

Freedom Fighters

Five stories of endurance and escape

By Clare Hyde

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About the author

Clare Hyde is Director of The Foundation for Families, a community interest company working with and for the most disadvantaged and marginalised families in our communities. The Foundation's work builds on the experience Clare gained during her 14 years as CEO of WomenCentre, where she and her colleagues developed and delivered innovative services for women and children at risk.

Clare was a member of Baroness Corston's Review Team, commissioned by parliament following the deaths of several women prisoners at Styal Prison. She also played a significant role in the development of the Department of Health's Offender Health Strategy, the Home Office Women's Offending Reduction Plan and the Women's Mental Health Strategy.

Clare joined the National Institute of Mental Health for England in 2005 and led a major mental health improvement programme.

Clare was awarded the MBE in 2005 for her contribution to women and children's health and social care. Clare's interests include her family, friends, foreign-language film, reading, writing, gardening and travel.

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Partners for Inclusion



Partners for Inclusion

What we do

Partners for Inclusion have a long history of providing support for people who have a learning or mental health difficulty or both – especially those leaving institutions like hospitals and group homes. Partners have particular expertise in supporting people whose behaviour challenges services.

The organisation's mission statement includes a commitment to share its learning with others and producing this publication is one way of delivering on that promise.

Here you can read the stories of five people who have been described as having 'high support needs'.

The aim of publishing these stories is to celebrate success, raise awareness and perhaps inspire people, families, local organisations and commissioners.

At the heart of Partners for Inclusion's work is a personalised or person-centred approach and a belief that everyone is equal, no matter their differences or disabilities.

Partners for Inclusion believe that:

- ✘ everyone is equal, different and has their own gifts
- ✘ everyone has the ability to develop
- ✘ everyone has needs and the right to support in keeping with their basic human rights
- ✘ everyone's relationships are valuable.



High costs, low
expectations



High costs, low expectations

Secure residential and group home services

In every village, town and city there are people and families who need support to live ordinary lives as part of their communities.

For some, living an ordinary life as part of a community has never felt possible because their disabilities, health or even their behaviour have been seen as too difficult, too complex, too challenging.

The term 'high support' is used to describe people who need intensive, often complex and long-term support. These are the people most likely to end up in group homes, secure institutions and, sometimes, prison.

Residential placements: £5,000 a week

'High support' is, to some extent, a subjective term. It may not be the way a person or family would describe their needs. The term is often based on medical diagnosis or a social care assessment.

Providing support to people with high support needs can be very costly. For example, a placement in a residential unit can cost from £500 to £5,000 a week, so developing an economically sustainable yet fair and effective adult social care system is an obvious priority at national and local levels.

People who commission support and other services are increasingly interested in something called 'social return on investment' or SROI. The New Economics Foundation has led the thinking and practice behind SROI and says:

'There are many things which we value, as societies and individuals, which cannot be easily captured in economic terms. And yet, most decision making in the private, public and third sectors are based solely on costs and price.'

Social Return on Investment (SROI) is an analytic tool for measuring and accounting for a much broader concept of value. It incorporates social, environmental and economic costs and benefits into decision making, providing a fuller picture of how value is created or destroyed.

SROI is able to assign a monetary figure to social and environmental value which is created. For example, New Economics Foundation research on the value created by a training programme for ex-offenders revealed that for every £1 invested, £10.50 of social value was created.'

Despite the huge costs of keeping people in institutions or caring for people using support workers, the ‘value’ of their lives has not been given much consideration. The expectations and aspirations of people with complex mental, physical and learning disabilities have not often been the focus of those commissioning or providing care and support.

Getting a job or a good education, having a home of your own, going for a drink or to the cinema with friends are ordinary things which most of us take for granted. But, for too many people, these ordinary things in life are hard to achieve or completely out of reach.

The barriers to living an ordinary life

It is widely accepted that disabled people (whatever their disability) face a wide range of barriers that prevent them from living a life they would choose.

The barriers faced by people with mental health problems or learning disabilities include:

- ✘ attitudes – among disabled people themselves and employers, health professionals and service providers: for example, lack of aspiration or expectations, ‘settling for less’ – for yourself or for people receiving services
- ✘ policy – resulting from poor policy design and delivery that does not take disabled people into account and

which can add to the problems already faced by people and families

- ✘ physical – for example, in the design of the built environment or transport systems
- ✘ empowerment – too many people with mental ill health or learning disabilities are not listened to, consulted or involved.

Despite the huge costs of keeping people in institutions or caring for people using support workers, the ‘value’ of their lives has not been given much consideration.

The cumulative effect of these barriers is to partially or totally exclude people from society and the economy. Some people, particularly those with complex problems, never get the opportunity to exercise their rights and responsibilities as citizens.

Each of the people whose stories are told here is someone for whom ordinary life did not seem possible. Each has needs that could be described as high-support and complex. All have behaviour that could be described as challenging and could be seen as a risk to themselves and their communities.

The most striking feature of these stories is how complex and different people's lives are even if, superficially, they have similar needs.

'These folk are freedom fighters'

Unsurprisingly, people want different things. They have different ambitions and different challenges. They draw on different kinds of support. And people's lives change as they age and mature or as their life circumstances change.

Doreen Kelly, Chief Executive of Partners for Inclusion, has a theory about challenging behaviour, which, when you listen to people, families and staff, is easy to believe.

Doreen says 'These folk are freedom fighters. Their challenging behaviour is sometimes the only way they can let anyone know that things are not right for them. They won't take it lying down and they'll fight to get what they need – the life that is right for them.'



