Physical and Sensory Impairment Needs Analysis 2016

Physical Disability and Sensory Impairment Needs Analysis

The following report is the product of a co-produced piece of work contributed to by Gloucestershire County Council, The Physical Disability and Sensory Impairment Partnership Board, Inclusion Gloucestershire and a number of self-advocates with a range of physical and sensory impairments.

It is the first time in Gloucestershire that we have attempted to draw together a range of qualitative and quantitative data to begin to establish the prevalence, needs, views, opinions and individual strengths of adults with a range of conditions traditionally categorised as physical disability and sensory impairment.

It represents the first phase in developing a better understanding of this diverse group, includes key findings and a range of recommendations for further work, including further exploration of the factors contributing to individual resilience. Many of these recommendations will now be taken forward by the Partnership Board. The report will also help inform the Council's strategic thinking.

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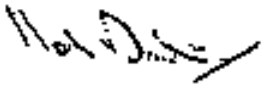
Signed: 

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Physical and Sensory Impairment Needs Analysis 2016

Executive Summary

Introduction

This report aims to develop our understanding of broad areas of life for people with physical and sensory impairments in Gloucestershire. A co-production approach was adopted for this piece of work which set the parameters for the range of issues considered and included. It will be used to inform our strategic thinking which in turn will support people to live as independently as possible. It brings together quantitative data from a range of sources and qualitative experiences through a survey to which 279 people responded and via 15 focus groups attended by 140 people, some of whom access Gloucestershire County Council (GCC) social care services.

The original scope of the work was to adopt an all-age approach and be inclusive of the wide range of conditions, which constitute a physical or sensory impairment. However, the way in which data has historically been collected and categorised is such that identifying who in the 65+ category (currently termed older people) has a physical impairment resulting in disability, is problematic. Therefore, the quantitative element of the research has focused on children and young people and those of working age up to 65 years.

The following report summarises key findings and highlights a number of recommendations which can be progressed through the Physical Disability and Sensory Impairment Partnership Board, GCC and other partner organisations.

Some of the challenges include to:

- Effectively manage resources as higher life expectancy due to further medical advances means that people are living longer with more complex needs, increasing the demand for services and support.
- Do more with less and create opportunities to work more collaboratively and creatively with partner agencies, third sector organisations and communities.
- Develop the market to enable greater choice and more flexible, sustainable models of care and support.
- Operate in a more person-led way to develop independent living options and maximise the resilience of people.

Building a picture in Gloucestershire

The needs analysis highlights that:

- The overall county population grew by approximately 46,300 between 2004 and 2014 and to 617,162 in 2016[1].

- The number of children and young people aged 0-19 years is projected to grow by 9,000 between 2014 and 2025[2].

- The overall number of working age people aged 20-64 years is expected to remain largely static in the next 20 years. In contrast there is likely to be a 63% increase in the number of people aged 65+ years by 2037[3].

- A total of 1,050 children were identified through Disability Living Allowance (DLA) claimant data as having a physical or sensory impairment.

- For adults, an estimated 9,000 people aged 18-64 years in Gloucestershire have a serious physical disability and a further 30,000 people are estimated to have a moderate physical disability[4][5].

- 414 children are currently receiving support for a hearing impairment in Gloucestershire Schools[6], with an estimated 63,000 people of all ages who are D/deaf or hard of hearing in Gloucestershire[7].

- 304 children receive support in Gloucestershire schools for a visual impairment[8]. 236 people aged 18-64 years are estimated to have a serious visual impairment, 3,746 people aged 65-74 years and 7,105 people aged 75+ years are estimated to have a moderate or severe visual impairment[9].

- DLA, and other sources of data, including GCC service user data, indicate that people with a physical and/or sensory impairment predominantly live in Gloucester and Cheltenham and population projections indicate this will be where most people with impairments will live in the future. Social care budgets could therefore be adjusted accordingly as demand in other districts and boroughs stabilises or falls.

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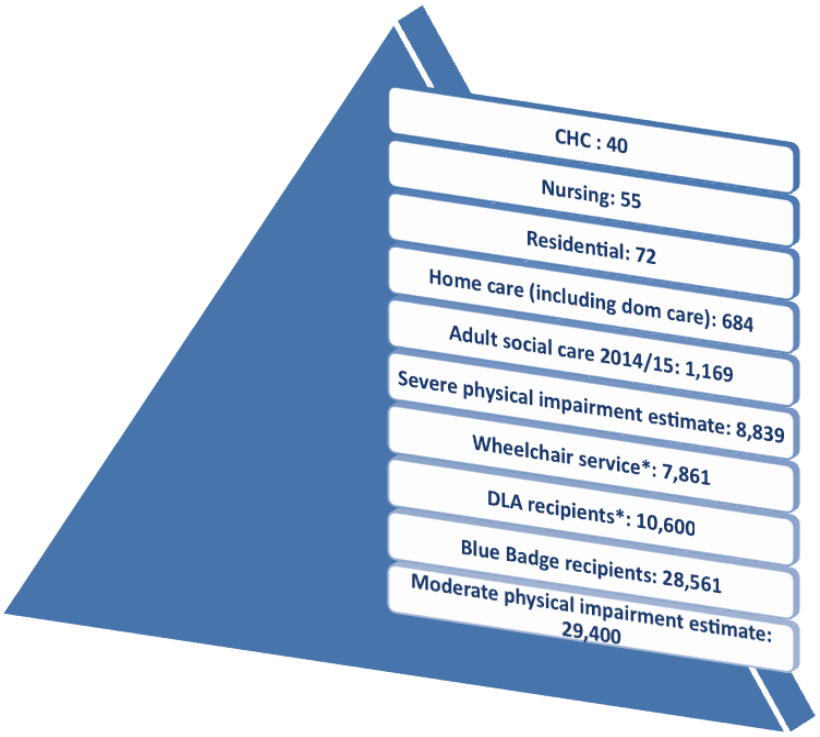
[1] Office for National Statistics (ONS)
[2] Office for National Statistics (ONS)
[3] Office for National Statistics (ONS)
[4] 'Serious' and 'moderate' disability is defined by a scoring system used in the 'Health Survey for England 2001' taking into account a person's ability to mobilise and carry out activities of daily living Prevalence rates of disability scores from this survey have been applied to the population of Gloucestershire to provide data.
[5] Projecting Adult Needs and Service Information System (PANSI)
[6] Advisory Teaching Service (Gloucestershire County Council)
[7] Gloucestershire Hospitals NHS Trust Hearing Services
[8] Advisory Teaching Service (Gloucestershire County Council)
[9] Projecting Adult Needs and Service Information System (PANSI) and Projecting Older People Information System (POPPI)

The following graphic highlights the numbers of people with physical and sensory impairments accessing different types of support/services. This illustrates that only a small proportion access specialist services such as Continuing Health Care (CHC).



(*includes Adults and Children)

Key Findings

- Data from the adult social care database indicates demand for social care services is stable; however data projections suggest an increase in people with complex needs, in line with medical advancements enabling people to live longer.

- There has been a reduction in children and young people who are in receipt of a statement of special education needs with a physical or sensory impairment (SEND). This is in part linked to the introduction of Education, Health and Care Plans (EHCPs). Demand 'on the ground' for support is actually increasing as GCC services are in contact with increasing numbers of children with complex needs. These children and young people are being supported through non-statutory methods using the Gloucestershire graduated pathway.

- Prevalence data illustrates that many people with moderate and serious needs do not use our services; similarly 52% of survey respondents funded their own care.

- Most service users accessing support because of a physical or sensory impairment are over 55 years and population projections suggest this will increase.

- 70% of people aged 18-24 years who have accessed GCC funded care for over a year are male. 52.5% of all service users with a physical and/or sensory impairment are male, with increasing numbers of female service users aged over 45 years.

- 75% of service users with a physical and/or sensory impairment who have received GCC funded care for a year or more have a carer.

- The uptake of Telecare (GCC assistive technology service) is particularly low amongst people with a physical and/or sensory impairment at present.

- Data suggests that people categorised as having a physical or sensory impairment in reality experience multiple conditions[10].

- Analysis of the 50 highest costing adult social care packages categorised as physical disability illustrates there is no clear definition of what constitutes physical disability within GCC.

- This analysis also demonstrates that just over 33% of people receiving these high cost care packages have an Acquired Brain Injury.

- Data regarding health conditions which can result in a physical impairment indicates;

    - Cancer is the medical condition increasing at the highest rate and the condition with the highest prevalence is arthritis[11]
    - Arthritis and musculo-skeletal conditions are the most common cited by DLA claimants.
    - Visual impairment is a common condition in those we surveyed and amongst our long term service users (accessing funded care for a year or more).
    - A neurological condition is commonly recorded across all datasets.

- 52% of survey respondents reported they or their family fund their care, demonstrating a majority of this sample do not receive public funding for care despite their self-classification of impairment as moderate or severe.

[10] GP profiles, DLA, GCC service user data, GCC survey
[11] GP profiles

- The comments received through the survey illustrate the concept of advocacy and knowledge of formal, independent advocacy services is not familiar to many from this sample of people.

- Social interaction and having a sense of purpose or something constructive to do is crucial to *what makes a good day* for many respondents to the survey.

> *"I help out at the girl guides and this gives me a sense of helping others and social connections"*

- Practical barriers still exist in accessing healthcare, both in making an appointment and getting to one. These barriers have the potential to cause disparity in access between able-bodied people and those with a physical and/or sensory impairment.

> *"I have issues with medical appointment letters. They often ask that you 'phone to book/confirm/change appointments'; I am deaf! I cannot use a 'phone!'"*

- 77% of survey respondents accessing education in the last 3 years said they had a good experience. The quality of support on offer appears variable when comments are analysed.

> *"There was no extra assistance and I had to ask for help – not conducive to learning. Felt a nuisance*"

- Survey respondents reported less satisfaction with the accessibility of the outside built environment than with access to public facilities. Only 38% agreed that the outside environment was accessible.

> *"Many of the pavements in Stroud are angled sideways which can make access with a wheelchair awkward"*

- We know that supportive friends and family can keep people independent in the community however we also know that not everyone has such support. This is why it is vital for these people to also have the support from community groups, should they want this.

> *"I go to lip-reading classes - I like it because it allows me to socialise with other deaf people whilst also learning"*

Key Recommendations
GCC Adult Social Care:

1. The high average cost of care, when benchmarked with our comparator local authorities, demonstrates a need for GCC to work with its partners to develop the care market to include a range of accommodation and specialist provision including for people with Acquired Brain Injury.

2. Future commissioning activity should refocus on personalisation and ensure the support that is commissioned and delivered across health and social care is truly person-led.

3. The evidence suggests we should develop an improved method to record a person's condition to reflect the complexity of their impairments and needs. We could develop a 'complex needs category', joint funded across organisations supporting people with physical/sensory impairment, mental health and complex health needs.

4. There are further opportunities to explore and promote preventative interventions such as assistive technology to increase numbers of people with a physical/sensory impairment living in more independent settings. This will include exploring new and emerging technologies.

5. There is a need to improve information sharing within, and between, provider organisations, specifically health and social care practitioners, so a person only needs to tell their story once.
6. Frontline practitioners must be better informed about the local community opportunities providing low level support, and specifically advocacy services, in line with the requirements of the Care Act 2014 to offer information and advice.
7. GCC commissioned information and advice services should be more broadly promoted, for example through GPs, to reach those who are not in receipt of GCC care services.

8. We need to continue to effectively support carers of all ages including young carers. 75% of adults with a physical disability, receiving GCC funded support, have a carer.

Children Services and Transition from Children to Adult Services:

9. Gloucestershire's Local Offer (through the Family Information Service directory) should be further promoted. This provides information about provision across education, health, social care, private, voluntary and community sectors for children and young people who have SEND and is in line with the move towards the offer of further non-statutory support.

10. We need to plan for, and better understand, children and young people transitioning between childhood and adulthood. This is to offer reassurance to parents and children to help explore options available to them post 18.

GCC Commissioning beyond Health and Social Care

11. We need to ensure there is a consistent offer of employment support to people regardless of the type of disability or impairment.
12. Physical Disability and Sensory Impairment Partnership Board members should report their experiences and feedback to the Building Better Transport links forum to highlight issues with public transport providers and highway issues.
13. The County Council could lead by example, helping people with a range of impairments to access work within GCC to improve employment opportunities.

Health Services:

The Partnership Board should:

14. Work with commissioners of health services to identify further support in pregnancy and early assistance for parents and carers of children and young people with disabilities.
15. Influence the range of health settings to improve physical access and access to information.
16. Explore how to influence practitioners to ensure people are considered holistically.
17. Consider options for increasing access to weighing facilities for wheelchair users in Gloucestershire including for private providers to offer this service.

Partner Organisations

The Partnership Board should work with partners including district and borough councils and third sector, community and private organisations to:

18. Centralise information about adapted properties so those who need access to social housing are more able to source properties suitable for their needs.

19. Improve information to aid access to appropriate housing, to include advice to private landlords and how to access Disabled Facilities Grants.

20. Explore opportunities to create countywide best practice guidance to encourage house builders to build to Homes for Life Standards.

21. Improve access to public and private exercise and sport facilities and equipment. This should include access to hydrotherapy pools, evidenced in this report as a form of exercise many felt they could take part in.

22. Review the provision of accessible toilets across the county with district and borough partners and private businesses.

23. Explore ways in which issues affecting access to the built environment can be fed back to district and borough councils.

Wider Community Influence

The Partnership Board should:

24. Further explore options with a range of community, condition-specific and third sector organisations to give practical support for people in their day to day lives. A card could be created and shown when required to explain to a stranger a person's impairment; a service already offered by some organisations.

25. Work with our partners to identify a suitable location for a toilet/changing room built to 'Changing Places' standards and share knowledge of capital grants available to fund this scheme.

26. Work with Gloucestershire mainstream further education colleges and the University to improve the support for those with higher level needs in the same way that those with lower level needs are supported.

27. Better understand the reasons why community transport is under-used by people with a physical disability/sensory impairment in some areas and explore what makes some providers more successful than others.

28. Encourage the use of alternative transport booking methods (e.g. via text) for community and private transport providers to increase accessibility for a greater number.

29. Encourage employers to be more disability friendly through provision of Disability Awareness training and promote the benefits and skills people with a disability can bring to an employer.

30. Undertake work to better understand the factors contributing to the resilience of the many people with significant impairments who do not access formal support services.

31. Work with partners to promote the range of social, community and support groups on offer in the county to help combat social isolation – a real determinant of both emotional and physical wellbeing.

Conclusions and further recommendations

- These findings will contribute to the development of a Market Position Statement for commissioning care and support for people with physical and sensory impairment in Gloucestershire in order to shape the market and increase the range and variety of support available.

- The responses from the survey suggest that people feel frustrated when there is not a joined up approach to support. Further collaboration with our partners, including closer working with the NHS and increased sharing of information, would improve the front line service to the public.

