



the brain injury association

**ACTION FOR**  
**BRAIN INJURY WEEK 2014**  
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# **A ticking time bomb: The false economy of cuts to brain injury support services**

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A study to examine the impact government reforms of the welfare benefits system and cuts to local authority budgets are having on the lives of people affected by brain injury

# A ticking time bomb: The false economy of cuts to brain injury support services

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## Introduction

In Spring 2014 Headway conducted two surveys to examine the impact government reforms of the welfare benefits system and cuts to local authority budgets are having on the lives of people affected by brain injury.

- ***Are funding cuts having an impact on the lives of people affected by brain injury?*** A survey of brain injury survivors
- ***Are local funding cuts having an impact on the ability of Headway groups and branches to support those affected by brain injury?*** A survey of Headway groups and branches

This report presents a summary of the findings of each survey and their respective implications.

The surveys were designed to inform Headway's 2014 *Action for Brain Injury Week* campaign entitled 'Don't cut me out'. The campaign set out to raise awareness of the impact of welfare reforms and spending cuts on brain injured people and Headway support services.

The questionnaires were hosted on the Survey Monkey website ([www.surveymonkey.net](http://www.surveymonkey.net)) and promoted via emails to all Headway groups and branches, the Headway website and social media channels. Groups and branches were asked to encourage as many service users as possible to take part and to provide any help necessary. Hard copies were also made available to download from the Headway website or sent out on request.

The surveys generated a good response, with 504 brain injury survivors and 92 Headway groups and branches taking part. Headway would like to take this opportunity to thank everyone who took the time to participate.

If you would like to discuss any aspect of the research please contact Richard Morris on [info.officer@headway.org.uk](mailto:info.officer@headway.org.uk) or Andrew Taylor on [website@headway.org.uk](mailto:website@headway.org.uk).

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## Key findings

### Reduced access to support services for brain injured people a 'ticking time bomb'

**48%** of people living with brain injury have **lost access to vital rehabilitation and support services** as a result of cuts to local authority budgets and welfare benefits reform

**70%** believe loss of access to support services **will lead to greater reliance on state support** in long term

**70%** **concerned about ability to cope financially** due to welfare benefits reform

**More than half report a deterioration in their quality of life**

### Charities struggling to cope with reduced support from local authorities

**57%** of Headway groups believe changes to local authority support have already had a **direct impact on their ability to provide support services**

**85%** of local Headway groups **concerned about long-term survival**

**89%** **forced to use reserves or additional charity funds** to maintain vital services

## Executive summary

The results of the two Headway surveys demonstrate that simultaneous cuts to local authority budgets and welfare benefits reform are having a detrimental effect on the physical and psychological wellbeing of brain injury survivors. They are also adversely affecting the services provided by Headway groups and branches.

The unintended consequences of the changes in funding, from reduced financial support for individuals and charities through to a loss of or reduced benefits payments to individuals, are multiple and could have a wider impact on society.

In the short term, people are struggling to cope with the practical and physical implications of reduced access to services. The psychological impact also appears significant as people are fearful of how they will survive further cutbacks.

An increased reliance on support from others has also been reported, both in the short and long term. Respondents stated that reduced access to support services, such as Headway and specialist neurological rehabilitative professionals, is hampering their ability to regain their independence and is therefore creating an increased reliance on NHS, local authority and social services.

In addition, 70% of respondents reported their long-term support needs will increase if they do not receive the support they need now. This is due to a number of reasons.

A brain injury is unlike any other injury. It does not simply heal in time and brain injury survivors require specialist help and support to relearn lost skills, rebuild their lives and regain their independence.

Cutting rehabilitation services or reducing access to them is a false economy as it reduces the chances of people with brain injury regaining their independence. This in turn is likely to lead to an increased reliance on state support in the long term as people are less able to maximise their recoveries and care for themselves.

The effects of welfare benefits reform are having an effect on families, with reduced specialist support putting greater pressure on individuals to care for their loved ones. This could lead to more people no longer being able to cope with the physical or emotional toil of caring, or will no longer be able to manage financially in the light of cost of living increases.

Many who feel unable to continue to care for their loved one in the face of reduced support services may feel they have no option other than resorting to residential care, which can cost thousands of pounds each week.

## **Charities under pressure**

Charities supporting people affected by brain injury are also under increasing threat due to reduced financial support from local authorities.

There are in excess of 120 Headway groups and branches across the UK, with many reliant on local authority funding in order to provide vital specialist services that are not available from similarly-experienced local organisations.