Five freedom fighters



Five freedom fighters

The five people whose stories are told here have, between them, attracted many labels and diagnoses.

These 'deficit' or 'diagnosis' labels come from judgements that others have made about a person's competence, capacity, ability to live independently, overall needs and the risk they pose to themselves or other people.

The labels attached to the five people featured in these stories include:

Autistic, learning disability, challenging, difficult, Aspergers Syndrome, mentally ill, sex offender, Developmental Dysphasia, vulnerable, aggressive, self-harming, suicidal, low self-esteem.

There has been a shift away from a system which has treated people as dependent, passive recipients of care towards a new approach that enables people to play an active role in determining how their needs are met. Nonetheless, there are still many thousands of people who, because of the labels and diagnoses given to them, have no control, no power and no choice about how, where or when they get their support or even who delivers it.

The Partners for Inclusion staff involved in supporting these five people, however, did not use deficit labels when talking about them.

The words they used included:

Incredibly resourceful, strong, independent, intelligent, very generous, confident, brilliant sense of humour, clever, determined, full of empathy, kind.

'...there are still many thousands of people who, because of the labels and diagnoses given to them, have no control, no power and no choice about how, where or when they get their support and care or even who delivers it.'



Sam

Sam

Sam is 28 years old. He spent much of his early life in institutions and foster care placements. Partners for Inclusion began to support him when he was 22.

Sam's behaviour at that time was challenging and chaotic. He had been given various labels and was thought to be a risk to himself and to others.

From pillar to post

Sam tells his own story:

'I was put in care when I was six months old. Basically I was passed from pillar to post. I was put with a foster family when I was 13 and it was them who got me into Partners for Inclusion.

I came out as gay when I was 16 and my foster parents didn't take it well. I finally left when I was 22 and that's when I came to Partners.

If I hadn't got into Partners I wouldn't be living in society. I would be in an institution. Partners have been supportive all the way through this. They were scared for me in case I got attacked.

I am happy now. When I lived with my foster mum and dad, I wasn't allowed to be me. They were strict. Even after college I wasn't allowed to do what 18-year-olds should be doing. When I left, I came straight into my own place but I had 24/7 support from Partners.

I'm living my youth – what I wasn't allowed then.

I get a lot of stick for being gay where I live. It's strange. I wonder why people can't accept me. I don't care what people look like, what they are. As long as they treat me with respect I will do the same back. I really deserve a chance in life. Everyone deserves a chance. I don't judge folk. Who am I to judge?

Where would I be?

I came from a big family and my mum couldn't look after us. We were split up but me and my sister went to the same foster family. But then we were split up when I was eight. I didn't know that was wrong at the time so I didn't question it.

Now I'm ready to ask a lot of questions but I just don't know if I'm ready for the answers.

When I was with my foster parents I tried to kill myself. I was about 13 then. I was very depressed. I took an overdose of acne tablets. I took about 10 of them and was throwing up within about an hour but at least my skin was spotless!

'I really deserve a chance in life. Everyone deserves a chance. I don't judge folk. Who am I to judge?'

I would definitely be in an institution if it wasn't for Partners. I wouldn't be part of society. Actually, I probably wouldn't be here. I would probably have killed myself.

Normal life for me is what I'm living now. Being what I want to be. Doing what I want to do. Going where I want to go. My dream is to get married and get a job. I

would like to move to Glasgow eventually. In a way I feel safer there.

I'm not ready for my relationship with Partners for Inclusion to end yet but one day it will and I'll miss it. But I know they won't ever lose touch with me. The secret is that Partners have got to know me properly. They don't judge. They help folk live a life. It was different from the word go.

I wouldn't want anything done differently. I help Partners with their functions, parties, the pantomime and I'm planning the X Factor for next year. I would love to be a support worker and help kids and adults who need help. I think it's amazing that someone like me can put a smile on someone's face. A lot of people have had worse lives than me.'

Sam's team: Amber, Gail, Ellie, Louise, Joe

Sam has influenced members of his team – as practitioners and people.

Amber *'Sam has got to know and trust me over the three years I've worked with him. It wasn't easy at first when he came out of foster care. Basically, he was policed 24/7 and he challenged that.'*

Gail *'I worked with Sam for two and a half years – from when he came out of foster care. It was 24/7 support and it was my first time in the job. I was 17. There were times when he kicked against us – as he changed we changed. Because I was younger than him, he challenged me.*

It was tough sometimes. The way I reacted to some of the conflicts would be different now and I have learned so much from Sam.'

Ellie *'I think Sam didn't know how to be with people. He had been so tightly controlled. He hadn't been allowed to socialise or make mistakes. But then I struggled to keep up with him – he was learning at 100 miles an hour. Despite the reputation he came with, there has never been any indication that he is a danger to anyone else.'*

Some of the labels that came with him are just not right. He learns from every relationship he has. He is so resourceful.'

Louise *'One of the main things that made it work was our relationship with other agencies. Police had regular contact with Sam. We helped them understand him better. It was the same with Housing. When Sam was in danger of being evicted we were able to work with them and change their view.'*

It was important to get the balance right. We had to work with Sam within the boundaries of the law and get him to realise there are consequences to his actions. He found it hard to turn up for probation appointments and failing to attend counted as a breach. He was close to getting a custodial sentence. He spent a weekend in custody – a long, long weekend. He makes sure he keeps his appointments now. It was a reality

check for him. He is maturing. The change compared to just a year ago is huge.'

