



# A Changing Wind

**Views from the front line: voluntary organisations in Newcastle and Gateshead working with people with physical and sensory disabilities**

**March 2017**





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## 1.0 Conclusions

The three key issues identified were:

- the ongoing reform of the welfare benefits system, and the impact in particular on people with disabilities
- the increasing complexity of peoples' needs and increasing numbers of people seeking help
- whilst at the same time organisations were themselves going through change in a difficult environment of reducing resources and services withdrawing or closing.

The benefit system for people claiming allowances in relation to their disabilities, has completely changed, including reduction in amounts and increases in conditionality. These include the benefits that support people to live independently, be included in society, and take up and keep work. It is causing great stress, anxiety and increased risk of mental health problems, amongst people with disabilities who are already vulnerable.

Many agencies have developed a response to help people facing welfare reform. But some report increasing stress on staff, and on volunteers to the point of losing them.

*"It's not just fluffy in the voluntary sector"*. Voluntary organisations are working with more people with increasing complexity of needs; offering essential support where previously services were provided by statutory agencies.

Since the Newcastle CVS report *Close to the Edge* in 2013, from the eight organisations then interviewed, one has closed, one re-structured to run without staff, one is considered de-registering as a charity and one is exploring a merger with another local organisation.

There were several instances of organisations adapting, innovating and evolving. Some organisations are continually refining their business model; changing the way they provide services and continuing to develop new ways of making their scarce resources go further to support people.

Organisations are embracing new opportunities, in particular social media to provide direct services to clients and to change and improve services and reach, and are working to mitigate cuts. Technological advances and accessible devices / apps are reducing many access barriers.

There are fewer agencies offering support and advice, and less training on equalities and full access requirements, which may not be met. As a result, consideration of access requirements for everyone does not routinely take place. For example organisations and agencies should ensure their public information is British Sign Language (BSL) friendly.

Finding help is difficult for many people; there is a need for clear coherent information about where to find out about support and services. This should be continuously and consistently promoted to all residents, agencies and organisations.



Organisations were aware of people slipping out of support or not reaching services. This was due to a combination of lack of knowledge of what help might be available, lack of ability to articulate need, the disadvantage and lack of expectation caused by poverty, the cost of services, being unable to communicate, or being unable to advocate for themselves. There is a need for more support to access what services and activities currently exist.

## 2.0 Introduction

Newcastle CVS spoke with and interviewed eleven voluntary organisations in Newcastle and Gateshead about their work with people with physical and sensory disabilities and about the issues and challenges facing both organisations and people. This revisits the subject matter of the Newcastle CVS report, *'Close to the Edge'* produced in 2013.

Most voluntary organisations are grappling with the unprecedented increase in need for help and support from people affected by the welfare reforms, in a situation of decreasing resources and funding. There was an ongoing concern that the true scale of the problems is not widely recognised.

*"There's a reaction to 'I Daniel Blake'<sup>ii</sup>, they say it was unrealistic as it is all problems. But people are in trouble; people are at multiple disadvantage, cuts in social care, the NHS, cuts in appointments, benefits, fuel [poverty], using a foodbank".*

Organisations were very concerned about the ongoing welfare benefits change for people with physical and sensory disabilities, and that for people with disabilities key issues remain about independence and systems. *"People slip under the net now"*.

*"This is really difficult, there's more people, bigger problems with difficult and complex situations, with less options. The impending situation is here, people are struggling. Brexit and the NHS promise being broken; it feels out of control. The impact we see, people have no support, there are finance sanctions, and there are more mental health issues"*.

At the same time organisations were in difficult and changing situations themselves. One organisation said

*"We have survived we're hanging on but we're not able to relax"*.

There were several instances of organisations adapting, innovating and evolving, with grace and a deftness of touch, scudding before the winds of change.

Statistics used in the recent *'Improving Lives: The Work Health and Disability Green Paper'<sup>iii</sup>* show that disadvantage is the greatest underlying cause of unemployment for people with health conditions or disability. For instance, the employment rate can be only



16% for people with a mental health condition who live in social housing, compared to an employment rate of 80% for people with disability and one or two health conditions, who live in a mortgaged house and are in 'good' jobs, which is the same rate as the overall employment rate for non-disabled people.

The recent years have seen and celebrated the emergence of well-known successful entrepreneurs, Paralympians and Chief Executives who have a physical disability. But people with disabilities or difference may still be excluded by the barriers of society which turn into physical hurdles, and which can leave people more vulnerable to exploitation, to being conned, and at risk of discrimination both direct and indirect.

*"Disability rights is not fine, no, people think it's already done".*

A steadfast seeking of social justice was a core value at the heart of all of the voluntary organisations interviewed, tackling disadvantage, exclusion and inequality, and offering support and services. It is the people who are using those services and the help offered by voluntary organisations in Newcastle and Gateshead that are the focus of this report.

*"Disability is at the bottom of the pile".*

*"Many other organisations do not understand the communication issues that deaf people face".*

*"Is the expectation by [Council] that people will do more for themselves; is it an expectation the voluntary sector safety net will protect and mitigate against the cuts?"*

*"But there is less user voice, less campaigning"*

*"We find there's a cumulative impact of reducing services and funding, which impacts on vulnerable people and carers".*

*"Just last month [February 2017] I was called a wheelchair, not a person. I was very fed up. I lost count of the receptionists and nursing assistants looking at my PA [Personal Assistant] for answers, not me".*



### 3.0 About the Newcastle and Gateshead populations

A complex picture of the people living with physical disabilities and sensory issues and long term conditions can be built up using various sources; there is no single depiction of people living with physical disabilities and sensory issues. The impact of disabilities and long term conditions is conditional upon poverty and compounded by deprivation, few opportunities, adverse opportunities and environments, and discrimination.

The Index of Multiple Deprivation is the official measure of relative deprivation for small areas or neighbourhoods in England. The Index of Multiple Deprivation (IMD) ranks every small area in England from most deprived area to least deprived area. The most recent IMD in 2015 shows that Newcastle is ranked 53 and Gateshead is ranked 73 out of 326 local authorities for deprivation (1 being the most deprived)<sup>iv</sup>.

In Newcastle over a third of people (35%) live in areas ranked in the 20% most deprived in England, an improvement from 38% in 2010. In Gateshead a quarter of people (25%) live in areas ranked in the 20% most deprived, an improvement from 39% in 2010<sup>v</sup>.

The Equality Act<sup>vi</sup> defines a person with a disability as a person with a physical or mental impairment and that the impairment has a substantial and long term adverse effect on their ability to carry out normal day to day activities. The focus is on the effect rather than looking at the condition as a cause, which would be ever changing due to medical and social advances.

The Newcastle population in the 2011 Census<sup>vii</sup> numbers 280,177 of whom 26,661 people reported an illness or disability that means their day to day activities are limited a lot, and another 25,916 people have their day to day activities limited a little. Added together, 52,577 people, 18.8% of the population, have their activities limited by illness or disability. Of working age people aged 16-64, 12,966 people (4.6%) said that their activities were limited a lot, and 14,012 people (5%) said they were limited a little.

The Gateshead population in the 2011 Census numbers 200,214 of whom 22,917 people reported an illness or disability that means their day to day activities are limited a lot, and another 21,435 people have their day to day activities limited a little. Added together, 44,352 people, 22.15% of the population, have their activities limited by illness or disability. Of working age people aged 16-64, 10,669 people (5.3%) said that their activities were limited a lot, and 10,831 people (5.4%) said they were limited a little.

