Peer Support and Peer Brokerage
For Self-Funders

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February 2011

Research and Report funded by the Department of Health
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Introduction

About the Research

The purpose of this study is to develop knowledge and gather information that will assist the development of peer support brokerage in Barnsley. In commissioning this work it was assumed that the experiences of self-funders in setting up their own care services can be used productively to inform the development of effective peer support brokerage services.

The expected outputs / outcomes of the study are:

1. A working definition of self-funders.
2. A study of the experiences of a sample of self-funders, identifying successes, obstacles and challenges.
3. An overview of a range of peer support brokerage services being operated in other local authority areas.
4. A final report detailing all the findings and offering a set of practical recommendations to assist the development and/or enhancement of peer support brokerage services.

Independent Living

Traditionally interpretations of the word “independent” have meant disabled people need to be encouraged by professionals to spend hours carrying out tasks, for example putting on their own socks or making a cup of coffee, which left people without time or energy to do anything else. The independent living movement interprets “independent” as having control over how support is provided, who provides it and when:

“Independent living for disabled people is often misunderstood. It does not mean disabled people 'doing everything for themselves' but that the practical assistance some disabled people need should be provided and based on individual choices and aspirations. It means having the same choice, control and freedom as other citizens at home, at work, in education, and as equal citizens.” (DRC 2005)
Disabled people’s organisations have identified twelve basic rights which, if met, would enable them to live independently and fully participate in society (Southampton CIL 2011). These are:

- Full access to our environment.
- A fully accessible transport system.
- Technical aids – equipment
- Accessible/adapted housing
- Personal assistance
- Inclusive education and training
- An adequate income
- Equal opportunities for employment
- Appropriate and accessible information
- Advocacy (towards self-advocacy)
- Peer support
- Appropriate and accessible health care provision

**Self-Funders**

Relatively little research has been conducted on self-funders and there is no clear definition of who self-funders are, other than people who pay for their own support. Research commissioned by the Putting People First Consortium (2011) highlights the importance of self-funders getting the right information and advice when it comes to understanding and considering their support options. It suggests that self-funders are not guaranteed greater choice and control unless they are properly advised. This study also found that many people do not wish to approach councils to get advice and concluded that comprehensive and consistent information about independent living and support options needs to be provided in different formats and from different organisations.

**Peer Support and Peer Brokerage**

Bott (2008) reviews the literature investigating the value of peer led support in the personalisation agenda. This found that there was considerable value in peer support across the personalisation agenda, particularly in supporting people to make choices about the best sources of social care provision. Peer support is seen as an essential element of transforming the delivery and outcomes of social care.
Method and Equal Opportunities Monitoring

Method

This research was conducted along two strands:

- Desktop research to explore peer support brokerage operating in other local authority areas.

- A series of focus groups with self-funders to explore successes, obstacles and challenges.

The results were used to support the development of a working definition of self-funders.

Invitations to participate in the focus groups were distributed via local organisations. Two focus groups were held: one at Age Concern Barnsley attracted 5 participants and another at Voluntary Action Barnsley had 3 participants attending. Although the original research brief specified a minimum of 12 focus group participants, it was subsequently agreed with the commissioners that 8 participants would be acceptable due to this being qualitative rather than quantitative research.

All of the focus groups were conducted on a confidential basis and none of the contributors are identified by name in this report. They were semi-structured as opposed to structured or unstructured, since this format enables the facilitator to elaborate on any unexpected issues which may arise during the course of the session. It also gives the flexibility to clarify responses, challenge theories and establish common meanings.

Every focus group was recorded using a digital Dictaphone. These recordings were then transcribed, analysed manually and written up in this report. Due to time constraints, participants did not get the chance to review the transcripts to make amendments and additions.
Equal Opportunities Monitoring / Profiles of participants

There were 8 focus groups participants.

All of the participants described their ethnic origin as White British.

Four participants said they had a mobility difficulty. One person had both a mobility difficulty and a visual impairment. One person was a family carer and two people did not disclose whether they had an impairment or were a family carer.

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<tr>
<th>Impairment / family carer</th>
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<tr>
<td>Mobility difficulty</td>
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<td>Visual impairment</td>
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<td>Family carer</td>
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Six of the participants said they were a woman, one said they were a man and one participant did not disclose this information.

