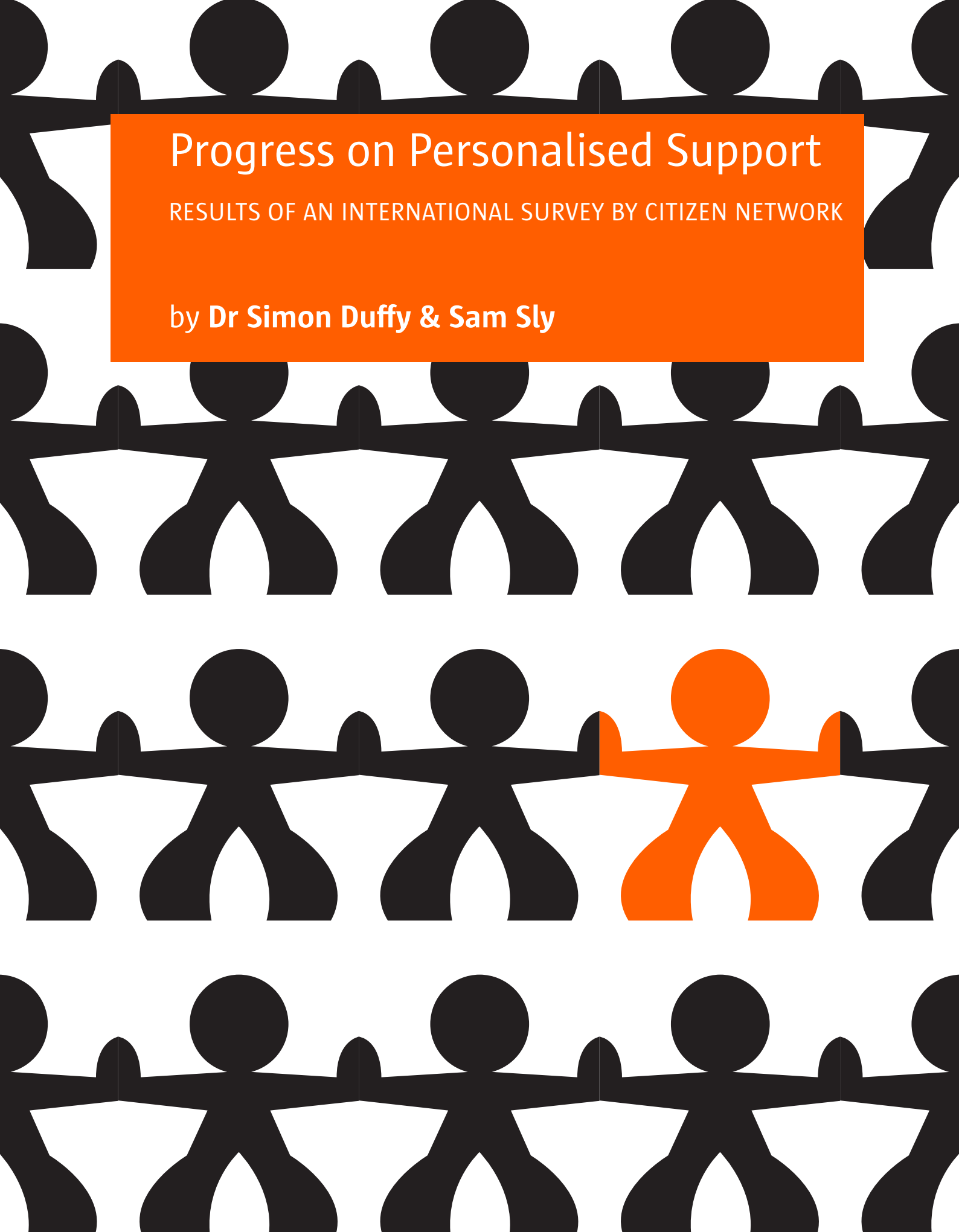
Progress on Personalised Support

RESULTS OF AN INTERNATIONAL SURVEY BY CITIZEN NETWORK

by **Dr Simon Duffy & Sam Sly**



Citizen Network
FOR A WORLD WHERE EVERYONE MATTERS

Progress on Personalised Support

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Summary

Personalised support is a particular model for providing assistance. It has existed for over 25 years and is often associated with high quality support for children and adults with complex needs, in particular people with learning disabilities, autism or mental health needs. However there are many other groups who are benefiting from this type of support and there examples of personalised support being used all around the world.

The five main features of personalised support can be summarised as follows:

1. **Citizenship is the goal** - People are supported to enjoy all their rights as full citizens, playing a full part in community life and developing to their utmost as a full human being.
2. **Fully individualised** - Service design, planning, housing, staffing and management are all organised around the needs and capabilities of the individual and their family
3. **Working in partnership** - Professionals are respectful of the expertise of the person and their family and accountable to them for their work
4. **Committed and flexible** - Professionals do not abandon people when times get tough, they stick with it and figure out the best solutions, changing things quickly to get it right.
5. **Creative and resourceful** - Support solutions are identified that build on the person's real wealth and the resources of their community.

Not only is this model of support consistent with human rights and the lessons of the independent living movement, it also creates better outcomes and makes better use of our shared resources. However, despite these strengths, this model of personalised support is still only found in small pockets. While the language of personalisation or person-centredness is now commonplace, the new practices demanded by these ideals have rarely been adopted in full.

Personalised support, for real, requires a willingness to radically rethink and reform standard organisational arrangements; and while there are organisations that have made this shift, most have not. Fortunately there is clearly a willingness by many around the world to work together and to learn from each other.

Some of the obstacles people face seem to be rooted in funding models that have locked service providers into traditional ways of thinking. A new approach will be required if change is to be achieved. There are currently a small number of commissioners in England who are beginning to take the necessary steps, and there are other examples of good practice internationally.

The slow development of personalised support creates obvious problems for the *Transforming Care Programme*, which works in England to close NHS institutions and private hospitals. A greater commitment to developing personalised support would be helpful, with a more intentional focus on developing the right kind of leadership, organisations and commissioning and support systems.

The Centre for Welfare Reform and many of its Fellows have played a leading role in the development of personalised support in England and Scotland. However radical change will not be achieved without greater collaboration and a focus on the true goal of our work - citizenship for all. For this reason the Centre, along with partners all around the world, has established an international cooperative called *Citizen Network*. One of the particular priorities for *Citizen Network England* will be to encourage learning and collaboration on personalised support.

1. Beginnings

Personalised support is a way of working that can be found all around the world; but it is still a relatively unusual approach. It has not yet found a way of completely replacing models of support that are more institutional or inflexible.

Since the 1960s leaders and professionals began to listen to people with disabilities, families and their allies. Over time the case against institutional services was accepted. However, instead of replacing institutional care with a more citizenship-based approach - enabling people to develop their own support solutions - large institutions were usually replaced with smaller institutional services:

- Day centres
- Hostels
- Residential units
- Group homes
- Adult placements
- Depersonalised domiciliary care services

Usually these smaller institutional services are better than the large institutions they replaced; but they fall far short of our highest expectations for each other. Furthermore they do little to break through the walls of prejudice and misunderstanding that face people with disabilities. For instance, many of the public still believe that community services were designed to 'save money' not to achieve inclusion. This is reinforced by the fact these community services often function as ghettos - excluding people who get support from ordinary community life.

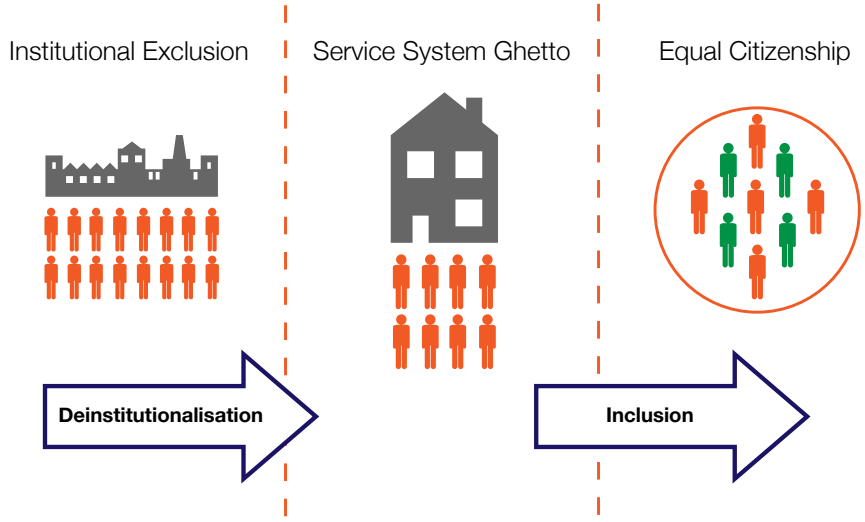

FIGURE 1. Partial evolution of community services

Moreover these services, with their inherent limits and inflexibilities, have particularly struggled to support people (adults and children) with the most complex needs:

- People with complex health care needs
- People on the autistic spectrum
- People who have developed dangerous or risky behaviours

For these people, too many community services have not been successful at supporting meaningful community life. What is worse, too often those with the most significant needs have found themselves abandoned or re-institutionalised, often in the most dangerous environments. When this happens they are sent to expensive private hospitals or statutory assessment units, often many miles away from family and home.

In 2013 the *Returning Home* report described the experiences of families whose adult sons, daughters, brothers and sisters had been at Winterbourne View, an abusive private hospital, which is now closed down, after a television exposé. Two clear messages came through:

1. Families were united in saying that Winterbourne View was one of the least bad services their family members had attended. They were much more critical of some of the other services, services that still continue to exist today.
2. Families all shared similar experiences of systemic failure. Instead of early support to help the family cope with problems or crises, they saw their family member placed in a so-called community service that was in fact institutional and inflexible. Problems would escalate, people acted from fear and anger, and then their loved one would be moved to an even worse service, further away from home.

