. Two of these are family members of people supported by Partners for Inclusion.

Where the Executive Director is also the founder of an organisation - particularly one with a passionate social mission - the role of Board members may be diminished, with consequent weaknesses in governance. The size and make up of Partners for Inclusion's Board means it has built in potential for a conflict of interest in 2 of its 6 members. The Board and Director are acknowledging the need to think about further development of the respective roles of Board members and senior staff in maintaining, sustaining and developing its shape and activities to support people to be in control, to be citizens.

6.3 Circles of support and advocacy

The individual planning and review process is designed to ensure that people are being supported to live their life to the full, and that their welfare is paramount in the way the service operates. But it doesn't always get things right. It is also conscious of the potential for paid support to create dependency and to act as a barrier to ordinary community participation and relationships. This is especially so where people may for the first time in their lives, or for a very long time, have experienced the liberation of a relationship with unrelated people who are truly committed to their personal development.

When people were first moving from institutional settings, the priority was to help them escape and start to build an ordinary life - supporting people to become familiar with an unfamiliar world, to start to expect and demand simple everyday choices.

Now those at most risk are those without committed, unpaid, relationships in their life. However good the service provider, people who have no one in their life who is not paid to be with them are vulnerable not only to abuse but to gentle neglect and complacency. Where the person has strong support from family or friends, this is most often the person's safeguard. Not everyone has this. Even when they do, it is not enough.

Partners for Inclusion's senior staff, with hindsight, now question whether they should have invested earlier in supporting people to develop friendships and relationships. They recognise that for people to be in control and 'of' the community, not just in it, then Partners for Inclusion needs to support people to develop wider networks, to become less reliant on Partners for Inclusion as their main source of informal as well as formal support and advocacy.

7. Creative Community

An organisation is much more than systems, structures and processes. At its heart is a real community of people, with values and relationships. It is a shared place where humans come together to make sense of the world around them and to achieve things they all value.

7.1 Leadership

Partners for Inclusion's initial development was built on Doreen Kelly's leadership and that of her early staff team: their personal drive, credibility, values, integrity, ability to build strategic and personal relationships and, crucially, resilience in the face of difficulties.

That it has survived is, at least in part, due to the way leadership has been developed and shared among the senior team; and the deliberate efforts to foster leadership in every member of staff.

Now Partners for Inclusion is past the start-up phase, the tasks of maintenance, improvement and staying true to its values are as important as those of development, growth and innovation and the style of its leadership needs to reflect this.

The focus of leadership effort is attending to and nurturing the culture of the organisation. This means having enough systems and resources in place to allow everyday management of the organisation to happen without dominating the senior team's agenda and crowding out time to think.

7.2 Beliefs

As we explored above, the leadership of Partners for Inclusion arose out of a wider community, who shared a common commitment to achieving citizenship for all. Their powerful beliefs included:

1. Everyone belongs - no one has needs so complex that they cannot be supported to live a good life, with their own home, friends and relationships and support in the community.
2. Everyone is different - his or her individual gifts, strengths, challenges and needs are valued.
3. Behaviours are how people communicate their intentions, beliefs, wishes, emotions, fears - they are not symptoms to be managed or cured.

These deep beliefs then also lead to more detailed beliefs about how a successful organisation, committed to citizenship and Personalised Support should operate:

- We are not ‘in charge’ - we are there to support the person to live a good life, to help them make choices.
- We don’t have all the answers - we learn from the people we support, and the others around them.
- There is a better way - we just haven’t found it yet.
- It takes time to get to know someone and to support him or her well.
- Every policy or process has to support the person well.
- The money is there to work for the person, not to accumulate in the organisation.
- Support is a relationship, not a number of hours.
- We take a positive view - about people we support, their families, the communities in which we work, and the other agencies we work with.
- Think person first, organisation second.

It’s not that Partners for Inclusion is against being organised. They know that good policies, procedures and backup are essential for them to support people well. They just insist on checking everything back to the people they support.

Although Partners for Inclusion is the legal employer, each staff member’s primary engagement and loyalty is to the person that they support on a day to day basis - “Dave’s the boss” or “I work for Harriet.”

This ‘psychological contract’ is very important. The formal contract means that people can’t sack their support staff, or increase their pay - but support staff talk and behave as if they could. And if the person is not happy with their support this will be dealt with by the organisation.