One participant did not disclose their age. The age range of the remaining participants was 51 – 81 years old. Three participants were over 65, four were 51 – 65 years old.
Overview of peer support brokerage services in other areas

This overview will focus on examples of sources of peer support and peer brokerage currently available in the UK for self funders. It will outline support being delivered by organisations run and controlled by disabled people and other organisations and investigate the different types of supports that may be available to self funders.

Peer Support

Centres for Independent Living (CILs) are organisations run by disabled people providing necessary support for disabled people to achieve independent living. In the UK CILs largely focus on peer support and advocacy to access Direct Payments and Individual Budgets.

We found several examples of UK Centres for Independent Living which are able to provide peer support for self-funders.

Lancashire CIL

LCIL runs a Peer Support Network, which is based on the simple idea of a person who has experience and knowledge supporting one who doesn't, and operates through local groups of disabled people. The groups hold regular meetings and invite speakers to provide ongoing information and advice about independent Living.

The network arranges regular drop in sessions and is able to provide home visits. LCIL largely focuses on, but is not exclusive to, Direct Payments recipients.

Cheshire CIL

CCIL piloted a Peer Support co-ordination project to increase the uptake of Direct Payments. It was anticipated that numbers could be increased by enabling service users in receipt of Direct Payments to share best practice with other people and become ambassadors for the scheme.

The aims of the project were to:-

- Set up a network of meetings which will ultimately be administered by their own members. These meetings currently require community-development, formal outreach and capacity building work.
- Eliminate social exclusion for some disabled people by promoting local meetings which will create opportunities to share ideas and best practice, promote social networks and enhance community employment.
CCIL carried out a survey on Direct Payments in Autumn 2007, this revealed:-

- 24% of respondents want to learn more about Direct Payments with more training.
- But 66% would prefer to learn from others first hand experiences.
- Similarly, 62% felt able to share their knowledge with others.
- A further 20% of respondents felt they lacked the confidence to attend meetings.

Following the results of the survey CCIL implemented local peer support meetings, the structure of which, have been designed by service users. These meetings included some education, some sharing of ideas and knowledge, and some social interaction. These occurred (usually monthly) at accessible venues around the county. People who may have lacked confidence to attend alone were encouraged to bring a friend.

**Southampton CIL**

Area-based Peer Support Groups are held on a monthly basis to enable Disabled People to support one another with Direct Payments and any other Independent Living issues. Discussions can cover anything which affects your day to day living.

Support offered by CILs is in the main targeted at Direct Payments recipients, they clearly provide peer support opportunities to disabled people outside this group on a wide range of issues. They may support disabled people and their families to investigate Direct Payments as a funding option for people currently self funding or provide other advice as appropriate.

**Direct Payments / Individual Budget Specific Support**

Our research found numerous examples of organisations which provide large amounts of support to access Direct Payments or Individual Budgets. In addition to the CILs already mentioned which provide a Local Authority commissioned service for Direct Payments recipients, there were other examples of support networks across the country which provided assistance not only to use self-directed support, but also to access it in the first instance. These kind of services are often not commissioned by Local Authorities. Some examples include:

**Direct Payments Users Network CIC (Essex)**

This organisation reiterates the value of peer support to achieve independence and cites its main strength as the network members themselves. The network adopts a social model approach to their work, addressing the barriers faced by their members in achieving their goals. Using this approach, the Direct Payments
Barnsley Age Concern

User Network in Essex has campaigned to try to effect changes to disabled people’s social care.

Examples of the types of support offered by the organisation include:

- Information on any aspect of Direct Payments or Individual/Personal Budgets
- Support to get on to Direct Payments or Individual/Personal Budgets
- Support to employ people, such as Personal Assistants/Support workers using your Direct Payments or Individual/Personal Budgets
- Support to buy services from a Care Agency using your Direct Payments or Individual/Personal Budgets
- Help with keeping a record of how you spent your Direct Payments or Individual/Personal Budgets money and filling in the financial forms related to your Direct Payments or Individual/Personal Budgets required by your local council
- Informal Advocacy around Direct Payments or Individual/Personal Budgets

**Personal Budgets - Peer Support Helpline (Leeds)**

This is a group of disabled people who work as volunteers to provide assistance to Disabled people interested in Direct Payments. All the volunteers are recipients of Direct Payments and staff a telephone helpline to offer advice based on their experience.

**Bristol and South Gloucestershire People First**

In addition to advocacy support, this organisation, run by people with learning disabilities, provides support and training to enable their peers to find out about Direct Payments and personalisation.