Joe *'I was part of the team till two years ago. At first, there was a high staff turnover because of Sam's behaviour. I dreaded going in – not knowing what mood he'd be in. He probably sensed that and it made things worse. I talked to my manager and I learned to manage myself. I've learned a lot from working with Sam.'*

When it was a 24/7 service, I think we were providing a mini institution. That probably contributed to the problems. Who would like that level of supervision? We changed Sam's working policy and challenged some of the labels. It took time but the whole multi-agency team then felt comfortable with reducing his support. Working together gave everyone the confidence to take risks – in a careful way.'

Martin, Sam's social worker

Martin is responsible for Sam's care package.

'I have worked with Sam for five years. I had never worked with Partners for Inclusion before. They are very different to the organisations I usually work with.'

Sam has presented lots of challenges and the Partners team have kept him at the centre of everything they do.

I have been very impressed by them and, from a personal point of view, they have been a joy to work with. They have had to

be innovative and flexible because Sam's behaviour was so chaotic and risky. He is a lot more settled now. There has had to be a subtle assessment of risk all the time. I can't fault them – another organisation would have struggled.

Sam has changed a great deal. He is less impulsive and engages with his support team. One day, he could do well with minimal support. Perhaps he won't need support at all.'



Adele

Adele

Adele is a 31-year-old woman who has many vulnerabilities and difficulties. But, when talking to Adele's parents, her support team and the local authority's social care lead, it is obvious that Adele is also strong, independent and is her own expert.

Adele is definitely a freedom fighter. She has developed battle skills, which have not always made it easy to parent or support her.

Adele's family, her support team and a key local authority social care manager each

describe their relationship with Adele and with each other.

It is clear that providing support for Adele is complex, sensitive and subtle work that has often required close multi-agency working.

Adele's Family

Catherine (Adele's mum) and Peter (her brother) talk about the profound changes that have happened in Adele's life.

Catherine describes what life was like immediately before Adele began to receive support from Partners for Inclusion:

'We have learned so much from working with Partners. I wish we had the information years ago that we have now because we understand so much better. We would have handled things with Adele very differently. With her learning disabilities and the usual teenage difficulties, things have been very hard.'

It's only in the last four years that we have started to think about the possibility

that Adele could also be autistic as well as having a learning disability.

Dramatic changes

Adele went away to school when she was 11 and was there until she was 18. She was very happy there and we were happy with the school. When she left, the change was dramatic. She went from a busy, school environment to a flat on her own with 20-minute time slots allocated for lunch and dinner.

There was no real choice about where she went and what happened to her.'

‘No one had ever asked Adele what she actually wanted.’

Peter: *‘She wasn’t happy in the flat. It was far too regimented. She was on her own for almost a year and was very isolated. We knew that it would be the wrong thing for Adele to come and live at home.’*

Catherine: *‘It wasn’t the right thing for Adele. She was terribly lonely.’*

Peter: *‘She did work for a while but she couldn’t be paid because it would affect her benefits. It was actually costing her to go to work. She finally decided that wasn’t fair and gave it up. She ended up just as isolated.’*

Catherine: *‘This was a terrible time for us. We knew that things were breaking down for Adele and we were being excluded from meetings that were being held about Adele to decide what would happen to her next. We lost all trust in the people and I came out of the meetings in tears.’*

Then Partners for Inclusion appeared on the scene. The senior social worker and Partners got involved before she left that flat so that there was a good handover.

I was a bit nervous at first wondering if it would all fall apart. We have been scarred as a family by what happened. We were amazed by how flexible Partners were. They have been as flexible as Adele can be contrary. We realise now that being flexible is the only way it will work for Adele.’

Peter: *‘We had gone through difficult times. We felt like we were left to pick up the pieces. We were not involved in the decisions that were being made.’*

Catherine: *‘We have seen progress in the past eight years. We have learned so much. We have such a good rapport with Shelly and the other staff at Partners. It wasn’t always easy. Partners challenged us. We had to step back and look at how we behaved as a family with Adele.’*

Adele has also learned a lot. On the whole, Adele learns from experience but sometimes the experience hasn’t been difficult enough and she makes the same mistakes over again.’

‘Partners have been as flexible as Adele can be contrary. We now realise that being flexible is the only way it will work for Adele.’

Peter: *‘She won’t take advice. She has to learn in her own way.’*

Catherine: *‘We don’t have much to do with Social Services now unless there is a need but we have been involved with Partners in all sorts of meetings over the past few years.’*

Peter: *‘No one ever asked Adele what she actually wanted. We have had so many social workers in the past. We’ve lost count.’*

Adele's Team: Shelly and John

Subtlety, consistency and patience are essential in order to keep Adele's trust, say Shelly and John: 'You can't go in heavy-handed.'

Shelly: *'Adele is strong-willed and intelligent but has very little self-esteem. To begin with, I struggled with some of the risks Adele took and I've had to learn how to respond so she doesn't shut down and stop telling me things. I think very carefully now before I respond so that I get it right for her and I give her lots of time to think about things.'*

It takes time to build trust with Adele and she is very particular about who works with her. She almost has an "I'll hurt you before you hurt me" attitude and you have to understand why she feels like that.

I feel privileged that she has chosen me to work with her.'

'I have learned so, so much from this young woman.'

John: *'Adele's experience is that social workers tell you what to do and take control. Her experiences have not always been good. We have to drip feed stuff so she doesn't reject it. We have to be very subtle and plant an idea and let it take root.'*

Shelly: *'You can't go in heavy-handed with Adele. She would be very agitated in a group home. It would be too rigid. She*

'Sometimes I've got my responses wrong. I've learned to give Adele time to change her mind and her thinking.'

would be very worked up and distressed. I think she would shut down completely.'