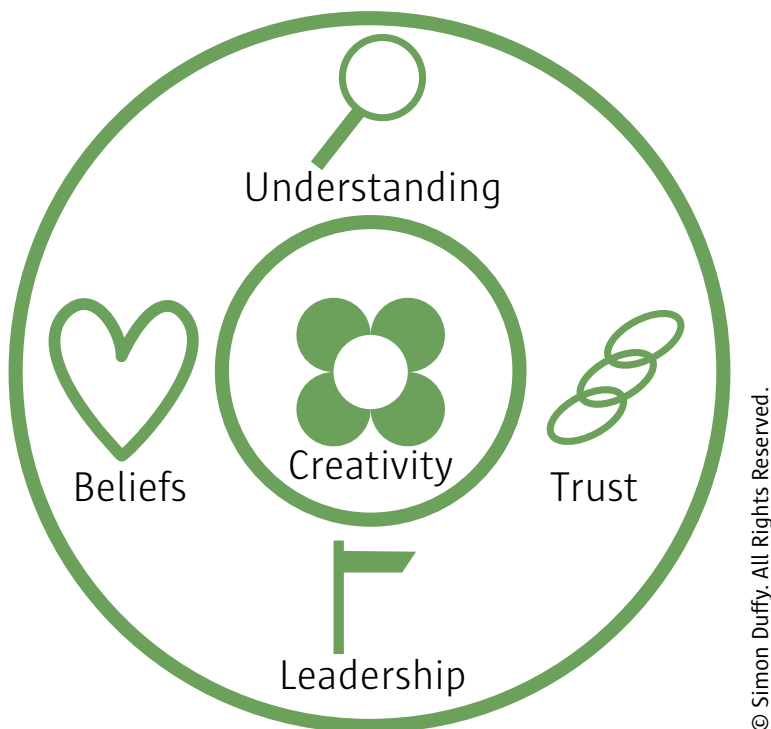


Figure 7 Creative Community for Personalised Support

“Our experience in other organisations has been that process and organisation has got in the way of providing truly personalised services; and we reacted against this with a fear of systems and processes that would inevitably ‘de-individualise’ the support we offer. But this leads to chaos. You do need organisation and systems and processes, and not just because of regulation and compliance - but they need to be carefully and thoughtfully worked out so that they serve the individual and the organisation; or, that if they only serve the organisation and have a negative impact on the individual, then they are not introduced or maintained.

This is one of the hardest balances to strike, and it is a critical element in the culture we have tried to create and want to protect. Everything that we do needs to be, and is, challenged and evaluated on a regular basis – yet not lead to a culture where there is so much navel gazing that nothing actually gets done.”

.....
June Jeffrey, Depute Director

Support staff usually work alone with the person they support, meeting up from time to time with the others in the team, but less often with support staff who work for other people.

There are good arguments for bringing people together more, to share experiences, tell stories and learn from other teams. And there are times when some people supported by Partners for Inclusion like to get together socially. But there's a fear of getting organisation-bound – of people seeing themselves as working for the organisation more than for a particular person, and of looking for solutions within the organisation rather than outside.

Part of the value of having an organisation is to build up a body of experience and knowledge. It makes sense to look at what is happening in one person's staff team where, for example compared with others, staff stay for a long time and don't get sick. However it needs to find a way of doing this that respects and maintains the individuality of each service.

So the organisation is at pains to emphasise that, in practice, people work for a person first, and organisation second. They use opportunities to do this, such as printing budgets and payslips with the person's name at their head, alongside or before the company name.

At the same time, the organisation recognises the need to support staff in what can at times be very demanding work - and acknowledge that while a staff person may be primarily working for one person she is also a part of a responsible organisation. This is therefore a work in progress; with the organisation trying to get the best fit between staff members' need for work-life balance and security of income, and the person's need for a flexible and responsive support service.

In its early days, with a very small staff group, there was no need to state or write down organisational values and assumptions, or what this meant for practice. It was the tacit understanding of a small team, without the need for explanation or argument.

Now, supporting 45 people and with some 220 staff, the assumptions are not as easily transmitted or maintained by osmosis. Modelling by senior staff is still an important element, but some incidents reveal misunderstanding or misinterpretation. New staff may see the individual autonomy, superficial informality, the commitment to flexibility and responsiveness and spontaneity, and believe that the culture is ‘anything goes’.