**Personal Assistance (PA) Registers**

There are PA registers being run across the country, often by organisations run by disabled people as part of their Direct Payments support services. Examples include UK PA register, the Essex Coalition of Disabled People’s PA register and the Hull PA database. These services are exclusively for recipients of statutory funded packages to enable them to recruit PAs, often in emergency cover circumstances. PAs are recruited to the registers and are often paid the set rate per hour allowed by their Local Authority.

**Brokerage Support**

The National Brokerage Network says that brokerage is ‘independent guidance to make sure you can live the life of your choice if you are a disabled person, older person or family carer.’

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1. [http://www.nationalbrokeragenetwork.org.uk](http://www.nationalbrokeragenetwork.org.uk)
The Centre for Welfare Reform says that community-based support, including brokerage, offers disabled people opportunities for greater choice and control and can achieve better outcomes\(^2\). However it concedes that there are few networks to enable this to happen at the moment. We found several examples of organisations which run community-based brokerage training and provide brokerage specifically to disabled people. This support was not limited to self-funders.

**Signpost Kent**
Signpost Kent is an umbrella organisation comprised of three charitable groups working to support people with mental health and well being. They are funded through Department of Health and have provided brokerage training to mental health service users and survivors in order that they can go on to provide peer brokerage support to others.

**HAIL**
HAIL is a group working in London to provide support to people with learning disabilities in various aspects of independent living. In addition to providing a bank of support workers, HAIL are currently running brokerage training, supported by the National Brokerage Network, for people with learning difficulties. Those who complete the course may become peer brokers for others. The course does not appear to be funded by external sources as it is purchased by participants.

**Step by Step Living Network**
Based in St Helens, Step by Step Living Network used Department of Health Section 64 funding combined with funding from Local Authorities to provide brokerage and brokerage training in local communities. The organisation also ran a course specifically for self-funders to find out about personalisation and brokerage.

**Services for Self Funders**
We found several organisations providing services which could be purchased by disabled self-funders and their families. These included Walsall People, a social enterprise which provides services such as gardening, decorating and handyman services. Workers were CRB checked by the organisation. The handyman scheme in West Dorset is an example of a free service provided through the Local Authority and Help the Aged which assists disabled people with household tasks. Similar schemes operate around the country and were often run by agencies or statutory bodies rather than disabled people and families. Best-care-home.co.uk offers advice specifically to self-funders but is focussed on traditional supports such as care home provision and domiciliary agencies. They provide information

\(^2\) [http://centreforwelfarereform.org/innovations/communitybased-support.html](http://centreforwelfarereform.org/innovations/communitybased-support.html)
about finances / financial supports and choosing appropriate services. These may not be the kinds of services required by many self-funders who require more flexible, informal support.

Conclusions

In conducting this research, the difficulty in obtaining information about organisations facilitating peer support for self-funders is indicative of the issues facing disabled people and their families who do not receive statutory funding. There are several organisations providing support to disabled people and families in the area of personalisation and peer support, however these largely focus on Direct Payments and Individual Budgets recipients. Similarly brokerage networks are often focussed on these groups of disabled people.

Our research indicates a dearth of peer support available to disabled people and families who are self-funders; however there is sporadic practical support across the country in terms of services that can either be provided or purchased by disabled people in their homes. Our search revealed a lack of information and support available to self-funders from Local Authorities which mirrors the findings of the People who Pay for Care report (Putting People First Consortium 2011).

This research suggests that opportunities for peer support networks of self-funders which could adopt similar approaches to those organising Direct Payments User Networks and supports such as PA registers. Direct Payments peer support groups could be useful to self-funders by supporting people who have not accessed statutory funding to do so. Links between these networks could therefore prove useful.

In addition there is a clear need for social enterprises or schemes to assist self-funders to find appropriate workers and support.
Views Expressed in the Focus Groups

The following sections give an overview of the various points of view put forward at the two focus groups.

What kinds of support do self-funders buy?

Many participants paid for people to come to their homes and help with a variety of household tasks such as cleaning, gardening and home decorating:

“I have help in the garden. A miner who is on unemployment benefit comes on Saturday afternoons and it gives him a little bit extra… Indoors I have a student but she can only come Saturdays. She can do what women do but for things that men do I give a little bit of support to a [disabled] young man who can do things like changing light bulbs and cleaning windows and things like that.”