Unfortunately this problem seems particularly severe in England. By international standards England was one of the earliest countries to close its large-scale institutions; unfortunately this may have also led to the development of particularly unimaginative and institutional community services. For instance, significant numbers of people, perceived as too challenging, were placed in private hospitals, directly from NHS institutions and they never had the chance to try out ordinary life. These private institutions (privately owned, but funded by the state) now cost an extraordinary £190,000 per head and there are still a small amount of NHS run institutions (Brown, James & Hatton, 2017)). Also, when community services fail to successfully support someone with complex needs, too often they will also be sent to these new institutional services.

It is worth noting that this problem has probably been exacerbated by current funding models. Local government, which has only modest resources, often does not take funding responsibility for people who are deemed eligible for NHS funded services. The NHS, which is funded by central government, has many more resources than local government and has been consistently better funded for at least the past two decades. This has created a perverse incentive for local government to allow the NHS to take on responsibility for funding people who can be assessed as requiring institutional care.

1. Usually the child or adult will start off getting support funded by a local authority in the family home. Often this support is inflexible and unimaginative.
2. If this fails they are move into community institutions like group homes, which are also local authority funded.

3. If this fails then the person will be 'sectioned' under the Mental Health Act. The local authority will have no incentive not to block these sections as the funding responsibility falls to local NHS commissioners. The individual may then spend years being 'assessed' or 'treated'.
4. Others may be sectioned by the courts or are deemed to need higher levels of hospital security. In this case funding responsibility falls to NHS England, further centralising resources and control. This means that there is no incentive for the local authority or the local health commissioners to bring people home.

It is interesting to note that these same issues of funding mirror the disincentives built into the national justice system (Hyde, 2010). The costs of imprisonment are borne 'elsewhere' and so the benefits of preventing imprisonment are not felt in the local community.

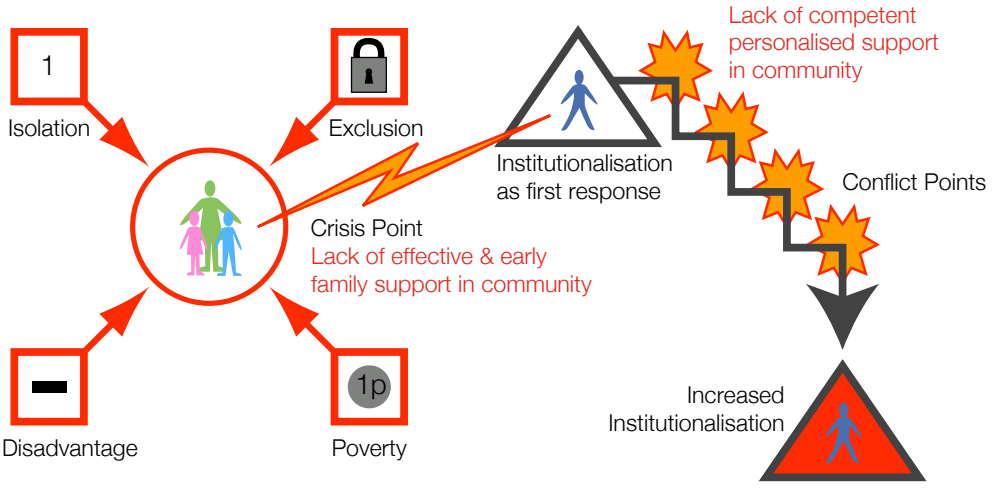

FIGURE 2. **How people still end up in institutional care**

However there have been exceptions to this pattern. As Julia Fitzpatrick describes in her report *Personalised Support*, a small number of agencies were created in Scotland, particularly to ensure that people with the most complex needs could be successfully supported in the community (Fitzpatrick, 2010). This reduced the pressure to fund private hospitals or NHS units; it led to an increased quality of life for the individuals concerned and it helped avoid the enormous financial cost of crisis-driven institutional provision.

However it is unclear how many organisations are providing personalised support nor how widespread the practice is. So, in 2016 the Centre for Welfare Reform used an internet-based survey to identify organisations providing (or aspiring to provide) personalised support. Interestingly that survey results, which are described in this report, suggests that personalised support is found in many different countries (see Figure 3).

The research methodology does not give any reasonable indication of the objective level of personalised support provided in these different counties. However it does suggest that there are a significant number of organisations, spread around the world, who are trying to provide personalised support (see Table 1). It is worth noting also that many organisations began to complete the questionnaire but did not feel that they could complete the section of the questionnaire focused on personalised support. This suggests

that there are also many organisations who may like the idea of personalised support, but find that they are not yet able to provide personalised support.

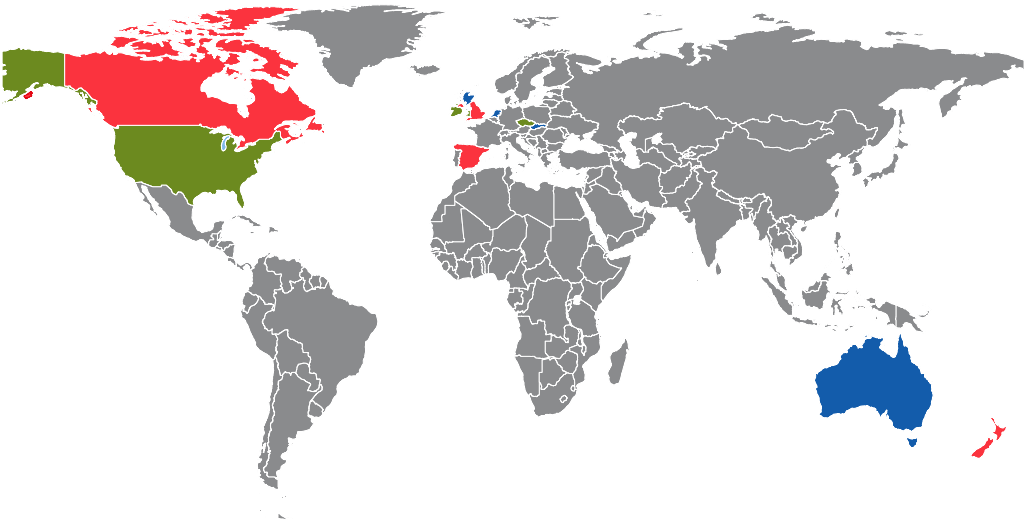

FIGURE 3. Personalised support is an international innovation

Country	Started Questionnaire	Providing Personalised Support
England	126	59
Canada	49	33
Australia	33	23
Scotland	21	12
USA	17	9
Czech Republic	10	7
New Zealand	3	3
Ireland	2	2
Spain	4	2
Wales	2	2
Greece	2	1
Netherlands	2	1
Northern Ireland	1	1
Slovakia	1	1
France	1	0
TOTAL	274	156

TABLE 1. Respondents to the Personalised Support Survey by Country

The survey also asked organisations providing personalised support who they worked with. Interestingly the international survey also showed that this way of working is being used to work with every conceivable group. However it also suggests that this way of working is most likely to be used with people with intellectual disabilities and those on the autistic spectrum. However this may also just be a function of the networks used to share the survey; so this data may not be representative of the balance of support internationally.

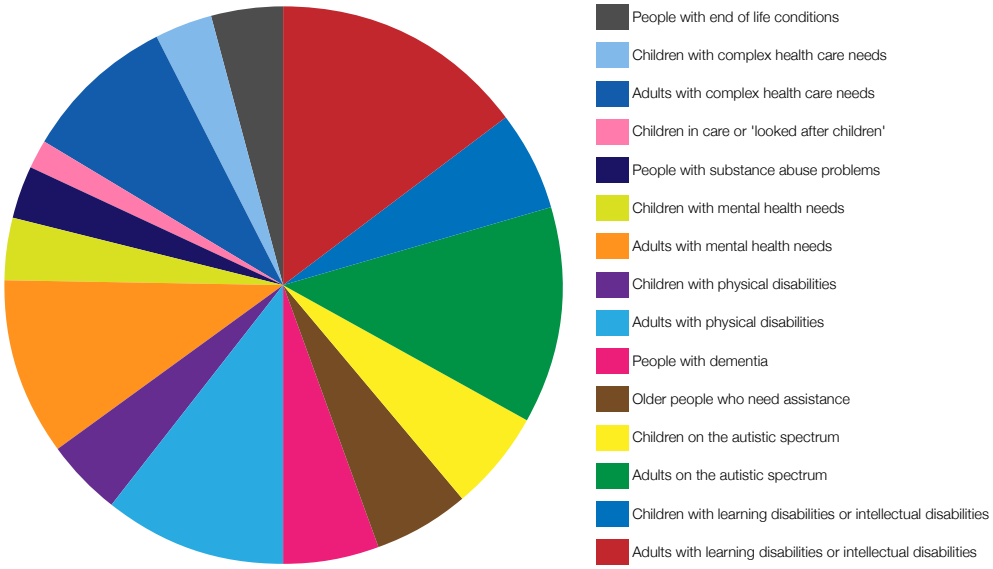

FIGURE 4. Use of personalised support

	Personalise	Share
Adults with learning disabilities or intellectual disabilities	142	91%
Children with learning disabilities or intellectual disabilities	57	37%
Adults on the autistic spectrum	125	80%
Children on the autistic spectrum	55	35%
Older people who need assistance	50	32%
People with dementia	49	31%
Adults with physical disabilities	101	65%
Children with physical disabilities	42	27%
Adults with mental health needs	98	63%
Children with mental health needs	35	22%
People with substance abuse problems	27	17%
Children in care or 'looked after children'	16	10%
Adults with complex health care needs	86	55%
Children with complex health care needs	32	21%
People with end of life conditions	33	21%
Other	18	12%
TOTAL	156	

TABLE 2. **People who use personalised support**

2. What is personalised support?

Professor Mansell, one of the leading experts in this field, identified 5 key features of good support for people with complex needs and challenging behaviour (Mansell, 2010):

- Good services are individualised and person-centred
- Good services treat the family as expert
- Good services focus on quality of staff relationships with the disabled person
- Good services sustain the package of care
- Good services are cost-effective

As we will see in the evidence that follows, these common-sense features of good support - while still too rare - are also reflected in the personalised support model that emerges from international best practice.