Over time the leadership team recognised that they needed to build a stronger coherence between “what we say we do”, “what we believe”, “how we behave” and “outcomes for the people we support”. Some of the ways they are trying to do this include:

- Carefully planned and mandatory induction training for **all** new staff - which introduces and explains the organisation’s values and beliefs - which has to be completed before any member of staff starts working to support the person.
- Starting to describe the behaviours that mean people are working in a way that is coherent with organisational values and beliefs.
- Adopting and promoting a leadership style with self-direction and coaching as central elements.
- Increasing the ways of engaging and communicating with staff to promote the shared understanding of these assumptions and stronger identification with the purpose of the organisation. For example, each team now has committed team reflection and development time built into the planning cycle around each person.

7.3 Trust

Partners for Inclusion works at getting relationships right and keeping them right. The people they support are at risk of exclusion - of having few or no relationships with people who are not paid to spend time with them. Good relationships mean increased trust, and it is trust that enables the creativity, flexibility and autonomy which is essential to Personalised Support. The relationships between people, their families and their community; between staff and the people they support; between support staff and senior staff; between the organisation and the wider world - all of these influence each other.

So at the heart of Partners for Inclusion’s work are questions like:

- Who is important in my life?
- How have people dealt with me in the past?
- Who am I to you?
- What can we expect of each other?
- Who’s in charge?

People consciously and unconsciously bring their past histories to relationships and may look for familiar patterns which don’t fit well with what Partners for Inclusion is trying to do. Partners for Inclusion works hard to resist the pressure to fall back into old and damaging habits and part of the senior staff’s role is to coach people through this.

For example, a new staff member may bring experience of a previous organisation and assume that she has to get permission or approval for everything. Her team leader can easily respond with an old pattern from her previous organisation by providing not only permissions and approvals but also prohibitions and disapprovals. This culture has a powerful effect on the person being supported, since if support staff have no or limited power to think for themselves, how can they help the person take increased responsibility? Equally, the people whom Partners for Inclusion support may bring a history of being told what to do and may need time to adjust to a relationship of mutual respect and give and take.

From the recruitment process through staff induction to ongoing training and development, staff are given the clear message that they are not a 'care' worker, they are a facilitator of people having a real life, with choices, relationships and employment.

Supporting staff to take up this role means that senior staff must work as facilitators. Most staff are more familiar with 'management' than 'leadership', and when problems arise the temptation is to revert to telling people what to do or assuming the responsibility for doing it. This approach is not consistent with a culture of retaining responsibility as near to the person as possible. Instead it reinforces a parent-child dynamic - the opposite of the relationship being promoted for people supported.

The coaching model doesn't come naturally to everyone, perhaps especially to the dynamic 'doers' who initiated the organisation. The leadership teams have recognised this and have sought external support to help them learn new routines.

For most of us, it is our friends and family who make life good and keep us safe. But many of the people that Partners for Inclusion supports have been isolated for many years - because they were in hospital, residential school or a care home. Creating new connections with someone at risk of exclusion is difficult, and takes years, not weeks. The starting point is often with and through paid staff.

Sometimes a friendship will develop between a person and their staff person; or will grow from introductions made by staff. Many close acquaintances don't grow into lasting friendships, and may not survive the staff member's move to another job or another area - but may still be a positive and memorable part of both people's lives.

Partners for Inclusion assumes that people have a right to choose their own friends, so does not try to prevent or discourage people spending time with staff or their friends outside 'work'. However challenges from commissioners, contract or care managers have prompted the organisation to think very carefully about its legal and moral responsibilities to the people it supports and its staff.

It has developed a written policy to help staff navigate the boundaries between their professional role and personal life with regard for the vulnerability of the people they support, while respecting people's right to choose their own friends on the same basis as any other citizen.

Partners for Inclusion is also clear that relationships with staff and family are not enough, and should be a bridge rather than a barrier to other relationships. Working out how to build and support these bridges, in ways that then lets staff step back, is one of their biggest current challenges.

Partners for Inclusion doesn't see families as a threat, or the enemy, or competition. They don't want to 'own' the person, and they don't feel the need to criticise or 'fix' other people's families.

