# What does 'good' look like?

The Evolution of Support Brokerage in the UK

July 2020



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## **Summary**

This paper is intended for social workers, team managers, heads of service, directors of service and commissioners within health and social care who are leading change in their approaches to personalisation.

It is written as a commentary paper about the development of Independent Support Brokerage in the UK as part of the wider concept of Self-Directed Support. The paper explores stories and iterations of good practice which have enabled and promoted increased independence, reduced inequalities, better involvement and connection in community life, achievement of outcomes and less reliance on statutory services.

The paper also examines some of the practices, challenges and restrictions which have held people back and prevented them from realising their hopes and aspirations for a good life; and provides a simple lens which could be used as a basis for reviewing changes to policy and practice - enabling a real shift towards citizenship for all.

As a conclusion to the paper, the authors have provided an outline of recommendations to progress the integration and embedding of Self Directed Support and wider community involvement.

(the names in these stories have been replaced to protect the identity of the person)

Published by Imagineer Development UK CIC & National Brokerage Network- July 2020

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### Introduction

Independent Support Brokerage is an approach which strongly aligns with the theory of self-determination and was first developed by families of people with complex needs, called the Woodlands Parents Group in British Columbia, Canada in the 1970's. These families wanted to be in a position to free up the financial resources allocated for the care and support of their family members; and to take control of those resources to use them in a way which made most sense to them as families to enable a 'good life' to happen.

When the person is in the driving seat of their own life, amazing things can happen; and solutions and opportunities can be discovered which were not even considered through the narrow lens of commissioned provider services and statutory provision from Health and Social Care. Self-determination is an important concept that refers to each person's ability to make choices and manage their own life. Self-determination means that people have control over their choices and lives. The Psychological theory of Self-determination suggests that people are able to become self-determined when their needs for competence, connection, and autonomy are fulfilled.

Deci & Ryan (1985) Self-Determination and Intrinsic Motivation in Human Behavior

Elements of Support Brokerage exist in many different models and approaches, but authentic and truly independent Support Brokerage is rooted in a wide range of Person-centred practice and strengths-based approaches, creating a completely individualised approach for each person; dictated by their personal preferences, hopes, dreams and aspirations. Support brokerage looks not only at what is available but at what is possible.

Brokerage started being implemented in the UK by Dr Simon Duffy in some of his ground-breaking work with the Southwark Consortium in 1991; and the subsequent emergence of a system of brokerage and individualised funding. This was further underpinned by the introduction of the Community Care (Direct Payments) Act in 1996; and the founding of 'In Control' which heavily influenced the development of the 'Putting People First' (2007) governmental policy- introducing personal budgets and helping to transform adult social care for the better. The National Brokerage Network (NBN) was founded at the same time as 'In Control'; developing as a community of practice and an active network for independent Support Brokers and organisations embracing self directed support. The NBN now sits as a sub-committee of Imagineer Development UK CIC - A small organisation based in West Yorkshire but with a national reach; innovating in the areas of personalisation, self-directed support and community development.

Support brokerage has been a developing concept; often misinterpreted as a Local Authority resource allocation function or a commissioned provision of payroll and managed accounts for those choosing Direct Payments. The emergence of the Care Act 2014 introduced the language of 'outcomes' and the wellbeing principles; which opened up the opportunity to think more widely about what a 'good life' means for people and the achievement of outcomes which underpin and uphold their wellbeing as a whole- not just focusing on labels or a diagnosis. We are currently in a position where the Care Act guidance is vague, and the interpretation of the Care Act principles varies greatly between local authorities; although there is an opportunity to work more flexibly and in partnership

to enable individualised and self directed support which makes sense for people and their families.

## **Functions of Support Brokerage**

The key function of Independent Support Brokerage is to listen to people and learn about what a good life means to them; based on the principle that there is much more to a person's life than just the services and support they access.

Support Brokerage always starts with the person, and recognising that the person is in the driving seat of their life. During the delivery of Support Brokerage, there may be a number of different people involved along the way who will provide support, advice, technical assistance, emotional support and guidance; but the person is always in control of who is involved.

The Support Broker can help to bring a range of skills, tools and knowledge to help facilitate the process; and this is often a combination of one or more 'Strengths-based' approaches. As a facilitator, the Support Broker is not in control of the process, the direction or the final outcome. They are present and available to the person as a resource. The Support Broker is available to offer information, advice and guidance when asked to do so and can also help the person with understanding what is available and what is possible in order to determine and drive their own support.

There are no predetermined timescales for how long the Support Broker stays involved. This is determined by the person and how much they want the Broker to be involved. The Broker may leave the process at any point according to the agreement they have made with the person about the extent of their involvement. This conversation is revisited continuously throughout the delivery of Support Brokerage to check in with the person and determine whether it is still appropriate for the Broker to continue to stay involved. The Broker may withdraw at any time that they have agreed with the person it is appropriate to do so; and can remain available to re-engage with the person at any future point. The process is not linear, in accordance with the fact that life does not remain static and people's circumstances can change continuously.

We acknowledge that by following the approach of Independent Support Brokerage, the person may eventually reach a point where they no longer require the input from a Support Broker as a direct result of the work the person and the Support Broker have done together; which would include becoming better connected in their community, developing skills and resilience, reducing dependency and reliance on statutory services and funding.

By working alongside people to understand their rights, entitlements and how to access what they need from both the community and statutory provision we are supporting the development of their resilience, self-management and independence.

## **Purpose of Support Brokerage**

Support Brokerage aims to support people to become the leaders of their own life, to become more informed about and better connected to the resources available to them; and to hold the belief that the life that they want to lead is possible.

Support Brokerage is embedded in the Citizenship Model (Duffy 2008) which places the person (the citizen) at the heart of the community where they belong, contribute and have meaningful connections. The Citizenship Model supports each citizen to feel valued and included rather than alienated and disempowered, (the outcomes produced through the delivery of social care supports via the professional gift model). This model also sits alongside the Social Model of Disability (Inclusion Scotland 2020).

The Keys to Citizenship (Duffy 2003) form the bedrock of Support Brokerage and provide the navigating points for conversation as we develop a picture of what a good life and an aspirational future looks like for the person. When people access social care and health care supports they can often feel that it is their conditions, labels and diagnosis that cause the limiting factors in their ability to live a fulfilling life. Although the social care sector may believe that it has moved away from the Medical Model (Allfie 2020); in reality the experiences that people have of accessing social care support are still very much steeped in the Medical Model.