Some voluntary organisations focus on hidden disabilities, often associated with a long term condition. Some long term conditions can be well controlled and have little day to day effect, but the same condition can also have very severe effects and limit day to day activities significantly. The statistics about long term conditions record the numbers of





people diagnosed with a particular condition, but do not record how many people have more than one condition, whether the condition is disabling, nor to what extent.

For example there are 9,980 people with Coronary Heart Disease, 11,408 people with Diabetes and 5,694 people with Chronic Obstructive Pulmonary Disease in Newcastle.

The numbers of people with physical disability and sensory issues increases as people get older, with a sharp rise in later life.

### Carers

In Newcastle the 2011 Census found that there were 25,810 people, which is 9.2% of the population, who are unpaid carers. Of those, 19.3% are aged 65 and over.

In Gateshead the 2011 Census found that there were 22,220 people, which is 11.1% of the population, who are unpaid carers. Of those, 22% are 65 aged and over.

These figures are expected to have gone up since the 2011 Census, due to the increase in numbers of older people.

### Newcastle and Gateshead – Census 2011

	Gateshead %		Newcastle %	
Total population	200,214		280,177	
<b>All categories: Long-term health problem or disability</b>				
Day-to-day activities limited a lot	22,917	11.4	26,661	9.5
Day-to-day activities limited a little	21,435	10.7	25,916	9.2
Day-to-day activities not limited	155,862		227,600	
Day-to-day activities limited a lot: Age 16 to 64	10,669	5.3	12,966	4.6
Day-to-day activities limited a little: Age 16 to 64	10,831	5.4	14,012	5.0
Day-to-day activities not limited: Age 16 to 64	107,971		166,506	
Provides no unpaid care	177,994		254,367	
Provides 1 to 19 hours unpaid care a week	12,588	6.3	15,248	5.4



	Gateshead %		Newcastle %	
Provides 20 to 49 hours unpaid care a week	3,381	1.7	3,726	1.3
Provides 50 or more hours unpaid care a week	6,251	3.1	6,836	2.4

The statistical picture of the Newcastle *'Know your City'*<sup>viii</sup>, which underpins the Newcastle Future Needs Assessment (the Joint Strategic Needs Assessment element), states that in 2012 it was expected that there were 13,320 people aged 18 to 64 with a moderate physical disability, and about 3,680 people with a serious physical disability living in Newcastle.

The Gateshead Joint Strategic Needs Assessment (JSNA)<sup>ix</sup> states that there were 9,676 people aged 18 to 64 with a moderate physical disability and 2,853 people with a serious physical disability living in Gateshead.

In 2012 there were 9,720 people aged 16 to 64 claiming Disability Living Allowance (DLA) in Newcastle and 6,960 people claiming DLA in Gateshead.

The Newcastle Future Needs Assessment reports that there are 4,274 people with a sensory impairment such as Deaf, Deafblind, Blind, Hard of Hearing, and visually impaired people on the City Council registers.

The Gateshead JSNA reports that there are 2,917 people with a sensory impairment on the Gateshead Council registers.

The Newcastle Society for Blind People estimates there are up to 8,000 people with significant visual impairment in Newcastle, of whom 1,800 are registered. The Society points out that within the figures for people in later life there are large variations. For instance, one in eight people in their sixties develop macular degeneration, rising to one in three people in their nineties.

In 2003 the report, *'Breaking the Silence'*<sup>x</sup>, found that about 0.6% of the Newcastle population, or 1,000 people, had a speech impediment that made it difficult to gain access to statutory services in the way that other people could. The same percentage in Gateshead would be 1,200 people.

### LGBTQ people

There is little research about the prevalence of illness or disability among the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) populations. It must also be recognised that the gender identify or sexual orientation of people with disabilities is often made invisible<sup>xi</sup>.





But a study by NHS South of Tyne and Wear in 2010, *'Mental and Emotional Health Needs Assessment of the LGBT populations of Gateshead, South Tyneside and Sunderland'*<sup>xii</sup> states that most research indicates general disability is at the same prevalence as heterosexual populations, but with a higher number of people with mental health conditions. Research by Islington Mind estimates that LGBTQ+ people experience mental health problems at a significantly higher rate of 40% compared to 25% of the whole population, primarily due to the impact of stigma and discrimination<sup>xiii</sup>.

### Perceptions behind the statistics

The voluntary organisations spoke about disability and perceptions of disability.

*"People think it's about visual stuff like furniture, wheelchairs. Three steps bench or toilet with steps; or toilet that you cannot get two people in. It's extra effort to do something to get out; assessors don't realise the extra effort. The physical environment disables / excludes and social model is still not enough".*

*"There is an image of physical impairment...Our advice is for everybody including people with hidden disabilities. We are working with Launch Pad, mental health groups. It goes hand-in-hand with mental health because there are barriers in society".*

*"Is deafness a disability? The society we live in makes it so. D/deaf culture is diverse and constantly changing. It is not as defined as it used to be. In the past British Sign Language (BSL) users would have gone to the same school and developed shared identity and friendships. Today young BSL users are sent to mainstream school and this can lead to isolation and the only other BSL users they see are on TV or the internet. There are fewer Deaf Clubs or places where BSL users can share experiences".*

For deaf people there is a communication gulf impacting on all aspects of life, but increasingly *"technology is shifting how people can exist in the hearing world but there is a lack of awareness"*.

Since the interviews took place Wayne Barrow, who grew up with deaf parents has set up an online petition<sup>xiv</sup> to teach BSL in schools.



## 4.0 About the organisations

Many local and national voluntary organisations are led by people with disabilities; others work closely with people with disabilities and long term health conditions. Voluntary organisations specialise in certain conditions, are expert in employment support, and are local, accessible and innovative. The voluntary sector has expertise, reach, user and peer led involvement support; it generates prevention as people are diverted away from statutory services, campaigns, provides direct services and activities, disability audits, provides advocacy and gives voice.

The user led movement began largely in the disability movement and remains a key part of working with people. Campaign and lobbying work tends to be user led as are many activities, audit work, retail, advice and advocacy, youth and cultural activities; although care services were not provided on a user led basis amongst the organisations interviewed.

Newcastle CVS interviewed representatives from ten voluntary organisations in person and two organisations by email with written evidence. The twelve organisations were:

Age UK Gateshead; Arcadea; Citizens Advice Gateshead; Crossroads Carers Trust Tyne and Wear; Deaflink; Gateshead Access Panel; Gateshead and South Tyneside Sight Service; Disability North; Newcastle Carers; Newcastle Disability Forum; Newcastle Society for Blind People; Northeast Special Needs Network.

### Age UK Gateshead

<http://www.ageuk.org.uk/gateshead/>

<https://www.facebook.com/AgeUkGateshead/>

Established in 1972, Age UK Gateshead is the lead charity for older people operating across the borough of Gateshead. The charity is an independent autonomous local charity and a member of the national Age England Association and the campaigning voice of older people. It is a registered charity and a Company Limited by Guarantee. It currently has 18 employed staff and 125 volunteers.

Social isolation, advice and support together with meeting the needs of older people in Gateshead is delivered by the Age UK team of staff and volunteers who provide services or run activities for approximately 900 people per week:

- Daycentres and social groups for people who are frail, isolated and living in their own homes
- A range of activity, leisure and learning groups(including Tai Chi, yoga, Pilates, line dancing, gentle exercise to music, chess, and a men's photography group)



- Telephone and traditional befriending
- Mental Health support and advocacy – Peer support groups and one to one provision
- Bereavement support
- Hydration, nutrition and falls prevention stability services
- No One Dies alone, this is a partnership approach to ensure those who feel they have nobody do not pass on their own.
- Information and advice (about a wide range of topics including benefits, financial concerns, housing, care and utilities)
- Gateshead Reconnections – providing a number of services resolving social isolation across the borough
- Reflections – An innovative dementia service providing one to one care provision, with tailored activities, lunch and transport.