John: *'Adele puts huge expectations on herself to be perfect. It's our job to take some of that pressure off her. She is also extremely thoughtful and very generous.'*

Shelly: *'We have to be consistent with Adele. Otherwise she gets confused. That's also why a small team works well for her. There has been some fantastic multi-agency working around Adele. Our instinct has sometimes been to swoop in and protect her but, between us, the family and other agencies, we have helped Adele to keep herself safe. She has a good filter system and can find her own way of assessing risk.'*

There have been nights when I have sat on her doorstep and worried myself sick. But the more you tried to restrict her the more she fought against it and the more secretive she got. We had to figure out ways to help her keep herself safe and to raise her awareness.

You can't express your anxiety or disapproval. You have to be incredibly subtle.

You can't tell her what to do or ask too many direct or challenging questions or she will tell you to leave. Adele sees authority as a bad thing. She is really determined to live her own life and make her own decisions.'

The Partners for Inclusion team has a high regard for Adele's local authority social care lead. Members of the team talked about the unique approach that was taken to identify and manage risk whilst supporting Adele to live the life she wanted.

Bernie, Social Services

Listening to Bernie, it becomes clear that, not only do you need a provider that can support Adele in a creative and careful way, you also need someone thoughtful and committed in social services.

Bernie became involved with Adele and her family at a crisis point in Adele's life. This was the time when Partners for Inclusion began to work with her.

Bernie had worked with Partners for Inclusion before. She described how subtle and careful the work with Adele needed to be to achieve a balance between managing risk and supporting Adele to live the life she wanted.

It is clear that Bernie and Partners for Inclusion have an open and honest relationship.

'The good thing was we that we learned together. We had plenty of discussions and some challenging debates about how we would work. We had to be flexible and think carefully about how we handled risk. We didn't want to drive Adele underground. She would have become

'The good thing was that we learned together. We had lots of discussions about how we worked. Some of these discussions were challenging.'

secretive and we had to be very subtle about how we handled things.'

Several protocols were drawn up to reflect changing circumstances and, on one occasion, to reflect new concerns around Adele's safety.

'It is this adaptability which is crucial in working with Adele. This is a young woman

who is headstrong and will get what she wants but she has little understanding of some very significant risks to herself.

Adele has challenged every one of us to think about how we respect people's decisions.'

Bernie's commitment to Adele is strong. She knows Adele well and understands that Adele is unique. Bernie has gone beyond the normal expectations of her own role to ensure that Adele is able to live her life in the way she chooses.

'Adele has challenged every one of us to think about how we respect people's decisions.'

The way in which Bernie and the team from Partners for Inclusion have worked together to support Adele is dynamic and, to an extent, organic. A flexible response to Adele's life changes has been a critical success factor.

Jane

Jane

Jane lives in her own home in Kilmarnock. She is 40 years old and has a learning disability. Before she moved into her own place, she had many unsettling years during which she was moved from one service to another. None of these services worked for her.

Jane has a diagnosis of Developmental Dysphasia. This means she has difficulty processing and understanding information. Jane spent her childhood at home with her parents and sister attending first mainstream then special schools. Jane left school and attended college independently. She went on to hold down two jobs.

Jane wanted the same things for herself that she saw her sister doing: having friends and boyfriends, working and getting married. Jane was very independent and tried to make these things happen using her own initiative. However, her difficulty in understanding made her vulnerable and she became increasingly unable to cope.

Jane wanted her own home just as other people did. She spent time in a training unit learning the skills of daily living. She liked it there and completed the unit successfully. After that, she lived in a couple of flats with indirect support. This arrangement did not work well for her. She became increasingly isolated and she struggled to fit in with her neighbours, who also had learning disabilities.

As time passed, Jane's mental health deteriorated and, increasingly, she began shouting and saying she was hearing voices.

In the end, she became very upset and was admitted to a psychiatric hospital. At this point, she was referred to a learning disability hospital for two weeks for assessment and treatment. She stayed there for four years, detained under mental health legislation. During these four years, Jane deteriorated. She lost many of the social and language skills she had gained and was physically aggressive on a regular basis.

Funding was eventually secured for her discharge as part of the closure programme for the hospital. However, there were many concerns about her ability to live in the community because of her erratic and aggressive behaviour. Assessment showed that she needed a supported-living service in a home of her own.

This would need to be a service that was tailor-made for her. Services that had supported her before had claimed to be individualised but, in reality, they were not. Partners for Inclusion was

commissioned to provide this service because they had the ability to provide a genuinely individual service and they

had experience in supporting people with a reputation for challenging services.

Jane's dad

Partners started working with Jane before she left hospital. They steadily got to know Jane and made a careful plan with her and her family.

Jane's dad takes up the story:

'At first, there was funding for just six hours a week. But this was enough for Partners for Inclusion to start to get to know Jane while she was still in hospital. They spent the time working out what sort of support would work for Jane. They thought about how they could use the hours. Then there was the house – what it would be like. And the staff – what sort of people would fit in well with what Jane needed?'

They also made their Working Policy. That's where they put down every detail about what to do if things are tricky. Some of the professionals that know Jane were worried about risk. But, in the end, they all agreed about how she would get support so she would be safe – other people too. Everyone was signed up.

'Slowly but surely, Jane is flourishing.'

It wasn't easy to find a house that was right for her. But, after a time, a private-rented place was found. When it came to

'Jane's mental health deteriorated and she started to shout more and more. She said she was hearing voices.'

the staff team, it had to be people who were a good match for what Jane needs. But all that was written down in the service design. They found people and Jane moved in. At first, she had two-to-one support, all day, every day. She needed this to make sure she was safe and secure. This sounds good but it had its own problems. Jane was quite good at playing one supporter off against another!