Independent Support Brokerage ultimately shifts the focus from 'fixing' a person or aligning the person to services according to their label or diagnosis (known as a 'deficit' or 'needs-led' approach); and instead listens to the skills, passions, interests and connections the person has in their life- facilitating conversations that focus on the building of these to achieve the outcomes that make sense to them (known as a 'strengths-based' approach. From the perspective of an Independent Support Broker, the only focus is on the person and the people that are important to them. There is no other agenda that needs to be juggled with this dedicated focus. An Independent Support Broker is never placed in the position where they are conflicted or compromised. Self-direction is the driver behind the purpose of Support Brokerage and this key element of independence enables it to happen.

Since the introduction of Support Brokerage to the UK, a number of complementary innovations and developments have emerged (often referred to as 'Asset-based' or 'Strengths-based' approaches); ranging from Local Area Coordination, Asset Based Community Development, Social Prescribing, Personalised funding streams and Community Circles. As practitioners, Support Brokers have embedded these innovations into their practice; and Support Brokerage has evolved into a comprehensive, well-informed and multi-skilled approach- drawing on a wide range of tools and approaches to tailor support to the individual.

## What 'good' looks like

The past ten years of delivery of Independent Support Brokerage has enabled those involved with the National Brokerage Network and Imagineer to gain an insight into 'what good looks like' when a person is pursuing self-direction. The only real way of determining 'what good looks like', is to listen to the voice of lived experience, and to really understand what it means for the person.

The following statements (shown in bold) capture 'what good looks like', and are illustrated by stories of people we have known and worked with using the practice of Independent Support Brokerage.

Good is when we acknowledge that the person is the expert in their own life and as such, they are best positioned to determine what makes most sense for their wellbeing.

Story 1: John was still attending school and preparing for his next steps after leaving school. There was difficulty in identifying something which would work for John, but most of this exploration had taken place without John leading or being involved in the discussions. John and his family were introduced to Imagineer via a connection with a local youth project. His family had not heard about Person Centred Planning before and were interested to learn more. John led the planning and preparation for a Person Centred Planning meeting. John listened to everyone's contributions and suggestions in the meeting and was able to respond and show his preferences to the different ideas. This led onto a clear plan for John's future that included activities based in the community and a place to live.

Story 2: An all-inclusive youth club requested to use some underspend from funding they had received to be able to run some Person Centred Planning sessions for the young people who came along to the youth club and were all due to leave school. The young people had no idea of what life after school would look like. The use of the funding was agreed for Personal Futures Planning. Work began with the young people exploring ideas for the future and individual planning work involving friends, family etc. The young people created 'future dream boards'. A 'Positive Futures' gallery was created displaying the boards and the young people invited friends, family and professionals involved in their lives to visit the gallery and view the future dream boards. Everyone who visited was surprised by what the young people had put onto their dream boards; and this opened up much wider discussions about future planning and what might be possible.

Story 3: A big day centre was closing and the people who attended with complex needs were notified that they would be given a place at a special care unit. They weren't given a choice or any alternative offers. They were later told that there wasn't enough space for them and the special care unit was full to capacity; leaving them nowhere to attend. Panic set in as the managers and staff of the day centre had no idea what they could do. A steering group was set up consisting of managers, senior managers and commissioners where a visual timeline of what needed to be done and by when was developed. This was fed into by the person centred planning meetings being held with each person and their family and friends. We ran open planning sessions where people could come and stay for as long as they wanted. Everyone was welcomed and people were invited to contribute ideas around what was working, what wasn't working and what a good future would look like.

This led to community mapping work capturing ideas from a whole range of people visiting the building about what was available and possible in the local area. We then explored the possibilities that had been mapped to start conversations with individuals, groups and organisations within the community. We talked to cafe owners and restaurants about their ability to serve food which accommodated special dietary needs; and we talked to the local facilities about access during the day. As a result of this work a local community centre offered a drop-in space for the people we had been working with to use each day and they converted a spare room into a larger than average accessible toilet. The group of people we planned with had a dedicated team who worked with them after they moved away from the day centre and they met at the community centre where they had a gallery wall capturing all the possibilities of what they could do together so that people could choose what they would like to do/be involved in on that day.

This project resulted in better community integration and being recognised as members of their community. Eg. cafes purchasing food processing machines to accommodate the special dietary requirements, and family members reported how they were seeing their family members out and about a great deal more than they had done previously which they were really pleased about. One family member said that she had hardly seen her sister in the 10 years she had been attending the day centre but now saw her nearly every day.

# Good is where the health and social care workforce (and its allied professionals) are able to work in a way which aligns with their value system, skill set and vocational calling.

Story 1: Susan's circle of support in the early days involved her family, social worker and other professionals who had been involved in her life at various points (and had since become friends). Together with her circle of support, a plan was developed for Susan and this captured how she wanted to live and be supported. The Support Plan recognised all the resources available to her to reach her aspirations. This included her personal budget alongside community-based resources and the use of other funds available to her. It was a well-considered and detailed plan. Susan's support plan was sent to her social worker who understood what was being proposed; but she advised that the panel would be unlikely to sign it off as they were only comfortable with approving support plans that documented how the personal budget would be used to cover home care, day centre costs and some small item costs. The Support Plan was sent to the panel and it was rejected as the Social Worker had predicted. They requested that the support plan be re-written as 'care hours' with a unit cost (equivalent to support hours being purchased from a traditional care provider) in order for the budget to be approved. Once approved, the Personal Budget could be utilised in the best way for Susan as described in her first support plan.

Story 2: Geoff had been contacted by his social worker to say they would be retracting his commissioned support because he hadn't been attending. Historically, a social worker had assessed Geoff, written his support plan and assigned/commissioned support on Geoff's behalf without involving him. Geoff did not engage in the services that had been assigned to him because they did not make sense to him. The support allocated was a respite provision that Geoff did visit once; and he referred to it being 'an old people's home'. he was 30 years old. He had struggled in school and found it a very stressful experience so when the social worker had allocated him a place at a local college, he did attend initially but the old anxieties returned and he didn't go back.

