**A group of people standing in front of a sign

Description generated with very high confidence**

**National Information Gathering Survey**

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**Introduction**

“Being the Boss” is a national network of disabled people who employ their own personal assistants (P.A.s)/support workers or carers. Our central role has been to support disabled people who employ their own Personal Assistants by providing peer support and a coherent voice for them in the wider community. The website and Facebook page are for disabled people who employ PAs no matter how they are funded - it is NOT just for disabled people who are receiving Direct Payments or Personal Budgets from the local authority or NHS. See: <http://beingtheboss.co.uk/>

The Directors of Being the Boss felt there was a need to obtain fresh data from the coalface and evaluate our own role in supporting disabled people therefore in May 2018 we launched our **National Information Gathering Survey**.

**Why we undertook a survey**

Since 2010 when the Coalition government introduced Austerity measures we have seen many changes in assessment procedures, funding regimes, criteria, the closure of the Independent Living Fund and an overall undermining of Independent Living.

Given the current climate Being the Boss believe it is essential to establish ourselves as the advocate for disabled people who employ their own personal assistants because all forms of living independent lives is under threat. Alongside maintaining Being the Boss’s existing service/role, we want to build on our experience by making our advocacy role more visible and proactive and extend it to other disabled people facing difficulties with benefits and other areas which impact upon their ability to live independent lives.

To be able to play this advocate role we saw a need to try and understand the national picture on the ground so that we could establish what are the key issues for those who employ their own personal assistants (P.A.s)/support workers or carers. We were also keen to discover if people who employ their own PAs were finding it difficult to live independent lives. To this end we designed a basic survey to help us gain a snapshot of the current situation.

**Framework of the Survey**

The Survey had three sections to it. The first section was simply to gather information about the individuals who completed the survey. It was decided not to compile data in terms of gender, age or the background of each person. We were however interested in their location and relationship with Being the Boss if there was one. The confidentiality of each person has been respected. This section also addresses the packages of support people receive.

The second section asked ten questions in relation to the national situation and the final part was concern with moving Being the Boss forward and posed a further seven questions. This report is about the responses to the survey and any patterns or observations we might be able to draw. It is recognised that our observations are limited by the fact that the people who responded were self-selecting and therefore not necessarily representative of all those who employ support workers, however, it is hoped that the evidence gathered can assist us to obtaining funding to undertake further research.

**Survey Findings**

Twenty-nine people (responders) made up our survey sample from various location. Not all questions were answered by everyone. We wanted to give people a voice therefore whilst respecting their confidentially, we have included the majority of their comments, some have been edited to aid understanding without altering the intended meaning. A number have been excluded for legal and ethical reasons.

**PERSONAL INFORMATION**

We were interested in knowing where people lived:

Cornwall 1

Devon 1

Durham 1

East Midlands 3

Hampshire 2

Hertfordshire 1

Kent 1

Leicestershire 4

London 6

Norfolk 1

North East 2

Suffolk 1

West Midlands 1

Wiltshire 1

Yorkshire 5

We asked if they were:

a) A paid up member of Being the Boss 0

b) A non-paying supporter of Being the Boss 7

c) Casual visitor to the Being the Boss website 18

Four responders had just found Being the Boss website via the Survey invite

The next set of questions of significance addressed their role as an employer.

When asked: do you employ your own Personal Assistant(s) support workers or carers people, twenty-eight people said they did and one person said they were no longer able to do so because their hours had been dramatically cut.

In relation to the funded of their support package the breakdown was:

a) Local Authority 22

b) NHS 4

c) Other 2 [Combined] 1 LA and self; 1 self-financed

We also asked the name of their package:

a) Direct Payments 20

b) Personal Budgets 6

c) Other 2 self-financed 1 unsupported

To the question: have you had a review of your Care Package/Personal Budget: six people had in the last three months, one in the last six months, two over a nine month period, and a further six within the last year. Twelve people said it has been over a year since they had a review. One person said they were on their 4th review as a result of trying to get correct joint funded package involving mental health services. Two people said the review process has taken over two years to complete.

The survey then asked to what extent the review was:

a) straight forward 5

b) hard going 12

c) tough 9

These are the reasons responders gave for saying the assessments/reviews were ‘hard going’:

* My problem is getting them to come out and review my care package.
* Long and exhausting.
* Repetition....energy draining and emotional.
* My Social Worker kept explaining my answers to me and putting words in my mouth.
* The assessment outcome did not match with my needs. People had little training when speaking to me.
* Council have privatised almost all Departments, so the Social Workers & OTs are now self- employed workers who are not accountable to anyone except to their Bank Managers. The ILF advisors/support is no longer available so the assessments have become very difficult for the disabled person having the assessment.