“We’re going to have to pay for somebody to come in and cook us a meal.”

“A lot of people I think are in my predicament where they've got to pay for help with the house, with little jobs that probably somebody who hadn’t got that particular disability might be able to manage themselves.”

Some participants wanted the ‘odd job’ service run by Age Concern Barnsley to be expanded to cover larger pieces of work:

“The help we need is little things… Age Concern do help… they’ll come out and put a rail on for you or fix things. But say you wanted a carpet fitted, you can get the carpet but it’s still £30 to have it fitted. Now if Age Concern had got proper joiners to do these kinds of jobs [then] that would be a big help. You know, not just putting a light bulb in… not just putting handles on front doors or the side of the bath… I've just had a carpet fitted and he charged me £30 for it. Even if I gave a minimal fee to Age Concern, maybe a tenner or 15 quid… at least we’d get something back and it wouldn’t be as much for me.”

Home adaptations to assist with independent living were also commonly purchased by self-funders:

“He got ill and it cost over £3,000 for a shower to be put in because he couldn’t pick his legs up to get into bath. I couldn’t get no help… And that’s what’s done me with my back and my legs because I have had my share in lifting him in and out.”
“I’ve had a handgrip fitted on the bath so I can get in and out.”

“I had a shower room done… I had a larger shower, more readily accessible, the floors tiled - so that if I was to use a wheelchair [the bathroom would still be accessible].”

Self-funders also said they had purchased aids and equipment:

“I pay thirteen pound a month for my alarm… I have a button… so that I press it if I need any help with anything and they answer.”

Another area of independent living that the participants typically paid for was accessible transport:

“A taxi is expensive and if I wanted to go to town with somebody I’d have to pay for a taxi there and back. Dial-A-Ride’s okay but sometimes they’ll not bring you back when you want to come back “

Participants also incurred additional costs as a result of their impairment connected to the clothing they wore:

“…buying shoes that are suitable to be able to [use with] …my calliper. I can’t really ever know how my left shoe’s going to be until it’s been adapted. So I buy the shoes, hope to God they’ll be alright and then if, by any chance, I can’t walk properly in them [then] that’s an absolute waste of a pair of shoes.”

Sometimes self-funders get support for some areas from statutory agencies but still have to fund other forms of support by themselves:

“I have a bath lift… which they gave [my husband]. When he was ill I was looking after [him] as well and they gave him it. They wouldn’t let me have one”

Reasons why self-funders pay for their support

There were a number of different reasons why self-funders paid for support. For some people it was simply because they were not eligible for support from the state:

“Because we’re in a 2 bedroom semi with stairs, well, he goes up the stairs on all fours which he has done for years… I just had to say to these 2 people who came from social services ‘do you think I could have some help
with a stair lift?’ My sister-in-law was in the kitchen as I was speaking to these 2 social workers and do you know what she saw him write down? ‘Mr and Mrs ***** live to a very high standard’. A few days later I got a letter [saying] I wasn’t entitled to a stair lift. And I still haven’t got a stair lift, even though it took all of what we’ve got for the shower so he could get in and out.”

Some people’s reasons were around their pride in remaining self-sufficient and not wanting to rely on support from the state:

“[We] don’t want to go through Social Services. We’re not asking for a care package.”

“I’ve always been independent... I’ve never asked for nought and the help I’ve got I’ve had to seek it privately simply because there’s nothing out there.”

“I’ve never been involved with the local authority. Never even asked [about], or particularly wanted care in my home. I don’t think I warrant that, but there’s a lot of jobs that I can’t do myself.”

Some people did not want to approach their local authority because they believed they would have less choice and control over how their support was provided:

“I know people are coming out probably to do an assessment, but there’s nobody can come to my house and tell me what I need.”

“I want to be independent… I want to make my own decisions about what I need and when I need it. That’s important to me.”

“I still say [I’d rather] choose what I wanted. I would not go back to social services for anything.”

“I would prefer to organise my own assistants rather than have anybody come and impose it for me... because I’ve always been used to being self-sufficient.”

“I manage my personal care, because I prefer that. I wouldn’t want a stranger.”

Another factor which deterred participants from seeking support from their local authority was the perception that it would not regard the type of practical support they needed as personal care:
“It’s the personal care they look at though… not so much the other things. If you get Social [Services] they come in and they’re not allowed to do… jobs that you need doing.”