### **Arcadea**

<http://www.arcadea.org/index.asp>

[https://www.facebook.com/Arcadea-Disability-Arts-1774994442712384/?hc\\_ref=SEARCH](https://www.facebook.com/Arcadea-Disability-Arts-1774994442712384/?hc_ref=SEARCH)

Arcadea was founded by disabled people in 1991 to address the inequality of disabled people in arts and culture. Arcadea is a user led organisation of Disabled People based in Newcastle upon Tyne. It works to create equality of opportunity in arts and culture for disabled people in the North East of England. It does this this by supporting and promoting the work of disabled artists, by enabling and facilitating disabled people to access all aspects of the arts, by assisting cultural venues to become inclusive and by presenting a programme of arts and cultural activity. Currently the core activity is a cultural day service for learning disabled people. This is called The HUB. Alongside this they run an arts / youth club on Wednesday evenings for young disabled people. This is called ICEBOX

### **Citizens Advice Gateshead**

<http://www.citizensadvicegateshead.org.uk/>

<https://www.facebook.com/CitizensAdviceGateshead/>

Citizens Advice Gateshead provides social welfare law advice to a population of over 200,000 people. Established in 1957 the service has continued to grow and now operates from purpose built premises in Swan Street, Gateshead.

Their vision for their service is to help people to take control of their lives through accessible, professional, quality assured advice, information, advocacy, casework, legal representation and training.



The mission is for everyone who lives or works in Gateshead to be able to access free, independent, confidential and impartial advice about their rights and responsibilities.

Their aims are to:

- Raise our profile in the community.
- Continue to be the best provider of advice and information in Gateshead.

Their principles:

- We provide free, independent, confidential and impartial advice to everyone on their rights and responsibilities.
- We value diversity, promote equality and challenge discrimination.

### **Crossroads Carer Services: Tyne and Wear Carers Trust**

<http://carerstrusttw.org.uk/>

<https://www.facebook.com/search/top/?q=crossroads%20carer%20services%3A%20tyne%20and%20wear%20carers%20trust>

Carers Trust Tyne and Wear Crossroads Carer Services is an independent local charity supporting carers and their families. As a specialist provider of carer services, their aim is to improve the lives of carers. It provides services to support carers from age five onwards, caring for a family member or friend with physical disabilities, mental ill health, learning disabilities, illness, dementia, or end of life.

The charity has grown and developed since 1990 to provide a wide range of holistic services which meet individual need and deliver positive outcomes to carers and their families.

### **Deaflink**

<http://www.deaflink.org.uk/>

<https://www.facebook.com/deaflink/?fref=ts>

Deaflink North East is a D/deaf led organisation that works with D/deaf people in the North East – but mainly Newcastle. It also works with Hard of Hearing people and DeafBlind people, mostly in groups and forums. It works to help people control their own lives by improving understanding and empowering people. It also works improve the quality of life of D/deaf people by providing learning opportunities and support.

Their aims are:

- Improve access opportunities for all D/deaf, DeafBlind and Hard of Hearing people in Newcastle and the North East



- To raise awareness of the needs of these excluded groups to statutory and voluntary/private organisations and agencies
- To act as a consultative group offering training support and advocacy

It also contributes to partnerships with other agencies and projects to address needs of the D/deaf communities. It does this by gathering views from the communities and feeding this into the partnerships to encourage understanding of the issues and barriers affecting the D/deaf.

### **Disability North**

<http://www.disabilitynorth.org.uk/index.html>

<https://www.facebook.com/DisabilityNorth/>

Disability North is a free Independent Living Service which promotes social inclusion, independence and choice for disabled and older people in the North East of England and Cumbria. Disability North is a user led registered charity which works with, and for, disabled people, empowering them to maximise the control they have over their own lives.

The Service Team can provide information and advice on equipment and activities for daily living (ADL), benefits and Direct Payments as well as advising on many other aspects of disability and signposting to other organisations who can help.

In the financial year 2015/16 Disability North Service Team has addressed the queries of over 6,000 people, it has represented 139 at benefit appeals, with 80.57% success rate and £19,716,001 has been accrued in benefit awards. The team has had 664 Direct Payment referrals, it completed 380 budgets for both adult and child services, 334 people were employed as Personal Assistants.

### **Gateshead Access Panel**

<http://www.access-gateshead.org.uk/>

Gateshead Access Panel is a charity and social enterprise, with a pan-disability background. There are two principle areas of work – one charitable and the other commercial - which although distinct are also complementary and interlinked. Its charitable roots provide the foundation of our commercial enterprise.

Gateshead Access Panel's initial aim was to empower and develop skills among disabled people in Gateshead.

Over recent years their aim to be predominantly independent and self-financing has encouraged the development of the commercial side of the organisation's structure, including: GAP Consultancy and Auditing, GAP Access Training, and more recently the Direct Payments Support Brokerage.



## **Gateshead and South Tyneside Sight Service**

[www.sightservice.co.uk/](http://www.sightservice.co.uk/)

<https://www.facebook.com/nesightservice/>

Aiming to enable visually impaired people to enjoy the quality of life others take for granted. Big enough to cope, small enough to care.

Sight Service is the leading local provider of services and support for people who are visually impaired and live in Gateshead, South Tyneside and surrounding areas.

Their advice, information and support can enable visually impaired people to have the quality of life which many sighted people take for granted.

It also promotes greater public awareness of sight loss and work towards achieving better and more accessible public services for visually impaired people.

## **Newcastle Carers**

<http://www.newcastlecarers.org.uk/>

<https://www.facebook.com/NewcastleCarers/>

This is a local independent charity working citywide to provide dedicated confidential information and support to adult unpaid carers who are caring for someone living in Newcastle.

It provides support to unpaid carers who care for a family member or friend who is ill, disabled, has mental health, or substance misuse problems, and could not manage without their help.

It provides a range of information and support services to help improve the quality of life for Newcastle carers including

- Information, advice and guidance
- Drop-in information and advice sessions
- Carer Cafés
- Carer Support groups
- Complementary therapy
- Counselling
- Training
- A chance to have your say

## **Newcastle Disability Forum**

<http://ndf.org.uk/>

<https://www.facebook.com/Newcastle-Disability-Forum-1604780536412861/>

For over 27 years the Newcastle Disability Forum has worked to help eliminate barriers, ensure fair access to information, services and facilities from all providers and offer





support and encouragement to empower disabled people to maintain their independence, fulfil their aspirations and live the life they choose.

NDF's access work can involve several categories:

- responding to Newcastle City Council consultations on Traffic Regulation Orders, cycle paths and planning applications;
- commenting on new housing schemes, refurbishment of public places, stopping of highways, realignment of traffic routes and enhancement of leisure facilities such as public parks and heritage assets;
- liaising with other public bodies;
- receiving presentations from, and commenting on, projects by architects, planners and developers;
- providing accessibility information for the City Council and charitable organisations, along with private companies and businesses based on the lived experience of the membership.

## **Newcastle Society for Blind People**

<http://nsbp.webs.com/>

<https://www.facebook.com/NewcastleSBP/?ref=hl>

### **Helping you see things differently**

The website's Front Page where the society tells you what is happening in the world of Newcastle Society for Blind People. For the very latest news please go to the Facebook page by clicking [Facebook](#)

The society was formed in 1867 but the ethos of the organisation remains much the same as it was when it was formed which is to help visually impaired people to be and stay independent through information and learning activities, keeping in touch with people services, social groups and empowerment work. It is a completely independent local society proudly serving over 1,000 visually impaired people in Newcastle.