These so called ‘assessors’ have not had full British training as they are Agency Staff. Nightmare for the disabled person and their family (if they have one) there is no accountability of the Duty of Care that LAs have to have when Central Government has encouraged and allowed LAs to privatise their Social Care ( e.g. Capita).

* Councillors have no means of helping the situation because there is no Department or named person in the Council to address any issue. The remit for the assessors (self-employed) is to reduce the package because of austerity.
* I rejected the budget when it went to panel, had to go to resolution
* Social worker was horrible, the LA lost my financial monitoring and then accused me of not providing it (they are 5 years behind in the monitoring of budgets). [The Social Worker] turned up unannounced one day, and I was too sick to see her, so she threatened my PA that she could lose her job!! They have now cut my budget back to just care.
* Social worker refused to fund certain aspects, I had to provide additional info, jump through hoops etc
* At my review the assessor was a self-employed Social Worker whose remit was to try and reduce the care package as much as possible. The LA do not recognise certain advocates and there is no longer an ILF advocate to support us
* Been under review for 12 months very stressful and lost a stone in weight.
* I've lost almost everything I had to help me have a life.
* I think they wanted to have an Agency with line-in career to be in more control.
* Review didn't go smooth, argued the hours requested then only offered 30% of hours required. NHS have not reviewed in over 12 months and local authority state must wait for NHS not their responsibility as it is a health need.
* Contact with Local Authorities of all kinds is always stressful. However, a review of support is particularly worrying because of austerity cuts.
* LA wants to cut hours.
* Had to call a multi-disciplinary extraordinaire meeting.
* It was very dragged out. It took from requesting more support in January 2014 until July 2016 for them to finalise the new plan. They backdated 21 weeks but never sent me the money!
* The review officer didn't take my previously assessed needs into account. They changed the goalposts and cut my package by almost half. I made a complaint to the Local Government Ombudsman which took 14 months. Couldn't have got through it without the support of Being the Boss!

We were also interested in the result of the review as to whether or not the support had been:

a) maintained at same level 10 b) reduced7 c) increased 8

One person said they were still waiting a verdict and another reported that they had been promised an increase in their funding, but it has never materialised.

This was almost an even spread. As a follow-up to this question we offered an opportunity for them to describe their current situation:

* Have had nothing in writing yet as CHC are now involved but the Social workers says I’m safe.
* Moved to double-handed for hoisting.
* It [has] ended because I do not want direct payments anymore and there does not appear to be any other options until I have had an autism assessment with NHS.
* Increased but did not solve my needs so my husband has given up work to be [my] full-time carer.
* I asked for my review immediately after I was give my original care package. I considered they had not originally awarded enough hours for my care.
* I Iost transport costs which helped with outing costs etc. so cannot socialise anymore.
* My support went from 28 to 42 hours per week.
* I used to get £700 with a monthly contribution of £39.45. Than reduced to £300 with a self-contribution of nearly £150. Things were very difficult when dealing with the Local Authority. I decided to buy my own care after that. I opted out.
* My impairments are many and severe without any hope of improvement in the future.
* This has took 3 year to get this far but with things going up I will need more.
* Increased by 7 hours but not enough hours considering stopped working and lost 40 hours of access to work and increasing need.
* Awarded more money.
* It's not a case of "what if they take away something?" It's more a case of "What will they take away this time?" You wonder what they are going to take back from you; for example, the last time I had a review, taxis were removed from my support and as a result I am unable to go out as much as I'd like to. My Blue badge was not renewed on the basis the council worker said he "Saw me walk from the waiting area to the desk."
* Cut back so much, it's easier just to do it individually.
* I was told I could not ask for help with personal care, meal preparation, keeping my house clean, filling in forms, medication, hospital or doctors’ appointments and the many other things specifically listed in my care plan as needed by me.
* Increased to 39.5 hours a week.
* Increased due to significantly increased needs and a long fight.
* Not enough hours for impairment level.
* I took out formal complaint against both council and local mental health trust (it's a joint budget). All upheld, but still no resolution. Took to two ombudsmen - all upheld again with compensation etc. that was only reason why the organisations responded
* Although the hours were kept the same the hourly rate has not increased.
* Hours reduced from 51 down to 30 per week. Resulted in one PA taking voluntary redundancy, and as a consequence it’s difficult recruiting for the lower package.

**The National Situation**

The survey wanted to know the views of people regarding the national situation. We asked them if they believed they have witnessed the crisis within Social Care and everyone stated that they believed they had.