Imagineer supported Geoff to challenge this decision. The Local Authority had completed an assessment which clearly stated Geoff was eligible for social care support but in retracting the provision without exploring ways to meaningfully engage meant there was a clear failure to meet statutory duty. Geoff with the support of an Independent Support Broker began to plan what would work for him. As a result, Geoff identified that he wanted to learn to play the keyboard; play darts; go to live dance performances and sporting events and visit his Mum in Scotland. He also clearly identified the type of people he wanted to be supported by - shared interests; calm personality; not domineering. When the completed support plan went to panel, the Independent Support Broker was invited to the panel meeting. Geoff did ask if he could attend the panel meeting himself but he was told that this would not be appropriate. There were twelve senior level professionals present at the meeting and the meeting took three hours of scrutinising the support plan before a decision was reached to sign off the plan. The professionals involved in the meeting fed back that they had found the approach to working in this way really interesting and refreshing to see what is possible when we place the person in the driving seat. It had reminded them of the reasons why they had trained in this field of work and wanted to be able to work with more people in this way.

Story 3: Karen was middle-aged when she had experienced a serious accident resulting in acquired brain injury and associated complex needs, including loss of speech and mobility. Karen spent a period of time in hospital for treatment, rehabilitation etc; but remained in the hospital setting due to lack of suitable support and accommodation for discharge.

Karen was initially treated in the Intensive Care Unit and remained in hospital for a long time after the hospital had provided all the possible care for rehabilitation and it was understood that a long term care setting needed to be found. Over a period of two years, no solution was found and Karen's family began to place pressure on the local Clinical Commissioning Group to identify a solution. The Clinical Commissioning Group eventually identified a room within a residential nursing home. This was located in an area far away from her family and everything she knew. The nursing home specialised in dementia care for older people so she was surrounded by people of a different generation and the team were not trained to meet her specific needs. Some of the treatment she received was questionable in regards to her human rights and safeguarding - it was extremely unpleasant. Her aunty visited on one occasion and found that she had largely been neglected and had been given the label of having challenging behaviour by those that worked there.

Her family felt it would be best for her to be back in her local community close to family and friends who knew her well, so they took a lead in planning for her move closer to home. As part of her plan, her aunty utilised funding to acquire and adapt a property for Karen. Through the combined use of the personal finance and a Personal Health Budget it was possible to employ her own team of Personal Assistants from the local community available to Karen. They found a way to manage the rotas, payroll and other administration duties. Her team included a Registered General Nurse and part of her budget was used to keep the Registered General Nurses skills & registration up to date.

Good is where the existing legal structures and policies are put into practice in an enabling way; with specific reference to the Care Act and the Mental Capacity Act.

Story 1: Sarah was about to move out of a residential setting that had not suited her for a long time; into a home that she had been involved in planning for. Before the move into her new home Sarah's circle of support held a meeting to go through a Best Interest exercise together which helped to look at all the options available to Sarah and weighing up the pros and cons of each option to ascertain the best way forward. This meeting and exercise was completed before there was any discussion or question of capacity as the circle of support felt that this would be the best way of supporting Sarah.

Story 2: Louise is a 'social butterfly'- enjoying the company of others, so it made sense for her planning meetings to take place around a social gathering. We planned a party where all Louise's family and friends were invited to enjoy the occasion. A table was set up with pens and paper and everyone was invited to add ideas and thoughts about what a great future would look like for Louise. Lots of ideas were brought together and shared. All of them were focused on Louise's community, her interests and what she enjoys - there was nothing about services. After the party, we had a smaller gathering to look at all of the ideas which had been shared and Louise was able to give her reaction to each of the ideas. This was the starting point for her plan, and we built on this to create a clear picture of a good life and a good future, starting to understand how we could support Louise to achieve it. We hired a room at the village hall and displayed the plans on the walls. We had laptops set up which displayed photos and videos of Louise showing all of the things she enjoyed doing and the people who are important to her. Louise had also decorated one area of the room with her favourite colours and things. Social workers were invited along and this was the first point they had become involved in the planning, although they were aware that the planning work was taking place. At the start of the meeting, instead of helping Louise celebrate the great work that had been done with her plan, the Social workers expressed that they were very concerned that none of the information in front of them represented Louise and she had not been involved in these plans. This greatly dampened the mood and Louise immediately switched off. Once the social workers listened to Louise's family and they began to understand the process used to develop the plans; their doubts were alleviated and they really began to support the planning work. The plans really highlighted how to promote, enable and support Louise's wellbeing in a holistic way; upholding the wellbeing principle within the Care Act 2014.

Story 3: Aaron spent some time with an Independent Mental Capacity Advocate. The IMCA had been allocated to Aaron by a Social Worker who wanted to establish where Aaron wished to live in the future. Aaron's family had made it very clear that they knew Aaron wished to continue to live in the family home after they passed away and would not want to move into a service setting. The Social Worker wanted to know if this was also Aaron's wish. At the end of the work, the advocate expressed that Aaron was clearly able to speak up for himself and express his wishes. Aaron told his advocate that he wanted to type his wishes on the computer and print it out so that the advocate could take a copy away with him!!

Good is when the person, their family and community are able to find ideas and solutions that enable them to live the life that makes sense to them.

Story 1: Sharon had applied to be on the local housing list. After submitting her completed application she was given gold priority status giving her hope that she would be able to resolve her housing issues soon which was a source of much stress and discomfort for her. She checked her status on the list but it had moved to bronze on the waiting list without any explanation. She requested it to be upgraded and was asked to provide supplementary evidence, which she did. Her status was then moved back up to gold.... She would then check again a few days later and she had been moved back down to bronze. Sharon found herself in this ongoing frustrating cycle whilst her housing needs were being ignored. Sharon spoke to an Independent Support Broker about it. At this point she had been on the waiting list for two years which was causing anxiety, frustration and a negative impact on Sharon's health and wellbeing.

Sharon was supported by the Independent Support Broker to supply extra information regarding her housing and medical conditions to the housing department again; and this was followed with communications between the Independent Support Broker and the leaders of the housing department so they could address the issues happening internally with the status Sharon was being given. Sharon's status moved to gold again and it was made clear that she needed fully wheelchair accessible accommodation. Within two weeks she was offered an apartment and she was informed it was completely accessible, when Sharon went to view it, it was inaccessible due to a raised kerb outside the front door of the property. Internally the apartment was ideal so communication and negotiation began between the Independent Support Broker, housing department, council and neighbours to organise a dropped kerb and parking availability. One of the issues was to change the parking bay outside of her apartment which was allocated to a different resident. Negotiation with the neighbour, property manager & landlord took place to address this issue. The neighbour agreed to have an alternative 'visitor' parking space allocated to them, freeing up the space outside Sharon's apartment. To prevent people parking in the space, a friend of Sharon's made some planters to place in the space to prevent vehicles from parking there but allowing enough space for her wheelchair access. Sharon was then supported to liaise directly with her Occupational Therapist for further adaptations to make the property fully accessible. The Support Brokerage input in this scenario brought together statutory and non-statutory input; as well as reaching into community connections to design a solution which worked well for everyone.