The survey asked questions about 10 different elements of good practice:

1. **An individualised approach to service design** - Support is organised around the needs, priorities and capabilities of the person, as opposed to slotting people into pre-existing service slots or placements.
2. **Creative planning** - Planning is not drive by standardised planning tools or person-centred planning tools; instead people take a creative and flexible approach to planning that enables the person to be at the heart of decision-making.
3. **People and families making decisions** - People and families are enabled to take control of critical decisions, in every area, but especially over the use of their budget.
4. **Quality checking by people and families** - People and families play a critical role in keeping the organisation true, checking the quality of support and making the organisation accountable.
5. **Individualised policies and procedures** - There is no reliance on standardised policies to reduce risk; instead detailed attention is paid to the specific needs of the person to help them, their family and others to work together to stay safe.
6. **Matching staff to people** - Supporters are recruited and contracted in ways that ensure that the person gets support from the right person for them.
7. **All housing options considered** - People are supported to find their own home, living with the people they choose; they are not placed in group or residential care simply for the convenience of the support organisation.
8. **Protected budget (or Individual Service Fund)** - Not only is funding individualised, it is also transparent and protected; it is used for the benefit of the person and safeguarded for their future benefit.
9. **People & families recruit staff** - People and families have a real role in recruiting and, if necessary, firing their own support staff.
10. **Direct management possible** - The organisation can support people to take on the direct management of support staff or it can share management responsibilities with them.

In the international survey respondents were asked a series of questions about how they provided personalised support. They were offered four options for each question:

- Yes, frequently
- Somewhat, not always
- No, not really
- Not applicable

When the responses were analysed it was clear that all the proposed elements of personalised support seemed relevant, but that some were much more frequent than others (see Figure 5).

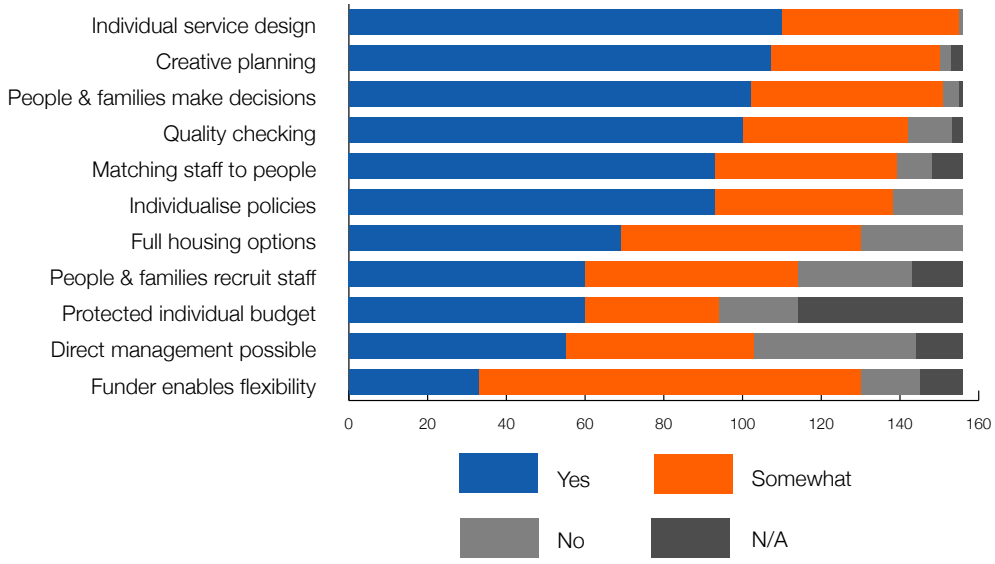

FIGURE 5. **10 elements of personalised support**

In summary this data suggests that, from within this self-selected group of organisations, most aim to plan and organise support with flexibility and a focus on the person's real needs. Many are also working in close partnership with people and families and giving people a high degree of control in a number of different areas. However fewer organisations are quite as personalised when it comes to questions of funding, staffing and housing. Many organisations are perhaps still moving away form older models, group homes or domiciliary care.

One further question was asked, not about the model of support, but about the level of flexibility allowed by the funder for the service provider. For this question only 21% of support providers believed that their commissioning arrangements consistently gave them the necessary flexibility. For the other questions responses rates were much more positive. Just to give some examples of the range of responses:

- **99%** of organisations provided support that was **individually designed** some of the time or all of the time, with **71%** saying that that **every service** was individually designed.
- **96%** of organisations did not use standard person-centred planning tools sometimes or always, with **69% never using standard person-centred planning** tools.
- **89%** matched staff to the person, sometimes or always, with **60% always matching staff**.
- **Only 35%** of organisations always allow family or the person to **directly manage** their own support staff, but in most other domains there was significant recognition of the need to give people and families high levels of decision-making power.

One important element of this model, although one which is only used consistently by 38% of support providers is an Individual Service Fund (or ISF) - protected individualised funding. However it is also clear that the use of this approach was slowly increasing (see Figure 6).

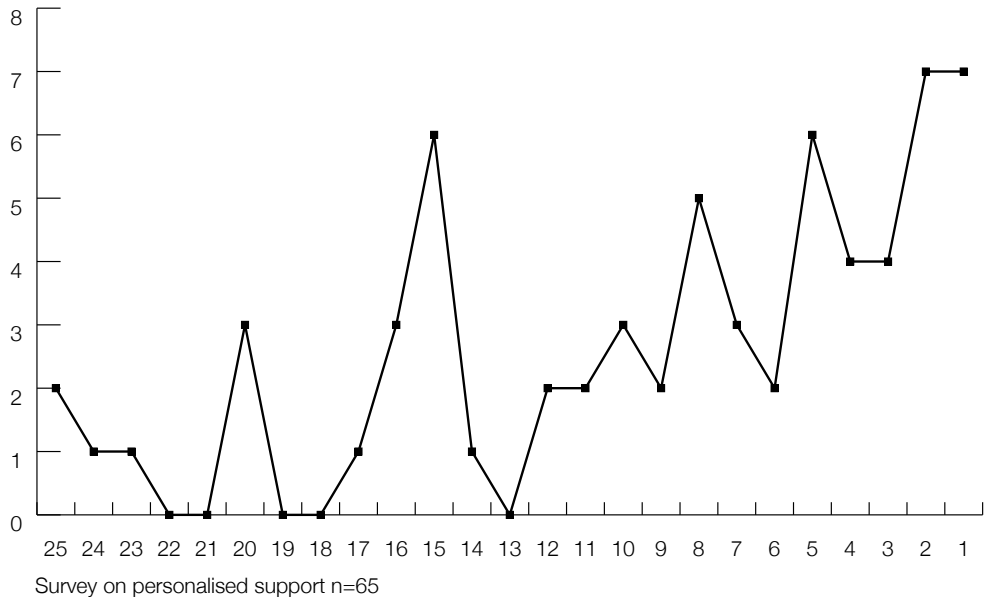

FIGURE 6. **How long organisations had been using ISFs**

Moreover, when the length of time using ISFs is compared to the consistent use of all the elements of personalised support it is clear that those organisations who have been using ISFs longest are also those who are most likely to be providing all the other elements of personalised support (see Figure 8). This reinforces the sense that there is a journey

towards personalised support and those organisations who have been trying to do this longest are most likely to be doing it more consistently.

None of this proves that personalised support is effective. These results are based on self-reported data and there is no proven connection between the organisation's use of personalised support and the quality or effectiveness of their support. However, these findings do suggest that there is a model of support, emerging around the world, which has many linked and coherent features and which has been in existence for at least 25 years.

Clearly these findings are also highly consistent with the model proposed by Mansell. However I am going to propose a small amendment to Mansell's model, based on this research and the more recent publications on this topic. We will define five essential features of personalised support as (see Figure 7):

1. **Citizenship is the goal** - People are supported to enjoy all their rights as full citizens, playing a full part in community life and developing to their utmost as a full human being (Duffy, 2006; Sly & Tindall, 2016).
2. **Fully individualised** - Service design, planning, housing, staffing and management are all organised around the needs and capabilities of the individual and their family (Fitzpatrick, 2010).
3. **Working in partnership** - Professionals are respectful of the expertise of the person and their family and accountable to them for their work (O'Brien & Mount, 2015).
4. **Committed and flexible** - Professionals do not abandon people when times get tough, they stick with it and figure out the best solutions, changing things quickly to get it right (Hyde, 2012).
5. **Creative and resourceful** - Support solutions are identified that build on the person's real wealth and the resources of their community (Murray, 2010).