Headway's network of groups and branches provide a range of social, physical and cognitive rehabilitation and support services to brain injury survivors. For many people, Headway provides a route back to independent living, further education or employment. The groups and branches also provide crucial support and respite for carers, many of whom have previously reported their reliance on Headway in order to be able to cope with the pressures of caring for someone with a brain injury.

Despite the importance of Headway groups and branches, both in the lives of those they support and in terms of providing a service that would otherwise not be available, the majority have reported concern about their long-term future if funding from local authorities continues to be reduced. Indeed, 89% have been forced to use reserves and additional charity funds in order to continue running services.

It is clear to Headway that unless action is taken to enable people to access the vital support needed and to ensure those services survive, more and more people will be cut out of society and tax payers will be left footing the bill for caring for those without the means to care for themselves.

## Survey one: Are funding cuts having an impact on the lives of people affected by brain injury?

This questionnaire was intended for anyone with a brain injury. The aim was to assess how recent changes to the welfare benefits system and cuts to local authority budgets have affected their finances and access to important services.

### Section one: Demographics

We asked a number of questions to find out the demographic characteristics of participants. Selected characteristics are summarised below.

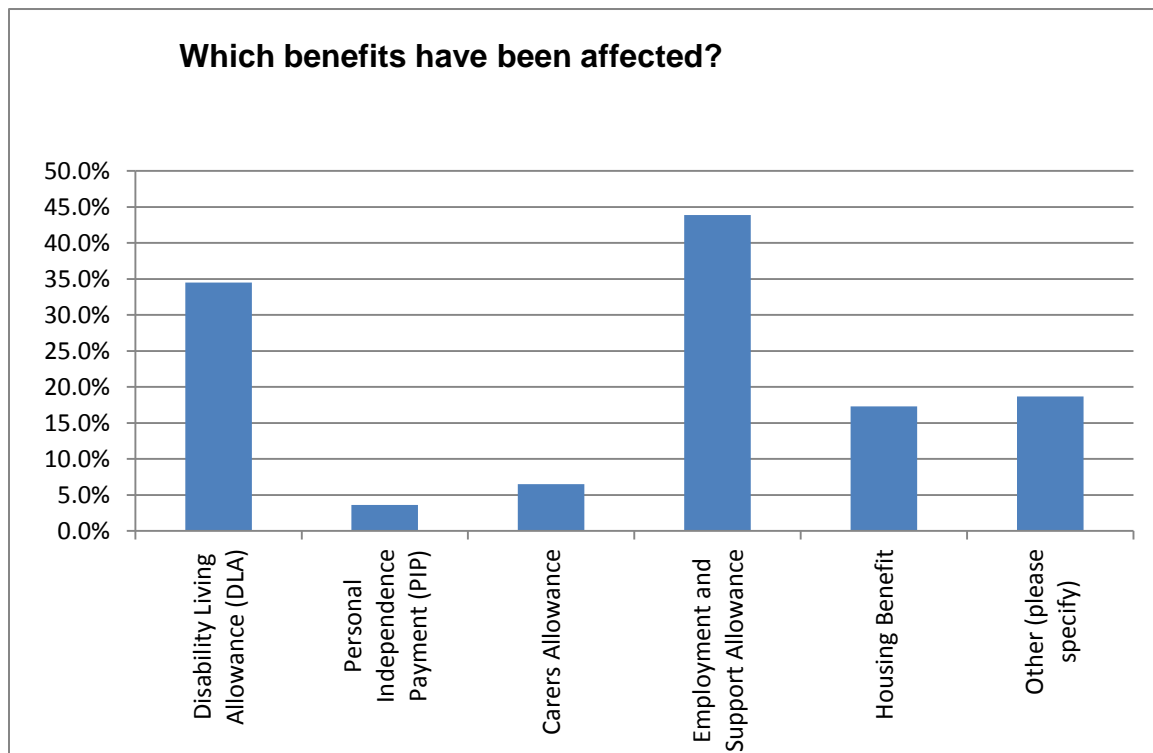
- 504 people participated in the survey
- Moderate to severe traumatic brain injury was the most common form of injury among respondents at 49.6%. Strokes (including haemorrhages and aneurysms) accounted for a further 39.2%
- The average age of respondents was 46
- 58.6% of respondents were male and 41.4% were female
- 29.6% sustained their injury in a road traffic incident
- 21.8% had no period of unconsciousness following their injury. 26.3% were unconscious for 15 days or more

**Comment on demographics section:** The high rate of moderate to severe injuries and strokes indicates a group with a significant level of physical and cognitive disabilities and support needs. It is interesting to note that more than one fifth of these people sustained no period of unconsciousness, indicating that significant disabilities commonly result from injuries which may have been assessed as non-serious at the time.