7.4 Understanding

The team at Partners for Inclusion think and talk a lot. But most of this thinking and talking is focused on the people they support. They are still passionately interested in their craft, and this - rather than organisational politics or processes - commands their attention. They tell stories, and over time these get overlaid and interwoven to create a history - so they can take a long view about a person or a situation. They don't disrespect people in the way they talk about them - and they don't let other people get away with doing this, and this helps their talk stay positive.

Part of the benefit of the organisation staying small is that senior staff know all the people they support. This oral history is supplemented with a culture of written stories, DVDs and photograph albums so that people's stories get repeated and remembered and then added to.

Partners for Inclusion is always ready to try another way and Partners for Inclusion does a good job. But it does not have a magic wand to stop bad things happening. There have been instances of abuse by staff, instances of staff being drunk at work, instances of stealing. The people whom Partners for Inclusion supports have hurt themselves, their staff or property. There have been neighbour disputes, and much more.

However the dominant mind-set in the organisation when things are not going well is: "We learn from our failures, we can do better, there is a better way, we just haven't found it yet. We listen, change, keep trying till we get it right - it doesn't come easily, we might have to work really hard to find it and it can be a slow and painful process."

When things are not working, despite an Individual Service Design being in place, despite Working Policies having been written, then the temptation is to revert to old familiar ways of doing things - and unfortunately this can trigger exactly the same responses which have been unhelpful for the person in the past.

When John is upset and things are going wrong, he may set something on fire. To keep him safe, his home is fitted with a sprinkler system. When he set his living room curtains on fire, all the furniture and carpeting was soaked and the house was very unpleasant to be in. He was very distressed and taken to hospital by the fire brigade. The incident was reported to John's care manager, who wanted him to be re-housed temporarily, and possibly permanently, in highly supervised accommodation. This is what has happened before - the end of his previous time living in his own home, and after the last fire in his current home. But his team thought 'this keeps happening and we keep responding the same way, but it isn't working - what is that telling us?' John loves his home, he is quite house proud and was very distressed after the fire about what he had done - so we decided that the Working Policy needed to be changed.

A multi-agency team worked out John's support plan. This team included psychiatry, psychology, nursing, social work and staff from Partners for Inclusion. The plan was worked out based on John's past and learning from what worked and what didn't in order to develop a plan for the future. John's incidents of fire raising, past and present, are a feature of who he is and how he deals with his own stress. The plan needed to take this into account and put support and systems in place that keep John safe whilst he is coping in this way. This meant that the Fire Service, Police and Accident and Emergency staff needed to be involved in working out and agreeing the Working Policy as at these times their reaction is important.

Working this plan out in advance, and getting people signed up to it, is done to avoid panic, confusion or over reaction when John starts to display this type of behaviour. Following any incident of fire raising or other behaviour used by John to cope, a de-brief is held firstly with John's immediate staff team who are employed by Partners for Inclusion and then with his

extended team, including the professionals involved with him. The aim of this is to look at what happened, get the full picture, and give all involved time to reflect on what, if anything, went wrong in putting the plan into action and how to avoid errors in future. The session is also used to try to work out what might have been happening for John, causing him to behave in this way.

So the response to get John another house temporarily or permanently was considered on hindsight to be an over-reaction. It fed into the 'drama' rather than working towards calming it all down and getting back to 'business as usual' for John. Unfortunately John is someone for whom when things are going well he panics and goes into self-destruct mode. It is the job of Partners for Inclusion and others involved to deal with this in a helpful manner, not cause more problems. This is easier said than done whilst in the midst of these difficult times, hence the necessity for time out for staff for reflection.

The new Working Policy, agreed by all agencies, is that John should stay in the house (providing some rooms are dry), and be supported through the process of drying out the other rooms.

When something is not working, people are willing to go back to some fundamental questions:

- Who is this a problem for?
- Is this part of a longer story?
- What's making sense and what's not making sense from the person's point of view?
- What could the person's behaviour be telling us?

The people at Partners for Inclusion are optimists. They look for the good in people and they have high expectations. They don't underestimate the ability of ordinary people in the community to accommodate difference. They start from the assumption that people have good motives and are doing the best they can from where they are. They assume that everyone can learn, and that in every situation there is an opportunity to learn.

They also know that they are **in** the situation, not floating above it, and so often they are part of the problem.