- The Physical Disability and Sensory Impairment Partnership Board will own and prioritise the recommendations, develop a plan and work with partners to progress the subsequent actions. These specifically include the recommendations for access, education, employment and housing.

This is the first piece of work in Gloucestershire which has attempted to build a picture of general life as well as access to GCC care and support for adults and children with a range of physical and sensory impairments. It has highlighted many areas where further work is required and provides a foundation for this work to develop. The co-production approach has ensured that areas of life important to this diverse group have been included which may not have been the case with a traditional quantitative approach. A key strength of this collaboration has been the numbers and range of stakeholders engaged throughout with whom we are able to continue the dialogue to inform our strategic thinking.

1. INTRODUCTION

This report aims to develop our understanding of broad areas of life for people with physical and sensory impairments in Gloucestershire. The report begins to identify:

- Predicted population trends and growth.
- The current and likely future demands on services.
- People's experience of a range of support and services.
- Where we could make improvements in the future.

We decided to co-produce the work with Inclusion Gloucestershire, members of the Physical Disability and Sensory Impairment Partnership Board and other people with "lived experience", called self-advocates, in order to gain a more holistic view.

The Needs Analysis brings together quantitative data from a range of sources and qualitative experiences through a survey, to which 279 people responded, and 15 focus groups attended by 140 people, some of whom access Gloucestershire County Council (GCC) social care services. The survey and the focus groups enabled us to capture the narrative of people with a physical or sensory impairment.

The report identifies key findings and a range of recommendations for the Physical Disability and Sensory Impairment Partnership Board, GCC and partner organisations. It will be used to inform our strategic thinking which in turn will support people to live as independently as possible.

1.1 Key Drivers

There are a number of national policies impacting on this area of work; most significantly the **Care Act 2014** and the **Children and Families Act 2014** which emphasise the requirement for people who need care and support, and their carers, to be informed and fully involved in the planning of that support. This is in line with **Putting People First 2007,** the personalisation of social care and a positive change to involve individuals in the planning of their care. The **Equality Act 2010** requires service providers to ensure information; service provision and the built environment are accessible. The recent changes in the benefits system from **Disability Living Allowance** to the **Personal Independence Payment**; has increased the eligibility criteria for people with disabilities to access benefits. This change could potentially influence subsequent demand for support in Gloucestershire.

GCC's own values direct how we work with our residents and include giving children and young people opportunities to reach their full potential, encouraging **Active Individuals and Active Communities** to support people to stay as healthy and as independent as possible. However much help is available from family, friends, neighbours and communities we know there will always be some people who will also require social care services.

Within GCC the commissioning of Physical Disabilities and Sensory Impairment fits within the all age, all disability vision of the **Building Better Lives Policy 2014-2024** and its seven core principles;

1. Early help
2. Inclusion
3. Independence
4. Contribution
5. Shared responsibility
6. Personalisation through choice and control
7. Coordination of a whole-life approach.

1.2 Key Challenges

Population trends are likely to increase the demand for Gloucestershire services. Higher life expectancy due to further medical advances means that people are living longer with more complex needs; people are living longer with frailty and impairment and may require increasing levels of support.

The current economic climate and increasing demand for support requires GCC to do more with fewer resources. Our challenge is to work effectively, creatively and in an integrated way with our partner organisations in the NHS, other public bodies and the third (voluntary and community) sector.

We need to develop the market to enable greater choice and flexibility, to increase the number of sustainable models of care and support and to operate in a more person-led way to develop independent living options which maximise the resilience of people.

1.3 Scope

The original scope of the work was to adopt an all age approach however, the way in which data has historically been collected and categorised means that we cannot accurately identify some data, particularly for older people with physical impairments accessing GCC services, therefore the quantitative data focuses on children and young people and those of working age up to 65 years, whilst the qualitative data is all age.

1.4 Defining Disability and Impairment

The term physical disability is generally understood as the limitations on a person's physical functioning, mobility, dexterity or stamina. Other physical disabilities include impairments which limit aspects of daily living, such as respiratory disorders, visual impairment, hearing impairment and epilepsy. Under the Equality Act 2010, to be

considered as physically disabled, a person's physical condition will have a *substantial*[12] and *long-term*[13] effect on their ability to carry out normal daily activities.

The social model of disability makes the distinction between impairment and disability, and considers that disability is caused by the way society is organised, rather than a result of a person's impairment. The focus of this approach is to remove barriers that restrict life choices and *disable* people, with the aim to improve life experiences of people with impairment.

There is neither a working definition nor a single source of data that provides a definitive headcount of people in Gloucestershire who have a physical or sensory impairment. The term physical disability has historically been employed by a number of datasets to describe those with a physical impairment. In addition, there may be some inconsistencies in recording. It is acknowledged that some people have complex needs and/or more than one diagnosis.

Both the terms disability and impairment are therefore used throughout this report.

[12] 'substantial' is more than minor or trivial, e.g. it takes much longer than it usually would to complete a daily task like getting dressed

[13] 'long-term' means 12 months or more, e.g. a breathing condition that develops as a result of a lung infection

2. BUILDING A PICTURE OF PHYSICAL AND SENSORY IMPAIRMENT IN GLOUCESTERSHIRE

2.1 Population Trends and Projections for Gloucestershire[14]

- The overall population of Gloucestershire grew by 46,300 between 2004 and 2014.
- The number of children and young people aged 0-19 years is projected to grow by 9,000 between 2014 and 2025 (i.e. 6.5%).
- The overall number of working age people (aged 20-64 years) in Gloucestershire is expected to remain more or less static in the next 20 years. In contrast there is likely to be a 63% increase in the number of people aged 65+ up to 2037.
- Numbers of 50-64 year-olds are projected to increase, by approximately 12,000 people, between 2014 and 2025, while the numbers of those aged 20-34 years and 35-49 years are expected to fall in the same period.
- Gloucester, Cheltenham and Tewkesbury account for the largest numbers of the 20-64 year old population in the county. They have been experiencing a growth of this age group in the past 10 years and are predicted to continue to see an increase of this age group in the next 20 years.
- By contrast, all other districts either experienced a decline of the 20-64 year old population or saw a very modest increase of this age group in the past 10 years. Projections for these districts also suggest either a reduction in the number of this age group or a static trend in the next 20 years

2.2 Estimated Working-Age Population with a Physical or Sensory Impairment (16-64 years)

A combination of Projecting Adult Needs and Service Information System (PANSI) and recipients of Disability Living Allowance (DLA) data were used to derive a broad estimate of the overall number of people aged 18-64 years in Gloucestershire who have a physical disability.

2.2.1 Serious and Moderate Physical Disability[15]

There were approximately 9,500 people aged 16-64 years in Gloucestershire claiming DLA as of February 2013[16] (excluding Learning Disability and Mental Health conditions), correspondingly PANSI estimates that 9,000 people aged 18-64 years in Gloucestershire have a serious physical disability and a further 30,000 people are

[14] Office for National Statistics population projections

[15] 'Serious' and 'moderate' disability is defined by a scoring system used in the 'Health Survey for England 2001' taking into account a person's ability to mobilise and carry out activities of daily living. Prevalence rates of disability scores from this survey have been applied to the population of Gloucestershire to provide this data.

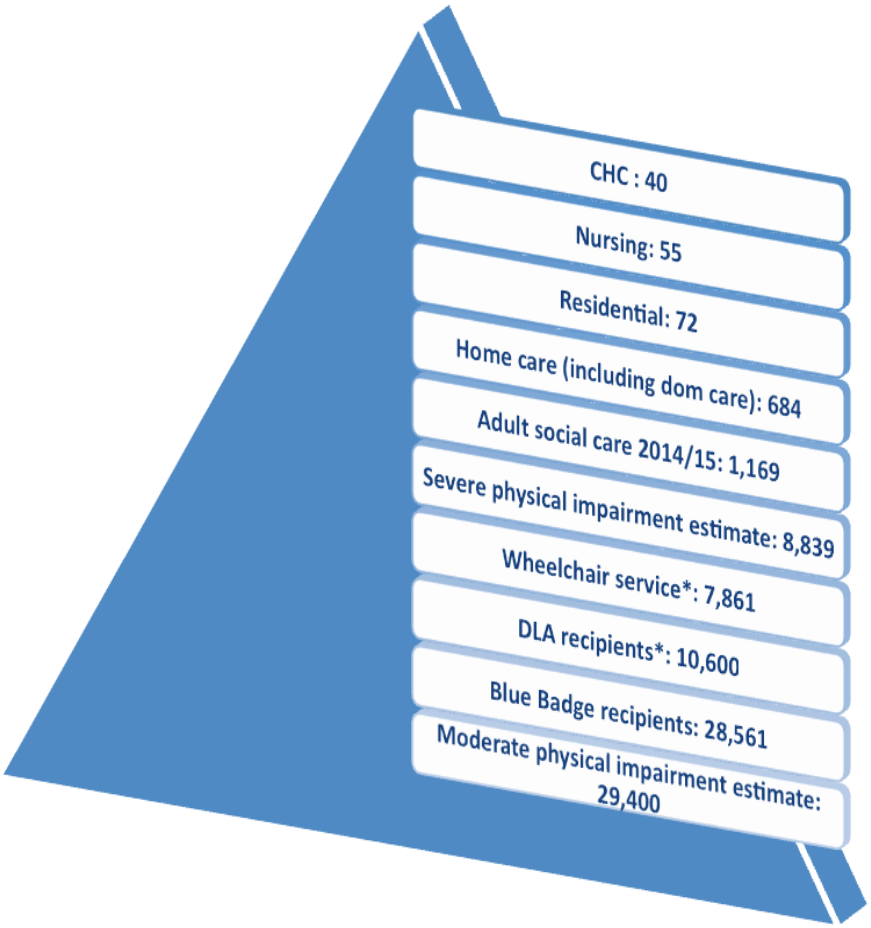
[16] More recent data is problematic in accuracy due to the gradual transfer of people from DLA to PiP

estimated to have a moderate physical disability. Just over a third of those with a serious physical disability (around 3,300 people) are estimated to have serious care needs due to their condition.

The PANSI projections predict the overall number of people with a moderate and serious physical disability will rise (by 500 and 350 people respectively) between 2015 and 2030, with the 55-64 year old age group accounting for the largest increase. The projections assume that prevalence rates of conditions will stabilise during the period.

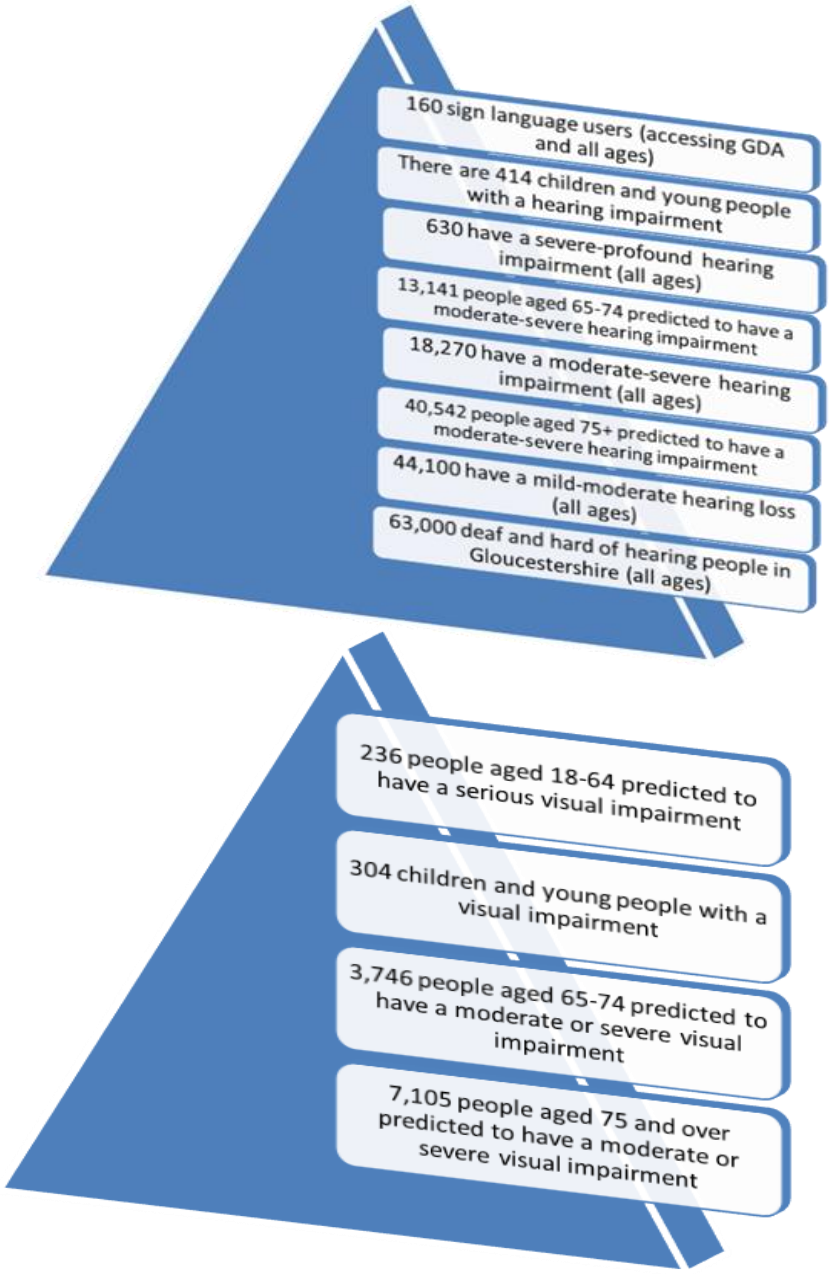
Figure 1: Highlights the numbers of people with physical disabilities and sensory impairments accessing different types of support/services. This illustrates that only a small proportion access specialist services such as continuing health care (CHC).