Good is when any support and care a person requires has the potential to be found within their networks; and this is explored as the first option. When this is not possible the person leads the exploration of other options available to them whilst supported by those with good working knowledge and areas of professional expertise.

Story 1: Doug wanted to be able to remain living in his local rural community. He was provided a list of home care agencies that covered his area. Due to the size of the budget available to him (which he was managing as a Direct Payment) Doug wanted to make sure that he was given the opportunity to choose the right provider. With support from his family

he wrote to the home care agencies outlining the support he was looking for, how he wanted to receive this support and the budget he had available and he invited them to a providers day that he organised with his Circle of Support. The providers day gave each home care agency

an hour to present themselves as a company. Doug chose one of the organisations that had presented and started to negotiate with them about setting up the delivery of his support. Unfortunately this wasn't successful as the chosen provider simply did not know how to deliver such personalised support and didn't have the systems and mechanisms to do so. Doug went back to the drawing board. It was really important for Doug to recruit local people, so he decided to become an employer and recruited a team of PAs from the local community.

Story 2: Andy had been given a budget to recruit his own PAs. Together with his circle of support we created an outline of the support Andy wanted and needed, and identified which people from his circle would be able to help in these different areas. This exercise then helped to identify what the PAs would be needed for as they would be covering the gaps that could not be met by his circle of support. The circle of support then completed a staff matching exercise with Andy, and the learning from this formed the basis of the recruitment of local PAs.

Story 3: When Anna was getting ready to move into her own home there was a lot of anxiety on her auntie's part. Her family had not visited her since she had moved from the hospital into a nursing home setting. When she moved into her new home, a house warming party was organised. People including her family were invited but nobody was sure if they would come. The whole family turned up for the party. Moving back into her home community had allowed her to reconnect with all of her personal networks.

Good is when a person can continue to feel purposeful, valued and connected when reaching a stage in their life where they need support and care; whether this is from birth or at a time in their life past this point.

Story 1: When Emma first had input from the local adult social care team she was in the final year at school. The social worker came to meet with her to talk about what would happen once she left school. At the end of the meeting Emma had been told about a Day Centre she could go to and was advised that transport could be arranged for her to get there. Emma had not had a chance to share what was important to her and the things she had enjoyed doing and what she would like her life to be like after school. The Social Worker had already done her research prior to the meeting and found something for Emma based on the physical environment Emma needed and the service that had the capacity to take Emma on. The Social Worker could only find this Day Centre that met this criteria and as Emma's only option, the Social Worker was keen to secure a place for Emma before someone else took it. This was a worrying time for Emma as she felt a pressure to take the option and was concerned that if she didn't she may be left with nothing, she also realised that if she did take the option she would be really unhappy and everyone who loves and cares for her was very Emma and her family started to hear about Personal Budgets and wondered why this had not been brought up in the conversation with the Social Worker. They made contact with the Social Worker to ask about this option, they were first informed that the council could make personal budgets available to people but for the initial delivery they were working with 'easier' cases. Emma and her family fought against this position and eventually received the agreement from the council to explore this option. This meant that Emma could explore

how to utilise a budget in a way that would make most sense for her, she loves going to watch horse riding, socialising and meeting up with friends and catching the latest film. Emma's life has been much richer as a result of being able to follow a life that makes sense to her, she is invited to parties, she is following the interests she has and meeting people with shared

interests and she is well known in her local community. If you walk down the street with Emma you can guarantee that at least one person will stop for a chat.

Good is when people have the freedom and control to be able to recognise all the resources available to them (which may include funding available to them due to being recognised as eligible for social care or health support) and they continue to have the freedom to determine the best use of these resources

Story 1: When Jim started to think about moving out of home he had a number of hurdles to overcome, one being his anxiety of taking this step (which would often hold him back) and the other was the availability of local housing. Jim and his family realised that if they waited for a property to become available through the local housing team they would be waiting for a very long time. So they opened up their thinking and started looking at a wide range of options; properties for sale or to let on the local housing market, talking to housing associations who would be interested in purchasing or leasing a property and local people involved in shared care schemes. This breadth of approach was at times difficult to juggle but it did mean a solution was eventually found with an ideal property in a great location and just the right size for Jim to manage.

Story 2: Sam had moved into his own home at last after three long years of waiting. He had been able to secure a personal budget and he was utilising this to employ his own team of support workers. His team are all based locally to Sam's new home and are able to introduce him to people and places in the local area. The property Sam moved into needed a lot of work to bring it to a habitable standard, but he is happy with it and feels like it is his home. Sam can struggle with his balance sometimes and the garden and path to his main door was unsafe for him. He did not have any funds to cover the cost of any changes (the Social Worker was clear that the Personal Budget could only be used to cover the cost of care and support and could not be used for this purpose - she was not prepared to discuss it). The occupational therapist was prepared to put some rails in the garden to support Sam but this was not enough as Sam didn't want his garden just to be function, it wasn't a case of just being able to get in and out of his house, he wanted to be able to sit and enjoy his garden and have a go at growing his own vegetables. So Sam and his circle of support started a search for help. Through their efforts they applied for and secured some funding; found people prepared to help and local donations of garden furniture and tools.

Story 3: Milly had been through a number of years of difficulty, her life had changed significantly when her health began to deteriorate. For many years she did not know why this was happening and it took three years to finally receive her diagnosis and then be referred for treatment. In this time she had lost her home, income and friendships and she felt lost in the complexity of the social work system. Through good support Milly was able to reclaim a lot of what she had lost. In response to her experience and her new lease of life she set up an

organisation to support other people with long term health conditions and to help them navigate the complexities that she had come to know very well.