### Section two: Welfare benefits

In this section we ascertained how people have been affected since welfare benefits reforms first came into force. We therefore focused on the past two years.

- Disability Living Allowance (DLA) was the most common benefit being claimed (65.9%), with Employment and Support Allowance (ESA) second most common (36.8%)
- Almost one-third of people (31.4%) had lost access to or had payments reduced on benefits received in the last two years
- ESA accounted for 43.9% of the benefits affected, with DLA accounting for a further 34.5%, as illustrated below:



- 70% of respondents were concerned about the impact of welfare benefits reforms on their ability to cope financially
- Three-quarters (75.5%) feared having their benefits cut in future as a result of changes in the welfare system
- More than three-quarters (76.4%) felt that welfare reform is unfair on people affected by brain injury. Reasons provided included the following:
  - *“It is hard to complete the forms and express your symptoms. One of the symptoms (of brain injury) is [difficulty] engaging with people, which makes it difficult during assessments.”*
  - *“People with brain injuries are easy targets for cutbacks as they cannot defend themselves.”*
  - *“Not enough understanding with regard to problems related to brain injury.”*
  - *“People with brain injury are treated by how they look not by the illness just because they may look fine doesn't mean they are.”*



- The majority of people feel that reductions to benefits affect their ability to live independently and place greater reliance on other people. The responses were broken down as follows:

How do you feel reductions to benefits affect the ability to live independently?	
	Response Percent
Creates more reliance on carers	60.7%
Creates more reliance on NHS services	41.0%
Creates more reliance on local authority / social services	36.6%
Creates more reliance on voluntary sector services (such as Headway)	55.7%
Makes no difference	2.4%
Reduces reliance on support services	8.4%
Not sure	14.0%
Other (please specify)	12.8%

People were asked to explain how changes to the welfare benefits system were affecting their lives now and may affect them in the future. Selected responses are provided below and make stark reading:

- *“Up until now I have been receiving DLA but have come up for re-assessment in the last month as my benefit expires this July. The stress of possibly losing this benefit is impacting on my mental health. I suffer residual epilepsy as a result of my ABI and stress is a risk factor for me in triggering a seizure, so I live in fear of this happening. The financial hardship it would cause is hard for me to even think about. It would cut off my ability to go and see my family, who live away from me.....I wouldn't be able to afford to travel. Utility bills would become a problem. Heat or Eat springs to mind.”*
- *“Due to less financial stability. You constantly worry. Adding more pressure on yourself. You then have fear of not being able to afford things such as food, heating, bills e.g. telephone. All these things are needed to give you some sort of quality of life. If you have less of this then you don't have a lot of hope for the future. Only fear and worry.”*
- *“I failed the ESA assessment and was told that I'm 100% fit when I can only cope with a few hours per week. I'm expecting the same with PIP. I've been made redundant from my supported permitted work after council funding was cut.”*

- *“I have lost housing benefit due to the Bedroom Tax. I feel that when I am formally assessed e.g. by ATOS, they will see that I am mostly mobile, have my speech back quite well and will deem me fit for work I am definitely not fit for. When I previously raised my post stroke fatigue with DWP the response was "we all get tired...". The welfare system is ignorant to people’s real problems and will only get worse as funding is cut and welfare with it. Their focus is cost cuts first, people second.”*
- *“It's very stressful. I'm more unwell now than I've been for years but not only welfare cuts but physio cuts – only allowed 6 weeks of hydro following a recent hospital admission as they have too many patients even though consultants recommend it etc.”*

**Comment on welfare benefits section:** It is clear that a significant number of people have already been adversely affected by the reforms. The number of people whose Employment and Support Allowance (ESA) has been reduced or terminated reflects widely publicised statistics and stories about the inadequacy of the ESA assessment process.

Also clear from Headway’s findings are the fear, anxiety and resentment caused by the reforms. Many people are confused and fearful for the future. They are also losing their independence and self-worth, placing a significant burden on both carers and statutory services, which are themselves affected by the reforms.

### **Section three: Local authority and NHS funding cuts**

This section asked questions relating to NHS, local authority and Headway service provision in order to ascertain how funding cuts are affecting access to these services. Again, we focused on the past two years, in which the cuts have come into force.