(* includes adults and children)



2.2.2 Sensory Impairment

Figure 2: The graphics below illustrate the prevalence of deaf, hearing impaired and sight impaired people in the county[17]



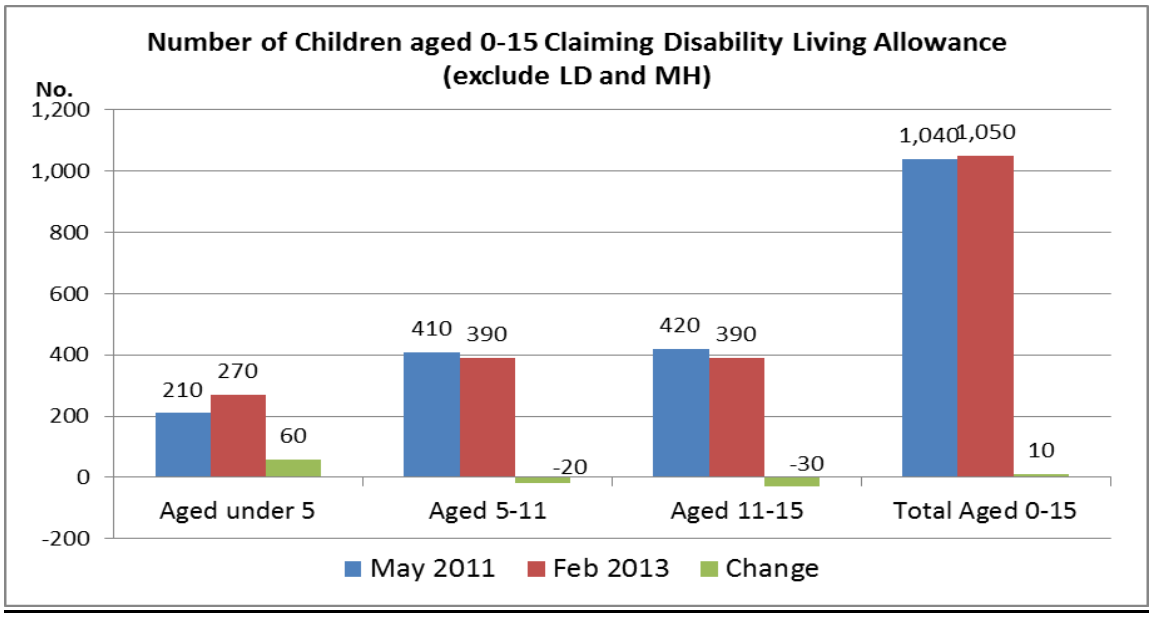
This data highlights the increasing prevalence of sensory impairment, particularly hearing impairment, associated with ageing.

[17] Data from the Advisory Teaching Service, Gloucestershire NHS Hospitals hearing services, Gloucestershire Deaf Association (GDA);Projecting Older People Population Information System (POPPI) and PANSI which applies prevalence information collated by the Royal National Institute for The Blind (RNIB) against population statistics for Gloucestershire.

2.2.3 Estimated Children and Young People with a Physical Disability (0-15 yrs)

There are two main sources of information to estimate the number of under-16s in Gloucestershire who have a physical impairment: Disability Living Allowance (DLA) and Special Education Needs (SEN). SEN statistics only identify those whose impairment has an impact on their educational needs and who are statemented or who have an Education, Health and Care Plan (from September 2014). In January 2014, a total of 216 children had a SEN statement because of a physical health condition (including physical impairment, hearing impairment, visual impairment and multi-sensory impairment) according to the School Census. This is compared with 1,050 children aged 0-15 years identified through the DLA. While the overall number of children receiving DLA has remained broadly the same since 2011, the number of pre-school children receiving the allowance rose by 29%. This is in contrast with the older age groups where the number has reduced.

Figure 3: Illustrates Disability Living Allowance claimants by age.

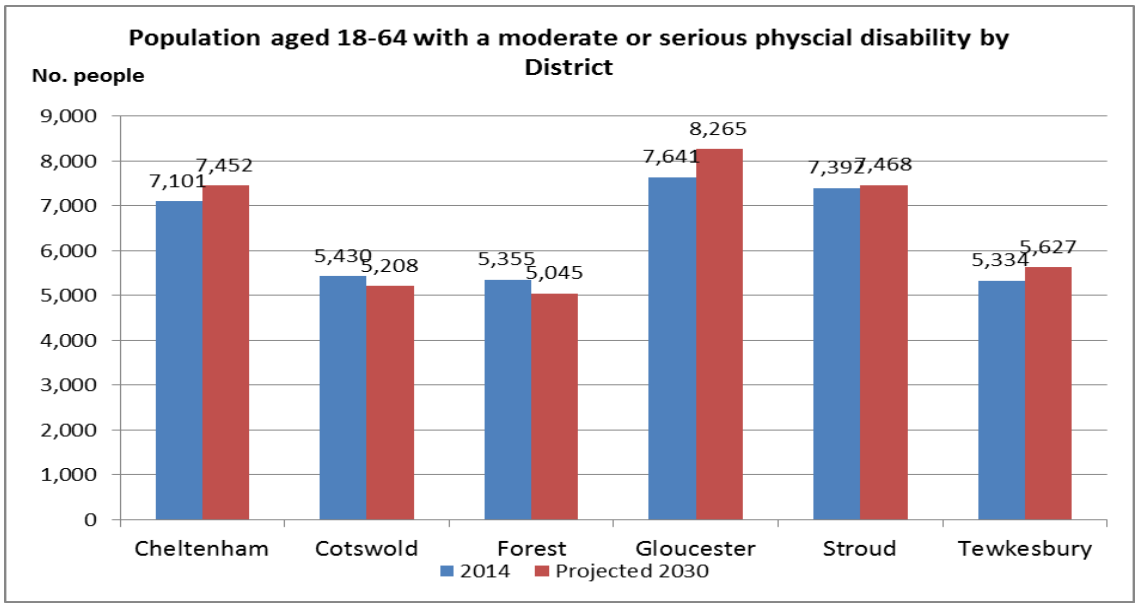


2.3 Geographical Patterns

2.3.1 Geographical pattern of population with a Physical or Sensory Impairment

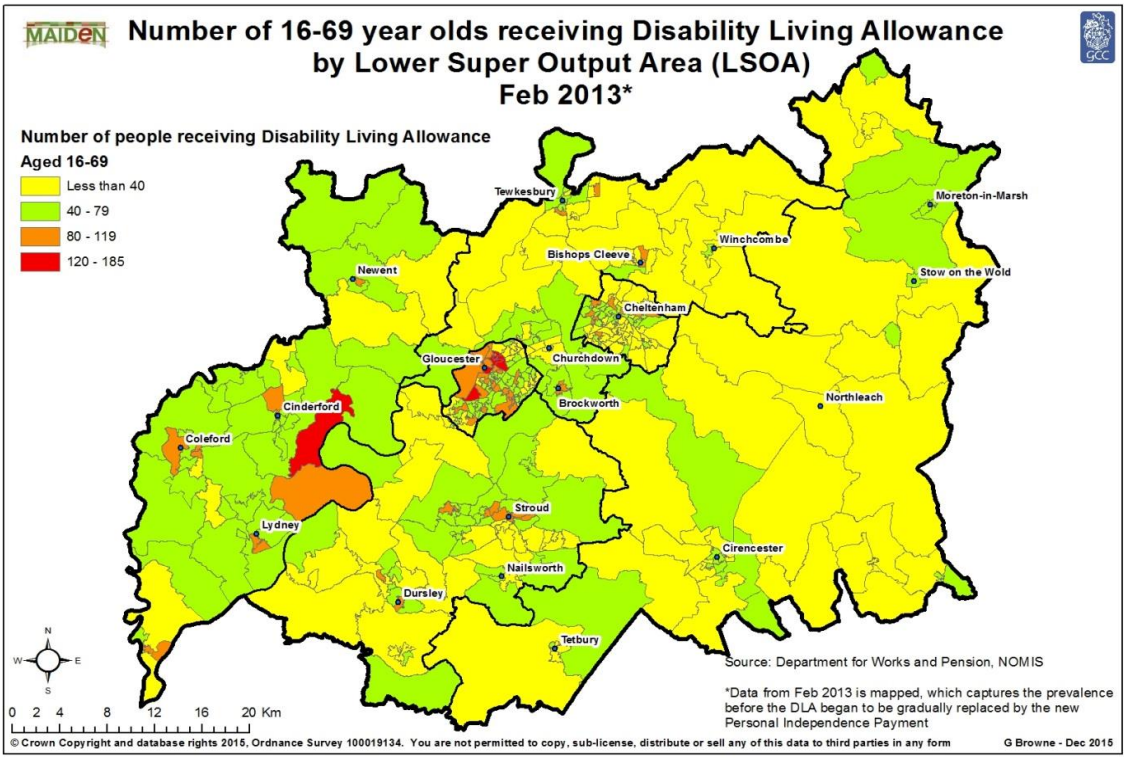
Applying national prevalence rates to the population in each local authority, the PANSI model suggests that currently, Gloucester City, Cheltenham Borough and Stroud District have the largest numbers of people of working age with a moderate or serious physical disability. The three districts are also expected to continue to account for the largest shares of population needs in 15 years' time, although the level of need in Tewkesbury is expected to increase as its population is projected to grow.

Figure 4: Depicts the number of people with a moderate/serious disability by District.



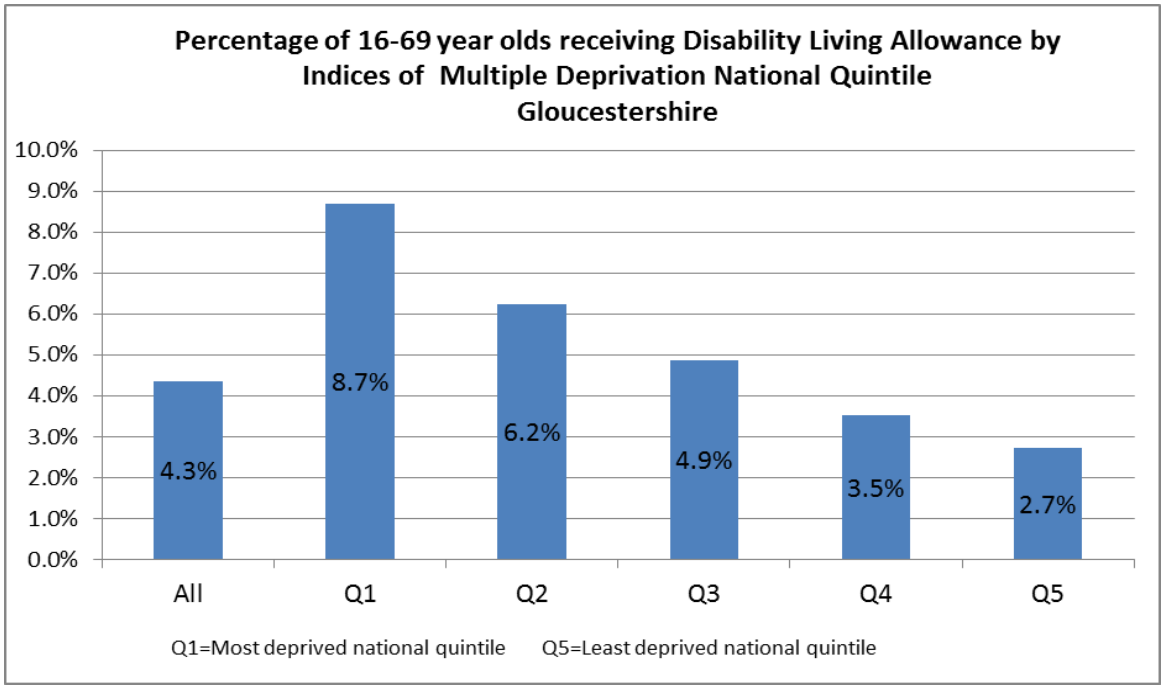
The numbers of claimants of DLA are available at district level, enabling identification of “hotspots”. However, this data includes claimants of all conditions and not solely physical disability. DLA hotspots are concentrated in large parts of Gloucester, to the west of Cheltenham, around Cinderford, Newnham, Lydney and Coleford in the Forest of Dean, as well as in the more urban areas of Stroud.

Figure 5: Maps the location of people aged 16-69 years receiving DLA in 2013



Analysis of DLA data and Indices of Multiple Deprivation also depicts a link between deprivation and prevalence of disability; the more deprived an area is, the more prevalent DLA claims are likely to be among the local working-age population.

Figure 6: Highlights the link between poverty and disability.



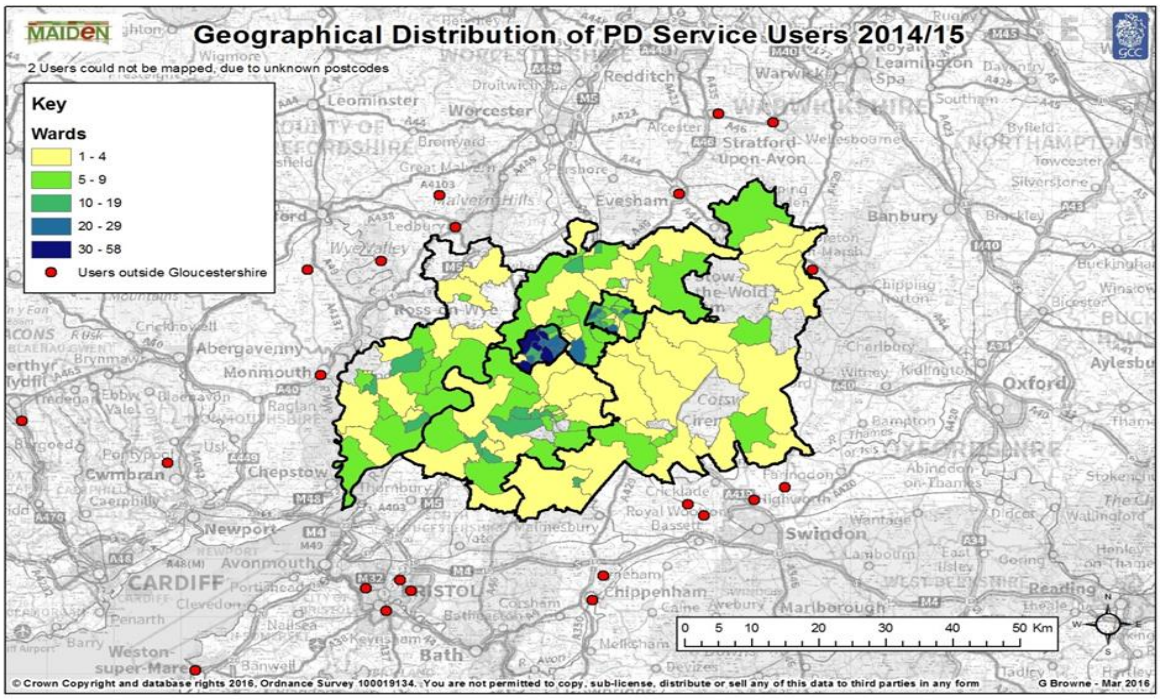
2.3.2 Geographical Patterns of Service Users

Gloucester accounted for the largest number of service users in 2014/15, totalling 373 or representing 31.9% of the cohort during the year, followed by Cheltenham (18.3%) and Stroud (16.0%). A total of 51 (i.e. 4.4%) of service users have a recorded address outside Gloucestershire.