People responded by giving their opinions on both what they have witnessed:

* Closure of ILF people’s packages being reduced has resulted in an increase number of phone calls from Being the Boss members.
* I've been fighting for a care plan review for years with no luck - social workers are too overworked to even see me
* I am aware of friends/associates who’ve had their care package reduced.
* I have nothing because most services have closed down so there is nothing for people who need supported living in the community.
* I have had to use agencies. So many friends have lost hours; I had to fight and still have insufficient support. My county struggled to recruit staff we therefore we don’t have enough social workers and now they have trained 'admin' coming out [to do assessments]. Hence, very long waits and slow responses.
* People aren't getting the care they need.
* Generally, feel its seen as less of a right, more as we should be grateful for what we are given. I know of friends who have no family support [and] who have lost their independence or have only little left as only the very basic is paid .
* After 1st assessment I was given 12hrs, so I complained. The 2nd assessment, 3 months later, increased to 27 hours. [In my opinion, the report contained 67 fraudulent statements or omitted ones within 10 pages. 6 months later after 2 suicide attempts I was on 56 hours, but wrong the wage written for night care; however, the social worker just reduces hours to 51 instead of sorting budget. A year later after sorting accessible Housing out and with support challenging care package again with several services doctors agreeing [with me]. In the meantime, I’m in huge debt covering the costs and [my] pressure sores worse. [Response edited]
* Central government is using austerity to reduce Social Care funding. Criminal!
* Just by the council trying to bully into what they want me to do
* Funding is only allocated to most severe needs, everything [has to be] justified and hours are whittled down as much as possible. Made to resort to things such as nappies or catheters/bags instead of a person to assist with toileting. Meals are based on microwave and batch prepared - not healthy food and no support for food shopping or accessing the community.
* I know people who have had their budget cut.
* Some days because carers are zero hours I don't get a wash and dressed until midday or later. Better pay, conditions, training and respect for carers is vital. End zero hours too.
* My support has been cut back in the form of the use of taxis.
* I’ve seen it happen to a lot of other people but luckily it has not, so far, affected me directly.
* LA cutting hours.
* I was literally forced to give up social care and hire a PA personally in order to get some of the help I desperately need. They say we’re better off going into a care home.
* There were attempts to cut my care despite significantly increased needs. They tried to cut my care without full reassessment but were stopped by a solicitor. More dirty tactics. Gaslighting in multiple reports etc. On the up side I've been expecting a 6 week review since September 2016 and have only just been told I'll have an annual reassessment who knows when they'll get around to organising it. I have also been affected by the changes in rules for minimum wage for live in which is coming in to affect at the moment.
* They are constantly cutting back and cutting back due to the government targeting the vulnerable in their austerity cuts whilst claiming lavish expenses and high wages.
* I am scared of [having] my next review, hence I haven’t contacted them at all. It is 3 years since I last had one. I am concerned they will decrease the amount. I have seen friends and colleagues experience this.
* The Government are not putting sufficient funds into Social Care, they are not interested in developing a system so that people can enjoy true independent living.

We followed up with an enquiry as to whether or not they believed they had seen a change in attitude towards them as employers of Personal Assistant(s)/support workers or carers.

Nine responders answered by saying they had seen no change whereas eighteen felt they had. One person was not sure either way, and another reported they had seen a negative attitude when they had to deal with a social worker.

We once again decided to provide space for people to explain their responses:

* It's seen as being a very luxurious privilege I've been kindly granted.
* I could not get people to last more than a week because they could not cope with my behaviour. I act weird with new people until I get to know them.
* I have had to take on much more responsibility for them against my will, having to arrange all my own training and pensions etc, without appreciation of how difficult this is to handle.
* [It’s] very hard to recruit for short 1 to 2 hour calls, [and] the rate set by council is not competitive, so we are a 'stepping stone' whilst looking for other work. Lots of 'only filling in application' to tick a box for Job Seekers Allowance type applicants. Applicants only want to work school hours and feel they can dictate - those who have come from an agency seem very keen to dictate/ mother/control tasks compared to those who have other jobs. I am lucky my PA team are pretty good to great, but retention when it is awkward hours at the rate disabled people are allowed is very hard.
* I am very lucky. My carer is retired and is not desperate for every penny he can earn. He doesn’t have to dash off to his next paid appointment. He is not running himself ragged trying to make ends meet to house, feed, and clothe his family, he works far more hours than he is paid for. He is a kind and caring man. As I’ve mentioned, he is already retired. I don’t know how I will replace him when he feels he is too old to help me anymore.
* No-one from my local authority cares anymore.
* Changes mean the LA impose more rules than they used to
* I as an individual have been treated as a lesser person by unprofessional staff. Most of the social workers are not qualified.
* Hard to put in words.
* The privatised Social Care department of …. is not accountable to the people it is supposed to support. It’s only accountable to its shareholders.
* There is a lot more responsibility as an employer of PAs, the council gives no support or advice in getting set up or maintaining this position. The general community does not understand how one can need care and employ their own staff.
* Doesn't matter if I employ my own or get agency, you're treated as either invisible or as a child by the rest of the world!
* Lack of authority due to proximity of work. I think the change in attitude has been towards me because of disability rather than an employer of my own Personal Assistant's.
* LA asking me to pay my PA less than they were paying carers by personal budget.