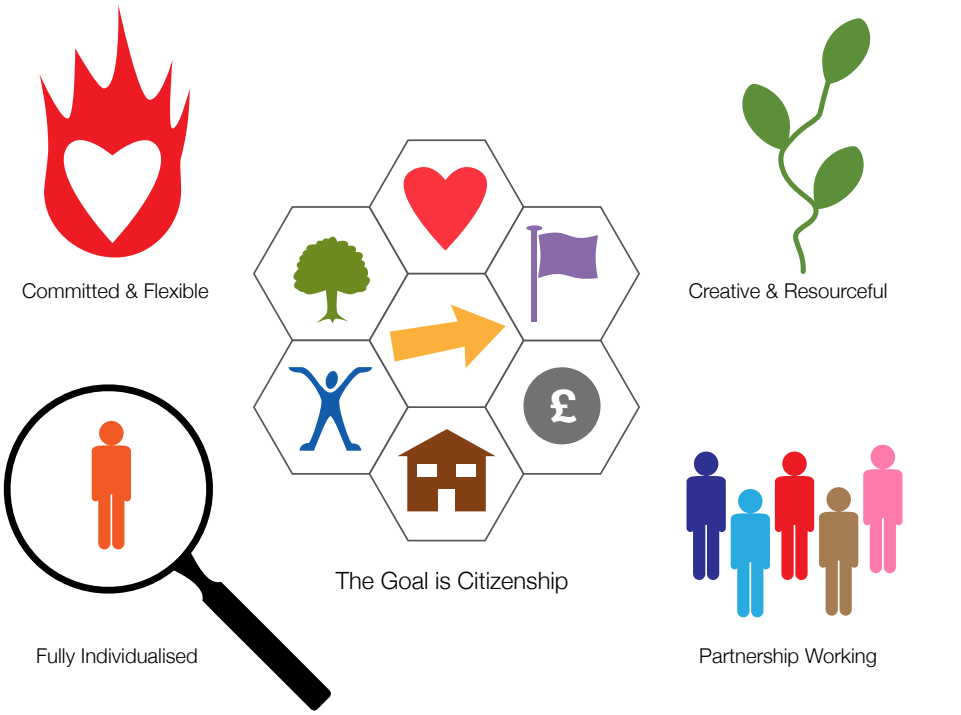

FIGURE 7. 5 features of personalised support

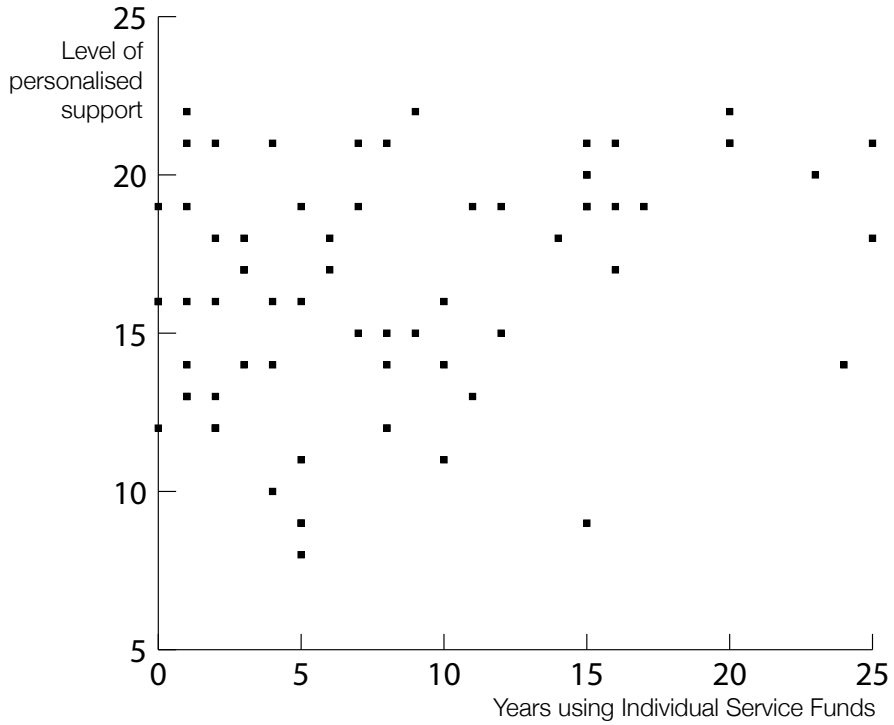

FIGURE 8. Link between ISFs and personalised support

While our international survey does not provide any new evidence on the effectiveness of personalised support there are a number of different sources of information which do reinforce the common-sense expectation that providing support that has been carefully designed around an individual's needs is more likely to be effective.

There is a significant international literature on the effectiveness of self-directed support. However these reports do not always distinguish when someone has chosen to manage a budget for themselves from when they have organised personalised support through a support organisation. Some times researchers treat the wide system reform as the critical innovation; less attention is paid to the important details which shape how people are supported.

Other times personalised support has not been an option. For instance the major *IBSEN* report which reviewed the first use of personal budgets in England found only 4 people using an individualised support provider (Glendinning et al., 2008). Interestingly the same report found that many older people did not like the responsibilities of managing a direct payment; however this has not yet led to an increased use of personalised support, instead of direct payments.

Reports that primarily focus on personalised support include the following:

- *Personalised Support* by Julia Fitzpatrick describes the model of support as applied by Partners for Inclusion in Scotland (Fitzpatrick, 2010). This report includes case studies but does not provide any overall evaluation. Five detailed stories of people supported by Partners for Inclusion are told in *Freedom Fighters* (Hyde, 2012).
- Financial data from Partners for Inclusion was analysed by the Scottish Government and this showed many of the efficiency improvements that come from personalised support, as people grow in confidence and form community relationships. This analysis is outlined in *No Place like Home* (Squire & Richmond, 2017).
- A review of Inclusion Glasgow's work by the Animate research team in *Individual Service Funds: learning from Inclusion's 18 years of practice* found significant efficiencies and outcome improvements (Animate, 2014) with reduction in support over time of 44%.
- Successful early piloting of personal budgets in Finland, described in *Personal Budgeting in Municipal Disability Services*, was carried out using Individual Service Funds as the only practical means to give people control within the existing legal structures (Eriksson, 2014).
- *Testing out Individual Service Funds and spending a budget flexibly* describes how the use of ISFs in the Highland saw increased "activity, community engagement and increased or renewed relationships" (Reekie, 2014).
- *Better Lives* describes the impact of a supported living service provider beginning to offer more personalised support as their block contract was converted in to 85 ISFs (Ellis, Sines & Hogard, 2014). Despite a 28% reduction in overall funding people experienced improvements in their quality of life.
- *Returning Home* and *Getting There* describe the development of a personalised support provider to develop services for people with complex needs (Duffy, 2013; Duffy, 2015).

We would be very grateful to know of any further research that might help us understand the value or challenges of providing personalised support.
Email: hello@citizen-network.org

In addition to providing data the organisations aspiring to provide personalised support identified a vast number of stories of success. What follows is a selection of different examples, demonstrating some of the diverse ways of working and their benefits. Not every organisation works in the same way, but they share a common aspiration to support people to achieve citizenship.

Minor amendments have been made to these stories for the sake of consistency, anonymity and to respect the dignity of everyone involved. Sometimes fictional first names have been applied and we have also tried to anonymise the support provider where possible.

Stories

Case studies in personalised support

Adam - Helping someone really be listened to

Adam wanted to leave school at 17 but this was not catered for and endless meetings led to ever increasing stress for him and his family. Things at home were breaking down as Adam lashed out at verbally and physically at those whom he loved most. The decisions as to what was available changed almost weekly! The spiral seemed endless. Bacon butties in the conservatory, with family and PA's gave Adam and his family their first taste of taking control - having choice - having the opportunity to talk about how Adam wanted his life to be. Although 6'4" Adam somehow grew taller and happier, for the first time being listened to. Adam's *One Plan* - the one by which he wants to live his life was formed. A normal one for a teenager - with as many questions as answers - "Where would I like to live, work, socialise and be me?" Going to meetings wasn't about what was available anymore but "How does that fit with what Adam wants?" He took HIS PLAN to the local authority panel - no-one had been allowed to do this before. With a visual prompt sheet he told the managers how he wanted his life to be and at the end turned to them all and said: "I'm sorry for my behaviour over the last 2 years - but no one was listening to me!"

Brian - Trust and creativity

Brian needs support to keep on top of his home, his bills and all of the boring stuff. He has a great talent for history, media and is passionate about his local area. We were approached to support Brian for 9 hours per week by his local council. After a bit of 'proportional' planning we asked the council if we could convert his 9 hours of support into an Individual Service Fund. Brian didn't want a worker from us but wanted to employ his own PA. We supported him to advertise for a PA who could help with practical household tasks and also with multi media. We interviewed a lovely university student on a media course; after the interview Brian decided he was worried about inviting a stranger into his home. So Brian now employs his sister for 3 hours per week. He trusts her to help him at home. We've used the rest of his Individual Service Fund to pay for a local social entrepreneur with a Media Company to spend 2 hrs every fortnight with Brian supporting him to create a documentary about the changes in his local area and supporting him to learn filming and editing skills – and bought some equipment. Result!

Chris - Real relationships

Chris is a 26 year old man with an intellectual disability. He lives at home with his mum and dad and has attended a special school and day centres all his life. He came to us because he heard that he could have a volunteer or friend from the community. David is another young man and volunteer who has been matched based on interests, age and location with Chris. They were matched through a process that we use to pair up a young person with intellectual disabilities and a volunteer from the community. All people in this matching are considered volunteers, both the person with a disability and the community volunteer with "typical cognitive functioning". After our staff (usually volunteers also) get to know the volunteers through formal and informal interviews, they pair them up as buddies. They are paired for at least one academic year and during that time they call each other once a week and meet twice a month just to hang out and do things they like together. They go out for coffee, they meet each other's friends and family, and they go to movies, parties, sporting events and whatever else they like to do. They have been friends for the past two years.

Dawn - Focusing on the individual

We are currently supporting a 39 year old woman, Dawn, who lives in a rented 2 bed house with 24 hour support from us. She was, until last year, at serious risk of harm, according to the local authority. Thanks to our 1:1 personalised support Dawn is expressing herself more vividly and started to sing again. Her family and the professionals around are moved by her positive transformation and the outcomes she has achieved with the help of our trained staff. She is now able to enjoy active citizenship.

Edward - Careful planning and building on relationships that work

Edward, who had been living in residential care for many years, with at times very challenging behaviours, was supported to move for the first time into his own home. We bought a 2-bed bungalow in a location and context ideally suited to his needs. We recognised his anxiety levels would be significantly increased by these changes. So we selected a team of 5 workers, all of whom had known him well for over 10 years, to support him and ensure that he was with people he trusted and was familiar with. His challenging behaviour has since diminished considerably. In the past his behaviours meant that he only left the care home once a fortnight. Now he goes out most days, sometimes by bus and attends a gym and work activity on a weekly basis. He is clearly more secure, confident and flexible.