Through their staff and volunteers it provides a range of information, support and opportunities for people from a coping with sight loss course to emotional support and campaigning to make Newcastle a more accessible place for visually impaired people.



## Northeast Special Needs Network

<http://www.nsn.org.uk/>

<https://www.facebook.com/Northeast-Special-Needs-Network-NSNN-250510538303404/>

Northeast Special Needs Network (NSNN) supports families with disabled children/young people from birth to 25 years. Their team of Family Advice Workers provide practical, targeted support tailored to each family.

- Working across agencies, covering education, social care, health, benefits, leisure, housing and services from the voluntary sector.
- Preparing parent carers for meetings and go with them so their views are listened to.
- Regularly organising workshops and courses.
- Working in partnership with groups to influence service provision and the development of services.
- Producing a monthly newsletter, information booklets and are on Facebook.
- Membership of NSNN is free for parents who can receive their monthly newsletters by post or email. Professionals can receive the NSNN newsletter by email only.
- The majority of the NSNN staff and trustees are carers or have a close family member who has a disability, they are well aware of the difficulties and stresses facing parent carers.
- We have developed the following services in response to requests from parent carers: Training, Transition, Information enquiry service

From December 2016 NSNN began to explore ways of continuing to support families with disabled children and young people with Skills for People. Subject to the appropriate checks the two organisations will merge by June 2017.





## 5.0 The findings

### 5.1 Changing organisations

Since the initial 2013 report, *Close to the Edge*, some voluntary organisations have closed such as Newcastle Toy and Leisure Library (interviewed for *Close to the Edge*), GVOG, and Them Wifies. Others have merged or been taken over by a large national – Edward Lloyd Trust by the Home Farm Trust, Outpost by AKT. Between the interview and publication of *A Changing Wind*, the Northeast Special Needs Network developed merger plans with Skills for People, a local charity.

*“This is a positive move for our beneficiaries and together we will be a stronger organisation, more resilient in the challenging times we all operate in”.*

Covering core costs was a serious issue for several organisations.

*“We’re on a knife edge”.*

*“It’s survival, is a real threat”.*

One organisation was considering closing as a charity and becoming an unregistered small organisation as they were fundraising to pay for an administrator to complete the charity annual report, but had few other expenses.

*“Volunteers have good cars some don’t claim expenses, it’s dire”.*

Another organisation was facing the dilemma of remaining user-led but precarious, with reducing demand for their core business of access consultancy and equality audits, or becoming a business to bid for tenders but with the risk of mission drift.

*“If there is no funding for volunteers and volunteer management how does an organisation like us with a peer staff team really survive?”*

*“The equality agenda has gone down the pile and case law is not being taken”.*

But nine organisations spoke about adapting, innovating, and evolving. Sometime it was in response to clients’ and users’ need, sometimes to cuts and diminishing resources, or to change in the wider environment. Some were reducing staff hours. Three mentioned investigating charging for services, but the ramifications of enduring poverty and multiple disadvantage also mean that the social enterprise business model may not be viable.

*“If clients cannot pay due to poverty – we cannot charge”.*



One organisation with a business model based on charging clients with personal budgets commented:

*“We charge for our services, we have a daily rate that includes, support, transport, trips and activities. Acknowledging that we operate in a competitive environment (which is fair) and that the budget for social care is extremely limited, this rate hasn’t changed for four years. Clearly this puts financial pressure on the organisation as costs rise around us, for example the cost of someone’s transport, taxis in our case, is set when they join us and there doesn’t appear to be a mechanism available to us to raise the price we charge as taxis fares inevitably increase. This is an issue we will be addressing in the coming year”.*

Some organisations are continually refining their business model; changing the way they provide services to do more and be better with less.

*“We’re doing more by phone and drop-ins – the new model is also more visible so people drop in. There’s phone triage and an info pack – we’re not having everyone wait for an appointment”.*

*“We’re running a 10 week programme of activities, and not in groups; we’re doing it differently, in partnerships. There are different expectations from the clients”.*

*“We’re skimming the surface it’s crisis work, you really really need to know [about it]”.*

Organisations were responding to the most severe need, the crisis, and developing tactics to survive.

*“Face to face work is reserved for those most in need, as it’s most expensive”.*

*“We’ve been working in a new way for six to eight months, before it was one-to-one work. Now it’s a better use of our stretched resources; we have set funding surgeries with booked appointments for advice workers on hand. We expect people to do more for themselves. We did it this year to protect the casework for those who really really need it”.*

*“We work in the daytime but we’ve reviewed our hours, maybe have later opening hours”.*

Several organisations were developing new projects and work. One had moved to new premises, was developing a quality assurance tool with a national partner, and was developing new services with gym equipment. Others said

*“We’ve supported a new counselling service, for people following a new diagnosis”.*

*“We’ve been lobbying on warm water swimming there is some at Walkergate for older people with hydrotherapy but only in six week blocks and there are huge benefits, if there can be courses in the community to carry on with the positive effects...”*



*“We’ve been going for 150 years next year. There is a history group we’re looking at the timeline and getting things out of the archives, might look at a book”.*

*“The sensory garden at Exhibition Park is great, we take plants”.*

Two thirds of the organisations were actively working in partnership with another three, four, or more organisations in the voluntary, statutory and private sectors, in many fields – arts, leisure, social care, planning, housing, parks, museums, developers. These interdependencies were creating and strengthening the support, preventative activities and campaigning offered by the voluntary sector.

*“We worked with Theatre Royal and they’re showing films that are audio described performances. Guide Dogs trained carers who go free, we’re promoting that”.*

*“We work with the University on trips and falls”.*

Four of the organisations interviewed are in Gateshead Advice Partnership, which has seven members. They work together to ensure the people of Gateshead receive the advice and information that is appropriate to their needs, and make referrals to each other if another is more appropriate to help.

Commissioning was a source of frustration, especially the high cost of the tendering application and the adversarial process. Social care services were particularly uncertain, with one saying that three out of five providers in Gateshead had closed recently. Competition came up repeatedly, with the private sector, with other voluntary organisations, and with local authority services. One organisation spoke about their fundraising which adds complementary capacity to a local authority contract.

There were concerns about a loss of local authority grant aid in Gateshead, which was used as a fundraising tool, a building block to secure further funding from other sources. Growth funds are essential.

*“With a small development grant from the Greggs Foundation, over the past year the director of the organisation has been able to spend more of his time building the client base of the organisation. This has resulted in an ongoing increase in revenue of £20,000 per annum. This may not be a huge sum, but it is enough to provide the organisation room to manoeuvre in respect of further development work”.*

### **How many people do the voluntary organisations support and work with?**

The numbers varied hugely, and where services are increasingly provided by social media, the potential range of even the smallest organisation is also increasing.



Some organisations such as Deaflink had well attended regular groups – for example 50 to 60 people at a weekend bi-monthly group depending on the topic; 30 going to a monthly mental health group. They provide weekly e-bulletins to members and information, such as how to make a Personal Independence Payment (PIP) claim, are available on the website and used by many more people. They do not offer one-to-one support, but with no other service providing support in Newcastle they provide support to about 230 people.

Age UK Gateshead have over 16,000 people on their mailing list and databases, and actively support 4,000 people; of those 80% describe themselves as with a disability or have multiple morbidity.

Citizen Advice Gateshead said that 708 clients described themselves as disabled and a further 3,048 as having a long-term health issue.

The Newcastle Society for Blind People has 1,600 clients.

Audit work such as that carried out by Newcastle Disability Forum involves a small group of people on the panel whilst the benefits and long term impact can be extensive.

Disability North addressed the queries of over 6,000 people in a year and their work with clients included representing 139 at benefit appeals.