After a couple of years, Jane moved house. The first house worked pretty well at the beginning. But it was far away from everything and she needed somewhere with a bit of life – shops and community and so on. Partners had a go at a new housing spec. It had to be somewhere with plenty of space – somewhere detached. A housing association found the right sort of place and rented it to Jane.'

Having a service individually tailored to her needs has resulted in fewer episodes of physically aggressive behaviour. Jane is no longer under a Community Treatment Order, which was in place when she moved into her house. Instead, Welfare

Guardianship is held by her mum and sister. It's taking time but Jane is doing well, working with her support team to build more into her day. Her support package has gone down from two-to-one to one-to-one on a 24/7 basis.

Jane's team

Members of the team describe how working with Jane to get her own place to live was just the beginning. Bricks and mortar are not the only thing that make a good life.

It took Jane a while to settle into her new place. By this time she had a consistent staff team. They tried to help her to get some structure and routine in her life so she could feel safe.

'Jane used a weekly planner to organise her weekly shop, pay bills, go to the bank, make family visits, go to pampering sessions and generally get out and about in her community. After a year or so, she managed without the planner. So, in some ways, things went well. But, at times, Jane was still unhappy with her life and would get upset.

So, at yearly planning days, we thought about what Jane wanted out of life and the team decided to step things up – to really try and make Jane's hopes and dreams come true. There were extra meetings specifically to work on helping Jane achieve the life she wanted.

Jane had always had animals when growing up. She was particularly fond of dogs and horses. After some patient

'I've supported Jane from when she was in an institution and I've seen massive change. Jane is a completely different person because she got the life she wanted.'

planning and searching, Jane and the team found Alfie, an eighteen-month-old dog – full of fun. Alfie had a big impact: Jane had a reason to go out everyday, he was a great companion and he gave Jane some responsibility in her life.

One of Jane's big dreams was a holiday abroad. Together we made up a document, "What Jane's perfect holiday would look like". She visited travel agents to check the options and, in 2010, she had a holiday in Portugal. It worked so well, she's been back there three years running.'

Paul

Paul

Paul is 45 years old. He has a profound learning disability, limited verbal communication and is partially sighted. All members of Paul's family are registered blind. Paul owns his own home, which is in easy reach of his family. He is settled and doing well.

'Over the past couple of years, Paul has achieved things never thought possible for him. He is settled and happy and his life is working in a way that is right for him.'

Paul had a difficult and unsettling childhood. From a young age, he struggled to make sense of the world and services failed to provide him with an environment that was right for him. He attended several special schools but was very unhappy.

Many of the schools were far from his family, which made regular visiting difficult. Students at the schools were other disabled children who had their own behavioural difficulties. This was a frightening experience for Paul, especially because he was partially sighted.

He was bullied and taunted by the other children. He kept himself safe by being physically aggressive. In particular, he would bite the other children and staff.

Lennox Castle

When he was 13, Paul's family was advised by their GP that he was a risk to himself and others and that the only place he could live was Lennox Castle Hospital, a large learning-disability hospital on the outskirts of Glasgow. (This hospital is now closed.)

Paul's family was very unhappy about the idea but were offered no other options. So, in 1980, Paul moved. He did not settle well and he let his family know when they visited that he did not want to stay there. However, there seemed to be nowhere else for him to go. Paul stayed in Lennox Castle for 18 years.

In 1996, Paul's father was visiting Paul and met Simon Duffy. Simon was part of the team developing Inclusion Glasgow, the organisation out of which Partners for Inclusion grew.

‘Paul was bullied and taunted by the other children. He kept himself safe by being physically aggressive.’

Simon told Paul’s father that a programme was underway to close the hospital in line with Community Care legislation. He told Paul’s father that Paul could have his own home with live-in support. Paul’s father was astonished but was keen to explore this opportunity for his son. Simon and the Inclusion Glasgow team met with Paul and his family and arranged a planning day. On this day, person-centred planning tools were used to help everyone think how a supported-living service might look for Paul.

Paul and his family learned about Inclusion Glasgow’s ethos: that everyone should have their own home held in their own name, have their own team and a service designed exclusively around them and no-one else. For the first time, Paul’s family started to believe that this was an option that could work.

Paul had a reputation within the hospital for being aggressive and there were many concerns for his and others’ safety if he lived somewhere else. Paul’s history and those concerns were taken seriously by the team. As well as working out how the service should be designed, a Working Policy was created. This was a document that detailed how Paul’s direct support would work, including a specification of all

the ways Paul communicated, including physical aggression, and how the support team would respond.

Housing and funding problems – the solution was creativity

Next, people at the planning day turned their attention to where Paul should live. He had particular needs that had to be met if this move was to be successful. He needed plenty of space. So it would have to be a big house. It would also need two bathrooms because Paul would not wait when he needed to use the toilet. Public-sector housing could not offer a house that met this specification so other options were considered. It became clear that Paul would have to buy his own property.

As Paul does not have ‘capacity’ (is considered to be unable to make his own decisions) a family trust was set up to manage the process on his behalf. A house was found that matched the specification and the complicated process of buying it began. The trust had some difficulty getting a mortgage payment through the Department of Social Security (as it was known at the time) but they eventually succeeded.