Fred - Getting the staff right

Four years ago we supported a Fred to leave a local Assessment and Treatment Unit. He had a massive reputation and many thick files, little was known of the real man. We worked alongside him in the hospital, 2 of his current support team worked with him for a couple of weeks before he moved. There was a detailed, and impossible to achieve, housing specification based on what the hospital staff felt was important. The creativity was working out what was really important and what could be managed without. A bungalow was bought for him with a big garden near open spaces to walk. It is an ordinary home in an ordinary street. The only modifications were to reinforce one piece of internal glass and to put hand rails in the garden, as he is losing his sight. The change in him is remarkable he now talks to us all, he jokes, he has reestablished himself in his family and is naturally part of family events. At his sisters wedding he walked her down the aisle. We made a film about his story for the local commissioners, this has been very powerful and challenging to people who see it. The creativity has been finding the right people to support him and to support them well so they stay. In four years there has only been one change in his staff team. We have not needed to use any physical interventions so have taken them off his support plan and have reduced the cost of his package by reducing the number of support hours he needs. Most importantly he is happy, healthy and beginning to be known for himself and his qualities.

George & Harry - Hopefulness

George, one of our support workers, who himself has a disability, supports Harry, a young man with autism, who was initially very anxious, slept all day and was about to lose his job. George persisted in encouraging and mentoring Harry who now does well in his job and has built up a micro-business, making and selling beautifully crafted wooden items, and is so happy with his life. The pair have a great relationship, having fun together.

Irene - Community-focused creativity

Irene, a woman in her mid 40's whom we support brings a zest to life, a quirky personality, and a keen interest in the world around her. She also has a range of physical and intellectual disabilities, as well as experiencing mental health issues. She has partial sight and communicates via sign language. Her appalling experience as a young woman in a large institution unsurprisingly exacerbated a range of challenging behaviours and on referral to our service, required 2 staff to support her around the clock. With highly intentional, creative and flexible support over many years, this woman is now living independently in her own home with daily support, contributing to her local community through volunteer roles (including teaching sign language to members of her church), she has a strong circle of friends, and 2 years ago she began her own small business selling dried fruits at local cafes. Her quality of life has increased exponentially with an inverse reduction in ‘cost’ to the service system.

Jacob - Spirit and belief

Jacob is an elderly, home-body of a man who lived most of his life in an institution. He is Jewish and had no faith community involvement. He was supported to find a synagogue that he wanted to occasionally attend, but he prefers to stay at his home. He is the only Jewish person at his home and there were no Jewish employees there at the time. A Sabbath in a Box was created for him to use every Friday evening to connect him with his larger community of faith and heritage. Many people from the local Jewish community assisted with creating the Sabbath Box with him.

Keith - People and technology

Keith moved from a fully staffed group home to a home of his own in which he is supported by family, neighbours and a small amount of staffing support over the course of a week. He has been supported to find some useful assistive technologies to help him live an independent life (reminding him when to is time to take medications, alerting him to phone and doorbell as he also has a hearing loss. He has a wide and varied social life, all of which he participates in with his friends as opposed to staff. He has a number of social roles and he is missed when he is not around (visiting family usually or on holidays). From a life determined by services, he now lives his own life and is content and happy. He has a circle of support made up of friends, family and some staff with whom he has a really good relationship and who he invited to be part of his life.

Lee - Communication

Lee is an elderly woman who lives in Perth, Western Australia. Lee's husband died last year, leaving her feeling isolated and lonely. She speaks Cantonese and it is difficult for her to communicate in English. Lee's son Foo lives in Singapore and supports his mother by email. We are lucky to have Mei who speaks Cantonese working with us. This has made communication much easier for everyone. Lee and Foo decided to find a support person from Lee's local community. Mei, a friend of Lee's from Church, introduced Wendy to Lee. Wendy is an ex-nurse and speaks Cantonese. Lee is now employing Wendy directly with some help from us. Lee worried about falling when she was alone. Mei helped her arrange an alert alarm and set up four friends' numbers to contact if there was an emergency. Lee also needed more help with window cleaning and pest control and Mei helped her find a contractor whom she could trust. These things have only cost about $3,000. Lee is now eligible for a $14,000 funding package which she can use to help her live at home and contribute to her community.

Mark - Finding people's passions

Mark came to us from a traditional service and he had a reputation for challenging behaviours. We were told by the commissioner that he required close supervision and 1:1 support in his previous day service. In a short time we were able to ascertain he liked cars by the fact that he spent a lot of time around staff's vehicles. We found him a role in a local car yard where he worked alongside other staff maintaining the cars in the yard. Mark was supported to develop roles he valued and skills that enhanced his sense of self and confidence. Staff at the yard were supported to understand how to support him, which led to the development of friendships and relationships. Within 6 months, he did not require staff support at all and he worked there for many years with no sign of the "challenging behaviours" we were warned about.

Norma - Freedom and responsibility

Norma is a young women with complex mental health needs and challenging behaviour. Norma asked us to be her service provider because she was unhappy with her provider. At the time Norma needed 1:1 support and did not go out alone. After one year of being with us, Norma is now travelling across the city independently and has a work placement once a week on the reception at our central office where she takes all the incoming calls - something that I as CEO would be hard pushed to do.

Oscar - Human rights

Recently, Oscar, a young man living in typical 24 hour group home accommodation, was told by the service he needed to move further away to another service, as the one he was in was closing. He did not want to move. This violated his human rights, I became involved and facilitated an authentic and individualised person centred planning process with him, his supporters and key people. As a result, and honouring his voice and vision, he now lives independently in his own home, with support tailored to him (despite 'the service' saying he could only live with constant support due to behaviour etc.), he has just secured a job in mainstream employment (first one ever), is self regulating his support, and uses each day his activity and support plan to take his medication, complete his tasks and plan what he needs to do. He is forming relationships in community and is beginning to live an 'ordinary life' like anyone else. His mental well being and coping has improved and he is more resilient to deal with anything. Oscar has a girlfriend, and is actively pursuing his goals and dreams that he wouldn't have thought possible. This came about by not deviating from his vision, often challenging 'the system', and taking measured and mindful risks. An experience I am very proud of.

Petr - A life of meaning

Petr used to live in an institution, for many years, and his legal capacity was restricted. His refusal to obey the institution's regulations (smoking and drinking beer) the institution and his (public) guardian decided he should leave. He was moved to a hostel, where he had more freedom but no support. Petr was absolutely not in control of his life. He wanted to restore his legal capacity and asked us for help. Our social worker coordinated the development of a support plan for decision making and legal acting and our lawyer prepared material for proceedings, including a proposal of a contract on assistance in decision-making. A lawyer also represented Petr in the court. In the end, Petr's legal capacity was restored and the contract was approved by the court. After restoring legal capacity his social worker organised a planning meeting. Using the PATH format Petr explored his own future and next steps: to find a job, change the place to live, have more friends, go to music festivals etc. Actually he is working on the fulfilment of his planned goals. His social worker also helped him to gain new skills – mainly to manage money, recognise and face an abuse etc.

Roger & Simon - Respecting disability & difference

I met with an Roger about finding him a support person and he told me he wanted me to find someone like him with point 3% margin for error (he has Asperger's). So I put out a call for a support person on the autism spectrum (we hadn't really done this in the past). I ended up finding Simon. When I introduced the Simon to the Roger and his mother, Simon was able to explain to the Roger where his mom might be coming from, and the same for the mother. We have gone on to match Simon with other individuals on the spectrum and the individuals open up to him in ways they don't with anyone else. They feel like they have someone who understands them.

Thelma - Housing matters

We have provided accommodation support for Thelma, a young woman who had been rejected by every other service provider and her family. Over time and with support from commissioners we modified our respite house to include a fully self-contained bedsitter with ensuite and decorated it in her style - 'funky!' Thelma is supported 24/7 by young staff who really like her and make her feel valued.

Victor - Putting people in control

A family came to us and said that their son, Victor, needed 24 hour supervision in a staffed environment due to potential verbal and physical outbursts. We listened to what Victor wanted to pursue, They had requested a $150,000 budget. We ended up finding him a housemate that he helped choose. We assisted him at his work. Victor now supervises other people in a kitchen at a local nursing home. He ran the show at work on Christmas this past year. He skateboards around the town of Littleton. He idolises his service coordinator. This past year, he shaved the top of his head, in order to look like his bald service coordinator for a Halloween Dance! He continues to grow in maturity as he navigates the bumps of life, with a little support.

William - Communication and technology

William, a young person with a diagnosis of severe autism challenging behaviour and epilepsy, started to attend our service. William had a history of exclusion from special school, college etc due behavioural issues. We believe that all young people who attend our service should have some method of communication. This person came to our service despite many exclusions, many professionals including teachers in special schools, SALT input without any form of communication. We designed a communication plan, an individual programme to enable this person to communicate. Initially this was through a visual timetable and communication book, over a year this was adjusted and adapted to meet his individual needs, likes, and targets, all of which interlinked with his person centred plan. We then purchased a mini iPad and using software with a voice output, transferred all of his communication to this. He now uses this when he is with us, when he is out in the community to say what he wants to say, request what he would like and feels totally included, ultimately his voice is heard. There has been a drastic reduction in behavioural incidents.

4. What's getting in the way?

The obvious questions, given what we've discussed so far, are:

- Why is there still so little personalised support available?
- Why do inflexible and institutional services still predominate?
- Why has the change to genuine inclusion and respect for human rights been so hard to achieve?