## 5.2 Welfare reform

The impact of welfare reform and changes in benefits was the most pressing issue for all of the organisations interviewed. The main changes are ongoing under the Welfare Reform Act 2012<sup>xv</sup>. The impact is on clients, staff, volunteers, time and resources. Voluntary organisations are grappling with the unprecedented increase in need for advice, help and support from people affected by the welfare reforms, against a backdrop of decreasing resources and funding, and decreasing services and support for individuals.

It is difficult to convey the desperation.

*“Going to PIP, people are terrified”.*

*“There is massive change coming and we have to manage it”.*

*“We have three benefits advisers; they are oversubscribed it’s gone through the roof it is unprecedented”.*

All aspects of the benefits system were causing great difficulty for the people who came to the organisations, from accessing claim forms, finding out how to claim PIP once the letter telling people that their DLA will stop has arrived, to going for assessments, to challenging





decisions about sanctions, Jobseekers Allowance (JSA) and Employment Support Allowance (ESA) decisions, and PIP claims.

*“The DLA becoming PIP – it’s big, it’s only rolling out now”.*

*“Benefit [client] numbers are high and rising and also as a pressure and worry it is going to continue as the new PIP assessments are rolled out Newcastle”.*

Some organisations were worried that it is just the early stages of change for many. The rate of payment of ESA Work Related Activity Group will reduce by £29 a week to the JSA level in April 2017. And Universal Credit which is being fully rolled out will entail a single monthly payment in arrears, and new ongoing requirements to manage claims daily, online.

Some organisations offered basic welfare benefits information and then signposted to more expert agencies: Newcastle CAB, Citizens Advice Gateshead, Disability North, and Newcastle City Council (NCC) Active Inclusion Service.

*“We have lots of people asking – we do the basic and then refer to NCC”.*

Some spoke about their concern as they turn people away:

*“There are too many, we have to turn away; we cannot reassure people”.*

*“The DLA is going moving to PIP a lot in this area, we’re inundated. People get a letter stopping the benefits then if they want claim PIP they have to phone; [the phone] does music options [which is inaccessible for deaf people]”.*

*“What I write affects if people get benefits. We are turning people away. We’ve done one or two a month; we cannot do five a week”.*

*“They have cut the disability advisors at Job Centres on the premise that everyone should be able to advise!”*

Citizens Advice Gateshead noted that benefits advice about PIP has overtaken debt as their highest number of enquiries in recent months. Age UK Gateshead now have many new clients aged 50 to 65, about PIP claims. From the smallest to the largest organisation there is a steady stream of extremely anxious people seeking help.

*“Staff and volunteers have finding the impact the two systems is very detrimental it has a detrimental impact on volunteers because of the stress and the situation that people are in, and there is no help for most people”.*

*“The forms, the DLA becoming PIP, each one takes two hours, two and a half hours!”*



*“I absolutely freaked when I saw the letter [PIP] it said if I didn’t do anything they will take my car away”.*

The organisations painted a picture of complex and entrenched difficulties, with increasingly *“no solution, no advice to give, we’re unable to advise a way out of it...”*

Deaf people face further problems accessing support as there is little capacity within most services to provide BSL interpreters. There’s a lack of routine interpreting at health or welfare benefit appointments. But even when there is a BSL interpreter, communication may still be difficult:

*“A woman was having PIP assessment at her home. We contacted ATOS to check they had booked an interpreter. They hadn’t. We asked if she could choose the interpreter and they said she couldn’t. She was nervous, she didn’t know who was going to turn up and wanted to cancel. So I went to support her, and a male interpreter attended. She was uncomfortable it was a man in her private space”.*

*“When they do PIP assessments the medical professional asks questions; they are often complicated and the interpreter’s job is to clarify and simplify the questions and translate into BSL. The medical professionals don’t always understand this, and then the PIP assessment looks as though the claimant understands complex information and loses points. But the BSL user doesn’t understand without communication support!”.*

Making a claim and accessing the claim forms for some people is difficult and confusing especially as systems are changing and some claims are made online, but some on paper. Claimants are asked to phone or use a minicom to get the PIP claim form – which is not possible for many BSL users.

Miss T has a learning disability, social anxiety and depression. She also suffers pain and mobility issues associated with bone malformation at birth and walks with the aid of a stick. She lives with her adult son who has mental health problems (NEET).

She received both the care and mobility component of Disability Living Allowance and came to us for help with her claim for Personal Independence Payment following mandatory conversion from DLA.

The difference we made:  
Generated £139.75 per week  
Got £3,000 was backdated  
Reduced social isolation - client now attends two social clubs  
Son has own income £92.50 per week  
Mother and son supported to make choices re: support services and / or training opportunities



*“For carers the key issue is access because it’s online; Carers Allowance forms are a big worry”.*

*“If it’s all online and not everyone is online you go to library but not everyone can get to the library. If you do it’s asking people to do what you wouldn’t do yourself, give out banking details in a public place”.*

The assessment is a source of extreme stress and an increasing reason for people asking for help. Again, there are strategies to respond and stories.

*“The DWP doesn’t provide plain English. When told the claimant whose first language was BSL couldn’t understand the complex information in the letters, the assessor asked will Braille do!! For someone deaf!!”.*

*“What’s “reasonable” for ESA or JSA...for example one client had had bowel cancer, they had no spine and could not sit but were assessed as fit for work”.*

*“It’s all about PIP, many people were on Independent Living Allowance and now asking about PIP; the benefit’s being cut and the work has been outsourced to different companies”.*

*“If you use a stick and have a bright jumper to follow (as we train people to do) somebody was assessed and lost benefit because the assessor said they were independent. When they walked across the room following the bright jumper”.*

*“People are worried that they’ll drop out of eligibility, must look for work, and it’s an uncertainty. The review is a stress with impact on the carer and the impact on the person whose they look after. Stress around ESA”.*

“The DWP doesn’t provide plain English. When told the claimant whose first language was British Sign Language (BSL) couldn’t understand the complex information in the letters, the assessor asked will Braille do!! For someone deaf!!”.

There is an increasing impact on staff and volunteers. In addition to the increase in demand from clients and decrease in support and capacity, advice agencies find there is increasingly no solution to find for clients. This is creating stress and having an increasingly adverse impact on the mental health of staff and volunteers. One reported:

*“There are effects on us as an organisation; we cannot advise a way out. We are losing volunteers because there is no point listening to people’s stories and having to say we cannot help”.*



## Arcadea reports on a key challenge: *Mental Health and Wellbeing*

*“At both the youth club and the HUB we work with a number of disabled people who are struggling with mental health issues. While, in general, parents and carers tell us that these individuals are well supported:*

*It is our (unsubstantiated) view that the impact, or fear of benefit cuts puts a huge strain on families and individuals. Which in turn affects the general wellbeing of the family/support network in a way that magnifies the mental health issues of those individuals concerned.*

*We know from our own experience and that of the families concerned that, again in general, the social workers and mental health professionals involved are efficient, effective and supportive work, but they are under immense pressure.*

*We think (and this is our challenge) that as both further cuts to benefits emerge and the changes to the eligibility criteria for PIP bite, we will see additional strain on the system and individuals who are supported. Over the coming year within our service we anticipate seeing increasing numbers of people presenting with mental health issues”.*

## The community response

The reform of the welfare benefits system, including those parts that support people to live independently, be included in society, and take up and keep work, is causing great stress and anxiety along with an increased risk of mental health problems and illness, amongst people with disabilities who are already vulnerable.

Many agencies have developed a response to help people facing welfare reform and are continuing to develop new ways of making scarce resources go further. Expertise is provided by Citizens Advice Gateshead and Disability North who were interviewed for this report, and Newcastle CAB is relied on by many other voluntary organisations.