- Almost one-third (30.6%) of respondents had difficulty accessing support services, such as their local Headway group or branch, in the past two years because of lack of local authority/NHS funding
- Almost half (47.9%) of brain injury survivors had lost or faced reduced access to brain injury services because of lack of local authority/NHS funding. This included Headway activities, neurological and other specialist services
- Over half (52.8%) felt their quality of life had been adversely affected by local authority/NHS funding cuts
- Over two-thirds (69.9%) felt that their long-term support needs will increase if they do not have access to the support they need now

People were given space to explain how funding cuts are having an impact on the lives of people affected by brain injury. A selection of responses is provided below:

- *“If I had no access to my local Headway, I would have very little social interaction with people outside of my own family.”*
- *“If the cuts take place I will rely heavily on Headway more often for support - as a voluntary organisation this puts more pressure on them.”*
- *“I think if I had had some help from the beginning, I may not have had to cut my hours at work so drastically.”*
- *“Due to the local authority cuts [my wife] no longer has a social worker with her social payment being reduced due to the cuts, we have to pay the difference for her to attend the local Headway group. She always looks forward to going to Headway, even more so now as she goes on a Tuesday as well as a Monday and Wednesday. She likes all the activities they do there and she would be lost without them.”*
- *“I have been told that I may lose my place at Headway House I have explained that if they take it away they'll have to spend the same money on anger management. It's a service that's beneficial in so many ways to people - often ways that are not easily measurable.”*
- *“The severe cuts being imposed on local authorities will result in the removal of the support that enables me to be in independent living and support my wellbeing. I fear that I will not be able to cope and could deteriorate to the state where I would need extensive help and support from the NHS.”*

**Comment on local authority/NHS funding cuts section:** A significant number of people are already losing access to vital services and we can only expect this to get worse if the current climate continues. The fact that over half of people feel their quality of life has been adversely affected is a distressing figure as this applies to a person's general sense of well-being and happiness.

All aspects of a person's life are affected when vital services are withdrawn. These don't have to be expensive and complex care services; something as simple as attending a support group and socialising once a week can make a huge difference to someone's life.

It is particularly damning that approximately 70% of people feel their support needs will increase in the future as a result of lack of support now. This shows the ‘false economy’ of the reforms, which simply postpone and increase funding requirements to a later date.

## **Survey two: Are local funding cuts having an impact on the ability of Headway groups and branches to support those affected by brain injury?**

This questionnaire targeted senior staff from Headway groups and branches. The aim was to ascertain the impact of welfare benefits reform on service users and the effects of local authority cuts on the ability of Headway services to provide support for people with brain injury and their carers.

### **Section one: Demographics**

We asked a number of questions to find out the demographic characteristics of participants. Responses were limited to two per group or branch. Selected characteristics are summarised below.

- There were 92 responses representing 69 Headway groups and branches
- 23.9% of respondents were senior staff, 30.4% were trustees and 45.7% were designated staff members

### **Section two: Welfare benefits**

This section attempted to complement the testimony of brain injury survivors themselves on welfare benefits reform by seeking the views of the people who support them.

- 85.3% of respondents were concerned about the impact of welfare benefits reform on either the majority or all of their service users. 0% had no concerns for any service users
- Two-thirds (66.6%) were aware of concern among either the majority or all service users about future benefit cuts as a result of welfare reform; 85.3% were aware of concerns among at least half their service users
- Of those who were aware of concerns among service users, 87% of Headway group and branch representatives were concerned about the physical and emotional well-being of their clients
- 85.3% felt that the implementation of welfare reform is not fair on people with brain injury and their carers

Respondents were given space to explain how welfare reforms are affecting their service users. A selection of responses is provided below:

- *“Members have needed assistance in filling in applications. Some head-injured members have filled in applications themselves then found they have been told they do not qualify for benefits. They admit that they have not really understood the questions when completing the forms.”*
- *“Concerns around benefit changes and service users and families are living on the edge not knowing if they will continue to get benefits and funding (to attend support services). Lack of availability of help for people for advice and form filling. Many services have reduced funding for dedicated services around advice on benefits. Medicals are also causing some difficulty as many get very stressed as it is heavily weighted towards physically disabled people and many brain injured people have a hidden disability.”*
- *“The effects of the welfare benefits reform will have a devastating impact on the individual; with reduced services of specialist provision all the family will have to bear the impact of less support hours as they will not be able to sustain loss of earnings and cost of living rises. Many will be unable to care for their loved one as a result and possibly have to resort to residential care, having a greater impact on local government funding.”*
- *“Most are frightened and anxious and some in our groups have stopped claiming benefits as the thought of interviews and form filling is too much for them to cope with. For others I fear that they will not be understood at interviews or be unable to complete forms correctly.”*
- *“Loss of vital benefits to provide basic needs to live, including money for food, housing and general living costs. Increasing evidence of service users becoming desperate and needing advocacy support, which is not funded.”*

**Comment on welfare reforms section:** These responses highlight the profound level of concern felt by people working directly with survivors of a brain injury. Quite apart from the financial difficulties being faced, there is an obvious impact in terms of stress, worry and anxiety. Even those who do not have their benefits cut are affected by the stress of filling in forms, going through appeals and attending assessments that are not fit for purpose. There is an overwhelming sense of injustice among those who support brain injury survivors on a daily basis.