Partners for Inclusion's staff and Board members regularly take time out in 'retreats' giving them thinking time to reflect on what they do and how they do it, challenge themselves and review what is happening for individual people and how the organisation and its services can be developed. They also value and seek out external observation and evaluation of what they do and how they do it.

As part of its Altrium membership, Partners for Inclusion commits to a 3 yearly external evaluation and learning process using the evaluation tool Person-centredness in Five Dimensions, designed for service organisations and groups that are working for inclusion (see www.diversity-matters.org.uk)

It also recently asked a Glasgow University researcher, working through the Scottish Consortium for Learning Disability, to evaluate its effectiveness in terms of its values and purpose. This self-critical examination of organisation and effectiveness is a conscious antidote to the dangers of complacency.

7.5 Creativity

Inclusion happens when patterns get rearranged and new connections made. For this to happen, staff have to see new possibilities and do the work to bring them to life. Most of us are hesitant to describe ourselves as creative, and see that as the domain of artists and scientists. Partners for Inclusion uses the word freely and actively nurtures creativity.

How does creativity get renewed? What stops people becoming complacent and the organisation stagnant? Many aspects of the organisation contribute:

- The way money is managed means there is built in flexibility to take a different path if this makes more sense for the person, and built in challenge about how the money is being spent.
- Conscious efforts are made to involve a diverse group of people in individual planning days - the more diverse the group of people, the more likely that new ideas will emerge.
- When things go wrong, the culture is to learn from this, to work out another way - not to blame: so staff are liberated to experiment.
- There is purposeful facilitation and coaching to help staff and the people supported to think beyond their own experience and expectations.
- Personal development is weaved into individual support plans. Time for staff training and development is included in Individual Service Funds.
- As members of Altrum, Partners for Inclusion supported the development of the award winning HEC (Higher Education Certificate) in Person Centred Approaches to social care, delivered by the Thistle Foundation (see www.personcentred-learning.org.uk).

A critical part to creativity is having the time and space to think - both in structured and unstructured ways, and with different groups of people. It is especially important for staff who may often be working alone. Every person's staff team schedules 'team time' in addition to individual supervision, to develop their thinking about how to support the person, particularly if, as happens, people get stuck in old patterns. As with most other aspects of the work of Partners for Inclusion, there is no 'magic formula' but they do look at what they do and how they do it: "why if we think we are creative are we trying to communicate with our staff by memo?" and they consciously adopt different approaches, for example, using a creative writing session to review their strategic plan.

One of the most striking things about the Partners for Inclusion's culture is its approach to money. The organisation is money-conscious - it knows what things cost, it is canny about having enough in reserve for emergencies. But it is not motivated by money: it is not trying to make money or keep money. It may be that, because Partners for Inclusion is quite small it has not developed a large infrastructure which then develops its own distinct needs. This helps people at the centre of its attention. Money gets moved to where it can do useful work - Partners for Inclusion uses money **to do stuff**.



Organisational

development,

Future challenges,

Conclusion and

Resources

Organisational Development

Personalised Support was developed by a family of closely connected medium-sized organisations like Partners for Inclusion. However there may be other ways in which suitable organisations can be developed. We can also draw some more general lessons from its development.

Leadership first

Without a doubt innovation will only come where there are at least some people who are dissatisfied with what else is on offer and are willing to work for something better. This desire for Personalised Support might come from within an existing service provider, from a commissioner, or from people who need support and their families.

However, any new initiative needs to be led from very early on by a person or small team who are willing to commit their time, energy and purpose to it. Unless a leader emerges to claim ownership, then no amount of official encouragement will make it happen.

However, commissioners can do more than wait for the right person to turn up. First, they can create some elbow room for the new agency - who are the people this agency could best support? Commissioners might start by looking at what's being spent sending a handful of people away to residential facilities outside the area, or talking to families whose young people are getting to the point of needing to leave home. Or maybe a crisis - such as a poor inspection report or a financial problem - could lead a commissioner to recommend breaking up a large providing agency into smaller units.

Organisational size

Partners for Inclusion supports 45 people with complex needs, each with their own home, supported by their own staff that tend to live nearby. The organisation has a total staff of around 220 people and a self-imposed limit of offering services to around 45 people. Partners sees its small size as an important element in staying connected with the people supported and the distinct communities in which they live.