The Tyneside Centre Against Unemployment and Tyne and Wear Unite Community Sector offer support with benefit issues, including to make a claim, if there is a threat of sanctions, and help with an appeal.

Newcastle CVS has allocated funds to employ a Welfare Advocate, and Advocacy Centre North (part of Newcastle CVS) has launched a crowdfunding campaign inspired by the film I, Daniel Blake to continue the post.

Newcastle City Council Active Inclusion Service<sup>xvi</sup> has developed an offer to support front line staff and volunteers with information, benefit bulletins, a consultancy telephone advice, training and other resources.



Gateshead Council has comprehensive information set out on its website and offers some benefits support and advice at Gateshead Civic Centre.

The People's Dispensary for Sick Animals (PDSA) in Newcastle and Gateshead offers free veterinary care for cats, dogs and other small pets when owners cannot afford private vet bills including when people are on welfare benefits.

### 5.3 Use of social media to provide services

Nine of the organisations spoke about embracing new opportunities, using social media to provide direct services to clients, in addition to the general use of websites to promote their organisations. Organisations are changing and improving services and reach, and working to mitigate cuts and provide services with fewer resources.

*“People can use Facetime, Skype, Glide [live text video messaging] if they choose. Deaflink use Glide; it’s text and video and people can reply if they want to, is fantastic for deaf people. NGT is available - Next Generation Text. It is replacing the Minicom / TextPhone, is available to anyone and is easy to use; all services should register and advertise that they use it. Smart phones and iPads are used by younger people; Minicomms are now a past device, very few BSL users own one”.*

*“Technological changes are also bringing about a great increase in access for people with disabilities – phones can talk to blind people as they walk along; it’s major advances for people”.*

*“We can reach more with fewer resources, offer more to help for people to help themselves such as web based guides”.*

*“We get Facebook enquiries the most”.*

*“We have several platforms. Young people especially use the text service, they can access support in their own time and place”.*

*“We have film on the website; and plan peer support with social media in future”.*

The proactive use of social media to provide direct services and support, and to better connect people is very new and was not a feature of the 2013 report, Close to the Edge. Organisations were acutely aware of the need to continue to be accessible for people who cannot access the internet. But in a short time a major shift in the use of technology means that the use of Braille is mostly by older people; devices such as mini-coms are largely obsolete; and the possibilities for much more inclusion are expanding.



## 5.4 Access

Despite the progress in rights and accessibility, the rights and duties under the Disability Discrimination Act and then the Equality Act, basic access remains an issue and creates a lack of inclusion for people. Seven organisations spoke about the barriers to inclusion and equality faced by people with physical and sensory disabilities, such as crossing roads, using services, transport, leisure, shops and the built environment, taking part in civic society, public life, meetings, and being employed in good jobs. Despite the long history of the user led disability movement and action by activists, many years of legislation for equality, and guidance and campaigns such as the government purple pound challenge, access is not always routine.

One organisation said:

*“Transport was not in a care package, and with social isolation you cannot separate social care and health from access and transport with services”*

*“People are still excluded if they can’t get out of the house”.*

And just as all people are individual and unique, many of the ways society excludes people are individual as well. What is shared in common though for those people who cannot communicate with others, is that access to the rest of society is as far away as ever; especially for deaf people for all services and leisure, culture, civic life and good quality employment.

DisabledGo reported on access to high street shops in February 2017, and found little improvement, slow progress over the last 10 years, and a reduction in wheelchair access and provision of hearing loops.

Three organisations commented on the built environment, ‘shared space’ issues, particularly pavements and cycle lanes. The problems are for blind people crossing new cycle lanes where there are traffic lights on cycle lanes to control cars, but not to protect pedestrians. Previously the lanes were car lanes and the crossings had pelican lights.

*“Benches are an issue when they are the same colour as the pavement, people don’t see them”.*

Some organisations commented that transport is a major issue in Gateshead due to its widely spread geography. Organisations were working with public transport, the buses and Metro, developing support aids such as cards that blind people can show to the bus driver.

Pragmatic support such as training to use specialised equipment was a large part of their offer for some.





*“We work on supporting people with their shopping, practicalities, using mobile phones; getting adaptations of properties”.*

*“We are on the cusp of technology being transformative with accessible devices, mobile phones and computers”.*

The organisations were engaged in a wide variety of activities to increase access, often with statutory bodies.

*“We’ve done lots of work on accessible play in the park, with many meetings and it’s funded; it includes a sectioned off area so groups can use or have quiet areas in particular for children with autism”.*

*“We’ve been working with NUTH [Newcastle upon Tyne Hospitals NHS Foundation Trust] on good practice for the Accessible Information Standard”.*

But organisations taking up the role of critical friend also found the balancing act can be a difficult situation.

*“With most things to do with access we’re not always popular but that’s what we’re there for”.*

## **Let’s Race**

*“We began developing an ambitious project that builds on our current work with young people at the ICE BOX youth club and aim to extend this into mainstream youth activity... it is a Soap Box Kart race for teams of disabled and non-disabled young people.*

*Let’s Race has proven popular to everyone we have pitched it to. Collaborative development has taken place with numerous agencies, both statutory and voluntary, most of which we have never formally worked with before, and is leading to partnership working at an unprecedented level for the organisation. These agencies include: six youth and play organisations, Children’s Social Services, Arts Connect and more recently the Nunsmoor Centre Trust, who we are now in talks with regarding playing a pivotal role supporting the young disabled people involved in the project”.*

Several organisations were members of the Disability Confident scheme<sup>xvii</sup>, to help employers employ people with disabilities, and suggested there should be more publicity about the scheme.



## Communication and access

Many people are not aware that BSL is a different language with a different grammar structure. Understanding written English is not easy for many BSL users and is not their first language. If services do not provide their written information in a BSL friendly format, then this makes those services and activities completely inaccessible to the D/deaf community.

*“If you are deaf, it’s a full stop - how do you explain to someone what the issues are or even that you need an interpreter?”*

*“If you’re deaf they expect family or friends to communicate for you, it’s disempowering for deaf people”.*

*“People might get into the city centre; access is not only about transport, it’s about asking for a burger or if you can see the shoes in a different colour! Once there what do you do?”*

There needs to be a step change to make services and places deaf friendly; for instance people should say they will book an interpreter, take a name and address and get back to the person.

*“Hospitals are going in the right direction with video relay ... but they shouldn’t replace the booked appointment with a real interpreter”.*

There is a communication gulf impacting on all aspects of life for D/deaf people.

*“The nine-month wait for [name] clinic: after two months there was no interpreter, so she went back to waiting. It happened again, the notes didn’t say she needed interpreter. One was booked the third time but the interpreter cancelled. The letter said DNA (the patient did not attend!). This is normal, this is what happens”.*

*“We keep having the same conversation...BSL users don’t make a complaint as the procedures are inaccessible. There are small numbers of people who need interpreters but it’s about communication not disability, it’s about your choice of health, of life...it’s about the empowerment of communities...We are skimming [the surface] we turn people away and it affects benefits...we are like a broken record but no one else is saying it”.*

One common myth is that while it is not ideal to use family and friends to interpret, it is better than nothing. But when asked, the consensus from deaf people was:

*“No, it’s better to have professionals to access the service like a hearing person”.*

There is a lack of understanding that BSL interpreters have levels of qualification. For instance a level one interpreter might be able to interpret colours and names, which is



inadequate for a hospital appointment or welfare benefits assessment. Interpreters have years of specialist training and education to become qualified interpreters. The interpreter is there for both the BSL user and the hearing person to aid communication. If services use a family member, the family member has a relationship with the BSL user that impacts on the service. It takes away privacy and confidentiality for the individual and could affect open communication.