Three possible reasons include:

1. **Loss of values** - Early progress in deinstitutionalisation was based on the explicit values of normalisation and social role valorisation. Later progress has been driven by similar values, such as the advancement of disability rights. However in the UK and in many other places policy is dominated by more ambiguous concepts like efficiency, best value or choice. Moreover some professional groups still seem to operate from medical or eugenic values that do not treat all people as equal. The movement for change seems to have lost its momentum, power and passion. We need to put fundamental values back into our work.
2. **Lack of drive** - Most of the services that have demonstrated the most innovative practice are small, entrepreneurial and rooted in values-based practice, often working closely with families and disabled people. However it is rare to see any strong drive for change at the level of the system or government policy. Even when the values of personalisation or human rights are expressed in official policy these values are not converted into any concerted plan for change. We need to challenge systems that have become too compliant and too ready to promote inadequate standardised solutions. We need to promote creativity and a focus on the gifts of communities and citizens, instead of relying on standardised commissioning and control systems.
3. **Lack of support** - Even when organisations want to change there is an absence of readily available information about what to do differently. Regulators, trainers, educationalists are still locked into the old models of provision. Only the families and professionals who have led these changes hold the necessary knowledge, and they are scattered and under-resourced. We need to work together, cooperate and reject the stale models and competitive ethos being promoted in so many areas.

Austerity may also be playing a negative role. Clearly some governments are using austerity to roll back on deinstitutionalisation and encourage the use of more congregate services (Jackson, 2017). However it should be noted that progress on true inclusion seemed to be slowing even during the period of relative growth, and so it cannot be finances alone that are shaping policy.

We will turn to the first of these issues in the following section, but here we want to outline some of the many practical issues that organisations - even those who aspire to provide personalised support - feel they could benefit from more support. In our survey we asked providers of personalised support to identify the issues that they'd like to find out more about.

4.1 Things people want to learn

Grouping similar issues together. In (descending order) these were the areas where people said they would like to learn more. The number in brackets is the number of organisations who mentioned this topic:

Personnel issues (23) How to recruit, match, train, accredit and support staff

Power and accountability (21) How to share power (direct PA management, shared management, family partnerships, circles etc.)

Financial management (21) How to use flexible individual funding in practice (ISFs)

Commissioning (17) How to build the right relationship with funders

Cooperation (16) How to learn from and work with other organisations

Quality (11) How to improve quality (quality checking, outcomes, management etc.)

Inclusion (11) How to enable community connections and natural support

Team management (10) How to organise teams, leadership and governance structures (including self-organising teams)

Risk management (9) How to manage risk for the individual and organisation

Housing (9) How to help people get the right home or how to organise home sharing

Change management (8) How to manage change, extend or transform the organisation

Planning & design (8) How to plan and design personalised support for people with complex needs

Empowerment (7) How to support self-advocacy and peer support

Leadership (6) How to create the right culture and organisational vision

Community engagement (5) How to build the organisation's relationship to its community, staff team and those they work with (participation and engagement)

Resourcing (5) How to access additional resources (volunteers, alternative sources of funding, pool funding etc.)

Education (4) How to help people learn, develop skills and have a healthy lifestyle

Non-verbal communication (3) How to support people who don't use words

Back-office (3) How to organise IT, on-call and other back-office functions

Legal (3) How to understand the legal context (legislation, protections, DOLS, forms of detention etc.

Advocacy (3) How to work with advocacy, brokerage etc.

Austerity (3) How to respond ethically to austerity, cuts, debt and the wider economics challenges

Jobs (2) How to help people find work

Spirituality (1) How to support people in their spirituality

Children (1) How to provide personalised support to children & young people

Social enterprise (1) How to develop social enterprises

System change (1) How to achieve wide-ranging system change (e.g. in all home-care services)

Out of the **215 issues** raised it is clear that the vast majority concern questions of organisational management, finance and personnel. It is not so much that people feel that they cannot create competent individualised solutions (although there are clearly some areas where people would like help). Instead it is a question of designing organisational solutions and forming new partnerships with funders.

It is also striking that many also prioritised learning and sharing with others, seeking collaboration, not competition.

4.2 Things people want to share

We also asked what they thought they thought they had learned something about and might be willing to share. **97 organisations** offered to share their learning in a range of different areas:

- IT systems
- Benefits
- Helping people find work
- Creativity in planning
- Induction programmes for new staff
- Creative use of funding
- Expertise in recruiting and matching staff
- Democratic decision-making across the organisation
- Share management
- Helping people manage their own support
- Managing individual service funds
- Self-help and peer support
- Use of people and families as Quality Experts
- Mapping community sources, creating circles of support, working with volunteers
- Testing whole organisation approach to personalised services for people going through tough times

In fact, to a very large extent, these areas of expertise reflect most of the issues that other organisations in the same survey identified as needs. This underlines the potential for **shared learning** as a model to advance personalised support.

5. Funding personalised support

A consistent problem for providers of personalised support - not just in England, but around the world - is that typically funders do not provide the right kind of flexibility to enable the organisation to do the best possible job. This finding is consistent with our findings in 2015, when completing research for Think Local Act Personal (TLAP) in preparation for writing the best practice guidance on *Individual Service Funds (ISFs) and Contracting for Flexible Support*.

5.1 A breakdown of trust

At its simplest there seems to be a breakdown of trust between the funder and the service provider. Contracts are designed, not to liberate, but to control and regulate the service provider. This is despite the fact that commissioners typically lack the experience or the means to manage the services they fund. The system seems to fetter the discretion of the agency whose expertise has been purchased - rather like paying a mechanic to mend your car, but then telling them exactly how to do it, even when you know nothing about how cars actually work.

In addition, it seems that the contracting culture also makes service providers less likely to collaborate, learn and share information. It may be no coincidence that service models have become ossified exactly at the point when the system was divided into purchaser and provider. People are less willing to share with competitors.

An important challenge to this policy was created by disabled people, who have taken control of their own support and who can purchase and organise their own support. (In England this is called direct payments, in other countries it might be called self-management.) However this approach has tended to be limited to people with physical disabilities or where families are willing and able to take on the role of directly managing a budget, with minimal support.

What seems lacking is what personalised support offers - assistance to personalise support and share in management responsibility. This does not mean that disabled people (the preferred term in England, internationally the term 'people with disabilities' is preferred) or families must give up control. It is quite possible for funders to commission personalised support by:

1. Allowing people or families to **select** the provider that is contracted
2. **Protecting** the budget, limiting its use to the support of the individual
3. Defining any **management costs** up front
4. Making the budget **transparent** to the person
5. Enabling the person or family to take on elements of the **management**

This approach stops people and families from facing an all or nothing choice - '…either take complete control or allow the system to continue commissioning support in the way that it did previously.' In order to commission personalised support funders need to do one or both of the following:

a. Create a system of direct payments which does not strip out all management costs but allows for people to **purchase support with some management costs included**, and/or
b. Create a system of **flexible contracting** for personalised support where the funder contracts, but does not over specify how support is to be provided, but allows this to be organised between the person and the support organisation.

These issues are explored in more detail in an open letter which was co-signed by many individuals and organisations and sent to the leaders responsible for health and social care in England:

This letter was sent to the Ministers responsible for personalisation of social care for children and adults in England, to the CEO of the NHS and to the leaders of the two associations for Directors of Social Services (children and adults). It describes the serious policy problem that exists within the current systems of commissioning. The principles of personalisation have not been applied to procurement and commissioning systems. Without proper attention it is likely that progress on personalisation will be seriously impeded.

Text of letter sent 15th March 2017

I am writing to you because progress on one of the key elements of the cross-government personalisation strategy (for children and adults and in health, education and social care) has now stalled.

One of the most important reasons for this problem seems to be a policy confusion about best practice in procurement. This problem could be resolved by a clear statement of policy and a change in the current monitoring systems for personalisation.

Best practice in support and the policy of personalisation both depend on ensuring that decisions about care and support are individualised and that they are made by the person, the family or someone close to them who has a good understanding of their needs and aspirations.

In 1996 the Direct Payments Act made it possible for people to take control of the budget for their support. Over the past 21 years this policy has been extended to enable growing numbers to use direct payments. Usually people are then required to use this money to employ their own support team.

However, not everybody wants to manage a direct payment nor to employ their own staff and take on the relatively onerous responsibilities of being an employer. It seems likely that we are close to the upper limit in the use of direct payments in this way. If the goal is to ensure that everyone can receive personalised support then another approach to personalisation is necessary.

Fortunately it is possible for people to get personalised support without forcing people to become employers:

1. People can use their direct payment to purchase support from an organisation that will employ and manage any support staff. The additional management costs necessary can be built into the direct payment.
2. Commissioners can enable people to choose who will provide them with support and then fund this support by contracting directly with the support provider in a way that gives the support provider flexibility to personalise the support and gives the person the right to terminate that contract.

These two approaches enable commissioners the opportunity to set up a system of managed personal budgets which give people choice, control and the ability to design more effective support solutions. This kind of support solution has persistently been associated with higher rates of satisfaction, safety, effectiveness and efficiency. These systems enable personalised support without burdening people with unnecessary additional responsibilities.

However, despite the fact that personalised support has been in operation for at least 21 years, it has not benefited from the same level of attention as direct payments. Currently it is only available in a few areas of England and for very small numbers.

In principle the idea that people can have personalised support without having to manage a direct payment and without having to become an employer has been either an explicit or implicit feature of official policy. Recent guidance from TLAP and from the NHS continues to reinforce the importance of this model. However, in practice, progress towards personalised support has been blocked by a series of significant obstacles:

1. Many commissioners do not make it clear that people can choose to spend their direct payment on a service provider, nor do they calculate the size of the personal budget in a way that makes this choice feasible.
2. Many commissioners believe that EU Procurement rules dictate that they must put contracts for support out to tender and that they therefore cannot give people control over the decision about who provides them with support.
3. Currently national monitoring systems do not count progress in providing managed personal budgets, although they do count nominal budgets, despite that fact these do not create any meaningful flexibilities or opportunities for personalisation.