“With Social Services, they mainly talk about your personal care… They don’t sort of go onto much with housework and all that.”

Finances were another reason why people chose to fund their own support. A number of participants admitted that community care charges were a deterrent from approaching their local authorities for support.

**Finding the right support**

Most commonly participants employed people they already knew to provide support:

“I employ people that I know.”

“[If] somebody’s going to come into your home, fundamentally, you have to trust them don’t you?”

“I think it’s important that you trust in familiar faces, not different people every time.”

“The girl I’ve got now was through somebody that I knew who knew her and I’d known her myself years ago. And it’s lovely.”

Some participants place adverts for someone to support them:

“I’ve actually in the past put little notes in the local post office window.”

“I’ve just put a notice up in post office for £6.50 an hour for a cleaner and I bet you nobody answers it because it’s only £6.50. But it’s above minimum wage.”

Someone found support by answering an advert in their local paper:

“In the Chronicle they’ve got a bit now ‘do you need your ironing done?’ which I’ve had done and she’s charged us £2.50 a kilo. It comes back brilliant.”

Some participants found people to support them by asking around:

“Somebody that you know happens to know somebody.”
“When I knew I needed a cleaner I rang the local school and asked the head teacher if any of the cleaners there would want to do extra time and oddly enough none of them did but a parent who was fetching a child from the school rang me to say that she would do it.”

“Mainly my problem is with supervision because I’ve only got a daughter. She’s got a career and I’ve no other family. So every time I need to go out, I’ve got to have somebody round when I’m not there…Basically I knock on one of the neighbours doors and ask ‘will you sit with [my wife] and I’ll pay you. It’s the only thing I can do.”

Some participants were able to do jobs for other people in exchange for support instead of paying money:

“I’m lucky in respect that I’ve got a joiner that lives next door and I help by sitting looking after their kids… but he does the odd jobs around my house. So …within this community we all help one another in a basic way.”

Participants who had used care agencies had encountered difficulties around getting staff to do the jobs that they needed doing:

“They’ll come in and they haven’t done their job, then the next person comes in and they’ll say ‘well I’m not cleaning that up because they were supposed to have done that’. I mean, we’ve been through all this and the thing is so there’s no continuity of staff so if you’ve got different people coming in the person that’s getting let down is that carer.”

“When you get help in that you pay, when I’ve had in before, like care, they’re not allowed to do the work that I need.”

Also the high costs of agency staff were another factor:

“If you go through an agency, the agency will charge you double.”

“If you go to the actual agencies that provide care, the charges are really, really expensive.”

“I once did get somebody in from Sheffield and I had two hours a week for her to take me out shopping. It cost me twenty-eight pound to start with for two hours. On top of that it cost me forty-five pence a mile [for] petrol.”

However most participants agreed that finding the right support was not easy:
“There is a limit to the people out there that’ll come and do the job anyway so the people that you’re going to get aren’t up to too much to start with.”

“It’s not easy always to find the person that you’d like, you know, that could do that particular job.”

“We look around until we get somebody who’s of a reasonable rate.”

**Risks and challenges of self-funding**

Participants highlighted a number of risks and challenges for self-funders. No-one in the focus groups used a payroll service to pay people who worked for them. Instead everyone said they paid people cash-in-hand:

“A lot of people won’t do [short periods of support work] because of this social security business… because they know if you were earning a coin more than what you should have done or you’re earning a coin what you shouldn’t be earning… You’re allowed to earn £20 and if you’re over that limit, you see, a lot of people won’t come and help.”

When the focus groups were asked what kinds of things they had to go without in order to afford their support, they listed food, making do with second hand clothes and heating:

“It’s over a year since I’ve had any heating on. Well over a year.”

Although some people said they received Disability Living Allowance and used it towards the cost of their support, the benefit did not cover the full amount that they spent:

“I do get some Disability Living Allowance so obviously, to some degree that can go towards the cost.”

“You know for me to get a taxi there and back, fair enough I might get my disability money, but when you start paying out for this, cleaning, gardening, everything else and then you’re paying what, it can be sixteen pound there and back for a taxi. Then [there’s] your shopping on top of it.”

Some participants felt they were charged more for some things just because they were disabled:

“Anything that’s an aid for a person with a disability usually is quite, quite expensive.”
“Somebody comes along to see to your house and they say ‘Oh, a lady in a wheelchair who’s on her own. We can charge them a bob or two here.’”

“Some people are more adept to being able to negotiate and haggle.”