Good is when the person is aware of the range of options available to them regarding how their budget can be managed, and enabled to choose the option which makes most sense for them (eg. Personal Budget; Personal Health Budget; Direct Payment; Individual Service Fund; Managed Account)

Every person we have worked alongside as Independent Support Brokers has been fleetingly informed about the option of a personalised fund and the choices this brings; but each one has reported how this was followed with warnings about the responsibility that comes with this and how they would be taking a great deal of extra work on by following this option.

People need to be fully aware of all the options available, what this means in practice with regards to their quality of life and the enabling of choice and control; rather than this being followed by a negative picture which scares people away from this option. People should instead be informed of the support mechanisms available to them to manage the option they choose.

Story 1: Jane had been receiving support through a home care agency for a few years and there had been a number of issues with how this support was being delivered (such as support staff turning up late, not at all or a completely different person to the one who was expected). For a person living with autism this was not a good situation and was in fact causing more anxiety and related health problems than the 30 minutes per day of commissioned support was helping with. Jane had been told that a Direct Payment would not be a good option for her and she did not have a chance to explore this further. An Independent Support Broker spent time with Jane to talk in detail about the difference between a commissioned service and managing your own team of people. Jane was able to map out the pros and cons of each option and then make an informed choice about what would work best for her. She clearly saw the Direct Payment option (and employing her own team) as the way forward. Jane then was supported to map out all the actions that would need to be followed to achieve this and the ongoing tasks that would need to be fulfilled. We then identified which people from within her circle of support would take on these tasks; and which elements she would feel comfortable and confident to do herself. Now four years on, Jane has a great team of people who are well supported and managed. Although at times there are still issues that need to be addressed they do not cause the same level of anxiety as that brought on by the uncertainty of the previous home care provision.

Good is when there are no restrictions or limitations placed on how a person's budget is spent; except for those clearly defined in law. The person is able to use their budget flexibly and creatively to source and pay for support which makes sense for them.

Examples: Geoff utilises his budget to cover the cost of keyboard lessons and towards the cost of sport events tickets. Louise makes use of her budget to cover the cost of training, horse

riding and towards her fuel costs. Fred utilised part of his budget to buy equipment for his home to be able to communicate easily with his family.

As Independent Support Brokers we have supported people to unleash the potential for support and care to be delivered in a way that makes sense to the person and their family; effectively meeting the needs as identified in the person's Care Act or Health assessment; and is a good and valuable use of public money. It is clear within the legislative frameworks including the Care Act (2014), The Care and Support Direct Payment regulations (2014), The National Health Service Commissioning Board and Clinical Commissioning Groups

Regulations (2014) that people should be given the choice and control to meet their care needs in the best way possible, as long as the use of the funding clearly maps across to meeting the assessed needs/outcomes; it is legal and it does not exceed the budget that would usually be spent on a traditional commissioned service. However, we see that there is a continuation of unreasonable restrictions placed on people accessing a personal budget where they are told that it can only be used on PAs or the cost of a care agency. This is not what the legislation states. This is policy created at a Local Government level; aimed at putting control and risk management measures around use of public funds. The budget holders often demonstrate an attitude of distrust of people who use services, and a reluctance to hand over the control and flexibility to use these funding options in the way they were intended.

There is also a disparity between the budget allocated to someone depending on which route they choose to take rather than the assessed circumstances. People choosing a home care provision will be allocated a budget to meet the cost of this at the commissioned provider hourly rate whereas those choosing to self-direct will be provided a much lower Direct Payment hourly rate. The discrepancy sometimes being as much as £5 per hour. There is no consideration given to meeting the employment responsibilities within a direct payment and PA arrangement, i.e. supervisions, team meetings, mandatory & specialist training, holiday entitlement, NI contributions, tax & National Living Wage requirements.

Good is when people are not held to restrictive practice and judgements that at times are more personal than professional; in relation to reviews and justification of budget spend. Making time to recognise people's achievement of outcomes and the improvement to their wellbeing.

Story 1: Susan had moved from a residential setting that had caused years of distress and unhappiness. The majority of the support to achieve this came from her family and Circle of Support. During the development of the plans to support Susan a number of meetings were held with senior management of the social work team. These meetings were to discuss the support that would be needed and Susan's plans for a good home. During one of these meetings a senior social worker commented that Susan could not expect to live in the area she was looking for a property as it was a lucrative area and 'wouldn't anyone like to live three' asserting that due to her circumstances she should expect to live somewhere less lucrative and more importantly away from the community where she had grown and where her family and friends remained. However, the plan went ahead because the family and friends persisted. There was a change in personnel involved with Susan's plan from the Local Authority, and the new worker was supportive of Susans ideas and her plan. This was a huge success and although there were anxieties from everyone involved when she first moved in as to how she

would adjust and cope she proved to everyone that this had been exactly what she wanted for a long time. Within the first year the Local Authority was able to draw back some of the funding allocated for her support as it simply wasn't needed, her mood was much more settled, the team were well supported, reliable and dedicated and Susan was doing more for herself.

Good is where people are actively encouraged to try the things that make sense to them, (even if they look nothing like the original service structures) so that the person can develop skills, interests and open up opportunities to be better connected in their community. This is seen as an opportunity not only for the person to live a life that makes sense to them but also an opportunity for those involved to learn about how this can happen and the difference it makes to the person.

Louise, Sam and Geoff have been brought up and nurtured by families and communities that have always encouraged them to strive for the best. This has included encouraging and supporting them to get out there and get on with life and to dare to do things in their own way. For these people, self-directed support made complete sense and it fitted in with their way of life and their way of relating to the world around them. When they reached a stage of life where they needed input from the local social work team, this way of thinking was initially met with some resistance. It took the investment of time to build the relationship between the social worker and the person. This time helped to develop the depth of understanding required for the social worker to become a driver for change. This helped them to work through the background system and structures within the social work world to make self-direction possible for the person. This very process of supporting someone to self-direct opens up the learning needed regarding how to adjust systems, structures and the founding principles to determine the direction of decision making within Local Authorities and Clinical Commissioning Groups.

Good is where those from within statutory services, structures and functions who traditionally hold power; hand this over to the person and their support network.

All the stories highlighted in this paper share an insight into the necessity of power firstly being recognised within the systems that administer the care and support for our citizens and how this power is played out within the interactions, decisions and communications between those who administer, and those who access. Within the systems that administer a recognition that their very position would not exist without those needing to access the system would be a good starting point; building on this with a sound knowledge of placing respect and equality at the heart of all interaction.