Unless there is much greater clarity about these matters it is unlikely that there will be any significant further progress in personalisation. For this reason we are requesting that policy-leaders address these issues directly. We would recommend:

1. Make clear that the existing obligation to offer eligible people and families a direct payment includes a responsibility to define that offer appropriately. That means people should be told clearly that they do not need to become an employer in order to receive a direct payment and that they can pay a third party to provide support or manage their budget.
2. Make clear that people are also free to choose a suitable service provider with whom the commissioner can contract on their behalf. This kind of citizen-led procurement should be treated as best practice in procurement, rather than as it is currently, somehow questionable.
3. All monitoring systems should be modernised to include a clear measurement for managed third party personal budgets, distinct from self-managed direct payments or commissioner controlled budgets.
4. Greater recognition of the value of personalised support and greater encouragement to service providers to develop more personalised solutions.

The replies to this letter have recognised that the aim of government policy is to open up these flexibilities and options. However there seems to be no clear commitment as yet to overcome the policy obstacles which obstruct meaningful progress.

5.2 Models of better commissioning

Fortunately there are now some examples of progressive commissioning and collaboration with community organisations to provide personalised support in several different ways.

Dorset's Commissioning Framework

In England the most important development has been in Dorset where a whole new commissioning system has been put in place to give people to option to choose personalised support (Duffy & Watson, 2017). This system involves:

1. Giving people and families indicative budgets at the assessment stage so that they can choose their own community support organisation.
2. Enabling people the chance to develop their own support plans jointly with providers and then agreeing final budget with the social worker.
3. Enabling all community support organisations the possibility of protecting the person's personal budget with an Individual Service Fund (ISF) and working flexibly around the person's needs and aspirations.
4. Moving away from rigid contracting by hours and fixed support plans that define outcomes and eliminate creativity and flexibility.

C-Change restructure institutional services in Scotland

C-Change, a Scottish community organisation, were invited by a local authority to help them to transform the lives of 11 individuals each of whom lived in their own accommodation across two communal properties. The people had a reputation of challenging services and their support was micro-managed by representatives from health and social work systems. Individuals shared a staff team who provided day and night support and the service was block funded. The organisation commenced planning sessions with each individual and their loved ones. Individual budgets were developed with a potential saving on the block funding. To achieve transformational change, it was necessary for the organisation to restructure the service. This was successfully implemented after consulting with senior representatives from health and social work to gain their 'buy in,' having already received the agreement from individuals and their families.

Each person now has their own individual service and personalised team. Outcomes are being met including employment, moving home, active citizenship and relationships. The majority of individuals are now free of any supervisory control and receiving less paid support, with no requirement for a team member sleeping over. People's services are no longer micro-managed by health and social work but controlled by the individual themselves.

Beyond Limits in Devon

NHS commissioners from Devon (NEW Devon CCG) worked to develop a new support organisation, Beyond Limits, building on the experience and leadership of Doreen Kelly, who had previously led Partners for Inclusion in Scotland. This involved providing initial start-up funding and enabling Beyond Limits to work with people as early as possible as they moved from institutional placements, often hundreds of miles from home, back to Devon.

Calderdale reforming home care

Calderdale council found that many people resisted having their home care moved from one service organisation to another. So they listened to local people and gave people the chance to stay with their existing organisation or pick a new one, using their existing personal budget. At the same time support organisations were given more flexibility to define their support in partnership with the person rather than working to time slots defined by the social worker.

Leeds City and community hubs for older people

Leeds City has an established track-record in providing support and advice through hub organisations led by local community members called Local Links. The City is now using these hub organisations to manage personal budgets for older people, rather than commissioning services centrally.

Southwark Council breaking down a block contract

Southwark Council successfully transformed a block contract for services for people with learning disabilities into 85 Individual Service Funds, by working in partnership with the support provider, Choice Support. This process and the outcome and efficiency improvements created are described in Better Lives and Better Nights.

WomenCentre Peer Support

Sometimes better support is provided when people come together to support each other. For example, WomenCentre in Halifax and Kirklees has done powerful work to support mothers with mental health problems who had lost their children as a result of care proceeding. These women came together to develop their Mothers Apart Network, which was a facilitated peer support network. These women found their voices and wrote a book about their experiences. They continue to operate as a growing network and to influence policy and practice nationally and locally.

Neighbourhood Networks, self help and connections

Neighbourhood Networks develops peer support networks in communities. It employs a community living worker who lives in the same area and works flexibly, (no shift pattern, evenings, weekends etc) to meet the needs of the network. Members are involved in the recruitment of community living worker. Neighbourhood Network's focus is on developing the capacities of the group to support one another and to be involved in their communities.

For example, a creative support solution was developed for Alan, who was discharged from hospital after an bad accident. His mobility was affected for a period and he was unable to leave the house. Home care support was limited in the area. The community living worker and the network delivered some short term support to Alan until he was back on his feet. The worker and members of the network visited him offered him practical support. They also provided much needed emotional support to Alan by regularly popping in to see him to see he was okay and keep him linked into to his network and community until he was back on his feet.

Equal Partnerships and the power of work

Personalised support can also be delivered as a means to increase employment. For example, Equal Partnerships supported Brian to use his budget to access a drama course, instead of using it to buy support hours. Brian is now an associate drama worker, and he receives a payment for this. He travels by taxi to and from his work and has a life and group of friends which he values enormously. Colin's personal assistant was trained as a job coach who then supported him to get a job in an office. (Prior to this Colin he was only offered jobs sweeping up in Macdonald's, which he did not wish to do.) Colin now has a good job two days per week, he travels independently and again has a group of friends through work. He has been nominated for a national award for his work. Douglas loves dogs, but his housemate is frightened of them. Douglas was supported to leaflet the local area, and he got a good response; now he does volunteer dog walking every Friday, which he prefers to attending any 'service.'

Social enterprise as the route to meaning and connections

Other organisations, like YACRO in Canada, have developed multiple social enterprises to offer work to people of various abilities. They create jobs for every individual who wishes to work that are appropriate to their abilities. The hours are flexible to meet the needs of the individual, as are the job responsibilities. They match each individual with a job that takes into account their interests and their abilities, as well as their desire to work. They also support people to get regular mainstream work in the community.

Brokerage solutions for personal assistance

SPAEN (Scottish Personal Assistant Employers Network) supports individuals and families to use Individual Service Funds through Option 2 of Scotland's SDS Act in order to create bespoke arrangements to meet their outcomes through a brokerage model.

5.3 The incentive for providers

Not all support organisations want to stop providing traditional models of support. Some organisations may even prefer to be contracted by the state to provide inflexible support. However there are a significant number of support organisations who will be attracted by more flexible funding models:

- **Values** - It is simply more personally rewarding to work in the right way, developing support solutions for individuals and working in partnership with disabled people and families. This is definitely what support workers say who work this way!
- **Effectiveness** - Working more flexibly is also more effective, it causes less harm to people and supporters and puts people at less risk of abuse.
- **Sustainability** - Current commissioning arrangements are inherently risky for service providers and communities. Some organisations pick up more and more business, often driven by cost cutting, but most lose business and must operate on the basis that they can lose large contracts over night. It is much safer and more sustainable to be accountable to people and families - winning or losing work one person at a time.

Personalised support should surely be the normal way we help each other. It is the responsibility of support organisations and of government, to ensure that the whole system of support works to support our mutual citizenship and stengthens our community life. Much would be achieved if support organisations abandoned competition and started to work together to advance the values of equal citizenship and inclusion. Even more could be achieved if government paid attention to the basic social rights of people with disabilities and their families and listened to their reasonable demands that they can get assitance which lets them live a life of freedom and meaning, without walls, institutions or segregation.

6. Case study: Transforming Care

One area where there remains a significant problem is the Transforming Care Programme. Where people have dangerous behaviours and where risk has to be carefully managed then being able to provide personalised support would seem to be the ideal form of support. However, in practice:

- Competent service providers and NHS commissioners seem disconnected from each other
- Processes for discharge are not designed to promote personalised support
- There is too little attention paid to the real level of capacity to provide support

Overall the on-going culture of mistrust between commissioners and providers, the mechanistic approaches to commissioning assistance and the lack of expertise within the NHS itself seem to have created some fundamental problems.

	Yes	Somewhat	No	N/A
Are you clear which individuals you will be helping to return home?	3	10	4	7
Do you know the budget for each individual that you are helping to return home?	4	4	7	9
Can you work alongside people before they return home?	10	6	2	6
Local clinical services and learning disability teams are powerful allies in bringing people home. Are you getting the support you need from them?	7	9	0	8
Are the psychiatrists overseeing a person's placement supporting a return home and providing good advice and support?	4	7	1	12
Is there a willingness to explore all possible housing options and is good housing expertise available?	3	8	4	9

TABLE 3. **The link between commissioners and providers of personalised support**

Our recommendation is that the NHS England takes a much more proactive approach to developing personalised support, engaging providers earlier in the process and building on competence and capacity - rather than organisations that have no track record in delivering personalised support (Rose, 2017).

The data contained in this report is only partial. There will be many organisations who did not fill out the survey and who are yet involved in the process of helping close the remaining institutions or bring people back home from private hospitals. However the data that was shared demonstrates that the organisations who are offering personalised support based in England are currently only to offer a fraction of those needing support.

How many named people are you currently helping return home? (If none please put the number zero)	85	1 was 50
Being realistic - estimate how many people you might be able to support to return home in 2016-17	166	
Maximum in 2017-18	254	
Maximum in 2018-19	274	

TABLE 4. **Capacity for personalised support**

Furthermore while there 49 Transforming Care Partnerships (TCPs), the leadership groups who are expected to commission personalised support, according to this survey only 24 have a relationship with a personalised support provider. This suggests that many are relying on more traditional and less flexible services, those which are likely to repeat the errors of the past.