Figure 7: Proportions of adult social care service users with a physical disability by District

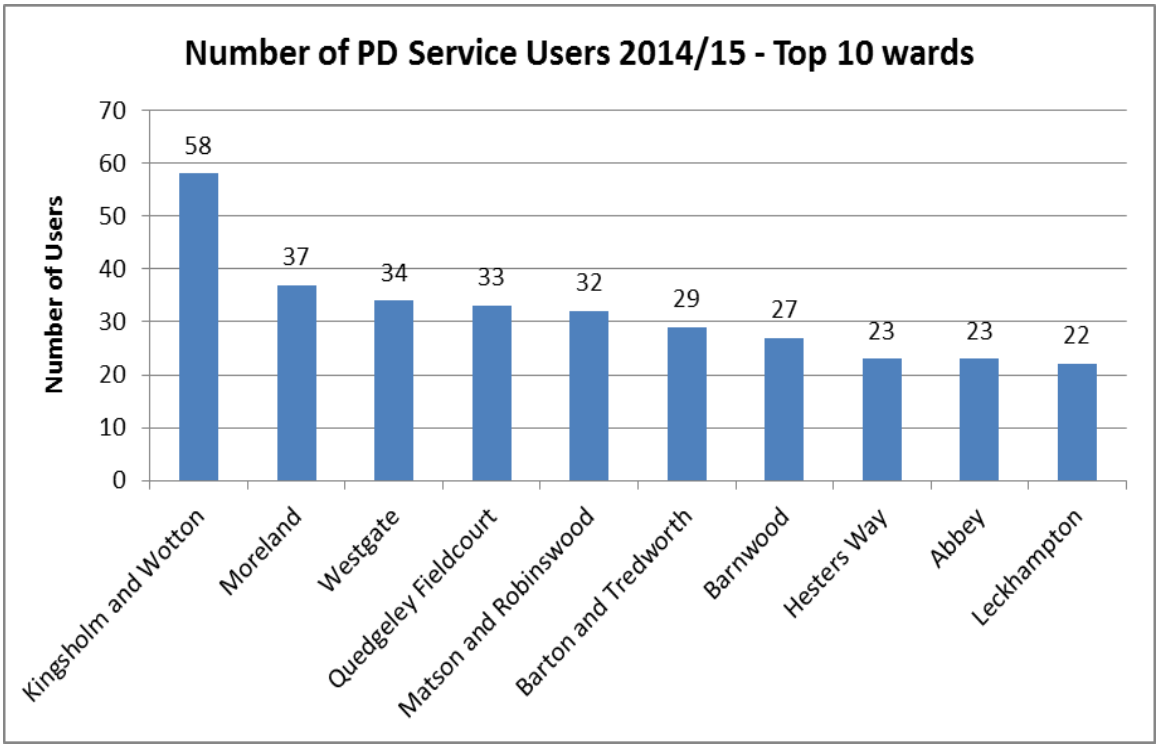
	% PD Service Users by District		
	2012/13	2013/14	2014/15
Cheltenham	18.1%	17.8%	18.3%
Cotswold	7.0%	8.1%	7.2%
Forest of Dean	13.5%	13.4%	11.7%
Gloucester	28.8%	29.6%	31.9%
Stroud	15.3%	15.5%	16.0%
Tewkesbury	11.9%	10.6%	10.4%
Out of Gloucestershire/N/A	5.4%	5.0%	4.6%
Total	100.0%	100.0%	100.0%

Figure 8: *The geographical distribution of the cohort across the county illustrating areas with high concentrations of demand.*



Of the 10 council wards with highest demand, 8 are located in Gloucester and 2 in Cheltenham.

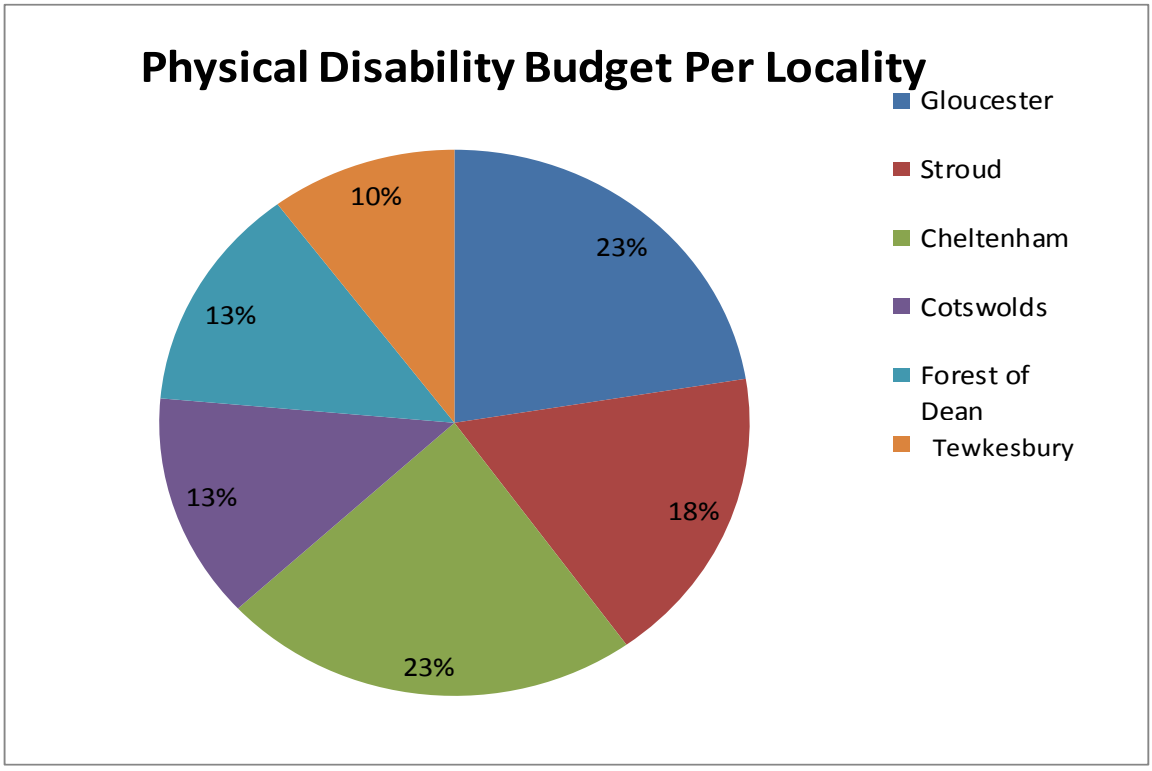
Figure 9: Links to map in Figure 8 and highlights the number of people receiving adult social care in the wards with the highest levels of demand of these services.



Data analysis reinforces a correlation between deprivation and demand for services. The rate of demand in neighbourhoods ranked as the most deprived 20% nationally is more than three times as high as that in areas ranked as the least deprived.

Population projections suggest that the increase in demand is likely to come from Cheltenham, Gloucester and Tewkesbury.

Figure 10: Depicts the breakdown of the PD external care budget by locality.



This has a potential impact on future delivery. At present Cheltenham and Gloucester each have a 23% share of the budget, however with increased demand in these areas and projected falls in populations in other districts a review of budget allocation may be appropriate.

Population projections for children and young people in the next 10 year period, combined with evidence suggesting that children are living longer into adulthood with complex health conditions suggests there is likely to be an increased demand for funded social care support. Population projections for working age adults overall predict little change; however information from PANSI suggests an increase in the number of working age adults with a moderate or serious physical disability. This could be due to increased life expectancy of children with complex health needs. Therefore increased pressure may be placed on transition services whilst they transfer between child and adult social care services. It is the population that is 65+ that will see the greatest increase overall with a moderate or serious impairment as people are living longer with impairment and frailty.

3. CARE AND SUPPORT

This section examines access to social care services, provides demographic data of those who access it, details how support is provided and also analyses our survey respondents' perception of the care and support they receive.

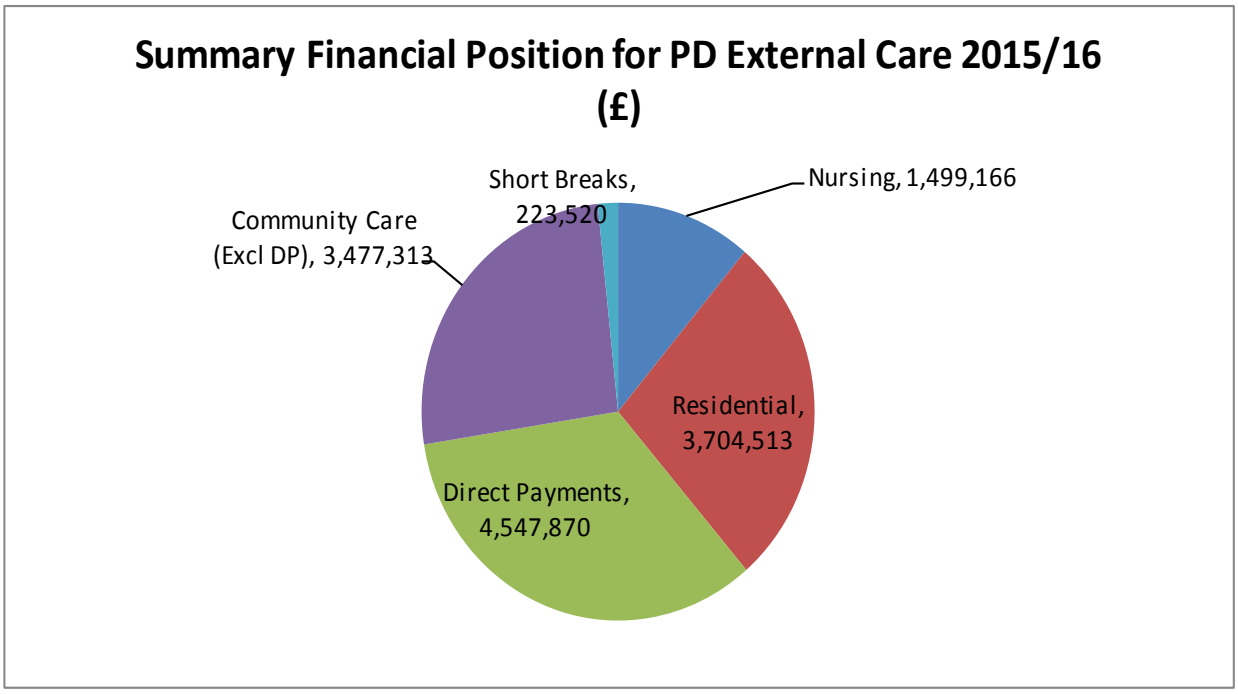
GCC funded services for care and support for people with impairment is delivered by the Children and Young People's Social Services (0-18 years) and Adult Social Care (18+). The Children and Young Person's service also supports young people up until the age of 25 who are transitioning between children and adult social care.

3.1 Adult Social Care

3.1.1 Benchmarking current costs of Adult Social Care

Gloucestershire County Council spent approximately £13.5 million on care and support for people with a Physical/Sensory Impairment during 2015/16. Figure 11 illustrates the breakdown by type of support.

Figure 11: Presents a summary of the physical disability budget 2015/16



(DP- Direct Payments)

GCC commissions a number of providers to deliver care and support for people with a physical and sensory impairment in residential, nursing care and supported living settings. Providers include Leonard Cheshire for nursing and residential care and settings such as The Dean for high level and complex acquired brain injury support.

Figure12: Expenditure of adult social care budget on physical disabilities by type of support

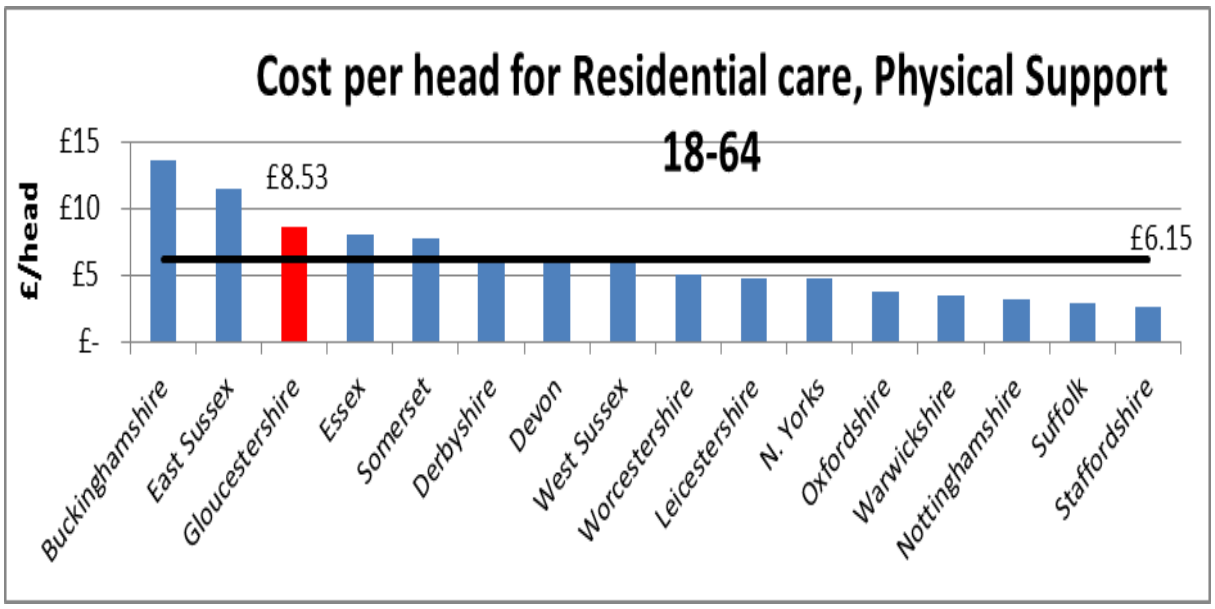
Expenditure	Gross Cost (£'k)	Income	Net Cost	Cost per Head	Average
Nursing	£1,578	£283	£1,295	£3.56	£2.92
Residential	£3,563	£461	£3,102	£8.53	£6.15
Supported Accommodation	£0	£0	£0	£0	£0.37
Community: Direct Payments	£6,054	£278	£5,776	£15.88	£13.46
Community: Home Care	£2,457	£4	£2,453	£6.74	£7.32
Community: Supported Living	£449	£1	£448	£1.23	£0.89
Community: Other	£2,154	£1,432	£722	£1.99	£2.42
Fairer Charging Income	£0	£226	-£226	-£0.62	-£0.76
Total	£16,255	£2,685	£13,570	£37.31	£32.77

Above average £/head Below average £/head

National benchmarking allows local authorities to compare their expenditure to authorities of a similar size and demographic of population. Gloucestershire appears to have a high cost per head of total population for service users aged 18-64 years receiving long term support, in comparison to other similar local authorities, this may in part be explained by differences in the way that the data is collected and reported.