### Section three: Local authority and NHS funding cuts

This section sought to establish the impact of funding cuts on the ability of Headway groups and branches to provide their services, as well as the effects on service users themselves.

- 89.3% of groups and branches represented reported having to subsidise services, events or outings as a result of funding cuts. This means using reserves in order to maintain vital services or having to use funds intended for other purposes
- Over half (56.9%) reported that changes to local authority support had a negative impact on their ability to provide essential support services
- 23.6% reported a decrease in the number of service users accessing their services as a direct result of changes in local authority funding
- Almost one-third (30.6%) have had to cut services or activities as a result of reduced local authority/NHS funding
- 83.3% were concerned about their organisation's ability to provide support services in the long-term if local authority/NHS funding cuts continue

Respondents were asked to expand on how the funding cuts are affecting their group or branch's ability to support those affected by brain injury. A selection of responses is provided here (further examples can be found in the appendices):

- *“Local authorities have increased their criteria for funding to ‘substantial or critical’ to agree to spot-fund our service. They are also now more reluctant to fund outside their area even if they don't have a service which meets the needs of the client.”*
- *“It places additional burdens on already limited funding, at a time when most charities are being hit the hardest. It is particularly affecting the most vulnerable, in what is supposed to be a civilised society, who need increased funding, not cuts!”*
- *“We are expected to provide a very high level of support with a minimum of funding. The paperwork has doubled and we have to “jump through hoops”. Staff are very thin on the ground and are stretched to capacity; if we can't afford to employ more staff then we are not going to develop our services.”*



- *“As funding continues to be cut, with an increasing number of people requiring our support, this will reduce our ability to support those affected by brain injury. A very gloomy forecast.”*
- *“We have needed to make redundant our Development Worker and consequently information about our activities is not being distributed as well or as often. The activities themselves have also been reduced.”*
- *“Cuts to statutory services, and charging for other services, has caused an increase in our (currently) free service. More people come along because they can't afford to use other services or want to save money, or the other service they have been using has gone entirely. It's been a slow effect but has been going on over the last five years or so, and has speeded up in the last year. We are trying to run the same service on the same budget for more people.”*
- *“We have had to reduce the number of days we are open, reduce activities on offer, cut out activities requiring extra resources, cut outings, reduce the number of paid staff (impacting on the range of activities on offer), and increase our reliance on volunteers to support activities. We have concerns about the quality implications of the above, with year-on-year uncertainty for clients that the service will be sustained. Projects which were developing between 2008-2011 have ceased.”*

**Comment on local authority/NHS funding cuts section:** The findings paint a gloomy picture, not least because of the implications for the future. While groups and branches are cutting services the number of people requiring support continues to rise. This creates a vicious circle as resources become more and more stretched. There is grave concern among groups and branches, both for current service users and the many thousands of survivors of a brain injury that they may never have the opportunity to help.

## Conclusion

The results of Headway's surveys provide striking evidence that simultaneous welfare reforms and local authority funding cuts are having a profound negative impact on brain injury survivors, carers and Headway groups and branches.

In addition to the human cost in the short-term, the long-term implications should be a concern to all in society as reduced access to vital services will lead to more people being reliant on long-term state support. The number of people surviving acquired brain injury and requiring services continues to rise, causing services to become increasingly stretched.

Headway appreciates the fact that budgets are tight and local authorities are being forced to cut costs. However, there needs to be an understanding that providing people with the help they need in the short-term will ultimately save money as it will lead to more people regaining their independence and therefore being less reliant on support in the future.

A brain injury can happen to anyone at any time. At Headway, we know that with the right help at the right time there can be life after brain injury. Sadly, that help is being denied to more and more people. Unless the false economy of cost cutting is reversed, people will continue to be cut out of society with future generations left to deal with the consequences.