* The attitude changed over the six years. I needed care and used the system from supportive and caring to abusive, dismissive and a drive to cut costs at any cost to the service users. Costs to the service user were constantly inflated by the council while care hours and the help received during those hours were cut at any and every opportunity to such a point that I dreaded calls and letters from the council and my social worker. In defence of the best carers I had I have to say they were not happy with the changing situation either and many have left for other jobs.
* They seem to understand more about my physical and mental health problems combined.

* Hard to describe. We seem to have to do all the hard work. When I was first set up with Direct Payments in 2013, ([receiving] care since 2011; I had to fight to get them), I was allocated an independent living support worker to help with writing a support plan to [take?} to Panel. That support has been cut except for CHC. If I have an emergency and need care from the council, they are no longer willing to help. They just say hospital or try the I depend living organisation for help.
* I think possibly PA attitudes have changed too. I don't know if it's just the attitude of live in workers, but people seem to think they can get the job without treating you as their boss, having sufficient English or common sense. People see it as a job they can mess about when they do come in or not.
* My Personal Care Assistants (PCAs) expect an annual hourly rate increase because of the constant cost of living rising but they hear in the news that the government is cutting everything under the austerity umbrella. Due to the stressful review that I had to go through, their jobs were threatened and therefore they became more stressful and even started looking at other employment options.

We were also interested to know if they felt as employers that their role is fully understood within:

1. Social Care Yes 2\* No 25 Don’t Know 0 \*A person waivered.
2. NHS Yes 3 No 23 Don’t Know 1
3. Wider society Yes 0 No 25 Don’t Know 1

Given discussions that Being the Bosshave been party to, we wanted to know whether or not since 2010 people believed it has become increasingly difficult to recruit Personal Assistant(s)/support workers. Where this was identified as an issue we sought to discover were seen as the main causes.

Yes 23 No 2 Not sure 2 Not too bad 2

The reasons for their responses were given as:

* Poor wages, applicants not understanding the difference between carers and PAs and the uncertainty of their job.
* In my area the wages are set quite high making recruitment difficult.
* Being a carer is seen as a negative career.
* Low pay, poor applicants, lack of understanding of the PA role.
* There has been no increase in the wage. I am expected to pay the same hourly rate now 8 years later as in 2010. this makes the role unattractive. The package I could offer my PA at the start was competitive with agencies but no longer is. The 'media' representation of poorly or disabled is less than positive and as we are run down it lowers the perceived value of the job in some people’s eyes; although to be fair, I don’t want them.
* Low pay, low status. I try to recruit staff for when my carer has holidays.
* The rate of pay is too low. The lack of respect given to carers by the medical profession.
* Lower wages, too few hours, needs of employer.
* Getting skilled staff for less than 16 hours is harder, because that is the threshold for in work benefits. Also, applicants often don't see working for a disabled person as a real job.
* One getting the right support to do it; trying to get my council to pay the right hourly pay LONDON living wage each April takes 6 months even though came in the November before. PAs see their rents and transport go up. Advertising on Gumtree got mainly people wanting to be my Secretary/PA. My PAs need more support and they are not getting it. I’m paying for a bit of it, but 6 months on it’s not been agreed yet by SS. It’s putting PAs off. The work, hours, low pay, stress etc. [plus] losing a specified Direct Payments advisor. **[Response edited]**
* Got an abusive pa who seem to believe government propaganda of government of disabled people of how I was treated, hurt, spoken to.
* Not sure maybe pay, long hours, Security of the Hours.
* I think it is a combination of wages been offered to carers e.g. minimum wage for what can be a challenging job with some PA's administering complex medications and doing complex healthcare. Also, the fact that PAs may only be working short hours e.g. 1 hour AM, 1 hour lunch etc. therefore struggling with income compared to working for a homecare or care home company. Additionally, I think there has been a decrease in the number of individuals interested in working in the care industry especially as many are not aware of the role of the PA compare to care homes.
* I am limited to what I can pay per hour.
* Zero hours contracts. Competition from higher paying or work or employers offering more hours per week. People are much worse off and Universal Credit rules force people into finding more work meaning they can't fit in a few hours care. Childcare costs mean carers who are mum's can only work when kids are at school or when partner/grandparents can have kids.
* Possibly funding; people not being interested.
* I have been struggling to replace one of the support workers who left some months ago. I have advertised on Disability Sheffield P.A. Register and interviewed some people, but they have not been suitable.
* The funding squeeze means there are less ‘private carers’ looking for work. In addition, the rate of pay I’m given is becoming far less competitive than it was.
* Care agencies cost too much and are inflexible. LA wants us to pay our pa minimum wage for very hard work and difficult hours.
* As I've said already applicants expect PAs to be ladies’ companions or social secretaries. They are not prepared for the caring involved and the often distressing and embarrassing side of it.
* I get a lot of applicants, but most seem to be box ticking for job centre or randomly applying on indeed. I can get over 300 applications, interview about 6 (with only a few more completing application process). I trial a few and find none suitable.
* I believe low pay is primarily the issue, but often the hours are difficult for people to fit in with other jobs, my hours include tea time so people with children find this difficult.
* Council putting limit on what I can pay people, lack of flexibility, choice and control over the whole process in general, lack of support from council re employing PAs.
* The Care Worker pool has been greatly reduced because the hourly rate has not kept up with the Cost of Living & another reason is that since Brexit the majority of Care Workers are going back to their EU countries.
* Wages not being increased in line with expected levels. Local Authorities not being given sufficient monies to support Social care. The closure of the Independent Living Fund. We haven't got sufficient political strength to make the government fund/develop adequate social care.