- Residential (£8.53) – Third highest out of 16 authorities
- Direct Payments (£15.88)– Third highest out of 16 authorities

Figure 13: Benchmarks the cost of residential care with comparative authorities



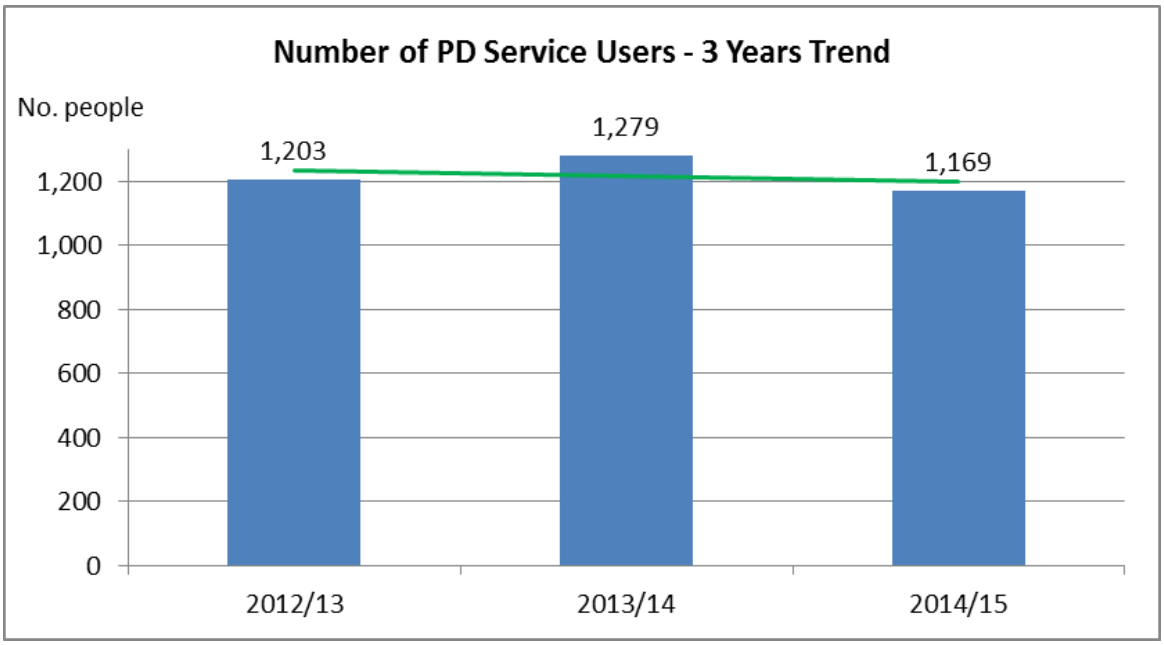
Recommendation: The high average cost of care, when benchmarked with our comparator authorities, demonstrates a need for GCC to work with its partners to develop the care market to include a range of accommodation and specialist provision including for people with an acquired brain Injury.

3.2 Analysis of Service Usage for Adult Social Care

This section examines the current level of access to GCC services defined as a 'Physical Disability' category among the local population aged 18-64 years. The information was sourced from ERIC, the GCC database for adult social care records.

In 2014/15 there were 1,169 unique individuals who had 'physical disability' recorded as their primary reason for accessing a service. The equivalent numbers in 2012/13 and 2013/14 were 1,203 and 1,279 respectively[18]. People accessing services could also have a range of complex needs which cannot be easily classified (e.g. learning disability or mental health needs). GCC is working on a more robust way of recording and representing the needs of people accessing its social care services.

Figure 14: The number of people accessing adult social care services



Data suggests that in the three years to 2014/15, the age make-up of demand was largely unchanged although numbers of people with a physical impairment in the 18-24 age group has increased slightly. At district level, Gloucester has accounted for a larger share of the demand while the Forest's share has reduced over the same period. There is increasing demand in Gloucester compounded by predicted population growth.

[18] This data should be treated with caution as accuracy of data recording and consistency cannot be guaranteed. This issue is being addressed through a new adult social care database

3.2.1 Age

The number of people accessing services due to a physical impairment increased with age. 38% of service users in 2014/15 were between 55 and 64 years of age; this was more than five times the number in the youngest age group (18-24 years). The 55-64 year old age group also represents the highest rate of demand for services; for every 1,000 people aged 55-64 years in the population, 5.8 people accessed the service. This compares to 1.7 of the 18-24 year old age group.

Figure 15: Adult social care service users receiving support for a physical disability by age group

Years	No. PD Service Users (2014/15)	% PD Service Users (2014/15)	Rate of Demand (per 1,000 population in respective age group)
Age 18 - 24	82	7.0%	1.7
Age 25 - 34	179	15.0%	2.6
Age 35 - 44	158	14.0%	2.1
Age 45 - 54	305	26.0%	3.3
Age 55 - 64	445	38.0%	5.8
Total	1,169	100.0%	3.2

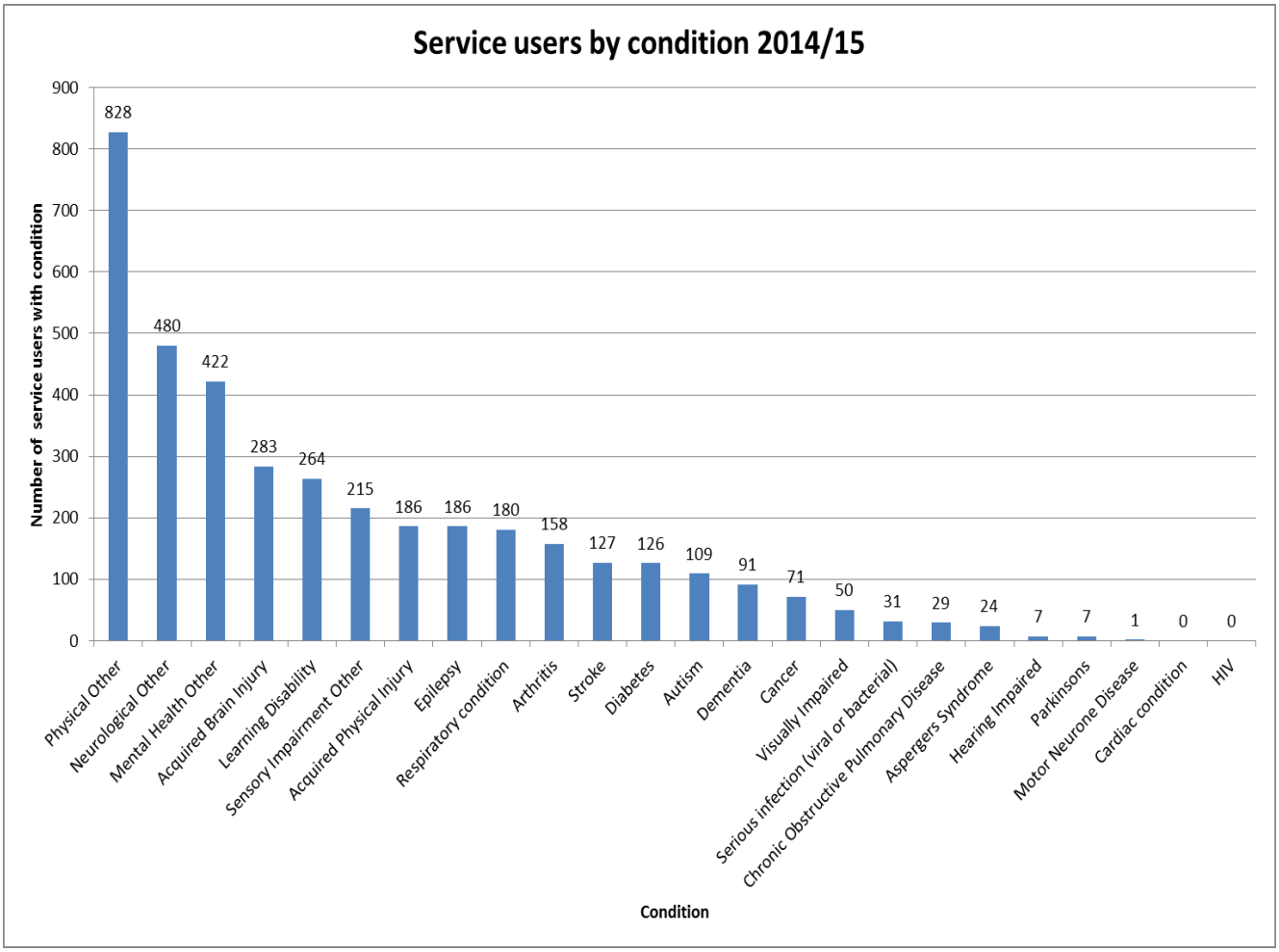
3.2.2 Gender

The overall gender split of the 2014/15 cohort was 52.4% male and 47.6% female. However, female representation increased as age increased so there were more females than males in the over 45 years category. Significantly, 70% of service users classed as physically disabled for the age range 18-24 years are male. This could be due to the higher prevalence of acquired impairment (for example through road traffic collisions and attempted suicide) for this age group in men.

3.2.3 Health Conditions and Needs of Service Users

The graph below highlights the health conditions recorded by social care staff for service users who were identified as having a ‘Physical Disability’. An individual can have multiple conditions recorded. Physical Other was the most common health condition recorded which may be due to the fact it has been recorded by social care staff who are not medically trained. It was selected for 828 individuals. The second highest recorded condition was ‘neurological other’. Significantly, when numbers of acquired physical or brain injury are added together this accounts for the third highest group of people accessing the service.

Figure 16: Prevalence of conditions of people accessing adult social care services, categorised as "physical disability".



3.2.4 Incidence of Multiple Conditions

The number of conditions recorded for each service user in 2014/15 ranged from 0 (i.e. none recorded) to 11. The largest group, 252 people, had 4 conditions. This accounted for 22% of the total. There were 227 service users with 3 conditions (19%) and 205 service users with 2 conditions (18%). Nearly a quarter, 285 service users, had 5 or more conditions (24%).

3.2.5 Overlap between the Top Six Health Conditions

The following matrix summarises the number of service users with one of the top six health conditions plus an additional condition.

Figure 17: Overlap of conditions for adult social care service users receiving support for a physical or sensory impairment

Overlap between conditions (number)	Physical Other	Neurological Other	Mental Health Other	Acquired Brain Injury	Learning Disability	Sensory Impairment Other
Physical Other	828					
Neurological Other	420	480				
Mental Health Other	333	179	422			
Acquired Brain Injury	242	121	124	283		
Learning Disability	172	85	81	26	264	
Sensory Impairment Other	188	126	86	82	47	215

This illustrates the difficulty in categorising people's need and the complexity of overlapping conditions.

3.3 Services Accessed

This section explores the support provided to assist the needs of people with a physical impairment accessing adult social care from ERIC records**.**

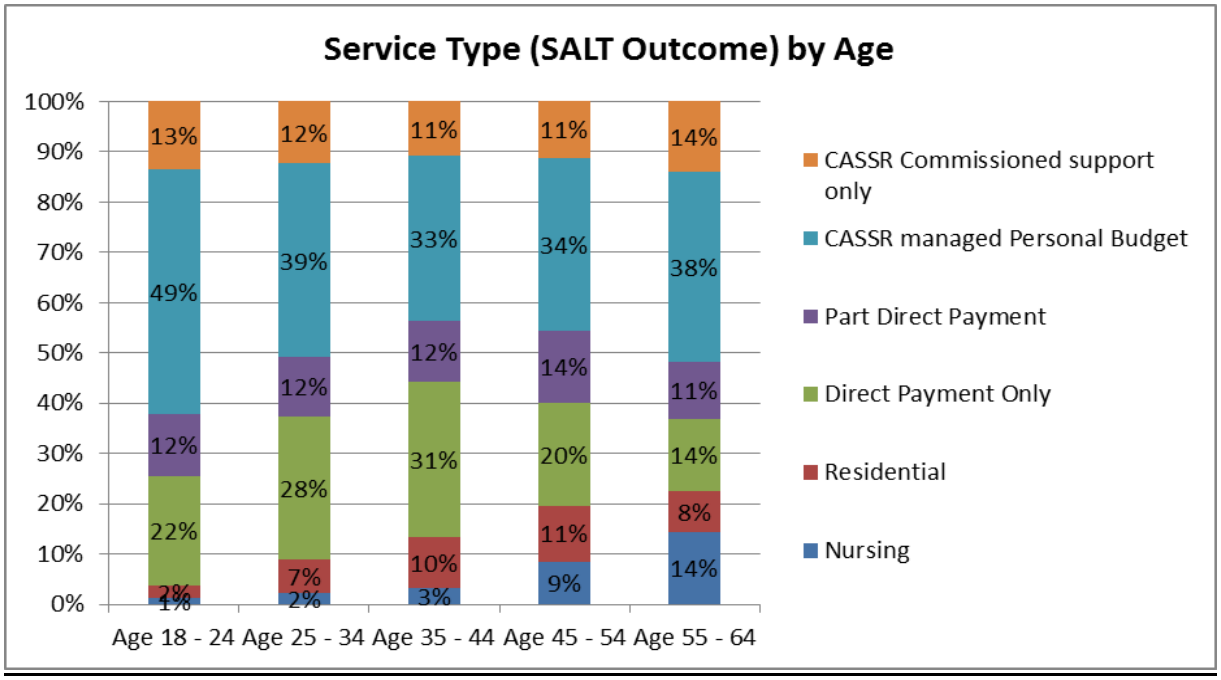
3.3.1 Service Type (Short and Long Term Outcome SALT)

All local authorities responsible for providing adult social care services are required to report to the Department of Health data regarding the support provided to service users. This data is recorded by Short and Long Term provision or 'SALT Outcome'. An analysis of this data is provided below to give a picture of the support that GCC funds for people with a physical impairment.