## Appendices

### Appendix one – Selected quotes from Headway groups and branches

#### How cuts to funding are affecting the ability of Headway groups and branches to support people affected by brain injury

- Welfare cuts have had an immediate effect on clients because of reduced referrals from Adult Social Care due to their reduced budgets. Fewer clients are being funded because they are not meeting Adult Social Care's critical/substantial criteria. This does not take into account cognitive difficulties, which for the vast majority of our service users is the biggest issue. Cuts in transport funding have also had a significant impact, as commissioners will not now fund transport for new people to attend the service. Exit strategies are now also being introduced for existing clients, even though those clients may not have support available in the local community.
- We are providing services in our local authority/NHS area that are not provided by them. Cutbacks in our local NHS Trust have impacted on our work dramatically e.g increase workload, lack of counselling for survivors and carers to help them cope with the dramatic change in family dynamics, lack of follow-up in the community to support people after discharge from hospital.
- Local authorities have increased their criteria for funding to substantial or critical to agree to spot fund our day centre service. They are also now more reluctant to fund outside their area even if they don't have a service which meets the needs of the client.
- As funding continues to be cut, with an increasing number of people requiring our support, this will reduce our ability to support those affected by brain injury. A very gloomy forecast.
- We have had to reduce the number of days we are open, reduce activities on offer, cut out activities requiring extra resources, cut outings, reduce the number of paid staff (impacting on the range of activities on offer), and increase our reliance on volunteers to support activities. We have concerns about the quality implications of the above, with year-on-year uncertainty for clients that the service will be sustained. Projects which were developing between 2008-2011 have ceased.

- It places additional burdens on already limited funding, at a time when most charities are being hit the hardest. It is particularly affecting the most vulnerable in what is supposed to be a civilised society, who need increased funding, not cuts!
- We are expected to provide a very high level of support with a minimum of funding. The paperwork has doubled and we have to "jump through hoops". Staff are very thin on the ground and are stretched to capacity; if we can't afford to employ more staff then we are not going to develop our services.
- We have needed to make redundant our Development Worker and consequently information about our activities is not being distributed as well or as often. The activities themselves have also been reduced.
- Cuts to statutory services, and charging for other services, has caused an increase in our (currently) free service. More people come along because they can't afford to use other services or want to save money, or the other service they have been using has gone entirely. It's been a slow effect but has been going on over the last five years or so, and has speeded up in the last year. We are trying to run the same service on the same budget for more people.
- While retaining a consistent service we have experienced no uplift in Social Services funding over the past four years and NHS funding in our area is virtually non-existent. We have addressed the issue by expanding alternative funding streams, maximising on the development of personalised budgets – marketing services directly to potential service users – and by improving housekeeping within the organisation. Forward planning is virtually impossible as there is significant uncertainty over the security of future funding arrangements. On top of this, demands placed on the service to support people in dealing with changes in welfare benefits have increased enormously.
- We have nearly 60 people on our waiting list, but there are not enough social workers to assess them. Those assessed need to be critical to get funding and then it will only be given short term for rehab. We think there will be many that do not get funding. Many will be losing some existing placements and many having to finish with us altogether. We may end up halving the amount of people we are able to support.

- We have definitely witnessed a growing demand for our services and we are under very great strain in terms of our resources and staffing. An example of this is within our Activity and Rehabilitation Centre, where numbers have doubled in the last two years but the money coming from local government has not increased in the past five years. This has forced us to make changes in how we operate to meet the demand and will in the medium to long term be unsustainable unless greater levels of funding are found. It is still unclear as to whether we can get over the next hurdle in April 2015 and this will be a genuine case of "do or die" as an organisation.
- This year we have seen the change. In previous years we have managed to secure additional funding that masks the subsidy that we provide. This year we have to fund a deficit. Next year looks bleaker, with interpretations of eligibility criteria tightening in our county and means-testing for day service charges arriving. There is still some funding for transport, but again this is likely to come under threat. We will have to manage more complex and multiple diagnosis referrals with reduced staffing and probably at a significant loss. Not sure how CCGs will affect us yet. Not a good prognosis, and really hard to hold a service together.
- Over the last five years we have had no uplift in funding, prior to this we lost our premises which had been provided free of charge by social services. We now have to rent premises and no recompense was made in the funding levels. We are rapidly approaching the end of our reserves and our future is looking somewhat perilous. Our SLA is out to open tender and is only for three years, it is for less money than we currently receive. The bureaucracy involved in bidding for this is unbelievable as we have to produce the same amount of information and policies that large organisations produce. This discriminates against small charities without large infrastructures.
- We are looking at alternative sources of income so that we can maintain and develop our services as we have evidence that we need to increase, not reduce, support for both survivors and carers. We are increasing our fundraising, activity and trust applications and seeking private clients through case managers. We also hope to attract NHS funding but are having difficulty with this due to the complexities of the new NHS commissioning arrangements and the difficulty (or rather impossibility) of engaging with the CCGs.