The issue of changes in policies at a national or local level was raised in terms of whether or not this had impacted upon their ability to manage their own package or agreement. Twenty said they thought it had, with six feeling it had not. Some people explained went on to explain the nature of the impact:

* Large increase in my contribution.
* I was moved to CHC funding.
* My funding from Access To Work has become difficult/inflexible to change to meet my needs with regards to some additional hours and sleeping-in payments I need in my national role.
* The support service was closed down due to a reduction in funding in the council.
* Employers have had to take on much more responsibility for things previously done by CILs or not applicable like pensions, wages etc
* My council still try to ignore Care Act 2015. They are less than clear on charging rules and policies and will cheat if they can; so I have to be very aware and fight them.
* Sadly the 'client contribution' has increased and they have removed any support for reasonable pa expenses from the budget which means I am finding things financially very hard. I don’t want to choose between heating and having a PA.
* The changes to employing self-employed PAs recently have made it much harder as although it’s possible it’s more likely the government will judge someone as employed. This puts off people diversifying e.g. cleaners doing short PA shifts.
* PIP means I have to contribute more to my care package. I have a constant battle with my council over what will be accepted as Disability Related Expenditure. This battle lasts a year or more each time before they finally reduce the amount I must contribute. It’s wearing me out. If I don’t fight, they overcharge me substantial sums - like about £1,000 - £2,000 a year.
* It has become very confusing for me. Forms have become harder to understand. I have less freedom.
* My LA used to allow money to be spent on the cost of activities if a PA had to be paid for. For example meals if we were out, transport or entrance fees. This is no longer the case.
* There is no accountability of a privately owned company. They only answer to their shareholders.
* Not yet but it will do with the Pensions and the minimum wage for night pay.
* No grasp that those with small awards find it hard to get regular support. Payroll companies taking the piss with fees.
* Parkside Payroll look after the payments, so no money comes directly to me.
* I live in fear of the goalposts being moved. I’ve held off recruiting until my review was completed just so I didn’t have to let go of a new employee if my package was changed.
* Financial assessments have changed. Most of money goes towards paying for my care.
* I've only had a PA for 4 month and have frankly been exceptionally lucky in my choice of employee.
* Yes changes to national minimum wage for live in workers.
* The pension business is super difficult as is the new data protection laws.
* Local Authority cuts I believe had a considerable impact on my receiving reduced hours.

We specifically asked if they believed that since 2010 Social Care and the NHS service providers have a better understanding of Independent Living or a poorer understanding.

Twenty three people felt they had a poorer understanding with one saying the poor standard was just maintained. Two were uncertain due to their personal circumstances.

Focusing on the cutbacks in Local Authorities’ budgets we asked if they felt this had resulted in an increased difficulty in obtaining support. Twenty six people said that they thought it had, with a further three not sure at the moment.

Sixteen responders believed there has been an increase focus on health over social needs however four people disagreed.

Many said both sides of meeting the needs were in a mess with one person saying:

* They don’t seem to care about our needs. They like to make out my care needs are health needs so that they can say it’s not their responsibility. It’s a health issue, so NHS should pay. Just another way of hammering people who are too ill to fight for the help they need

A couple of people stated they were not in a position to comment.

When asked if they felt less attention paid to independent living, twenty six people thought that was the case with a single person disagreeing. The same number of people believed cutbacks in Local Authorities' budgets resulted in less service user involvement in care planning, however two people disagreed.

A number of comments were added:

* All directed and accepted from Central Government.
* I believe people are wrongly seen as consumers. Poorer people are out of the equation

We were also interested to know if the participants thought the increased role of the NHS and decreased role of the Local Authority in Social Care was a good or bad thing. There were four people who thought it was a good thing, seventeen who was it as a bad thing, with three others not being sure.