3.3.2 Access for Long-Term Support (12 months or more)

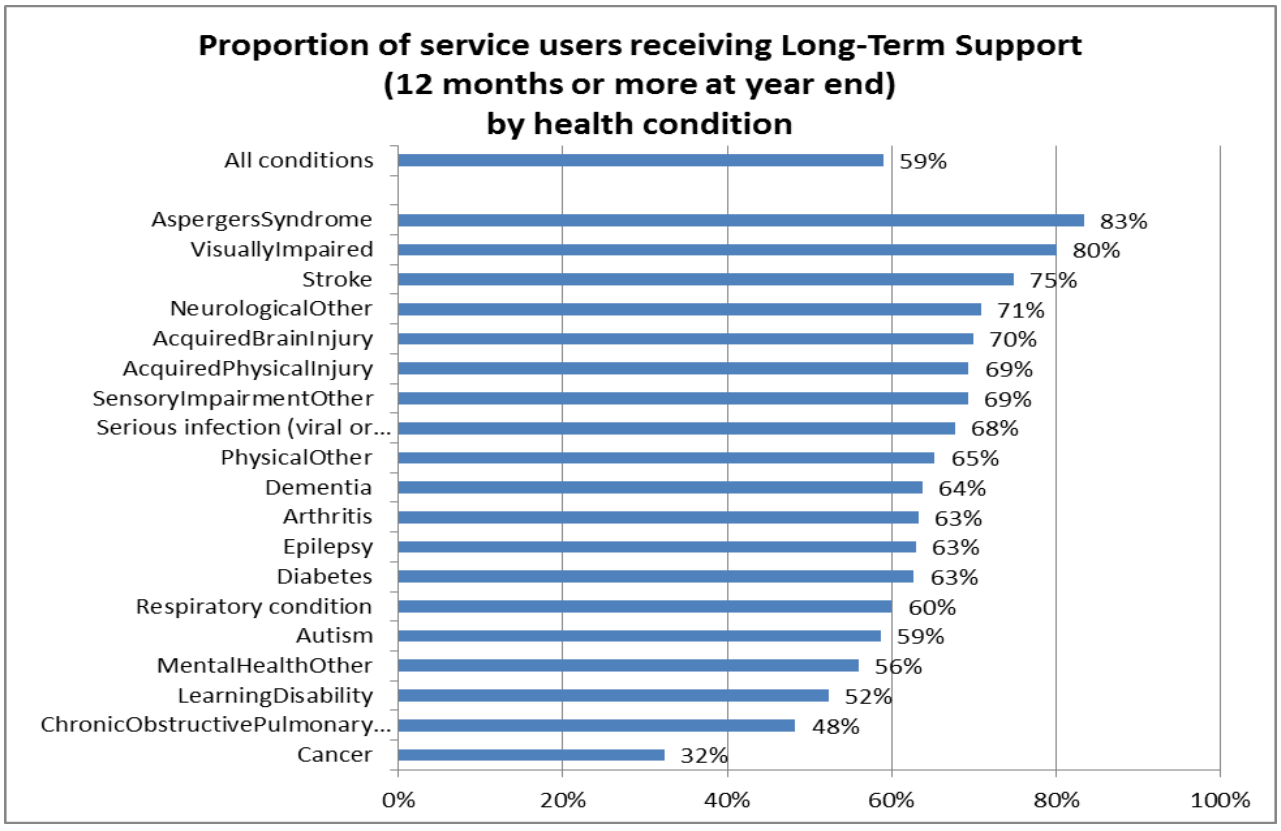
In 2014/15, 59% of service users had received support for 12 months or more (long-term) by the end of March 2015.

Figure 18: Highlights the percentage of people accessing service type by age.



The two graphs on this page show the highest proportions accessing long-term support were in the 25-44 age bracket and among those with 'Aspergers Syndrome' (83%), 'Visually Impaired' (80%), 'Stroke' (75%), 'Neurological Other' (71%) and 'Acquired Brain Injury' (70%).

Figure 19: The percentage of people accessing services for more than 12 months by condition

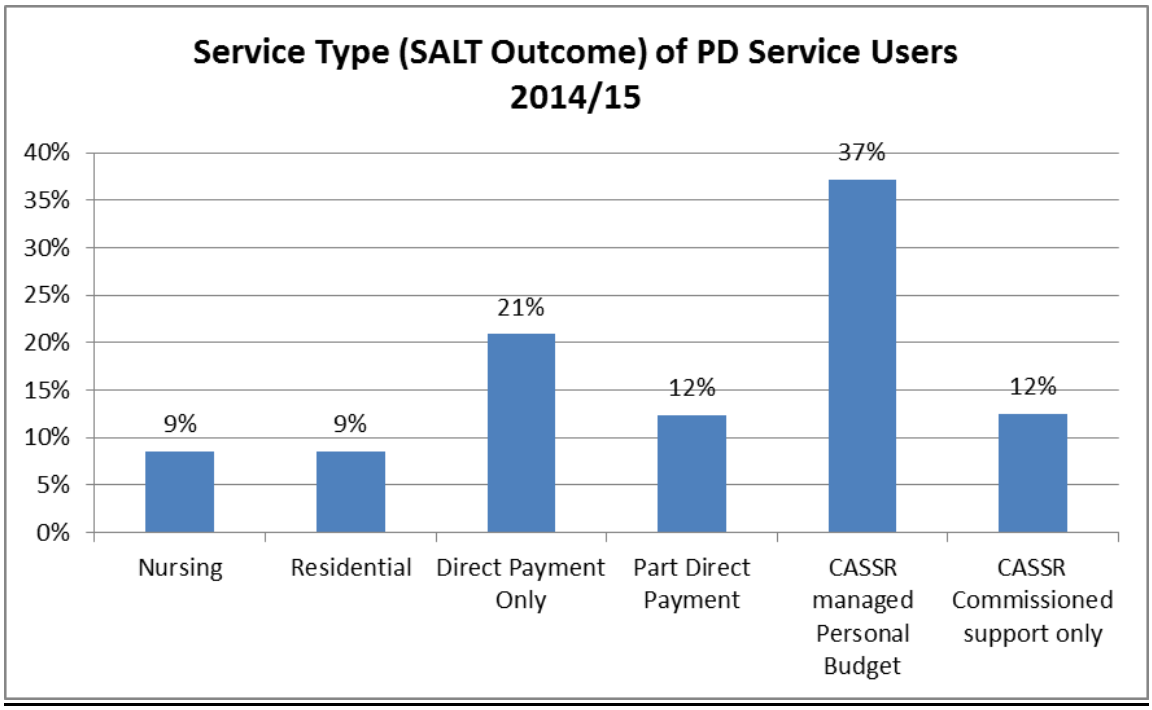


3.3.3 Personal Budgets and Direct Payments

A personal budget is money that is allocated by a local authority to pay for care or support to meet an individual's assessed need. That person can choose to take a personal budget as a direct payment or opt for the authority to arrange services on their behalf[19]. In 2014/15, 37% of those categorised as having a physical disability had a personal budget, 21% had a direct payment only and another 12% had a part direct payment, 18% received support in a care home.

Further analysis suggests that personal budgets were most prevalent among younger service users (49% of 18-24 year-olds) while direct payments were most common in the 35-44 age group (31%). There is a higher provision of direct payments amongst service users receiving support for a physical disability compared to those with a learning disability or requiring support for their mental health.

Figure 20: Highlights the percentage of demand for different types of services



3.3.4 Experience of Direct Payments of survey respondents

Only 12% of respondents to the survey were receiving a direct payment, of these there was an even spread across age ranges and gender. Most identified their impairment as moderate, severe or profound and as having multiple needs. 50% of these agreed or strongly agreed they could make a positive contribution in their lives.

60% agreed/strongly agreed they had access to good quality care and support – only 1 respondent strongly disagreed. Most were accessing a range of sources of support with family and friends most often identified.

[19] http://www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/Direct_payments/

Some use a direct payment to fund a personal assistant (PA). For those receiving support from a PA all highlighted their importance in promoting their independence.

'Having a young personal assistant to go out with him without parents'

'A PA that knows and understands him'.

However, less than half identified the use of a PA, citing difficulties with sourcing appropriate individuals.

'It is very hard to find reliable available personal assistants'

'It is not easy to find a PA to help. As a result family exhausted'

A number said having access to a PA would improve their independence –

'My independence could be improved if I had someone to help me to go out on long days out'.

Recommendation: Future commissioning activity should refocus on personalisation and ensure the support that is commissioned and delivered across health and social care is truly person-led.

3.4 Analysis of the 50 highest cost care packages with a Physical Disability

Analysis of the 50 highest costing care packages suggests there is no clear definition of what constitutes physical disability in categorising need. The majority of these service users do not appear to have a physical impairment as their primary need; they have complex needs which could include learning disability, mental health and/or autistic spectrum condition in addition to a physical impairment. It is difficult to tell whether or not the placement is due to the physical impairment or a range of other needs and issues.

The commissioning categories are inflexible and do not allow for fluctuations within the conditions experienced. It appears that for some the initial and primary condition was diagnosed in young adulthood as mental illness. However because they have a physical disability classifiable condition in addition, they have been or become categorised as 'Physical Disability'.

One of the packages that is high cost seems to be so because of the individual's age (younger than 65). The service user has had a stroke, and although is physically capable to undertake many of the usual activities of daily living, it appears he has a high cost placement in order to live with other people of a similar age.

Figure 21: Highlights the average cost of different types of care within the 50 highest cost cases

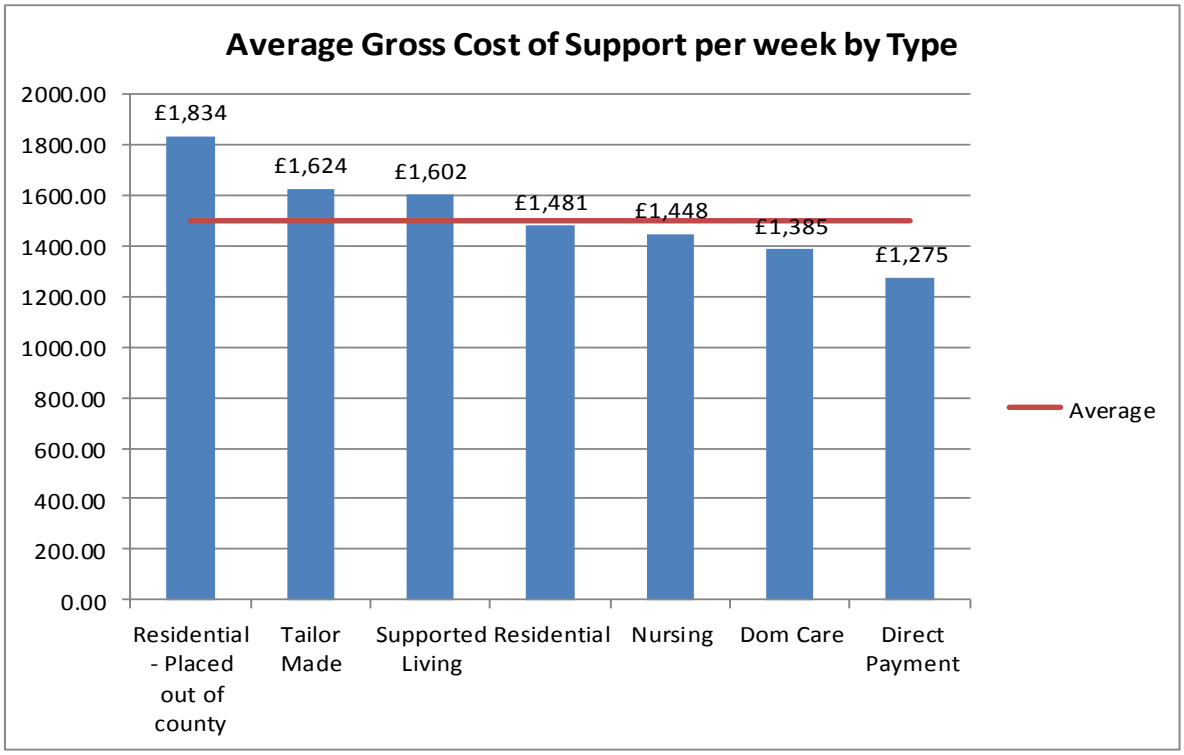
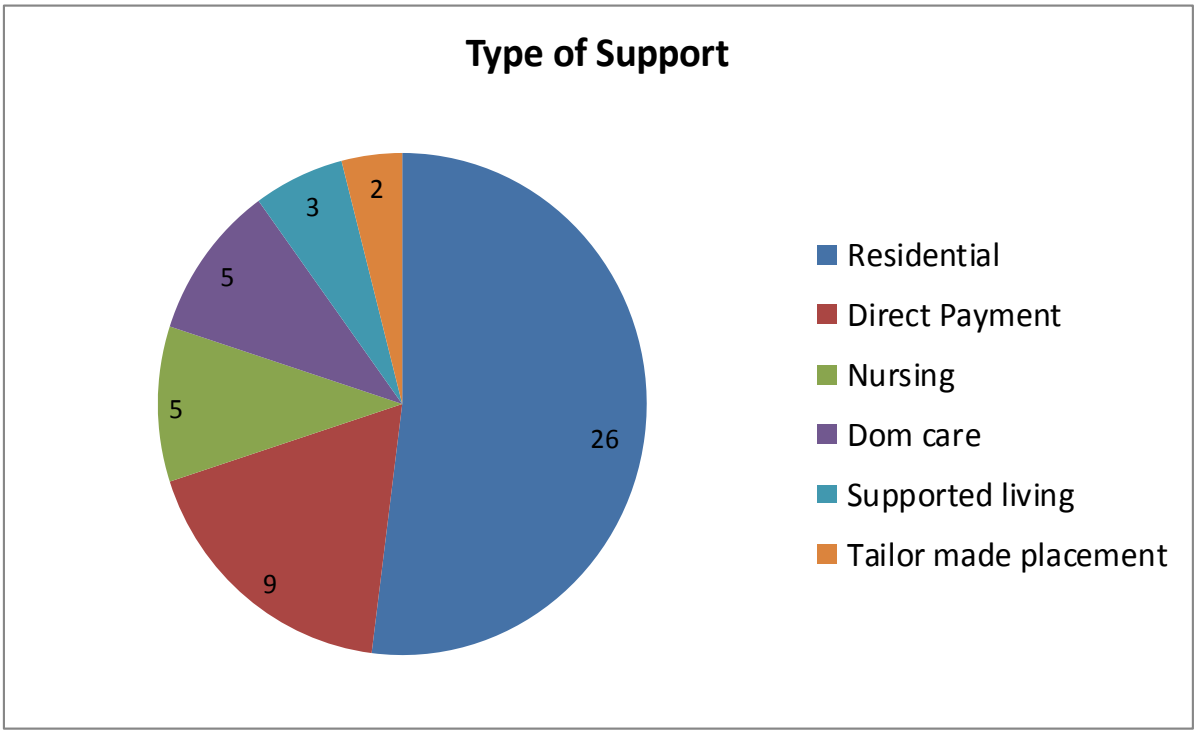


Figure 22: Highlights the breakdown of service usage of the 50 highest cost cases



3.4.1 High level trends

Trends identified through analysis of the 50 highest cost placements include:

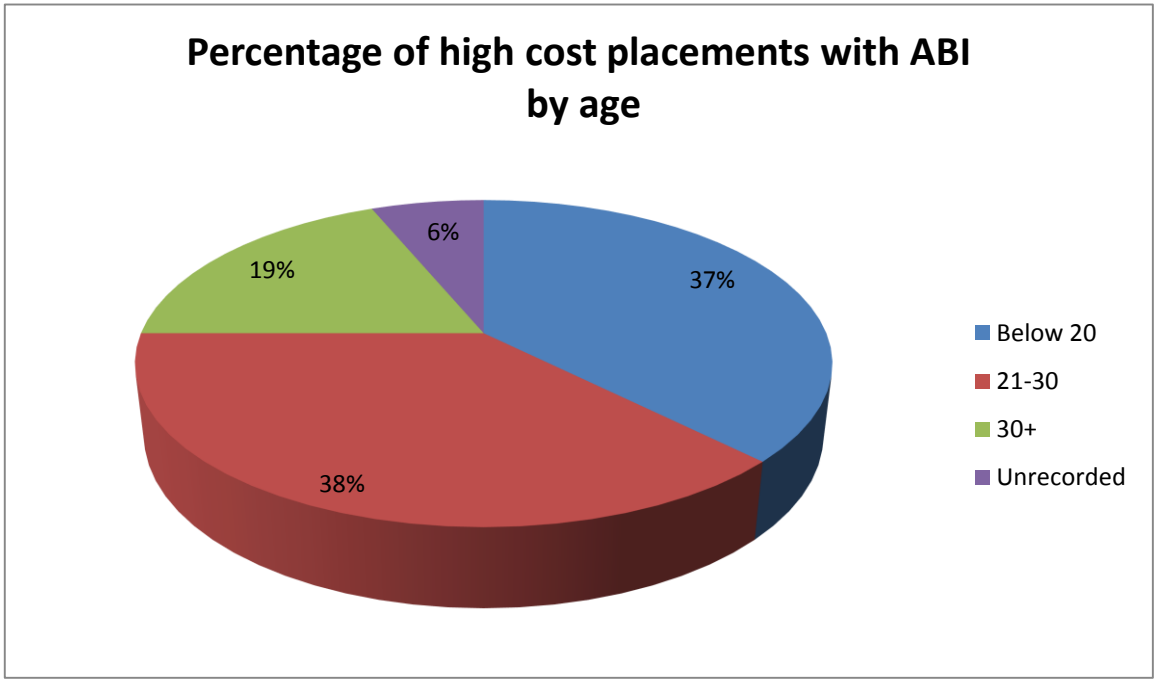
- 4 of the 5 individuals receiving highest cost packages have complex needs including Autistic Spectrum Condition (ASC), mental health and learning disability; many of whom were recorded to present with behaviours “that challenge”. Often these individuals are assessed as being able to physically perform activities of daily living; however they need to be prompted to do so to avoid self neglect. Occasionally the support appears to be a form of social policing to ensure socially acceptable behaviour.