Through the planning process it was agreed that Paul needed two-to-one support at all times. Funding for this level of support proved difficult to get, so the Inclusion Glasgow team started looking at creative options. Eventually, it was decided Paul should have a flatmate who, in return for board, would provide some

of his support. This arrangement would reduce the cost of support. Finally, the support team members were recruited, a process that included Paul and his family. The planning process had detailed the traits and skills that people supporting Paul should have. This meant that the recruitment process was as individualised as the service itself.

Paul found the move difficult and he needed a lot of time to get used to his new home. He still got angry and was aggressive at times while he and his support team figured out how the service could be made to suit him. During this time, Partners for Inclusion was born. It was based on the same principles as Inclusion Glasgow. Paul was the first person supported by the new organisation.

Sticking with it

A principle of Partners for Inclusion's support is that, when things go wrong, a 'debrief' should be held with all those involved: everyone would examine the detail of what happened and think about how they could provide support differently in similar circumstances. This stick-with-it attitude meant that the team continually built what they learned into Paul's service design and working policy.

The result was that Paul's service was always developing and Paul could gain more and more confidence.

Over the past couple of years, Paul has achieved things never thought possible for him. He is settled and happy and his life is working in a way that is right for him. His support levels have reduced from two-to-one at all times to one-to-one.

He regularly spends time with his full extended family and often travels to places with his young nieces and nephews which, in the past, would have been ruled out because of worries about risk. He regularly has family meals out and goes on family holidays. He goes shopping and has recently begun using the bus, an experience he greatly enjoys.

Paul also has a voluntary job a few hours a week in a local library. There has been a big reduction in the number of aggressive episodes. When he was in institutions he would seriously hurt people around seven or eight times a year. Since leaving Lennox Castle 14 years ago, he has seriously injured people on four occasions. The development of a service around his individual needs has reduced costs to the Social Work Department and supported Paul to flourish.

Jim Brady, Paul's Service Leader

Jim Brady has been Paul's Service Leader for the past four years. He has seen significant changes in Paul's progress, particularly in the last three years.

'It took a long time for Paul to trust us after his life at Lennox Castle. He uses very few words to communicate and we have all had to learn different ways to communicate with him. He is certainly

more contented now. He loves music and swimming. He works for a few hours in the local library and meets his dad for a pint and some lunch.'

Donald, Paul's dad

Though upset by Paul's situation in Lennox Castle, his dad was still sceptical that Paul could have his own place with his own team. But he decided to run with the idea.

'When Paul was in Lennox Castle I think he had to fend for himself a lot, not just for food. He was left on his own. He used to sob uncontrollably. He was so distressed and unhappy. It was terrible for me as his Dad that I couldn't do more for my own son.

When I first met Simon Duffy in 1996 he told me what was possible for Paul and I said "You must be mad or a genius."

But if it meant better things for Paul, I decided I'd go with it. Within two years, Paul had his own house and car and a

'It was terrible for me as his Dad that I couldn't do more for my own son.'

team of people to support him. He goes swimming. He likes to get the bus and go out for a meal. We all go on holiday together. He is happy and is doing more and more.'



Roddy

Roddy

Roddy is a young man of 21. He works full time and was recently promoted. He passed his driving test some time ago and now has his own car. He has had several girlfriends although he is single at the moment. He lives at home with his mum and dad but is planning to get his own place in the future. He also has autism and life hasn't always been easy.

Roddy was born in 1989. It was a difficult birth. He met his developmental milestones up to the age of 11 months. His parents say that, when he had the MMR vaccination, he became a different child. When he was 18 months old, Roddy was referred to the psychology service but they struggled to understand what was happening. They talked about Attention Hyper Activity Disorder and behavioural difficulties. They also questioned his mum and dad's parenting skills.

They recommended special schooling. However, Roddy's parents did not want this for their son so he started in a mainstream primary school. Roddy did not enjoy this experience and things quickly broke down. He moved to another local mainstream primary school. The psychology service was still involved and Roddy was diagnosed as having Dyspraxia.

His parents, still convinced there were further complexities, took him for a private assessment and he was diagnosed as having Dyslexia. By year five at primary

school, Roddy was struggling to cope and had a nervous breakdown. He attempted suicide. His parents took him out of school and he went on to be diagnosed as having an autistic spectrum disorder and mild learning disability.

Roddy was then home-educated for 15 months. During this time he continued to deteriorate. He began to self-injure and was frequently physically aggressive.

Eventually, he was moved to a Special Communication Base, linked to a mainstream primary school and this new situation worked well for him. He went onto a mainstream secondary school. This, however, proved to be a difficult experience. He had problems understanding the environment and was bullied for being 'different'.

No direction

He left school at 15 and went to a local further education college. To Roddy and his parents, this move seemed to lack

‘Roddy was struggling to cope and had a nervous breakdown. He attempted suicide.’

direction: he was approaching adulthood with no idea of what he wanted to do.

Roddy and his parents began working with Social Work to consider his future. Lots of options were offered. These included respite care, day services and a placement at a residential establishment for young people with autism. Neither Roddy nor his parents felt that this represented a real plan for his future.

Roddy’s mum had heard of Partners for Inclusion. They liked what they heard about Partners’ ability to provide really individualised support services. But getting the funding proved difficult – at least for the immediate future. At the age of 16, Roddy began to regress. He could see the life he wanted and was aware of what other people his age were doing. But he didn’t see a way to get the things he craved.

His mum and dad thought that, emotionally, he was very young and needed help to mature. His self-injuring increased and he threatened suicide. He became afraid to go outside. Eventually, funding was secured for eight hours support a week and Partners for Inclusion was commissioned to provide the service.