People were again encouraged to express their views on this issue:

* The CCGs have not had enough training of the clinicians to tackle both the health (especially the mental health issues) or the social needs of disabled people to live independently
* This is down to individual circumstances, but every human needs a social support element and not just medical needs, washing and eating.
* I think ensuring health needs are met as well as care and independence can only be a good thing, however it can be used to reduce the hours of support available and often having another agency involved makes things harder and take longer.
* Focusing on health rather than social needs.
* Even as my condition progresses my care plan doesn't increase because funding is constantly cut. The focus on health over social needs meant being moved to CHC funding which saved me money, but means they're not interested in my desire to access the community etc.
* The NHS have always been brilliant with me offering me the best services they can. Social Care just kick me out as often as they can.
* There is a huge move to push the social and community support onto charities. My council will do anything they can to remove hours for cleaning and hobbies even though it’s part of Care Act. The more recent assessments have been about someone 'doing task a quickly efficiently for me' even if I want to be part of doing it when able; whilst this would take a lot longer, their way removes choice. They are extremely ignorant of mental health needs of any long term poorly person and how that interacting with people and activities are vital.
* I think it’s just another way to add extra assessments that are undertaken by people trained to find ways of not providing the help we need. We don’t know how to argue our case. They aren’t trained to help us get the care packages we need, they are trained to reduce the amount of care we get. They know how to use the system. We don’t.
* It makes Social Care sound like a medical need.
* Provision has returned to an emphasis on basic need not lifestyle choice. Leaning more towards health allows use of the medical rather than the social model of disability. The latter being essential for upholding the principles of choice and independent living.
* My medical needs are predominantly the reason why I need more support.
* Health (clinical) and social care should be equally assessed and provided for to enable a healthy independent life for the disabled person and their family.
* I feel that social care has become very impersonalised and does not focus on the individual and what they would like to achieve in life (despite the Care Act outcomes). The NHS involvement means that social care and NHS simply pass the buck to one another stating the individuals care is either a social need or a health need or they argue over the percentage split. It is all about money and numbers and not about the person, their life and what they want and need.
* NHS likely to just want to cover health need (meds, personal care, etc.) I can't see them seeing support to go out as a priority. I only go out a few times a year but if that stopped I'd be seriously pissed off.
* Local Authorities and NHS are privatising so businesses are competing to fill the role and therefore people are wrongly seen as consumers.
* My needs are complex and expensive to meet, it makes far for sense for the NHS with its larger budgets, larger remit and lack of means testing to support me.
* I don't know if it will be better as my condition is one with a difficult history and perception within the NHS. It may work better for other people, but I doubt it will for me.
* It is very hard to get CHC and involves a lot of gatekeeping!
* I guess as mental health is not well funded in NHS; but it’s part of my health problems.
* I think that if NHS and Social Care monies are integrated, the NHS will cream off monies from what should be spent on Social Care.

In line with discussions going on among disabled people’s organisations in relation to new forms of delivery we asked if they would welcome the idea of having services around Independent Living set up as being separate from the NHS and Social Care but with pathways for multiple service delivery where necessary.

Twenty responders said they would support the idea as opposed to two who would not. Four people were not sure or stated they did not understand the question. The comments however make interesting:

* Even as my condition progresses my care plan doesn't increase because funding is constantly cut. The focus on health over social needs meant being moved to CHC funding which saved me money, but means they're not interested in my desire to access the community etc. Not quite sure how this would look but it sounds very interesting as a concept.
* I hate social care
* If it streamlines and makes the process simpler and faster yes but if it ends up with more red tape and admin no thanks.
* I don’t want anything that means I have to have extra assessments. They make me too ill, I need fewer assessments of any kind. Assessments are cruel, demeaning, exhausting, and for many of us they make us even more ill.
* I believe so, but the question is not totally clear for me
* Our independence is compromised by the ever changing political agendas. It is a human rights issue and it should be fought for from an independent body rather than a statutory service.
* Clinicians and agency staff are not trained adequately to address and fully support a disabled person especially for those that have hidden impairments. There should be peer support.
* Because it'll meet the needs of the people who are severely disabled, but they just want to pass the book on to the NHS so that they get out of paying.
* I think independent living should be a separate entity where individuals’ needs are assessed; and the funding can come from the relevant area and support from the relevant area e.g. NHS/social when needed. Having independent living set up as separate with its own clear structure and budget and transparency may help focus more on individuals and outcomes.
* We are all different therefore different approaches to care and support should be a human right.
* I would like someone, ideally an independent living organisation, to run my care for me but under MY direction. I would like them to handle payroll, scheduling and recruitment.
* It's hard to tell what will be the best and frankly I'm not hopeful that ANYTHING other than a new party in government will make things get any better.
* I don't like how even the local DPO is council funded so has to follow their rules, can't argue back, and is subject to massive cuts.
* Disabled people’s needs change over time or as their impairment or disease changes which can have an effect on both mind, body and soul which effects the disabled person and their family/friend/carers.
* Disabled people’s needs change over time or as their impairment or disease changes which can have an effect on both mind, body & soul which effects the disabled person and their family/friend/carers.