In every instance of power being equal with the person accessing the support systems, it can be clearly demonstrated that the experience has not only been empowering for the person and their family but equally for those who find themselves administering a system that quite often does not represent their own values, beliefs and purpose.

Good is where the things that could go wrong or could cause harm are given the correct amount of time and attention to address the question - How can we still make this possible whilst still staying safe and free from harm?

The best way to avoid harm and alleviate risk is for people to understand the risk and be fully involved in making decisions about how to manage it in the best way possible. Identifying and assessing any potential risk should be a conversation that is held with the person, their family, the people who support them and the professionals involved in their life.

Recognising risk should not result in an 'avoid at all costs' approach, as this is a risk in itself which leads to a limited and disconnected life. Independent Support Brokers (as part of the

process of developing a care and support plan) can facilitate the discussion regarding risk and capture the ideas about mitigating risk if they are asked to do so.

# Good is when Circles of Support and/or Community Circles are developed and recognised as a valuable source of support, connection and information.

Story 1: James is an expert in anything to do with building things out of wood. This is an area of life where he thrives and is a huge source of expression for him. He still lives in the family home. He likes to be adventurous and prefers to be out on adventures each day and he is strongly connected to his faith. James' circle of support meets on a regular basis and is a huge source of support. James's circle meetings are a chance to share and celebrate the good things that have happened since the last circle meeting, to talk about problems and concerns; and to provide reassurance, emotional support and solution-finding conversations. James' circle members have attended local authority meetings to demonstrate the level of support James has available to him in his community and the people who are available to represent James when needed.

# Good is being able to connect in with experts in certain fields as needed, but led by the individual.

Simon has a really good team of PAs who have been with him for a long time. Over the years, Simon's health had deteriorated and he had needed more input from the local community nursing team. The PAs noted an improvement in Simon's health immediately after a nurse visit but was aware that this benefit quickly subsided. They spoke to the nursing team to enquire about the PAs position in being able to provide Simon with the same input so they could factor this into his day to day routines to support the maintenance of his health. The nursing team agreed to provide the training to the PAs and now Simon's health is much stronger and more consistent from one day to the next; meaning he can continue to be active.

#### Good is when we go at the persons pace and not at the pace set by the Authority

To make sure that the person is fully involved in their assessment and the development of their care and support plan we need to develop and go at a pace that makes sense for them.

## How this compares to what we have seen

People have been told in a restrictive manner how to, or how not to use Direct Payments; without allowing the correct interpretation of the guidance

Story 1: Francis had a settled arrangement with a small number of hours support per week. Francis can find relating to others very challenging but she was happy with the support arrangement she had in place. She then received contact from a social worker she had not met or heard of before. Francis finds telephone conversations with people she knows really well challenging at times, so therefore this unexpected call (from someone who was a stranger to her) caused an emotional meltdown. She reached out to the people who she knew well and she asked for help. The social worker was asking her to meet a new care provider and she didn't understand why. When people dug a bit deeper, the current provider had contacted the social work team to give notice. This had not been explained to Francis and the social worker had arranged to match her with a new care provider with no explanation as to why. When Francis understood why, she asked if it would be possible to know what options would be available to her. She was especially keen on exploring an Individual Service Fund via a Direct Payment. A meeting was held with the social worker and after the meeting a letter was sent to Francis explaining that her whole care budget had been revoked. It has now been two years since Francis received any support from the Local Authority despite her needs escalating. With involvement from her Support Broker, Francis is managing to access some community-based support which she is having to self-fund whilst managing an ongoing challenge with the Local Authority.

Story 2: Mohammed had met with a social worker once and then received a letter from them to say that he could access a day centre provision two days a week. He had not wanted this outcome. As a busy working man he needed his support to work in a very different way but he didn't know where to turn. An Independent Support Broker helped Mohammed to access the documents that had been written as part of this process. At this stage Mohammed was not aware that an assessment or a support plan had been completed on his behalf as this had not been explained to him and he had not received any copies. When he received the documents it stated in his support plan that he was in receipt of a Direct Payment and he had chosen to use this to cover the cost of the day centre. There had been no discussion with Mohammed about this, so effectively he was being allocated a commissioned service which was not appropriate for him.

#### Misuse of power

As Independent Support Brokers we have attended meetings where each person has been asked to explain why they are at the meeting and how they have been invited. We have even witnessed people being told that they should not be at the meeting.

We have witnessed people sharing the assessment document that they have completed themselves, with care and consideration (and with the support from family and friends); only

to be told that the document will not be taken into consideration as the Social Worker has to do their own assessment.

We have witnessed people being told that they will have to take a significant reduction in Personal Budget if they choose to have a direct payment to employ their own team of people.

When people have chosen a Personal Health Budget there has been the expectation that the person would cover their own costs for employer's insurance and that this would not be paid for out of the Personal Health Budget.

We have witnessed people being told what they will receive and how they will receive it without any dialogue about what makes sense to the person.

All of these examples demonstrate when the power balance between the Local Authority or Clinical Commissioning Group representative and the person requiring support is uneven and heavily weighted towards professionals determining what is best for the person, rather than recognising that the person is the expert in their own life.

Story 1: During one of Steve's meetings, the care coordinator announced that their manager had reached the decision that Steve did not have the capacity to manage his own team of PAs and therefore the Direct Payment was to be retracted. The care coordinator's manager had never met Steve. Steve's capacity had never been questioned and a formal capacity assessment had not been conducted in relation to the Direct Payment arrangement. This appeared to be a step being taken by the Local Authority to try and relinquish Steve's control of the budget without a fair and justifiable reason. This was challenged at and after the meeting, and a full history of Steve managing his budget was presented to the care coordinator and his manager. Steve never received a response, and the question about his capacity has never been raised in a meeting again but the family are aware that his presumed lack of capacity remains on his case note records.

# People being disproportionately scrutinised year after year for how they are spending their individualised funding to meet their outcomes.

Story 1: Susan's Support Plan was amended in accordance with the guidance given by her social worker and the budget was approved but then when the audit took place, it was scrutinised. Why was Independent Support Brokerage listed as a cost within the support plan and paid for out of the Personal Budget? Why were the staff on that rate of pay? Unfortunately this questioning took place every year as part of every annual audit, even the answers and evidence had already been provided by Susan. This meant that Susan was constantly having to justify herself and this led to an overwhelming feeling of stress and anxiety when the time of year for the audit was approaching.