Partners apply the same method of service provision no matter how many hours are commissioned. A Service Leader from the organisation met with Roddy and his family and arranged a planning day, an opportunity to think how Roddy’s service should be designed using person-centred planning tools.

Roddy wanted to be a ‘teenager’ and do all the things he saw other young people doing. His parents wanted that for him too and hoped that as he had those experiences he would begin to work out what he wanted to do with his life.

Not straightforward

Gaining these new experiences was not straightforward. Both Roddy and his parents understood he could not do those things with his parents yet, due to the nature of his autism, Roddy found it difficult to make friends.

The Service Leader listened and began to design the service taking account of these views. The plan was to find male support workers in their 20’s.

They had to be young enough to blend in and mature enough to stay within their role. Roddy wanted to go out drinking, try smoking, have sex, go to concerts and festivals and generally do what all young people that age do. A lot of joint working between Partners and Social Work was needed. The service needed to support Roddy in a way that met Social Work’s criteria for safety and also fitted

the working principles of Partners for Inclusion.

Each week, the eight hours support would be provided in a flexible way to fit what Roddy needed. This arrangement was different from that offered by other providers and services – fixed support at a fixed time. Roddy would also be able to save up and bank hours if he wanted to go to something special.

Roddy and his family were involved in the interviews to recruit members of staff. Recruitment was tricky as it only involved a small number of hours, not provided at fixed times. However, by persevering and not compromising on the specification, the right person was found. The Service Leader worked with Roddy and his family to develop a Working Policy, a document explaining how the direct support should work for Roddy. This policy included detailed descriptions of how Roddy self-injured and could be aggressive and how his supporter should respond if this happened. Further, the different roles of people and services in Roddy's life were set out in detail and explained in order to keep everyone safe and clear about how things should work.

Hanging out with a friend

Roddy and his support worker began spending time together and exploring the hangouts of other young people. Roddy never said he was with a support worker. He simply referred to him as a friend. As Roddy began to experience regular, ordinary things he gained some

‘Roddy wanted to be a “teenager” and do all the things he saw other young people doing.’

maturity. He began to learn about the consequences of his actions – always backed by the safety provided by the support worker. He was able to talk through events and slowly gained understanding of how and why things happen.

Roddy's mum and dad began to feel like parents. They were glad to see their son behaving like a regular teenager while still being able to play the role of disapproving parent at the same time. This more ordinary parental role contributed to Roddy's developing emotional maturity. Slowly but surely, Roddy started to develop his own identity. He left college and his support hours increased to 21 a week. The focus of his support moved on to finding employment. Roddy's confidence had increased sufficiently for work to be a viable prospect.

Taking the lead

As the service developed and Roddy gained maturity, he began to take the lead and deferred less to his parents. The Service Leader was able to support Roddy's parents to let their son become more independent. This was a difficult

process for them although they wanted their son to find his own feet.

Roddy got a part-time job in a local sandwich shop. At first, his support worker went in every shift at Roddy's break so that Roddy had the opportunity to talk through any concerns.

This was done in a discreet way as Roddy's employers did not know he received support. Gradually, Roddy and his support worker were able to scale down this part of the support to a meeting when Roddy's

shift finished. After some time, he left that job and got a job in a local hotel. As at the sandwich shop, support to Roddy about his work was offered discreetly in the background. Roddy continued to gain in confidence. Slowly, he made some friends and got a girlfriend. It became clear that he no longer needed support. The ending of the service was planned – a holiday was the climax.

Roddy continues to go from strength to strength. He does not have any support from Social Work or services.

Kath and Mike, Roddy's mum and dad

Roddy's parents say his support arrangements have enabled Roddy to grow up and they could become parents again.

'We will always be grateful for the opportunities that Roddy has had due to having an individualised service. This arrangement has allowed him to become the man he is today by meeting his needs and empowering him to make informed choices.'

For us, as parents, it has allowed us to watch and be involved in the process of him moving from being a child to an adult. We have been able to become parents again. We strongly feel that, if Roddy hadn't been given this chance with Partners for Inclusion, he would not be achieving what he is today.'



Making
it work

A learning organisation

Partners for Inclusion makes a commitment to the training and development of each member of its staff and has a comprehensive induction and ongoing training programme. This training programme is structured and planned many months in advance.

However, in interviewing the staff teams, it became clear that much of their learning came from working with the individuals they supported and from agencies like Social Work, the Police and Probation, which were also involved with some people.

Unlearn what you think you know

This hands-on learning often came from the collaborative working – both with people who get support and staff from other agencies – to solve difficult issues and from negotiating and compromising, sometimes over long periods of time.

This learning was conscious. That is to say it was a deliberate part of the process – people knew that they were learning and were highly reflective when they spoke about their experiences.

These learning experiences probably form one of the essential success factors in supporting someone in a personalised way.

One member of staff said:

'You have almost to unlearn what you think you know because everyone is so different. You can't make assumptions and, if you come in with hard-and-fast rules, it won't work.'

Commissioning for outcomes

It is clear from these five stories that the financial costs of providing services for the people involved have been high. It is also clear that, not only did some of the previous services not work for the individuals or their families, they actually made things worse – aggressive behaviour got worse, there were suicide attempts and there was great stress and strain on families.

The costs of providing a service in a secure residential mental health or learning disability service can be as much as £250,000 a year. These services were used or proposed for some of the five people whose stories are told here.

These five people and their families did not want a residential group home and have, in some cases, had to fight to get a service that met their needs. In each case, the highly personalised service provided by Partners for Inclusion is not as expensive as a secure residential service. All five people (and their families) are achieving, contributing and flourishing within their communities.