## Appendix two – My Story: Susan and Nicola

Nicola Scott sustained a traumatic brain injury (TBI) on 4 May 2008 when she was knocked down by a car. Her mother, Susan Osborne, was with her at the time and narrowly avoided being hit by the car herself, only to see it strike her daughter.

Nicola's TBI affected the entire family – emotionally and practically. Susan had to leave her full-time job as an Advanced Sales Consultant in Manchester Airport to become her daughter's full-time carer. But aside from six months of neuropsychology, the family was left to cope alone once Nicola came home from hospital.

Susan believes that had the family received help, not only would Nicola have made a better recovery and be more independent, but also Susan's own health would not have suffered. In addition to the human cost, Susan believes treatments for her own stress-related issues, as a result of not receiving adequate support, have caused a burden and financial cost to support services, such as her GP. These costs would have been saved had the appropriate rehabilitation and support been made available to her daughter.

"Nicola and I had been out for the evening with a friend of ours to celebrate all our birthdays, which fall within a week of each other," explained Susan. "But rather than celebrating, the evening ended with my daughter sedated in intensive care to allow the swelling in her brain to subside.

"Nicola was in intensive care for four weeks, followed by three months in a rehabilitation ward. When she was discharged home, however, we were offered no help whatsoever, despite Nicola's brain injury meaning she was a changed person.

"She was constantly agitated and aggressive, had difficulty with speaking and comprehension, and found it incredibly difficult to accept that anything had changed. She also needed help with dressing, cleaning and feeding herself as her brain injury had left her with one-sided weakness compounded by a broken collar bone and two fractured ribs.



*Nicola (left) and Susan*

*"I truly believe that had Nicola been given support...she would have made much better progress and be far more independent than she is today. This would have also meant her being less reliant on state support for the rest of her life.*

*"I hate to think of the cost to the public purse of my health needs – all of which could have been avoided had the right level of support been given to Nicola when she most needed it."*

“We desperately needed help from specialist brain injury professionals who could not only help Nicola understand what had happened but also begin the process of relearning the basic life skills that most of us take for granted.

“With a brain injury, doctors always suggest that the first few years after the injury are vital in terms rehabilitation. But we were given no help once we left hospital – Nicola just slipped through the net and was seemingly forgotten about.

“After approximately 18 months, we did receive some temporary help from a neuropsychologist who helped Nicola make great progress in a short period of time, but the funding soon ran out for this and we were once again on our own.

“I truly believe that had Nicola been given support by the likes of an occupational therapist and a speech and language therapist, she would have made much better progress and be far more independent than she is today. This would have also meant her being less reliant on state support for the rest of her life.

“My own health has also suffered as a result of a lack of appropriate care and support. I’ve had various stress-related illnesses, for which my GP has had to prescribe anti-depressants. I hate to think of the cost to the public purse of my health needs – all of which could have been avoided had the right level of support been given to Nicola when she most needed it.”

## Appendix three – My Story: Graeme Dodgson

In August 2012, 54-year-old Graeme Dodgson was the victim of a suspected assault on his own driveway. Although Graeme can't remember anything about the attack, police believe that Graeme may have been the victim of mistaken identity.

Graeme was left for dead by his assailants and lay unconscious for seven hours before being discovered and taken to hospital.

For the past 18 months, Graeme has been left to cope with the effects of his brain injury alone – with no specialist rehabilitation or support. This, he believes, has ruined his chances of rebuilding his life and career and has made him reliant on state support in the future.

"I don't remember anything that happened," said Graeme. "The first thing I can recall is waking up in hospital five days later. I'd been put in an induced coma to help the swelling on my brain to subside.

"As I live on my own, with my driveway obscured from the main road, no one noticed me lying there until morning.

"After coming out of the coma, I spent two weeks in hospital recovering from a fractured skull. I had to relearn how to walk during that time; my balance was so poor I could barely stand up unaided at first.

"But after just two weeks, I was sent home – with no help, advice or support whatsoever. I was just expected to get on with it. I wasn't even given any information about brain injury, so I didn't know it is unlike any other injury in that it doesn't just 'get better' in time. The reality, as I've come to understand, is that the effects of brain injury can last a lifetime, which is why it is so important to get specialist help to enable you to adapt and develop new strategies to overcome any deficits.