- 5 of the 10 highest costing packages are for Gloucestershire residents placed out of county

- 32% of the top 50 placements are for people who have needs resulting from an acquired brain injury (through accident or suicide attempt). The highest cause of brain injury, resulting in physical impairment, is road traffic collisions followed by suicide attempts.

- The table below shows the age the individuals were when they acquired a brain injury (through accident/suicide)

Figure 23: Numbers of service users with acquired brain injury (ABI), by age who form part of the 50 highest cost care packages for people with physical disabilities



- Health conditions present at birth do not contribute to the highest costing care packages. 22% of people have needs due to impairments caused by Cerebral Palsy. These do not tend to make up the highest cost packages with the majority found at the lower end of those examined.

- 20% of high cost packages are recorded as having some form of ASC including Asperger's Condition.

- Only 8% have needs due to a developing condition in adulthood. All these service users are aged 49-55 years, 3 first accessed support aged 38-45 years and 1 first accessed support in their 20s.

- 4 of the 50 moved to the area for education purposes and settled here, 3 attended the National Star College and 1 attended Gloucestershire College.

- Supportive contact with family does not appear to be a factor in the extent of care required or associated cost, other than where individuals largely supported by family in their younger years progress through transition into adulthood and are then supported outside of the family unit to gain increased independence.

Recommendation: The evidence suggests we should develop an improved method to record a person's condition to reflect the complexity of their impairments and needs. We could develop a "complex needs category", joint funded across organisations supporting people with physical and/or sensory impairments, mental health and complex health needs

3.6 Carers

The number of unpaid carers in Gloucestershire has risen by 12% since 2001 and is expected to rise by another 12% to 70,000 by 2017[20] One in five people aged 50-64 are carers, the peak age for caring. 75% of service users with a physical and/or sensory impairment who have received GCC funded care for a year or more have a carer.

3.6.1 Older Carers

The number of carers over the age of 65 years is increasing more rapidly than the general carer population. Whilst nationally the total number of carers has risen by 11% since 2001, the number of older carers rose by 35%.[21]

[20] ONS 2011 Census
[21] The Carers Trust, 'Prepared to Care?', 2013

This is particularly the case for Gloucestershire, where 15,569 people over 65 years are carers, accounting for 25% of the caring population. This can be largely attributed to the higher than average concentrations of older and retired people in the county. At a district level Stroud is forecast to have the largest numerical increase of carers aged 65+ during the next few years (an increase of 324 carers) and the Forest of Dean is projected to expect the largest proportional increase (9.7%) of carers of this age group.[22]

3.6.2 Mutual Carers

The ageing population is also likely to lead to a substantial increase in the number of mutual carers, generally older partners looking after each other. The latest data from POPPI[23] projects an increase of these carers aged 65 years and over in the next four years.

3.6.3 Young Carers

2011 census data indicates there are over 1600 children and young people aged 17 and younger providing unpaid care in Gloucestershire. The caring role undertaken varies from a child helping parents to bathe a disabled brother or sister to being the sole support for a lone parent with a severe mental health or physical condition. Evidence suggests that young carers are more likely to have significantly lower levels of educational attainment than their peers and are more likely than the national average to be 'not in education, employment or training' (NEET) between the ages of 16 and 19[24].

3.6.4 Carers with Impairment

Many carers report that caring results in a negative and often lasting impact on their physical and mental health, but as with the rest of the population, many people with existing impairments or long-term conditions also take on caring responsibilities. Contributions from carers with impairments to Carers UK's Caring and Family Finances Inquiry[25] indicated that they are significantly more likely to give up work to care (61% compared to 52%) and were much less likely to be in paid work alongside caring. Many working age carers with impairment were caring for partners. Carers UK also report that because many working age carers were caring for partners they were also substantially more likely to be on lower incomes or have no-one in their household in paid work – 74% of carers receiving Disability Living Allowance were in this situation, compared to 55% of all working age carers.

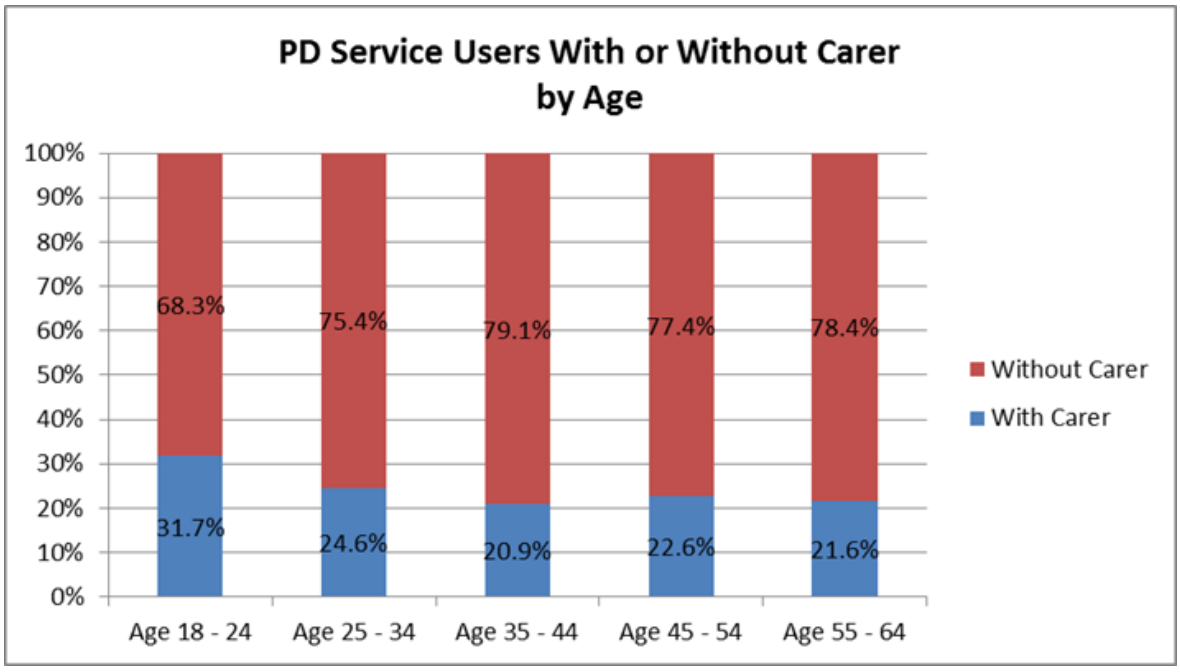
3.6.5 Working Age Service Users with a Carer

[22] Understanding Gloucestershire, JSNA, 2015
[23] Projecting Older People Population Information system
[24] The Children's Society, Hidden from View, 2013
[25] Carers UK (2014) Caring & Family Finances Inquiry UK Report

Data from the ERIC highlights that in 2014/15, 268 physically disabled service users had a carer providing support, representing 22.9% of the cohort in the same year. The proportion increased to 75% among those who had a long-term need (i.e. had accessed services for more than 12 months).

Data also seems to suggest that the likelihood of having a carer decreased by age, with 31.7% of the 18-24 year old age group having a carer, compared to 21.6% among the 55-64 year-olds.

Figure 24: Highlights the number of service users by age with a carer



3.6.6 Support for Carers

In response to identified and increasing carer population GCC and GCCG jointly commission the following carer support services[26], which are designed to be all-age and all impairment/health condition support on a countywide basis.

- Carers Breaks
- Carers Emergency Scheme
- Carers Assessment and Support Planning (Including Carers Flexible Budgets)
- Information, Advice & Guidance
- Emotional Support
- Positive Caring Programme
- Carers Voice

[26] http://www.gloucestershireccg.nhs.uk/your-health/carers-2/

These ensure consistency across the county and replace a previous wide range of contracts with a variety of organisations which provided support to specific groups of carers.

Carers are able to access information and advice via a helpline and face-to-face and where eligible receive an assessment of their needs which leads to a personalised response through support planning, enabling them to manage their caring role. In addition to compliance with statutory duties of assessment there is also a particular emphasis on preventative support through provision of breaks for carers, emotional support and the Positive Caring Programme, a learning and development service up-skilling and supporting groups of carers. These interventions are successful in promoting resilience and positively maintaining stability within caring situations.

A number of third sector organisations, both national and local, carer and condition specific also actively operate independently across the county.

Recommendation: We need to continue to effectively support carers of all ages including young carers.

3.7 Access to council low level support by service users

In line with the national trend, and our own commissioning intentions to keep people independent for as long as possible, GCC is increasingly investing in preventative support including through the use of assistive technology for all those accessing adult social care.

3.7.1 Telecare (GCC assistive technology service):

The percentage of people with a physical/sensory impairment currently accessing telecare is low, at 2%. People with chronic obstructive pulmonary disease, dementia and cancer, however, are three times as likely to have been provided with a telecare service.

3.7.2 Car Badge:

Within the county 28,561 Blue Badges are currently issued. Of the 1,169 people categorised as receiving care for a physical or sensory need, 161 had a car badge issued, representing 14% of the cohort. Older age groups (45 years plus) were more likely to have a badge compared to younger age groups. People with chronic obstructive pulmonary disease (COPD) (31%) and cancer (27%) were also most likely to be issued with a car badge.

3.7.3 Hard of Hearing Assessment Service

The Hard of Hearing Assessment Service is commissioned to provide people with hearing impairment assistive equipment such as flashing fire alarms, door bells and

technology for them to hear the telephone and television. 1,092 people aged 18+ received an assessment for the year 2015/16. 84% were aged over 65 years old.

Recommendation: There are further opportunities to explore and promote preventative interventions such as assistive technology to increase numbers of people with a physical and/ or sensory impairment living in more independent settings. This will include exploring new and emerging technologies.

3.8 Children and Young People's Service

The aim of the Disabled Children and Young People's Service is to assess the needs of children and young people with impairment and ensure they have access to services to meet these needs. Eligibility criteria are used to assess a child or young person's need in order to provide them with additional support. Families may be offered a personal budget to meet these needs.

A child or young person with a home address in Gloucestershire is eligible for support if they

- have a substantial and permanent disability[27], and
- appear to have needs arising from his/her disability that can only be met by accessing specialist support, or there is a need for additional funding to enable short breaks to take place, and/or
- meet the criteria for assessment for a personal budget within adult services

In July 2014 there were 433 children and young people receiving support from the Disabled Children and Young People's Service.

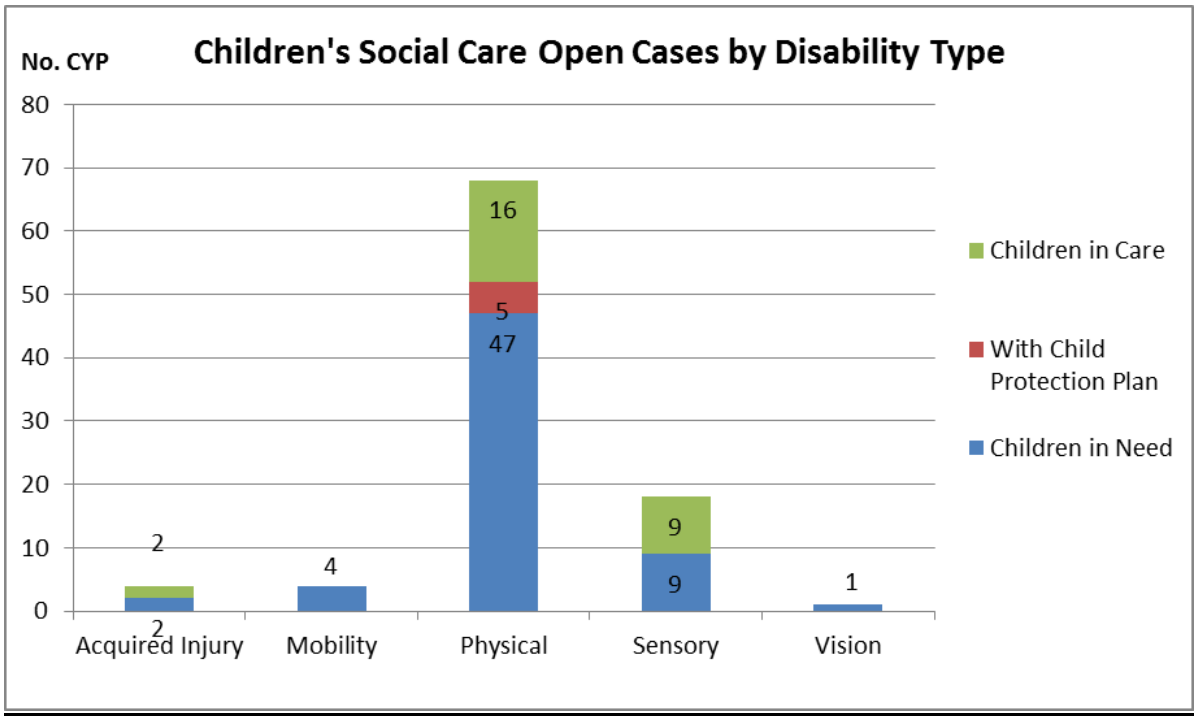
The people accessing the service have a wide range of conditions, with nearly 60 different primary conditions and 168 different combinations. Around 200 have more than one condition, representing 45.5% of all service users. .