Even when people purchase support, they may not feel confident to challenge when that support is not provided in the way that they wanted:

“Some get a cleaner that they’re not happy with and they’re a bit scared of saying ‘Well you’ve not done that right.’”

Finally self-funding had a detrimental effect on the health of some of the participants, as not being able to afford the support they needed resulted in them not purchasing that support and instead trying to do tasks by themselves:

“Well I never get out now and it’s having an effect on me.”

“So many times when I’ve tried, I’ve thought, I’ll just do a little bit… and I end up with bruises.”

**Current advice available**

Focus group participants agreed that there’s not enough information and advice about choosing the right support:

“You don’t phone up nowhere do you because it’s these 08 numbers that cost you bloody money to ring and then they’ve got you there for 20 minutes.”

“I think formally, no there isn’t a lot of information available.”

Everyone spoke very highly of the information and advice service provided by DIAL Barnsley.

“If I want to know anything the first place I ring is anyone from DIAL, because I always think if they don’t know, no one will know.”

Often information, advice and support came informally via word of mouth from friends and family:

“The only thing that is keeping me going at the minute is word of mouth.”

“I meet my 2 friends weekly and we discuss our problems with each other and we try to support each other.”
Advice and support needed

All of the participants agreed that there should be a group run by people who use support to enable them to give information, advice and support to one another:

“You need somebody who’s been on that ground floor, who’s in that situation, who’s done that job, who knows what that person’s going through. That’s why you are finding it difficult to find somebody... you want somebody who knows.”

“Peer support… you’ve got to get out there to people who are paying for their own support.”

“I think when you reach a stage where you need a lot of support from other people it makes you happy to be able to support somebody else yourself.”

Participants wanted peer support to be part of a clearly signposted information and advice service:

“If you had them at the hub centre then everybody can go there and they can tell them where to go [for support].”

“If it does provide advice then it needs to be available via the telephone because of immobility.”

“You could have somebody you can go to and talk it through with them and that would be less stress for you as well.”

In addition, participants wanted a register of personal assistants to be set up that they could access:

“It would be nice to have some kind of a register of people who are registered, approved and at a reasonable cost.”

What differences has having support made?

Finally participants were asked what differences having support had made to their lives:

“It’s a lot easier. I don’t take as many pills… I’m without a cleaner at present so, like I said I’ve just put a [advert in the post office window] so that to me is good because you know I would have tried to do it and I’d probably hurt myself. I’m frightened of getting hurt so the thing is it would have been
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left. It would have been definitely left. But if you’ve got that support it’s brilliant.”

“I think I’d just sink under a tide of weeds and dust.”

“You’ve got to have a little bit of help because if you don’t, you’re crippled. Even doing some shopping today my leg is swelled up like this… And that little bit of help’s worth a lot of pity… I’d rather say I’ll come in and sweep your floors for you or come and listen to you than say oh, I feel sorry for you.”

“Knowing that you’ve got somebody coming and gonna do what you want to do takes all the pressure away.”

“It’s even nice when my cleaner comes because I have somebody to chat to.”

“It’s not just the amount of pressure, it’s how hard work it is… like cleaning the bath out. I’ve got to get down on bathroom floor. I don’t do it immediately when I get out, because I want to get back into bed while me legs are still warm. But if I wanted to and I had to clean the bath, I’ve got to get down and it’s just hard work. I do it sort of half nearly leaning against it and then clip me calliper. It’s hard work. And I think the thing that makes me cross, not that I particularly want Social Services, but they talk mainly about your personal care being important. They don’t sort of go into much with housework and all that, but no matter how well you keep yourself clean, if your house isn’t clean then you can’t be comfortable.”
Barnsley Age Concern

Interpretation of Findings

Introductory comments

As with most research of this type, it is not intended to be representative of a whole group of people, but rather give a range of views from a small sample. However there were many areas of agreement between all of the self-funders who participated and some clear themes emerged around common experiences and viewpoints. In contrast to the self-funders who participated in the ‘People who Pay for Care’ research (Putting People First Consortium 2011), all of the people who came to the focus groups accessed informal support to live independently as opposed to residential services.

Purchasing support

The types of support typically purchased by participants included people to perform household tasks (such as cleaning, laundry, preparing meals and gardening), home decorating and other DIY tasks, adaptations to the home, accessible taxis, aids and equipment.