"My brain injury has affected me in many ways. The part of my brain that controls my appetite was damaged, so I never feel full or hungry. My short-term memory is also very poor, so I can't then remember if I've eaten. This means I have to live in a very regimented way to ensure I do actually eat during the day.



Graeme Dodgson

*"I believe if I had received appropriate support, I would have made a much better recovery and would now be more self-sufficient and less reliant on state support.*

*"The money it would have cost to enable me to see a neuropsychologist or occupational therapist, who could have helped me get my recovery under way, would have been recouped by me regaining my independence."*

“I have been to see my GP on numerous occasions to ask for help, but he doesn’t feel equipped to help me. He’s tried to refer me to a neuropsychologist, but I’ve heard nothing and have received no help. I’m at the point now of giving up as it would appear that no matter how many times I ask for help, I get nowhere.

“I was self employed as an independent financial advisor before being attacked and was part-way through a degree, which I am now unable to finish due to my poor memory, inability to process and retain information, and severe fatigue, which is not uncommon after brain injury.

“I find myself getting incredibly frustrated and upset about not being able to do the things I once took for granted.

“I was given Employment and Support Allowance, but only for a year. It has now run out and is not being renewed. Apparently, I am not entitled to any other benefits although my cognitive impairments have made it impossible for me to work.

“I now have to live off my pension, which I have been able to draw early but I am struggling to live on this and I know I will need more support in later life.

“I would love to be able to work again and had I been given appropriate support over the past 18 months, who knows where I would be now? I believe if I had received appropriate support, I would have made a much better recovery and would now be more self-sufficient and less reliant on state support.

“The money it would have cost to enable me to see a neuropsychologist or occupational therapist who could have helped me get my recovery under way would have been recouped by me regaining my independence.”



## Appendix four – One Headway group’s experience

### “Our members are being denied vital services”

#### One Headway group’s experience

“Over the past two years we have increasingly been forced to challenge and appeal local authority decisions to reduce the care package of survivors of brain injury and their families.

*“...survivors of a brain injury and their families are not having their needs properly assessed and as a result they are being denied access to services, which are of a significant benefit to*

“In many instances the person and their family have simply been informed that they will no longer be able to use our services, without any clear or appropriate explanation of the reasons why their needs have changed and or why they are not eligible under Fair Access to Care criteria.

“We have met with senior management at the local authorities to voice our concern that survivors of a brain injury and their families are not having their needs properly assessed and that as a result they are being denied access to services, which are of a significant benefit to them.

“A large number of people accessing our services have, in our opinion, been instructed inappropriately that their service would be cut or reduced and we have been forced to challenge these decisions on behalf of our members. The local authorities have, in many instances, acknowledged that there are a number of issues to be addressed, including the competence of the staff undertaking reviews and assessments.

“However, whilst to date (as of May 2014) no members have had their service reduced or cut, it is not clear as to what the eventual outcome of the longstanding appeals and challenges will be. As a result, members have been left anxious and concerned about the future. For a group of people which are already highly vulnerable this is adding a detrimental burden onto them.

“We have had to expend considerable staff resources helping people to challenge these decisions and hopefully counter any inappropriate and unqualified review decisions by the local authority. It is critical, however, that survivors of brain injury and their families have appropriate and effective advocacy to challenge inappropriate practices and procedures, which are likely to significantly affect their overall wellbeing.

*“...members have been left anxious and concerned about the future. For a group of people which are already highly vulnerable this is adding a detrimental burden*

“It is clear that local authorities are under immense budgetary constraints and are also dealing with the significant consequences of wide scale changes to welfare and housing benefits. However, what we require is more effective partnership work with them; this will require more



transparency, openness and joint working, which in turn will hopefully allow us to work together to mitigate the negative impact of any 'cuts' on this vulnerable group of people.

“This needs to be happening from the top down and the bottom up; requiring all aspects of the relevant local authority workforce to be better informed regarding the complexity of a brain injury and the subsequent impairments survivors have to contend with in their daily living.

“We are informed by senior staff and commissioners that a person’s entitlement to a care package will not be affected by the cuts, which have been imposed on local authorities. Worryingly, however, it is being reported to us that some social workers are informing people that their care package needs to be reduced as a direct correlation with the financial constraints the local authority is facing. This is at best poor practice, as clearly this cannot be a factor when accessing a person’s needs.

“It is not clear if this message is being disseminated down but what is clear is that vulnerable people who need support are instead increasingly feeling uncertain and anxious. At the moment we are wasting valuable resources chasing shadows as we try to second guess and or challenge the sometimes inexplicable and unclear decisions of local authorities, who in turn are wasting their own resources in having to reassess people following multiple ongoing appeals.”