They also see this human scale as a core component in helping to:

- Maintain and manage productive relationships.
- Sustain a strong, shared vision and culture.
- Hold and protect organisational memory and knowledge.
- Focus on the people it supports and keep corporate structures, policies and procedures in the background.

- Operate efficiently - small enough to support co-operation and efficient internal communication, big enough to support co-operative and cost effective purchasing from dedicated back office services.
- Keep accountability lines short.

However smaller organisations can find that limited size brings a cost of limited scope and thinking, restricting its ability to respond to new opportunities. One way that Partners for Inclusion tries to counter this is through participation in the federation of organisations and individuals called Altrum (www.altrum.org.uk), which works together to promote inclusion and citizenship in ways that might be difficult for any one of its members to do alone.

This may also suggest a solution for larger organisations who want to provide Personalised Support. It may be helpful to think about federal structures which give more power and authority to local leaders. It may also be important to think about how those leaders will be recruited so that they have an incentive to stay with and focused upon the needs of their local organisation. Personnel structures that only enable vertical career improvement may struggle to attract the right kind of leaders to support Personalised Support.

Organisational support

In principle even the needs to support one person can be the seed that can start a new organisation or new service. This was how Partners for Inclusion began, by serving one person in North Ayrshire. This was possible because for the first years of its life Partners for Inclusion was based within another organisation - Inclusion Glasgow.

Inclusion Glasgow was able to act as the incubator for Partners for Inclusion and this gave Doreen Kelly the safety and security to begin the development of an organisation which, in due course, was able to become an independent organisation in its own right. This enabled Partners for Inclusion to develop at a slower pace, to develop one person at a time, designing individual services and recruiting the staff around each new person it was asked to support.

The organisation's start up overheads were therefore very low and it benefited from shared services, experience and mentoring support until the number of people being supported brought an income level which could sustain an independent operation. Staff transferred to the new organisation under TUPE rules and it had the choice of continuing to purchase central services such as HR, training and finance on the shared services model, or look at the cost and benefits of providing these in-house. The clarity of individual funding also enabled negotiation of individual service start up costs to be met in full by the commissioning agency.

It is very hard to build a business one person at a time, given that typical commissioning systems tend to favour established organisations and block contracting. But it's clearly better for an organisation to grow gradually than to start off with 30 or 40 people. However, until the organisation grows to that size, it may be unable to generate enough income to pay for its own management and central services. So it may either need deficit funding to provide these services itself, or money to buy in these services from one or more trusted third parties.

Commissioners should expect to work with the new organisation operating a deficit budget for three to five years. Although Inclusion Glasgow and Partners for Inclusion were each able to be self-financing in under two years.

Commissioners and other divisions in local authorities and elsewhere can encourage leadership in this field by seeking out applicants for social enterprise funding, looking at financial instruments for investing in growing new organisations and backing entrepreneurs' business plans with small grants that enable people to go and learn from the small number of organisations that are providing local services for people with complex needs.

Future Challenges

Partners for Inclusion is still changing and developing. It does not always manage to achieve all it hopes but it has learned over time that some matters require more focus or attention.

The world it is operating in is also changing and there are big questions in Scotland about the future shape of support and funding for disabled people. In particular more focus needs to be paid to:

- Help people, with family, friends or representatives, to take more control over their budget and their support.
- Help people get paid work.
- Help people make more friends in the wider community.
- Help people explore how to use their Individual Service Fund more creatively.

Increasing control

While Partners for Inclusion works hard to listen to the views and wishes of the people it supports, in practice the relationship is often too one-sided. Where the person does not have some sort of circle of support or an independent advisor or advocate, the idea of a reciprocal contract is hard to realise.

In the future it will be important to improve and make clear the individual contract between the service provider and the person seeking support, to reflect the cost of the service, and to be transparent about the power balance, in terms of rights and responsibilities, between the parties.

Employment

Partners for Inclusion employs an Employment Development Co-ordinator to increase the organisation's capacity to make connections, which could provide or lead to work for individuals.

Supporting people with work is now included in the core job description for support workers. Every new member of staff has training on employment for the people they support - part of embedding the cultural assumption that everyone can and should contribute. Staff are supported to think differently about what a 'job' is and about the different skills and approach needed when the person gets a job and the worker's role changes from support worker to job coach.