*“If you’re given a prescription, to take it three times a day. A communication professional will clarify, for example if it’s after or before food, or with food, while family and friends just take the prescription”.*

In March 2017 Dawn Butler MP used sign language to ask a question in the House of Commons. She spoke as well as signed when she addressed the Chamber saying it was time British Sign Language (BSL) was given further protection.





## 5.5 Articulating need

Organisations had a constant awareness of people slipping out of support or not reaching services. This was due to a combination of a lack of knowledge of what help might be available, lack of ability to articulate need, the disadvantage and lack of expectation caused by poverty, the cost of services, being unable to communicate, or being unable to advocate for themselves. There is a strong crossover with access issues, although the barriers are not physical.

*“People are not asking for help – and not accessing services that most people need, because of cost”.*

*“We only reach half of people with sight loss; half don’t know about services and so do not ask for help”.*

*“We had a home visiting service for people with multiple issues, which has now closed but they still don’t come into the office...”*

*“We still come across people who don’t know what’s available, they’re grateful for a little information; they wish someone had told them years back. One woman with two sons didn’t know about the radar key and using disabled toilets, £2.30 made a huge difference in her life not to worry”.*

*“We provide voice, advocacy; it’s hard to advocate for yourself”.*

*“People don’t recognise themselves as a carer. Still”.*

A reluctance to ask for services around hospital discharge was also identified. Examples of calls organisations have from neighbours and volunteers included:

*“Mr so-and-so has gone home and the ambulance’s dropped him off and there’s no meal, the house is freezing...there’s no food, there is no electricity, there is no gas...there’s electricity heaters but there is no electricity supply...And older people sometimes lie through their teeth trying to leave hospital to get home so they’ll all say my daughter’s going to look after me”.*

There is a legacy of the criminalisation of gay men, where older people are not identifying themselves as gay, with all of the attendant issues over next of kin and sharing care.

*“The neighbours were identifying a couple and he is not asking for help, as he’s worried his partner will be taken away into care. They’re not out, not identified as next of kin anywhere; gay men, not asking for help”.*



## 5.6 Changing needs, changing services

The availability of services, the complexity of people's needs, and the wider environment are all changing, often moving in opposing directions. Seven organisations spoke about an increase in complex needs, increase in numbers of people asking for support, and reducing services.

*"It's taking longer hours with more calls through the telephone. Preventative services are closing; clients coming with issues such as sexual exploitation, mental health, rehabilitation of offenders".*

The social care model has been changing for some time. At a time of regular news about an NHS crisis and the lack of social care for people going home from hospitals, organisations were acutely aware of the reduction in social care. Only those people with the greatest need are being assessed as eligible for support, with less time allocated than previously.

*"But need is not going away. More people with quite significant care needs are not eligible for local authority care".*

Most organisations reported an increase in the sheer complexity of problems people had and the entrenched difficulty preventing them being resolved for more people. In addition, some people with physical disabilities from disadvantaged areas were far more likely to have more than one disability or health condition.

Citizens Advice Gateshead reports on that clients have, on average, five issues to resolve. But a special home visiting project for those with ten issues where the people could not access services has closed.

Having more than one issue or disability reduced the choice of support, access to services, and healthy life expectancy in disproportionate ways.

*"Some [Deaf] people also have other disabilities, cerebral palsy or other disabilities with mental health, it's a massive issue; deaf people have no choice of social worker; there might be maybe two social workers".*

*"Ten years ago it started, Daniel Blake type of cases, they were few and far between but now everybody has a multiple issues".*

The 'triple whammy' of complex multiple conditions, complex entrenched problems, and less support and services also results in more mental health problems. Organisations spoke about increasing their preventative role in response. One organisation was





promoting Your Homes Newcastle (YHN) six weeks telecare which people did not know about, nor how to navigate. Another said

*“We keep people connected with early intervention stuff, if they have not reached the threshold, it keeps people out of services for another two years. Then when young people transition to adult services – it’s as if it’s a surprise they turn 18!”*

Organisations spoke about the impact of the reduction in social care. One illustration of the ongoing scale of cuts is that five years ago Newcastle had 9,000 adult social care clients; now there are 5,000. This is during a time of increase in the number of older people.

*“There is reducing social care – more people assessed as not eligible, the bar is higher than it was and people are not offered support”.*

*“Care packages are being reviewed and become reduced. Especially for respite but long waits for reviews and when people have deteriorated after months is unclear what the criteria is”.*

*“Many local authorities are struggling...the bottom line is about safety, it is not about quality of life any more. If they are stable in the home and don’t go into hospital or go in and out...that’s all they get”.*

*“It is a worry there is no money to see people or they are forced to buy privately, even if it’s only getting comfortable shoes, a family has to buy it. How many people fall through the gaps?”*

*“People are paying more for care. Some say they won’t bother because of the contributions that they must make to their care costs. We don’t know what happens to them; do they use the NHS more?”*

Another of the shifts taking place is the increase in direct payments and demand for Personal Assistants (PAs), which combined with fewer allocated hours and despite the higher minimum wage means that some people are finding it harder to recruit PAs.





## 5.7 Safeguarding

People with disabilities especially if they are older, with several health conditions, or both, are at more risk of abuse and being exploited. Organisations were aware of this and involved in safeguarding adults work. Newcastle Society for Blind People (NSBP) specifically employs a safeguarding officer. Deaflink provides safeguarding adults videos on their website. Some of the organisations are Safe Reporting Centres<sup>xviii</sup> to enable people to more easily report disability related hate crime.

The protective element of their work was referred to by several organisations in relation to its safeguarding element. Befriending visits and visits to determine the offer of services carried out at people's homes are opportunities for checking safeguarding. Although it might appear to just be a visit and a chat over a cup of tea, the befriender or the home care assessor is also looking out for fall and trip hazards, making assessments about safeguarding and about risks in the home.

*"We make alerts – Gateshead Council is very responsive".*

Much work with newly blind people is focused on safety and accident prevention, such as training on using equipment, for instance to pour hot water safely into a cup. There clearly have to be managed risks to enable people to live as independently as possible.

Concerns were raised about the financial abuse of deaf people and blind people with instances cited of money being stolen by visitors to their home, or people being exploited by companies.

*"Private agencies are not providing communication support; if somebody has lived with their family all their life they are very vulnerable, they can't communicate" In the past the Sensory Support team would have provided assistance to the BSL community but they no longer exist".*

A lack of awareness about safeguarding issues amongst families and carers was raised. And particular difficulty in tackling abuse was highlighted when a PA is being employed by the person with disabilities.

*"I had to sack one PA for verbal abuse. They were shouting at me. I had to do the whole disciplinary process, getting them in, going through the meeting, and then ending up dismissing them".*

### Newcastle Society for Blind People Safeguarding Adults Project

Newcastle Society for Blind People has been delivering the Safeguarding Adults Project for 10 years. The project continues to support blind and visually impaired people who have





been victims of abuse or crime or at risk from these occurring. This is a valuable service to visually impaired people at a time when they are struggling to cope following abuse or crime, and also for those people who are extremely vulnerable and are at a higher risk of being a victim of crime or abuse.

During 2016 thirty five Safeguarding concerns were raised. The types of abuse encountered during 2016 were financial, neglect, physical, psychological, discriminatory and self-neglect.