Many of the forms of support purchased would traditionally not be considered part of ‘social care’ or healthcare provision. However, in all cases, the need for the support purchased arose from the purchaser being a disabled person unable to perform the task unaided or without adaptations. In addition, some readers may consider some of these forms of support to be luxuries, such as taxis, gardening, or someone to cook meals. However whilst non-disabled people might also want these same things, they will not experience the same degree of disadvantage if they do not get them.

Participants agreed that finding the right support workers was never easy. The most common way people found someone to support them was asking someone they already knew to either provide support themselves or recommend someone else. Others advertised in the local press and post office and did jobs for other people in exchange for support. Those that had used support workers from agencies had been put off by the high costs involved and the staff who came not wanting to do particular jobs for them.

Participants were in favour of establishing a register service for personal assistants that would solve some of the difficulties they had experienced finding people to support them. This way support workers could be vetted and approved and costs could be kept at a reasonable level.
Information and advice

All of the focus group participants agreed that there was not enough information and advice available around choosing the right support and managing their support.

Most commonly information, advice and support came informally from friends, family and other disabled people rather than from local authorities and statutory services. Therefore all of the participants agreed that a peer support group for self-funders would enable them to provide information, advice and support to one another.

Reasons for self-funding

There were a number of different reasons why self-funders paid for the support they received. Some were ineligible for help from the state, some had reasons around their pride in remaining self-sufficient and not wanting to rely on the state, some believed they would have less choice and control over their support and didn’t want to deal with Social Services, some were deterred by community care charging and some thought that the type of practical support they needed wouldn’t be considered ‘social care’ by their local authority.

The desk-based research did not find any explicit definition of the term ‘self-funder’. Therefore, based on the views and experiences of the self-funders who participated in this research, a new definition is proposed:

“Self-funders can be either disabled people or their family members who may be unaware, ineligible or choose not to take up support from statutory organisations. Instead they themselves pay for the support they need to live independently. This support may not traditionally be considered social care or healthcare; for example gardening, small home maintenance tasks etc.”

Risks and challenges

All of the self-funders who participated said that they paid the people who supported them cash-in-hand instead of using a payroll service. This means potentially tax and national insurance contributions may not be being paid if the support worker is not registered self-employed. Also the rules around how much someone can earn whilst receiving benefits deter potential support workers from undertaking small jobs for people. In addition, it is unlikely that a self-funder would have employers’ liability insurance and, if the worker is not insured as self-
employed, may be liable legally should an accident occur whilst they are working for them.

Being able to afford the support they need is another challenge for self-funders. The kinds of things participants said they had to go without in order to afford their support included food, making do with second hand clothes and heating. Self-funding even had an adverse effect on the health of some of the participants, as not being able to afford the support they needed resulted in them either trying to do tasks by themselves and hurting themselves, or the task not being done at all which lead to low self-esteem and depression.

Some participants felt they were overcharged for some of their support solely because they were a disabled person and seen as 'vulnerable'. Also some self-funders may not feel confident to challenge when the support they are paying for is not provided in the way that they want. These risks and challenges could be addressed if there was more practical support available to self-funders around finding and managing their support.
The following are a set of practical recommendations to assist the development of peer support / brokerage services which cater for and include self-funders:

- Avoid referring to the disabled people who use the service as ‘users’ since this term can be taken to mean ‘people who use social services’ which can imply that self-funders are not included.
- Be clear that support people to achieve independent living involves looking at the 12 basic rights of independent living and not just ‘personal care’. Therefore peer support and brokerage should help self-funders to identify and manage support around things like housework, gardening, etc.
- Hold regular peer support meetings and invite speakers to provide on-going information and advice about independent living.
- Match peer brokers to self-funders who approach the service for informal peer support and advice.
- Services should be able to advise self-funders around getting the right insurance if they are going to employ people to provide support.
- Provide a simplified way in which self-funders can pay people through a payroll. Ideally this service should be free-of-charge to self-funders to encourage them to use it.
- Provide on-going information, advice and support on issues around employing staff.
- Establishing a personal assistants register service to vet personal assistants and match them with self-funders.
- Ensure that any peer support brokerage service is run and controlled by local disabled people.
- Make links between local Direct Payments recipients’ networks and those used by self-funders.
- Develop social enterprises or schemes to assist self-funders to find appropriate workers and support.
- Develop an online resource for self-funders to access relevant information about accessing a range of support to live independently.
References