In other words, outcomes for these five people supported by Partners for Inclusion are better than if they had remained in the services they were previously getting.

If Partners' individualised services can be cheaper and achieve better outcomes – such as better mental health and greater inclusion in ordinary life – we might ask why these families had to fight so hard to get them.

The commissioning of support for people with complex needs has traditionally been in relation to social care and health services. But this focus is limited. A broader approach to commissioning now encompasses the role of prevention, informal family and community support, community inclusion and universal services. There has also been a shift in focus from service outputs to the outcomes experienced by end-users.

Commissioning is often represented as a chain or cycle of activities, which can be split into four main stages:

- ✘ analysis
- ✘ planning
- ✘ implementation
- ✘ review.

Commissioning also takes place at three levels:

- ✘ the authority or strategic level
- ✘ the community or neighbourhood
- ✘ the individual.

However, commissioning is not merely a technical process. Commissioning

activities are located within a set of more or less explicit values, principles and outcomes that shape who gets what, how, when and where.

‘...there is an inherent resistance towards change within the social care sector. As presently configured, this sector employs vast numbers of people; provision of care to disabled people is their “bread and butter” service and there is some reluctance to let go of this. By relinquishing commissioning responsibility service providers are, in effect, sacrificing their power and control, a departure that some may find difficult to accept. Among care managers and service deliverers, therefore, there is somewhat of a vested interest and perverse incentive in keeping disabled people “passive” and dependent so that the status quo position in terms of institutions, processes and workforce skills can be maintained.’

Office for Disability Issues: The costs and benefits of independent living, Jennifer Hurstfield, Urvashi Parashar, Kerry Schofield (2007).

But achieving improved individual or family outcomes is only part of the picture and Social Return on Investment (SROI), referred to previously, provides a means of capturing and valuing the longer-term costs and benefits that stem from this improvement in outcomes.

Partners for Inclusion are working to define their services in SROI terms so that they can understand the value of their work for different ‘audiences’. It then becomes easier to work out what is needed to demonstrate this value to their staff, people they support, families,

funding bodies and commissioners. By clearly demonstrating their social value, Partners for Inclusion will be better able to contribute to policy development, service design and the proposal of new ideas.

‘Some people want to be independent and to self-manage their condition; others want advice and support from a personal advisor, sometimes quite intensively, to help them make choices; others are highly dependent upon professionals. However what all these people share is a desire to feel in control, to have a voice in shaping what is happening to them. These personal measures of progress should matter as much as those of the system, with its concerns about efficiency, case loads, targets and getting people into work.’

Demos, London, Personalisation Through Participation The Future of Social Care in Scotland (2005).

This is not rocket science. These people do not need high-tech solutions to complex conditions. They want a sense of dignity, that they count as a person and that what makes them distinctive as individuals is taken into account in the way care is provided for them. They need more personalised support from public, voluntary, family and private sources that is better coordinated around their needs and allows them to make progress in realising their aspirations for a better life.

They want to be seen as a person not as a condition. They want to be participants in their care not just recipients. It is not just that these people want more say in

how public services assess their needs. They want to be able to make plans. Personalisation means support tailored to people’s distinctive needs and aspirations

to allow them to shape those plans and enact them. What would it take to make this the defining feature of social care in Scotland by 2015?

Summary of success

Partners for Inclusion’s approach in supporting people with complex needs has several elements which, when combined, have proved successful with people who were trapped in very expensive, traditional services and for whom the future looked very bleak.

These elements are:

- ✘ Keeping the person at the centre of everything – even when this may seem to be at odds with what others, including family members, may think is best for that person. Working with families to bring them on side with the plan for the person. Partners for Inclusion never forget who they are supporting. They promote and protect that person’s rights and choices.
- ✘ The ability and willingness to be flexible, based on a recognition that each person is unique and will respond differently to any situation. Understanding that sticking rigidly to the ‘rules’ will not always achieve the best outcome.
- ✘ Being innovative and creative – not getting stuck in ‘the way we always do things’.
- ✘ Building a bond of trust is a vital element. Many of the people (and their family) who are supported by Partners for Inclusion have had poor experiences of services and, in some cases, have had to fight hard to get even their basic needs met and their human rights respected. Partners for Inclusion have to build a trusting relationship with people and their families. Often, this can only be achieved over many months – it requires a sensitive and patient approach.
- ✘ The ability to work in partnership with other agencies such as social work, police, probation and health. This partnership working is highly valued by Partners. The relationships between Partners for Inclusion and local agencies is well established and productive.
- ✘ Supporting and developing the workforce through supervision and informal and more structured development programmes. Each staff member who contributed to this publication was happy to acknowledge

how much they had learned from the people whom they support. That learning is conscious and embedded in Partners' culture.

- ✘ Keeping it small and personal – Partners for Inclusion, as a matter of policy, will not support more than 45 to 50 individuals at any one time despite external pressures to accept more referrals. Limiting the number of people enables Partners to remain focused on each individual. The organisation is able to resist pressure to prioritise the processes and systems that can dominate larger organisations.
- ✘ However, Partners do not ignore the needs of those people excluded from its support by its policy of staying

small. The organisation responds by supporting the development of new organisations which will support people in the same way. Partners has started and fostered a new organisation in Scotland called Just Connections and supported the development of a new organisation in Plymouth in the south west of England called Beyond limits. These organisations will remain small and person-centred. Partners and these new organisations share support services such as finance, training and human resources. This arrangement creates an economy of scale without causing the tendency towards bureaucratisation experienced by large organisations.





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