The Employment Development Co-ordinator coaches staff teams to think about what the person enjoys doing, how a job can be carved out of a larger task. The coaching may need to focus on changing the way that the staff team sees the person, and about how they see work, so they can imagine and then find or create the right niche for that person's gifts and interests.

Staff are supported to seek the opportunities and relationships that will work for the person, which may be different from those they would seek for themselves. Part of the Employment Development Co-ordinator's job can sometimes be working alongside the person's support worker, modelling how to build relationships with prospective employers.

George used to go to the newsagent every day with his support worker, Mary, to buy chocolate and a newspaper. They knew the names of the people who worked there. Mary was encouraged to ask Lorna, who worked behind the counter to do her a favour – the next time George came into the shop, would she ask him to put some packets of crisps

on the shelf. Over the next 6 months, the number of tasks grew and George is now working half a day a week in return for an exchange of goods from the shop (as cash is not meaningful to him). This is a first step in being employed that can be developed slowly at George's pace.

Partners for Inclusion has also paid attention to making relationships with community organisations and businesses. They, along with others in the area, created a local 'Business Diversity Employment Award', which raises awareness and gives recognition to local employers, adding to a climate where employers are receptive. The organisation is a member of the Ayrshire Supported Employment Network, developing relationships with job centres, and building links with local employers. This is slow and persistent work, but it is crucial to developing relationships with the local business community.

"We have been socialised into expecting that we should get a job, the people we support haven't. No-one ever said to them 'what do you want to be when you grow up?'"

.....
Doreen Kelly, Partners for Inclusion

New connections

Partners for Inclusion is also now focusing on helping support teams and individual staff to think more creatively about how to help the person they support to make new relationships and stronger and more durable community connections. They are learning how to facilitate circles of support and looking at ways of making this independent from their role as a support provider. They are also exploring the benefits of community circles.

Partners for Inclusion now aims to have more local community members on their boards of management or as advisors on particular issues. There could be more contribution back to the local community, whether giving a prize for the school fete or a talk to the sixth form. The organisation's staff could be encouraged to become more connected themselves - singing in the choir or joining the campaign to save the swimming pool.

Partners for Inclusion has recently begun to grow a new organisation - Just Connections - as a separate 'project' which will then be able to become independent. A large part of its focus is on younger people with a base in the communities it works in, and developing its work into schools and colleges. It benefits from Partners for Inclusion's track record, back office services, and development support. It needs, and receives, intervention to protect it as well as to nourish it in its initial stages.

Increasing creativity

As individuals take more control the support providers may see their role shifting towards that of facilitator - helping people to spend their Individual Service Fund more creatively on more appropriate supports. This is already an inherent feature of Personalised Support, but it is at times too easy to provide support that is in-house or more familiar.

In future the service provider may see their role as being more focused upon:

- Helping people develop friends and relationships
- Finding a new home
- Recruiting managing and training staff
- Managing money and individual budgets
- Finding employment
- Accessing educational opportunities
- Getting connected to the community

Conclusion

We began by considering the underrated value of ordinariness. Some people, like Alison, achieve it because they can get the right support from their family, the community and the state. So many others, as Professor Mansell states, are excluded from ordinariness because we do not seem to understand how to provide the kind of Personalised Support which makes ordinary citizenship a reality. This report from Julia Fitzpatrick is important because it provides one of the few detailed accounts of how to make ordinary happen for people with the most complex and challenging needs.

This report is also published at a critical time for services in Scotland and England. Scotland has led the way in developing Personalised Support. The early work of Inclusion Glasgow, Partners for Inclusion and the other members of Altrum has blazed a trail - demonstrating that a whole new level of individualisation and personalisation is possible for the very groups that are most often excluded from citizenship.

The very ideas of Individual Budgets and Self-Directed Support, which have recently dominated social policy in England, were actually developed and tested first in Scotland. However policy leaders in Scotland are still reticent about promoting more radical forms of personalisation.

On the other hand in England, where the political support for personalisation has been extremely strong, the actual delivery by service providers has been very patchy. Too often service providers are still treated with mistrust by local authorities. They do not feel that they have a place within the new system and many are resisting change.

There seems to be an enormous missed opportunity here. In Scotland we should be able to recognise and build on what has already been achieved - Scotland could be leading the way in personalisation. England could also learn from these earlier experiences and begin the process of transforming the service provider sector and encouraging the development of genuine Personalised Support.