The awareness of the safeguarding project was raised through:

- **Safeguarding newsletters** - Sent out to all people on their database in their chosen format (Large Print, Braille, CD or email). Safeguarding newsletters keep service users updated on a number of issues around keeping safe including the Safe Reporting Centre.
- **World Elder Abuse Awareness Day** - An event held last year was successful with around 70 people attending; we are planning this year's event.
- **Website information and signposting** – Keeping the website updated to ensure people are aware of the project and where to go for support if needed.

The society provides vital 1-1 counselling support for as long as required for people who have been the victims of abuse or crime. This is essential as people who have been victims of abuse and crime are often frightened, anxious and depressed at these often traumatic times of their lives.

Ongoing support from the Safeguarding Officer has enabled people to feel safer. Some people have stated that they felt that someone cared about them, believed their concerns and was able to offer whatever support was needed for as long as required.

Without this vital project people have said they would not feel confident to report their concerns directly to the Police, Adult Services or other organisations. The Safeguarding Project has been described as a lifeline and 2 people have said that without the support they have received they would not have been here anymore as life was so difficult to cope with following traumatic events in their lives.

### **Age UK Gateshead approach to safeguarding**

Age UK Gateshead is the leading charity for older people in Gateshead and is committed to safeguarding and promoting the welfare of vulnerable adults engaged in the breadth of its activities. It takes its duty of care to the older people of Gateshead very seriously, and is committed to playing an active part in the detection and reporting of suspected abuse or neglect.

For the purpose of the Safeguarding Adults the term abuse is defined as:



**... a violation of an individual's human and civil rights by any other person or persons which results in significant harm. (DH, 2000)**

It recognises abuse may be:

- a single act or repeated acts;
- an act of neglect or a failure to act;
- multiple acts, for example, an adult may be neglected and also being financially abused.

Abuse is about the misuse of power and control that one person has over another. Where there is dependency, there is a possibility of abuse or neglect unless adequate safeguards are put in place. Intent is not an issue at the point of deciding whether an act or a failure to act is abuse; it is the impact of the act on the person and the harm or risk of harm to that individual.

Abuse can take place in settings such as the person's own home, day or residential centres, supported housing, educational establishments, or in nursing homes, clinics or hospitals.

A number of abusive acts are crimes and informing the police must be a key consideration.

The people who use the Age UK Gateshead services are people who are more likely to experience abuse. This group may include people with:-

- frailty due to age
- a learning / physical / sensory disability
- mental ill health or dementia
- acquired brain injury
- a drug / alcohol problem
- certain types of physical illness

In line with recommendations where confidentiality may be breached, at all times it must be remembered to seek consent from the person making the disclosure before proceeding. This means that no information will be shared outside of the organisation unless in exceptional circumstances:

- *when required by Law - as in relation to the Child Protection Act*
- with the consent of the person who is making the disclosure
- when people would be put at risk by non-disclosure for instance death or serious harm
- when the person making the disclosure lacks the capacity to give consent but breaching confidentiality would be in the interests of the persons care for instance the person making the disclosure is not taking medication



To date 2016/17 the organisation has referred 14 Safeguarding issues to the appropriate agencies and received a further 16 referrals and requests for ongoing support in safeguarding incidents.

## 5.8 Poverty

Underlying many of the reasons that people with disabilities seek the support and services of the voluntary organisations interviewed is poverty – both of those people claiming benefit and those in low paid or precarious employment. Six organisations directly raised poverty as an issue impacting on the lives of their clients. Foodbanks feature as a daily aspect for most organisations:

*“Who would have thought we would have a list of food banks”<sup>xxix</sup>.*

In Gateshead the Davidson Building where Citizens Advice Gateshead is based is a major distribution centre for the foodbank in Gateshead.

*“Schizophrenia correlates with poverty; there’s evidence about mental health and poverty. And talking therapies are not enough if you’re in poverty; you need to get out of poverty”.*

*“Everyone’s poor – it binds people in offering mutual support”.*

Citizens Advice Gateshead reported that debt, now their second largest enquiry, had been the top issue for a long time. Along with the impact of austerity on individuals, there are fewer other support agencies, and a rising volume of need.

The financial costs of a disability can be high. Joseph Rowntree Foundation<sup>xx</sup> has calculated that 27% of people in families where someone is disabled were in poverty, compared with 19% of families where no one is disabled. But when income related benefits such as Personal Independence Payments were taken out of JRF’s calculations the percentage of families in poverty rose to 31%.

The impact of the welfare reforms on people with disabilities has been widely criticised by charities and disability rights groups. Disability Rights UK,<sup>xxi</sup> in a submission on implementation of the UN Convention on the Rights of Persons with Disabilities accused UK governments of failing to account of disabled people’s rights in new policies and in some cases making things worse for disabled people.

A House of Commons briefing paper<sup>xxii</sup> on welfare reform and disabled people highlighted criticisms of the coalition government’s target of 20% saving through introduction of Personal Independence Payment’s as “arbitrary and punitive”. Other changes to Employment Support Allowance it was argued, would “increase poverty” among disabled people.



## Glossary

**Employment Support Allowance (ESA)** paid to people unable to work due to sickness or disability; people are allocated into one of two ESA groups

**ESA Work Related Activity Group (WRAG)**, have regular interviews and other activity such as courses to prepare for work. The rate of payment of ESA WRAG will reduce by £29 a week to the JSA level in April 2017.

**ESA Support Group** paid to people unable to prepare for work.

**Disability Living Allowance (DLA)** is a benefit for disabled people who need help with mobility or care costs; being replaced by PIP

**Jobseekers Allowance, JSA**, paid to people looking for work – fortnightly payment

**Personal Independence Payment (PIP)** helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16 to 64. PIP is replacing DLA, with the government aiming to have 500,000 fewer claimants and to save £2 billion. Newcastle was one of the early areas to start to replace DLA. People who had a long term or indefinite award of DLA will receive the letter telling them that DLA was ending and they can claim PIP by the end of 2017/early 2018.

**Sanctions** are a punishment by the welfare benefit system of reduced or no benefit. The system of possible sanctions starts from four weeks of reduced or no benefit, increasing to 13 weeks, and then up to three years if the sanctions are repeated.

**Universal Credit** merges six benefits: JSA, ESA, Housing Benefit, Child Tax Credit, Working Tax Credit, and Income Support. It involves a single, per household, monthly payment in arrears, and new ongoing requirements to manage claims online. Due to be fully rolled out by early 2018.

**For information about the government's welfare reforms**, including a timeline of the changes, visit [www.newcastle.gov.uk/welfarereform](http://www.newcastle.gov.uk/welfarereform)



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<sup>xiii</sup> Lesbian, Gay, Bisexual, Trans and Queer good practice guide  
<http://www.mind.org.uk/media/5204367/mind-lgbtqplusguide-2016-webres.pdf> [Accessed 29 March 2017]

<sup>xiv</sup> Make British Sign Language part of the National Curriculum petition  
<https://petition.parliament.uk/petitions/178095> [Accessed 29 March 2017]

<sup>xv</sup> The main changes under the Welfare Reform Act 2012 include

- Changes to Council Tax Benefit with caps imposed
- Replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP)
- Removal of an amount for 'spare' rooms, or under-occupation, commonly known as "the Bedroom Tax"
- Benefit and tax credit cap
- Changes to the Social Fund
- Changes to tax credits
- Introduction of Universal Credit

<sup>xvi</sup> Active Inclusion Newcastle Information for professionals and volunteers  
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## About Newcastle CVS

Newcastle CVS gives people who struggle to be heard a voice, supports voluntary and community organisations to be resilient and sustainable and promotes a fairer society by influencing and challenging the debate.

Our established reputation, extensive networks and integrity and strength of approach makes us the go to source in supporting voluntary and community action.

We improve the quality of life in Newcastle and Gateshead by supporting the voluntary sector.

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