- Bedford, Luton and Milton Keynes = 1
- Bristol, Bane and South Gloucester = 1
- Buckinghamshire = 1
- Coventry, Rugby, South Warwickshire and North Warwickshire = 2
- Cumbria and North East = 1
- Devon = 1
- East Riding and Hull = 1
- Gloucester = 1
- Greater Manchester = 1
- Hampshire and Isle of Wight = 2
- Inner North East London = 1
- Kent and Medway = 1
- London North West = 1
- London South East = 2
- London South West = 2
- Norfolk = 1
- North, Central London = 2
- North Yorkshire = 2
- Nottinghamshire = 1
- Oxfordshire = 1
- Sheffield, Doncaster, Rotherham and North Lincolnshire = 1
- Shropshire = 1
- Surrey = 1
- Sussex = 1

Unless there are large numbers of competent organisations who did not complete this survey and who are working closely with TCPs without our knowledge it seems that:

Most TCPs are not making the provision of personalised support central to the process of deinstitutionalisation.

If this true then it is likely that:

1. Much of the re-provision process will fail as people are move into institutional or congregate services that will be unable to offer personalised support.
2. There will be no development of competent community support and the cause of service breakdown and crisis in the community will continue.
3. The current level of unacceptable abuse in institutional provision will go unchanged.

This cannot be acceptable and it requires urgent action by NHS England and ADASS.

7. Why Citizen Network?

However this cannot be a problem which we expect the NHS England or other statutory bodies to try and solve on their own. It is important that citizens and organisations work together to strengthen their capacity to enable everyone to live a life of citizenship.

Interestingly, as part of our survey, we asked organisations whether they would want to be part of an international network to learn together about personalised support and 133 said they would. Furthermore 69 organisations said they would be willing to host learning events on personalised support. This suggests that there may exist an appetite for collaboration, instead of competition.

Building on this the Centre for Welfare Reform has come together with a range of organisations to create a cooperative support system to advance citizenship for all. Citizen Network, an international cooperative, was launched in November 2016 in Auckland, New Zealand. Already it has established national coordinators in:

- Australia
- Canada
- Czech Republic
- England
- Finland
- Greece
- India
- New Zealand
- Scotland
- USA

Citizen Network will:

- Recruit the widest possible membership to achieve citizenship for all
- Assist people to learn from each other, sharing expertise and resources
- Develop national strategies to promote citizenship and create real change

You can find out more on the Citizen Network website. If you are an individual or group passionate about social justice we'd encourage you to join. Membership is free.

CONCLUSIONS

There is a strong case for shifting support away from institutional and fixed models of care and towards personalised support, including, but not limited to the greater use of direct payments. In England it seem that progress towards the greater use of personalised support has been held back by a mixture of:

- The protection of contracting and procurement practices that have a restricted innovation and personalisation
- Market developments that have led to values-free and competitive approaches that have undermined collaboration and the development of citizen-centric approaches
- A drive to promote low-cost direct payments with minimal management costs, which has been particularly prevalent post-austerity
- The tendency to focus on shallow measure of personalisation, changes in planning techniques and language, rather than deeper changes in power, organisation and approach

The problems this creates are multiple:

- People are not getting the lives they are entitled to by right and they are not getting the chance to contribute as citizens
- People are remaining stuck within the systems of health and social care and not being able to develop their own resources and real wealth enabling them to be free of services
- Money is being wasted in institutional services rather than being reinvested in meaningful community life
- The failures of inflexible services also drive up costs, not just in the costs of expensive private hospitals, but also by failure in the support young people in care, people at the end of life, people with learning difficulties and mental health problems and many others who can end up in prison or hospital for the lack of the right support

However where local leaders are prepared to challenge these bad practices the benefits are significant:

- Respect for human rights and citizenship
- Greater creativity and local capacity for problem-solving
- Reduced reliance on costly institutional solutions
- Stronger partnerships and a culture of sharing and collaboration

In principle, the 2014 Care Act, NHS policy and best-practice guidance does support this shift towards the commissioning of personalised support; however this legislation and guidance has not been enough to bring about the necessary changes. Based on previous research and the international research described in this report then we would suggest a number of measures that might be helpful.

1. **Clearer economic policy on personalisation** - There is a need for much clearer guidance from Government, the NHS and the LGA about the need to shift away from current contracting and procurement practices. Local leaders who are eager for change are still continuing to get advice from legal, procurement and finance colleagues which contradicts the recommendations in this report and the thrust of policy in health and social care. In particular there is still a tendency to cite EU procurement guidance, developed in HM Treasury, and which tends to assume social care will be purchased in blocks and driven by value for money principles. Personalisation offers an even more effective economic model for purchasing, but it requires citizens and support organisations to be given much more freedom within the constraints of overall funding.
2. **Foster an environment of collaboration and innovation** - The changes required are not always easy. Shifting from old forms of practice and experimenting with new models requires great leadership, flexibility and support as you face inevitable hurdles and sometimes make mistakes. Competition or command and control approaches will not work. Instead people need colleagues and connections to help them solve problems and learn from others. It is for this reason that the Centre for Welfare Reform and Choice Support and a range of international partners have come together to form Citizen Network.
3. **Intentional change built on developing capacity** - Innovation cannot be purchased; however it can be fostered. In order to increase the pace of the development of personalised support in England it is recommended that a much more focused and intentional process is applied. Energy should be focused on areas where (a) local leadership is willing and (b) there exists real leadership capacity within the community around which positive change can be promoted (as it currently does in Dorset). Where both conditions are fulfilled then real progress can be made and attention can paid to converting all practice over to the improved model. We would recommend focusing energy, but then working to maximise the pace of change in those areas capable of making real change. Overall momentum can then build around these models of good practice.

Deinstitutionalisation has never been easy. It means swimming upstream, unlocking resources from where they are currently being wasted (but where vested interests are also strong) and developing new forms of practice in which to invest. Austerity makes this challenge doubly difficult. Nevertheless, the current harm caused by institutionalisation, particularly for those people who ordinary community services have not been able to support successfully, makes the case for change unstoppable.

The challenge is begin, to really begin, to make the necessary changes and to return to the values of equal citizenship for all which began the drive to end institutionalisation and create true community inclusion.

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About the authors

Dr Simon Duffy is the Director of the Centre for Welfare Reform, and secretary to the international cooperative, Citizen Network. Simon's writings include *Keys to Citizenship*, *Women at the Centre*, *The Unmaking of Man* and *Unlocking the Imagination*. He was awarded the RSA's Prince Albert Medal for social innovation in 2008 and the Social Policy Association's award for outstanding contribution to social policy in 2011.

Sam Sly feels honoured to have worked with people with learning disabilities and their families for over 25 years. She has worked as a social worker and within health & social care and regulation as well as part-owning and managing a support provider, bringing people home to Plymouth from Specialist Hospitals. Sam now facilitates Life Planning for people to get them out of Hospitals into home's of their own and leading the great lives they deserve.

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

We produce a monthly email newsletter, if you would like to subscribe to the list please visit: bit.ly/subscribe-cfwr

You might like to follow us on twitter: @CforWR

Or find us on Facebook here: centreforwelfarereform

Citizen Network

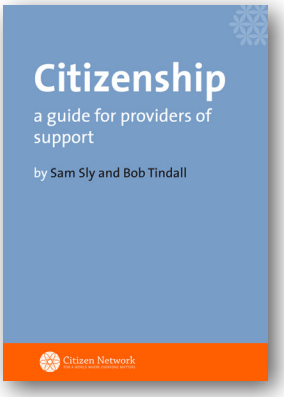
Citizen Network is an international movement to advance citizenship for all by tackling prejudice, poverty and powerlessness.

Individuals and groups who believe in human equality and the value of diversity can join for free at: www.citizen-network.org

You might like to follow us on twitter: @Citizen_Network

Or find us on Facebook here: citizennetwork

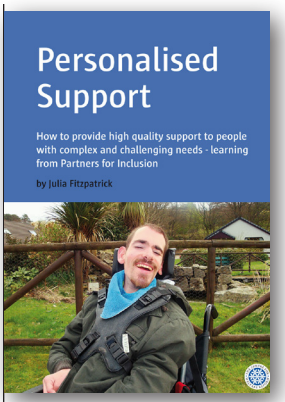
Relevant publications



CITIZENSHIP: A GUIDE FOR PROVIDERS OF SUPPORT

Sam Sly and Bob Tindall explain why support should be focused on helping people to be full citizens and explain how this can be achieved in practice.

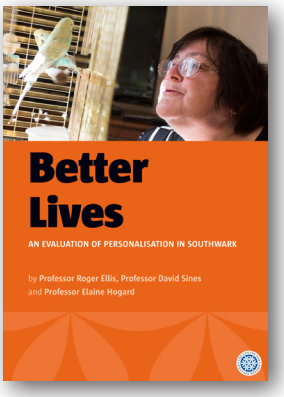
http://bit.ly/citizenship-guide



PERSONALISED SUPPORT

Julia Fitzpatrick describes the work of Partners for Inclusion who work with people with complex needs and describes how support can be designed and organised one individual at a time.

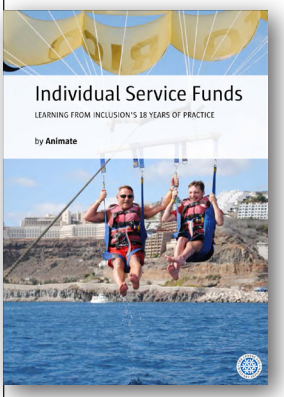
http://bit.ly/personalised-support



BETTER LIVES

This research report describes the life and efficiency improvements that were achieved by reorganisng funding on an individual basis by converting a block contract into Individual Service Funds.

http://bit.ly/BetterLives



ISFS

Inclusion Glasgow was one of the first personalised support providers and this report outlines the results of a survey of people's experiences and the improved outcomes achieved.

http://bit.ly/IndividualServiceFunds

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