The greatest opportunity offered by Personalised Support is a system for offering people flexibility, control and greater citizenship - without unnecessary complexity. Personalised Support means that people do not need to become employers in order to get the kind of support that people want. People do not even need to directly manage their own individual budgets. The service provider is paid to specialise in these functions and this makes personalisation much less burdensome.

In addition Personalised Support will enable those who have been most excluded, the most challenging, the most complex, who are still perhaps languishing in inappropriate services, perhaps many miles away, to come back home. This could lead to enormous improvements in quality - but it will also mean the repatriation of millions of pounds that is currently wasted in spending outside the local community.

Finally Personalised Support offers an opportunity for increased efficiency - without abandoning quality. In difficult economic times it will only be by increased attention to helping people make the best of their own real wealth that we will avoid returning to damaging and institutional solutions.

Simon Duffy

Director of The Centre for Welfare Reform

Useful Resources

Writings

- Department of Health (2007) **Services for people with learning disabilities and challenging behaviour or mental health needs**. (Mansell Report)
- Covey, S. R. (2004) **7 Habits of Highly Effective People**. New York, Simon & Schuster
- Duffy, S. (2003) **Keys to Citizenship**. Birkenhead, Paradigm
- Duffy, S. (2010a) **Individual Service Design**. Sheffield, The Centre for Welfare Reform.
- Duffy, S. (2010b) **Personalisation in Mental Health**. Sheffield, The Centre for Welfare Reform.
- Etmanski, A. (2004) **A Good Life**. Vancouver, PLAN
- Falvey, M. Forest, M. Pearpoint, J. Rosenberg, J. L. (1997) **All My Life's A Circle - using the tools: circles, MAPS & PATHS**. Toronto, Inclusion Press
- Mount, B. (1987) **Person-Centred Planning**. New York, Graphic Futures
- Pearpoint, J. O'Brien, J. Forest, M. (1993) **PATH: Planning Possible Positive Futures**. Toronto, Inclusion Press
- Scott, P. Kowalchuk, P. Hasbury, D. (2006) **You and Your Budget: A guide to understanding and managing your funds**. Highland Park NJ, Neighbours Inc.
- Smull M. W. Harrison, S. (1992) **Supporting People with Severe Reputations in the Community**. Alexandria VA, National Association of State Mental Retardation Programme Directors
- Vidyarthi, V. & Wilson, P. A. (2008) **Development from Within**. Herndon VA, Apex Foundation

Websites

- www.inclusion.com
- www.neighbours-inc.com
- www.centreforwelfarereform
- www.equalfutures.org.uk
- www.scie.org.uk
- www.plan.ca
- www.altrum.org.uk
- www.partnersforinclusion.org
- www.diversity-matters.org.uk

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The Centre for Welfare Reform

The Centre for Welfare Reform is an independent research and development network. Its aim is to transform the current welfare state so that it supports citizenship, family and community. It works by developing and sharing social innovations and influencing government and society to achieve necessary reforms.

To find out more go to www.centreforwelfarereform.org



Partners for Inclusion

Partners for Inclusion is a service provider working with people with learning disabilities leaving long stay hospitals; people with mental health problems leaving long stay in patient care; young people leaving their special schools and people whose services have broken down and were in danger of exclusion or institutionalisation. If you want to find out more about Partners for Inclusion contact Doreen Kelly

Doreen.Kelly@PartnersforInclusion.org

or go to www.partnersforinclusion.org



Altrum

Altrum is an organisation of organisations and individual people committed to fostering creativity, community and citizenship for all. Its members include Partners for Inclusion, Inclusion Glasgow and many other pioneering providers of Personalised Support. For more information about altrum go to www.altrum.org.uk

Find out more...

For those who want to explore the issues raised in this book more deeply, Partners for Inclusion, along with other Altrum organisations offer study sessions lasting from half a day to three days. You can also find out more about the HEC in person-centred approaches to social care from www.personcentred-learning.org.uk



To find out more about this publication contact Partners for Inclusion
West Kirk, 84 Portland Street, Kilmarnock, KA3 1AA
Telephone: 01563 825 555 • Email: reception@partnersforinclusion.org
website: www.partnersforinclusion.org

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