The final section of the survey asked questions about how they thought Being the Boss should be moving forward. Participants were asked if they thought Being the Boss should continue to be a national network of disabled people who employ their own personal assistants (P.A.s)/support workers or carers. Twenty six were in favour of this with one disagreeing and another abstaining.

To the task of providing peer support and a coherent voice for them in the wider community the same number supported. Twenty people believed Being the Boss should have a website and Facebook page.Two people said they were not on Facebook.

We were interested to know if participants had any practical suggestions on how Being the Boss could become more effective as a national network. The responses were:

* Have a Facebook group of its own
* Sorry only just heard of you from a different Facebook group. I'll have a look round next.
* We need them to be more visible. I didn’t know about them. I’ve only just heard about them and will be looking at how they can help.
* Greater advertising - I've been a DP employer for 3 years and never heard of Being the Boss until today when it cropped up accidentally on Facebook. I use Facebook daily and spend a lot of time on disability related pages, but I've never seen anything about it before.
* Have several forums led by disabled people.
* Should be advertised wisely not just on social media because not everyone is on Facebook or has access to the internet.
* Be move widely available
* I wish I knew about your organisation earlier, may have stopped me being forced into going from employer to direct payments to a care company to now, being directly funded.
* Have branches of Being the Boss in every major city.
* I've only just found you, so am not able to advise.
* TV advertisements.
* Independent advocate network for attending appointments etc.
* Open social groups where people can meet face to face to help those that don’t/can’t use electronic social media. Meet in supermarkets/religious centres/shopping centres etc
* Partner with any like-minded User Led Organisations.
* Similarly, we sought practical suggestions on how Being the Boss could improve the peer support work it does and/or continue its role as a coherent voice in the wider community.

We also asked for practical suggestions on how Being the Boss could improve the peer support work it does and/or continue its role as a coherent voice in the wider community?

* Having a section on website to recruit PAs.
* Have a twitter account.
* Need links with local political parties, need links with people on social media, etc.
* Firstly, it needs to stay independent from government funding. Use several social media platforms.
* Get into to every Town/village/street through local free press or personal referral.
* Could consider a YouTube channel for people to upload videos/peer support. Some information in BSL would be useful ( I would be happy to do this if required BSL Interpreter).
* A mentoring service?
* TV and magazine articles.
* When funds were available, we could set up telephone conferencing groups.

Our final request for practical suggestions related to how we could make the Being the Boss website and Facebook page useful tools in light of our limited resources.

* Wider section with more example documents that members can suggest.
* Just have a Facebook page.
* More publicity of who you are.
* You need to be sharing info and asking for your Facebook posts to be shared widely so that we can all become aware of what you do.
* More advertising on related pages.
* Do more YouTube, live video feeds to explain the work you are doing. Go into local supermarkets to advertise because working with charities are no longer for the benefit of-for the people but another privatised company with very limited resources
* Get the Authority and the NHS to put it in the paperwork which they give when someone is going on to Direct Payments.
* The website could be more accessible, I understand resources are limited but the website is difficult to navigate. It can be a little hard to find relevant pages
* I think the Being the Boss website is fantastic! - this is the first time I have used it independently and as a totally blind person, I have found it very accessible. I haven't got much experience of the Facebook page.

Being the Boss also wanted feedback on our proposal to develop **be more visible and proactive we intend to develop areas of training which would benefit members and supporters of Being the Boss. We will update the website and Facebook when we have training packages ready for delivery.**our work in four distinct yet interlocking ways. The four areas are: Information and education, Peer Group Support, Campaigning on Independent Living, Advocacy and Training. There was 100% support for the proposal. A couple of people made comments and asked questions about our future direction:

* Advocacy work is critical
* Looks like a grand plan to me
* How do people become members of your organisation if they don’t have a Facebook account?
* Being the Boss should be everywhere . I can't get any support in my area
* Independent living organisations locally are there to make a profit at the expense of clients. It must have took 20 minutes at most to log the hours my PA worked with HMRC once a month, yet I paid over £50 a month for the pleasure which in my opinion is not on. Empowering disabled people to either do the paperwork themselves out find someone who charged a fairer rate would be doing a huge service too.
* I would love to see our membership increase.

We wanted to know if people woplanning to be more visible and proactive we intend to develop areas of training which would benefit members and supporters of Being the Boss. We will update the website and Facebook when we have training packages ready for delivery. be more visible and proactive we intend to develop areas of training which would benefit members and supporters of Being the Boss. We will update the website and Facebook when we have training packages ready for delivery.uld be interested in having face-to-face meetings. There were fifteen people in support of having face-to-face meetings with six declining. Many raised the practical problems of having face-to-face meetings and suggested various other forms such as Skype. Someone suggested regional meetings and others focused upon the need to have a voice and influence local and national policies.