#### Taking too long to address changes or carry out assessments.

There are people that have been waiting for over eighteen months for a Care Act assessment and reports show how there has been an increase in people requesting access to help and support through their local health and social care support structures but a significant reduction in the number of people actually receiving support. This wait is largely due to the capacity within the social work teams to complete assessments but also due to an unwillingness to enable people to prepare for and write their own assessments to be discussed with a social worker at a later stage if they wish to do so. This may be due to the way that the

referral and assessment system is structured and resourced within Local Authorities; but it may also be an issue of an unwillingness to hand control to the person.

#### People requesting assessments and not receiving them.

There is an increase in the number of people who are reporting that they have requested an assessment through their local authority but that they are still waiting for one to take place. The fear is that with the increasing pressure on services (due to the ageing population and the challenging financial climate) that the waiting time for assessment may increase. The Local Government Ombudsman has said that complaints about adult social care – especially about assessments – are on the rise. (Redmond 2017)

# Being offered a service and no other options (services which are based on the persons label/diagnosis)- being told there is nothing else available.

Story 1: Colin had really challenged his Local Authority to let him access his support via a Direct Payment. Eventually Colin's support plan was agreed and he was able to get on with putting his plan into action. Two years into his support being arranged in this way, he was contacted by a Local Authority representative who thought he might like to hear about a new project being set up in the local area. This would be a possible employment opportunity working in a facility that placed lids on the top of product jars. The Local Authority representative assumed Colin would like this as it was a routine and repetitive task (and as Colin had a diagnosis of autism, they thought that this would work well for him). The Local Authority representative and Colin had never met.

Person-centred solutions having to be cleared via Local Authority legal team for approval (which is a costly, time-consuming and inefficient use of Local Authority resource) and difficulty signing off on release of resource due to siloed budgets (eg. Social Care vs Transport).

Given the opportunity to come up with unique ideas, people and their families can find interesting and sensible solutions to the issues they face. Cost savings and efficiencies seem to be an innate driver for a lot of people. In one instance the Local Authority was ready and willing to purchase a piece of expensive equipment for a young woman living in accommodation that did not fully meet her requirements. This included some equipment to increase accessibility within the home and to aid in physiotherapy at home. The family were intrigued to know how much this would be costing the Local Authority. After conducting some research the family were astounded at how much the cost would be on the Local Authority and felt they could come up with a better solution, which they did. They decided to do some research and started to find alternative, practical, safe and workable solutions for a quarter of the cost. The solutions the family were finding also placed less restrictions on the young woman regarding the use of the equipment as they were finding portable solutions that could be used when visiting friends, family and whilst on holiday. Practically and financially the solutions found made more sense and the family shaped up their ideas and findings into a well considered document to share with the Local Authority. It took a long time for these ideas to be agreed, going from one department to the next to be signed off. It took 4 months and eventually the proposal was agreed. The amount of time involving each local authority representative in the process of making this decision was never talked about. It is likely that it

cost a significant additional sum of money to make the actual decision but the family was appreciative that the local authority had taken it that seriously.

# People receiving an outcome of a financial assessment where their client contributions match the cost of their support.

Anybody accessing social care support goes through the financial assessment process to determine the contributions they would need to make to their own care costs.

In a number of situations as Independent Support Brokers we have worked alongside people who have been confused by the process and unclear as to how their calculations have been made. In some instances the assessment has been over the telephone and people have not been provided a copy of the completed assessment. In many situations the local authority has placed an arbitrary amount on daily living costs such as utility bills, which represent the national average but does not to take into account the likely higher amount people with a disability will pay due to their increase in usage, i.e. increased laundry, the need to be in a warmer environment; which is known as 'Disability Related Expenditure'.

Disability related expenses are often misunderstood and although the cost of living with a disability is significantly higher (Scope 2020) people are not provided the guidance on how to capture these expenses when completing a financial assessment; as part of the process of agreeing their Personal Budget.

# People being told they can use the resources from the community but they would need to self-fund; and then being asked to use these resources to complete a statutory duty.

Jane was very clear that she did not want to work alongside the social worker when completing her assessment or support plan. She also did not want to access her local advocacy provision as she was not confident in speaking openly to them. She had no immediate family and friends but had formed a good working relationship with an Independent Support Broker. This was the only person she wanted to help her with her assessment and support plan. The social worker informed her that she would need to self-fund this input, if this is how she wanted to develop her plan. There had been no scope for discussion with the local authority or the social worker about how this would be assisting with them meeting their statutory duty to assess and plan with Jane, and no recognition that Local Authority could have discretion over using resources flexibly to fund this input in completing the task.

# Local Authority reviewing and reducing budgets arbitrarily, causing a negative impact and then failing to recognise the role they played in it.

George had a really good set up where he had employed his own team of people through his Direct Payment and he was living in his own tenancy. A social worker asked to review his support arrangement and after the visit he was informed that his budget would be reduced by 20% as the social worker felt that there were elements that weren't needed. This placed a pressure on his team to meet his support with a much lower resource. After three years of the team trying to fit everything within the limited budget available there came a time when there was not enough left in the budget to cover that month's wages for his staff. The direct payments team were alerted and they completed another review; after which he was informed

that the social work team had taken the decision that he was not capable of managing a direct payment and they would be retracting this and arranging for a home care agency to provide his support. There was a reduction in George's sense of stability and security which not only impacted on George's wellbeing but also on his staff team.

#### Local Authority procurement arrangements taking priority over a person's choices

We have seen commissioners and social workers focused on utilising the commissioned and contracted services where the 'money' has already been allocated and the pressure to make use of all the commissioned services (regardless of whether they are appropriate for the individual) rather than identifying and linking in with what would make sense to the person.

Story 1: When Mohammed accessed adult social care for the first time his social worker signposted him to a day centre that was specifically set up for people with physical disabilities. He was informed that it was a commissioned service and as a local authority they needed to prioritise the use of this service over other options, as the budget available had already been spent on this service.