**Key themes and issues arising from the National Information Gathering Survey**

**Introduction**

Being the Boss acknowledges that our survey was limited to a self-selected group of just under thirty people and cannot be considered as truly representative of all those people who employ personal assistance. This said, we believe the data collected nevertheless chimes with comments, research and articles that have appeared on many platforms. Given this, we also feel our survey’s information needs to be taken seriously and built upon.

The first two sections of our survey are particularly relevant to national debates around social care and independent living. By drawing out key themes Being the Boss hopes to stimulate further debate and research.

**The responders’ personal situation**

The overwhelming majority of the twenty-nine responders were funded by Local Authorities and received Direct Payments. The experience of having reviews of their care packages was very mixed. Two thirds of the responders said that the reviews were hard going or tough. Many responders expressed dissatisfaction with their Social Workers’ or assessors’ practice. Roughly a third reported however that their level of support had been maintained, but the inference was that it has taken a lot out of them to achieve this situation.

**The crisis within Social Care**

We asked the responders if they believed they have witnessed the crisis within Social Care and everyone stated that they believed they had. The closure of the ILF was seen as a significant factor for some. It was suggested that Government funding of Local Authorities has led to severe budget cuts in service provision. People spoke of reduced services, hours and rates; others also referred to harsher attitudes among Authorities and professionals. This sea change was one of moving away from social support being seen as ‘a right’, back to the old fashioned view that people ought to be grateful to receive support. If this is a fair reflection of current attitudes, then this trend goes against the grain of both the Care Act and Article Nineteen of the United Nations Convention on the Rights of Disabled People.

**A change in attitudes regarding them as employers of personal assistants**

A significant number of responders felt that there was also a change in attitudes regarding them as employers of personal assistants. There was a feeling that recruiting and retaining staff had become increasingly more difficult. Among the reasons given for this was uncertainty over funding, low rates of pay and the expectations of potential employees. A few responders suggested that changing societal attitudes were also rubbing off onto their employees whereby the ‘carer’ mentality was stronger than the ‘independent living’ one.

**Lack of understanding of role as employer of personal assistants**

Almost all responders stated that in their opinion their role as employer of personal assistants was not understood within Social Care, the NHS or wider society. This would suggest there is a need to make more visible the culture that actually exists behind independent living rather than allow the ‘dependency of being cared for’ stereotyping to continue unchallenged.

**Negative impact of national and local policies**

Many of the responders felt changes in policies at a national or local level had impacted upon their ability to manage their own package or agreement. A range of examples were given including increased personal contributions and responsibilities as an employer. Outsourcing and privatisation were also given as policy changes that had had a negative impact.

**Lack of understanding of independent living**

When specifically asked if responders believed that since 2010 Social Care and the NHS service providers have a better or poorer understanding of Independent Living, twenty three people felt they had a poorer understanding. Many blamed the cutbacks agenda, lack of training and commitment among professionals, with many passing the buck. Just over half the responders felt that there was an increasing emphasis on health over social care. In the opinion of Being the Boss there are a number of possible explanations for this. Firstly, government policy is attempting to give greater responsibility to the NHS for Social Care. Secondly, there is a move towards a bio-psycho-social approach within many assessment procedures which has increased the medicalisation of the ‘need assessments. Thirdly, relating to the second, is the fact that strapped for cash authorities are looking at ‘critical needs’ as opposed to supporting independent living as defined and understood by disabled people’s organisations. Seventeen responders felt the increased role of the NHS and decreased role of the Local Authority in Social Care was a bad thing.

**Towards new forms of delivery for independent living?**

In line with discussions going on among disabled people’s organisations in relation to new forms of delivery Being the Boss asked if they would welcome the idea of having services around Independent Living set up as being separate from the NHS and Social Care but with pathways for multiple service delivery where necessary. Twenty people said they would support the idea as opposed to two who would not. With hindsight, this may have been a difficult question to answer because the discussions on this idea remain at an embryonic stage and therefore it may still be had to visualise what these new forms of delivery might look like. Being the Boss nevertheless was encouraged by the high percentage of support for such an idea. As an organisation we will continue to work with the Reclaiming Our Futures Alliance and others to develop this into concrete proposals.

**Conclusion**

Being the Boss believes our National Information Gathering Survey has been a useful exercise in terms of identifying key themes and issues which resonate with employers of personal assistants however as stated elsewhere, it indicates that a larger piece of research is required and that in turn means funding for such a research project would need to be obtained.

Being the Boss is also happy to know that there is general support for the direction we wish to travel in and the responders have given us much food for thought.

Bob Williams-Findlay MA

Director and Project Manager

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