## **Practical Application**

#### How Social Work could support this movement

- Recognise that everyone has a part to play, this includes the person, their family and their circle of support
- Remember we would not be in the roles we are in if people within our communities didn't require support and that we may all require support at some stage of our lives
- Make sure people take the lead on their assessment and support plans
- Let people create full life plans that take into consideration all resources available to them, (not just the personal budget, but looking at the full range of resources available including what is available in the person's immediate network and community).
- Do not build dependency on statutory provision
- Do not squeeze people's lives into what is available through statutory provision alone
- Practice as a facilitators rather than gatekeepers
- Make sure people are fully informed of ALL the options available to them
- Share the options in a neutral and non-judgemental way
- Ensure you are legally literate without prejudice. Keep up to date with current case law which sets precedents for your practice
- Feel confident to challenge other colleagues (even those in senior positions) when you have concerns. Seek support for those challenges and how to record the experience
- Make sure people are aware of the support structures available to them if they wish to choose a self-directed support option. Make sure people are aware they can have mixture of funded options (eg. Direct Payment plus a commissioned service)
- Enable people to do things that are not on the approved providers framework or an established Local Authority procured service list
- Be considerate when supporting someone through a review be aware that people are anxious about social work involvement. Recognise people's achievements and celebrate self-management
- Make it possible for people to make changes to their funding and support arrangements without going through lengthy bureaucratic processes
- If people make changes to how they make use of their Personal Budget, make sure this is communicated internally so that the audit team are aware and there is no inappropriate scrutinisation at the time of audit (this requires communication between social work team, finance team & quality team)
- Emotional intelligence is a core social work skill and should be recognised as a priority practice and personal development area
- Follow the principle of not intentionally or unintentionally making people's lives more difficult than they already are
- Be conscious of how many times the person has had to share their story with professionals to be able to gain access to the support they need
- Recognising Person-Centred Planning and Self-Directed Support as an essential component to upholding people's rights and achieving the best outcomes.

#### How Commissioning could support this movement

- Do not squeeze people's lives into what is available through statutory provision alone
- Applying the legal right to Self-Directed Support within commissioning and procurement practices understanding how this sits within other citizen rights eg. Human Rights Act; Equality Act etc
- Recognising Person-Centred Planning and Self-Directed Support as essential components to upholding people's rights and achieving the best outcomes
- Enable people to do things that are outside of an approved providers framework or an established Local Authority procured service list
- Create a system where the satisfaction of the citizens determines the service structures and community response rather than needs analysis and Service Level Agreements/Contracts
- Enable people to co-produce their own packages of support with the social worker, family, friends and local community
- Adopt more flexible approaches in applying the commissioning cycle
- Remove commissioning 'silos' so that budgets can be used jointly, flexibly and creatively
- Enable agile and flexible responses
- Support innovation through encouraging collaboration and partnership working between providers and community organisations
- Try new approaches, provide seed funding to grass roots, community and voluntary sector organisations' new initiatives
- To learn from the pilot stage of new innovations and to build on this into long term practice, including the celebration of failure as a learning opportunity to inform future practice
- Develop and embed what has been learnt through pilot projects to support the shifts needed within the existing systems and structure to enable the realisation of Self-Directed support and personalisation
- Enable people (and communities) to become their own commissioners
- Promote a market for Support Brokerage and make it clear how it is different from traditional local authority brokerage services

# How Chief Execs/Directors of Adult Social Services and Primary Care Groups/CCGs could support this movement

- Ensure that annual budget setting and cycles do not stifle innovation
- Carry through learning, resources and budgets from time-limited innovation pilot projects to effect real and lasting change in systems, structures and processes
- Ensure evaluation of new ways of working is carried out comprehensively over a reasonable period of time to be able to demonstrate and embed the long-term outcomes
- Influence local council decision-making to uphold the rights of citizens and observe the wellbeing principle within Care Act (2014) and The National Health Service Commissioning Board and Clinical Commissioning Groups Regulations (2014)
- Explore devolution of power and resources to communities via approaches such as Participatory Budgeting & Neighbourhood democracy to underpin and connect with a range of asset-based approaches which strengthen people and communities; and are complementary to self-direction

#### Conclusion

Support Brokerage is not a new idea; but the acceleration of community-led approaches and personalisation for health and social care services against the backdrop of austerity has caused a groundswell of interest and opportunity for new ideas and innovations. We hope that this paper will serve to better inform people about the scope of opportunity in applying Support Brokerage to the commissioning of social care and health within the UK.

## References, further reading & links

Are people experiencing problems accessing Social Care support? Redmond (2017)

https://www.healthwatch.co.uk/news/2017-01-26/are-people-experiencing-problems-accessing-social-care-support

#### Care Act 2014

http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

#### Extra Costs (Scope 2020)

https://www.scope.org.uk/campaigns/extra-costs/?gclid=CjwKCAjw88v3BRBF EiwApwLevdXz8TUK2j6UrLvZOBrbRSUmjQJMuyEQfhTHUi89VYDB2qnOv-RWzh oCu9QQAvD\_BwE

#### Medical Model (Allfie 2020)

https://www.allfie.org.uk/definitions/models-of-disability/medical-model-disability/

#### Simon Duffy - Citizenship Model and Professional Gift Model

https://www.centreforwelfarereform.org/library/shift-to-citizenship-model.html

#### Simon Duffy - Keys to Citizenship

https://www.centreforwelfarereform.org/library/keys-to-citizenship1.html

#### Social Model of Disability (Inclusion Scotland 2020)

https://inclusionscotland.org/socialmodelofdisability/

#### The Care and Support Direct Payment Regulations (2014)

http://www.legislation.gov.uk/uksi/2014/2871/pdfs/uksi\_20142871\_en.pdf

# The National Health Service Commissioning Board and Clinical Commissioning Groups Regulations (2014)

http://www.legislation.gov.uk/uksi/2014/1611/contents/made

#### Woodlands

https://www.communitylivingsociety.ca/wp-content/uploads/2017/11/Woodlands Parents Group.pdf

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First published July 2020

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## **IMAGINEER**

Imagineer Development UK CIC is a social enterprise based in the North of England with a national reach; originally set up as a test bed for Independent Support Brokerage in the UK. Imagineer is the hosting organisation for the National Brokerage Network, which is a community of practice for independent Support Brokers. Imagineer provides a range of training in Support Brokerage, Person-Centred and Strengths-Based Approaches.

Liz and Sarah are both practitioners of Support Brokerage; involved in delivering training, 'proof of concept' work and consultancy projects which focus on developing community and embedding Self-Directed Support across the UK.

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First Published 4th August 2020

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