3.8.1 Children and Young People with a physical impairment and social care need

The graph below illustrates the breakdown of impairment type of children on GCC's children's social care database as at 31st January 2016 and where their disability was recorded. Physical impairment is the most common condition across children in different care categories, followed by sensory impairment. Some children may have more than one impairment. It is also important to note that the child's impairment may not be the reason for requiring social care

[27] Substantial and permanent disability for the purpose of eligibility is defined as being a severe learning disability, a severe physical disability, a severe sensory disability, complex and severe health needs, or Autism/Asperger

Figure 25: Illustrates a breakdown of the cases open to children's social care services by disability type.



Non-statutory support

Gloucestershire has invested in targeted, early and low level support through the use of 'graduated pathways' in schools. This is to give children and young people with impairments the support they need when they do not meet the threshold for statutory intervention (e.g. through social services intervention for their care needs or through an Education, Health and Care Plan (EHCP) in school). GCC has also increased its offer of information and advice. The Children and Families Act 2014 requires every Local Authority to publish a Local Offer for Special Educational Needs and Disabilities (SEND). This provides information about provision across education, health, social care, private, voluntary and community sectors with the purpose of providing clear, comprehensive, accessible and up-to-date information about available services and how to access them.

Please see GCC Children and young people (0-24 years) with Special Educational Needs and Disabilities (SEND) - Needs Analysis 2014 for further detail.

3.8.2 Transition from Children's Services to Adult Social Care

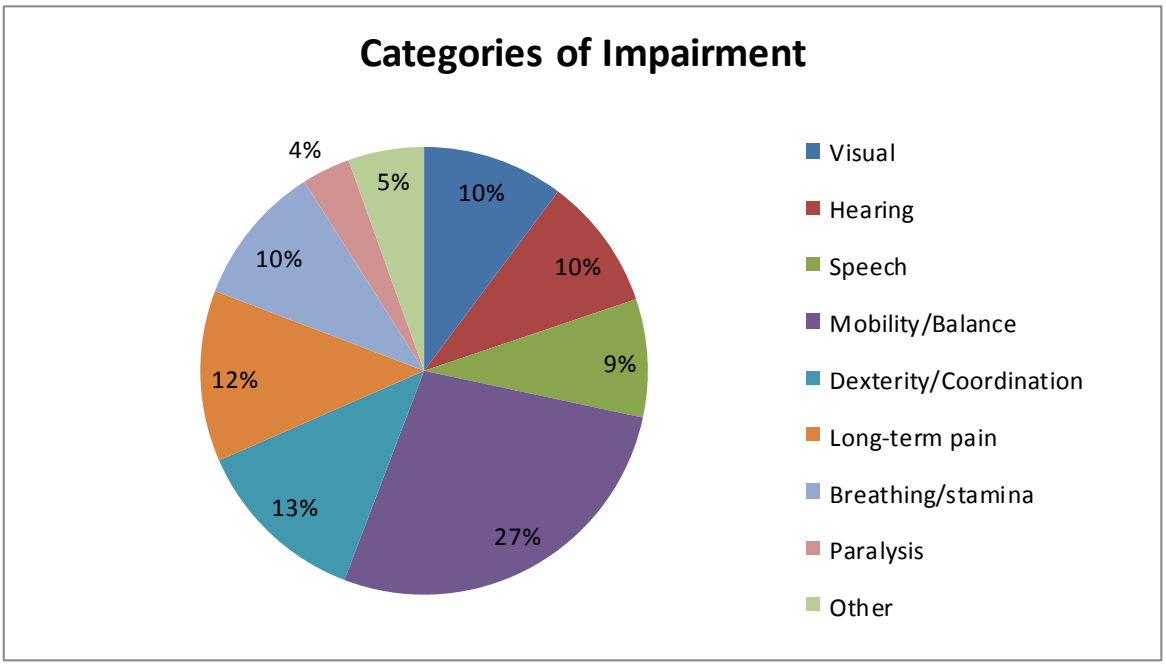
In 2014/15 116 people were identified as in "transition" by GCC's Adult Social Care Services. This represents slightly fewer than 10% of the total number. The highest proportion was in the 18-34 year old age bracket; the most predominant conditions were Asperger's Syndrome, Learning Disability or Autism.

4. EXPERIENCES OF PEOPLE LIVING IN GLOUCESTERSHIRE WITH A PHYSICAL OR SENSORY IMPAIRMENT

During March to May 2016 we surveyed 279 people living in Gloucestershire with a physical or sensory impairment and met with 140 people at 15 focus groups. The survey was co-produced with a number of people with varying physical and sensory impairments.

It was open to all people who self identified as having a physical or sensory impairment, not just GCC service users. People categorised their impairment and indicated the underlying cause or condition. They were able to select multiple categories and reported a variety of different types of impairments. The most prevalent category was mobility/balance and almost 20% had a sensory impairment.

Figure 26: Depicts the percentage of survey respondents from the different categories of impairment.

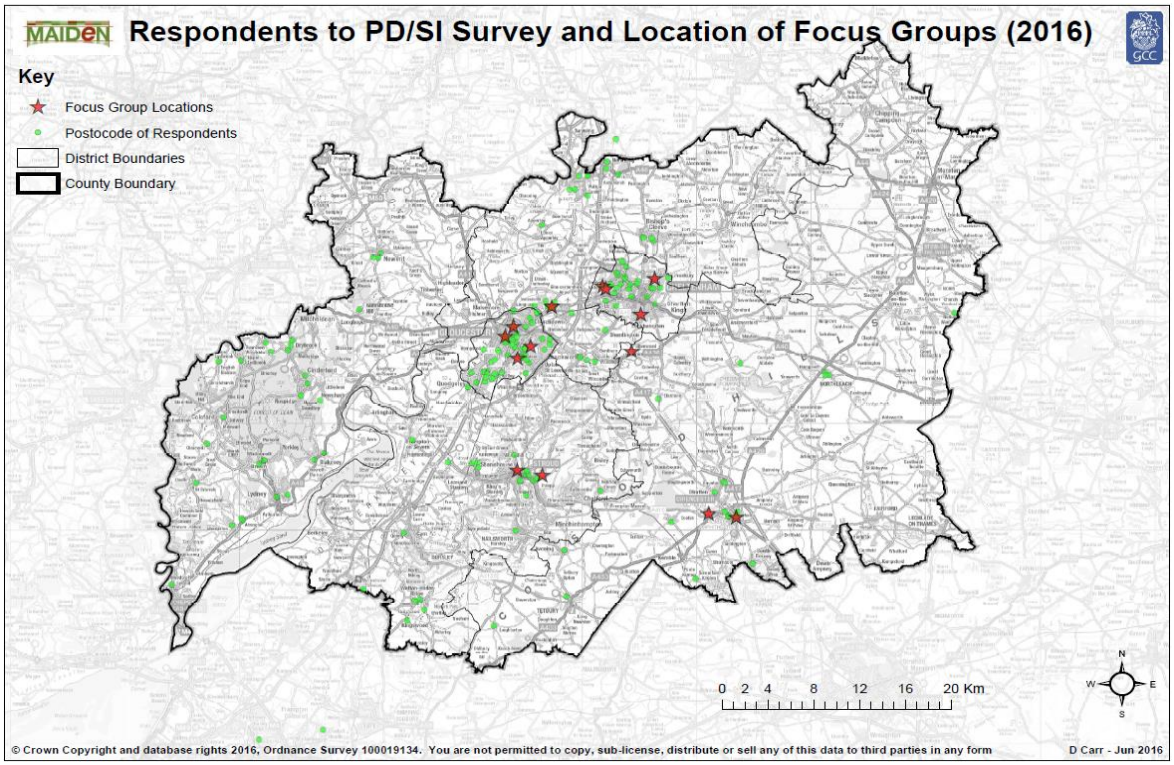


The most prevalent underlying cause was a long term health condition, followed by visual impairment and chronic pain. Neurological/neuromuscular and hearing conditions were the joint fourth highest[28].

Respondents were therefore, drawn from a broad range of the target population, the large majority of whom identified their impairment or disability to be moderate or severe.

[28] Accuracy is likely to be affected by individual conditions fitting into several categories

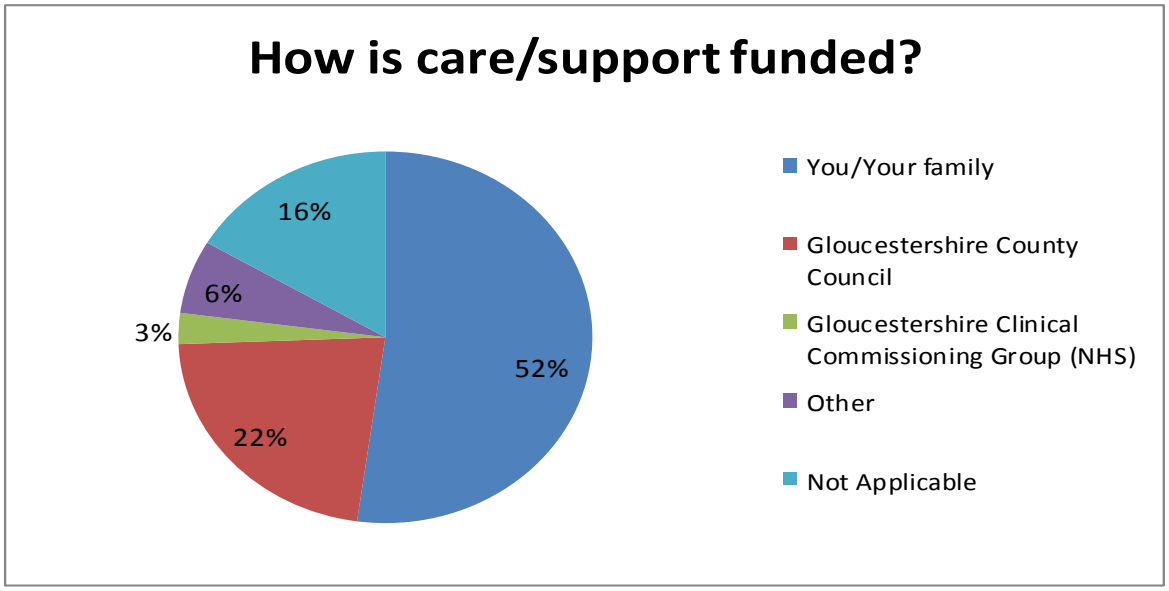
Figure 27: Depicts the geographical spread of responses to the survey



4.1 Experience of care and support received by survey respondents

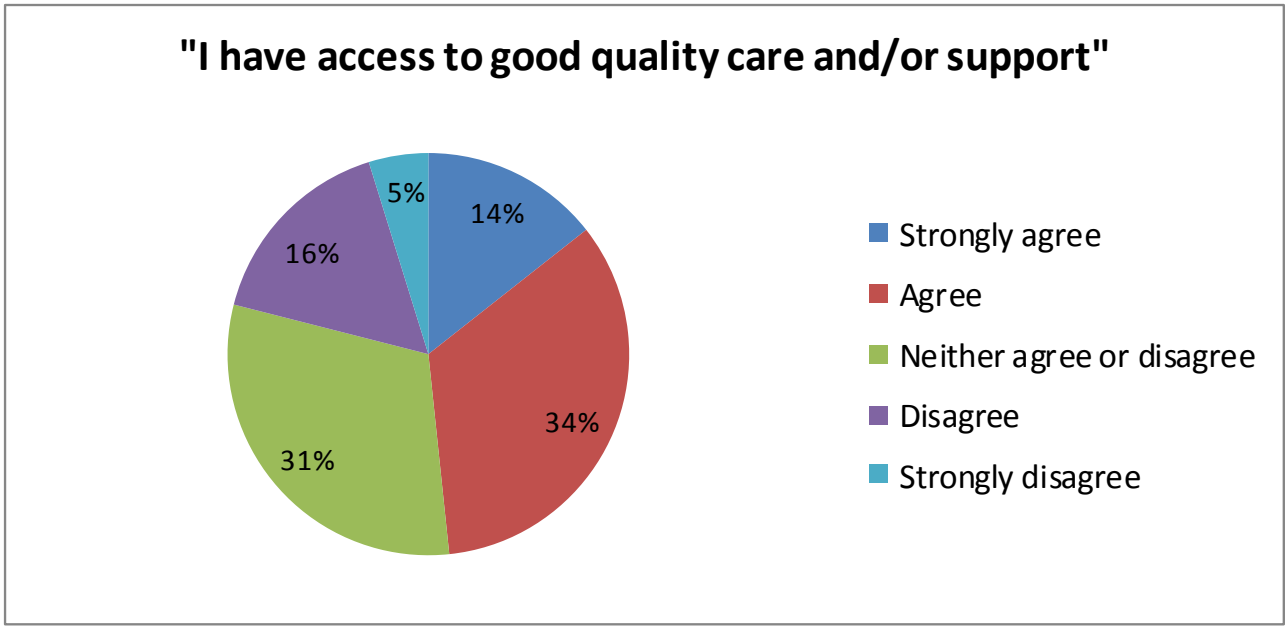
The survey included questions to help us understand people's views regarding the care and wider support they receive. 52% reported they or their family fund their care demonstrating that a majority of this sample do not receive public funding for their support despite their self-classification of impairment as moderate or severe.

Figure 28: Highlights how the care received by survey respondents is funded.



48% reported that they had good access to quality care and support, whilst 21% disagreed.

Figure 29: Depicts respondents' views regarding the quality of care and support received.



Respondents accessed a range of provision and generalisations cannot be made from the size of the sample across each. However the comments do suggest a very mixed picture of the experience of care and support services received at all ages.

The support from family and friends was cited most consistently in providing high quality care,

> *'Only because the care comes from my husband'*
>
> *'Care from family member unpaid is good but more care/help/assistance would help'.*

Some were concerned about the impact of caring on their carers and dependency on them,

> *'I receive good quality care from members of my family however this is often too much which actually makes me more and more dependent on them'.*

A number expressed dissatisfaction with the amount of available support, lack of continuity of care in terms of care practitioner, punctuality from domiciliary/home care and the waiting time for different assessments,

'We have MS nurse in Gloucestershire. I would like to see more of them and quicker accessibility / response which can only come with additional staffing'

'There are insufficient community rehabilitation services for people with spinal injuries …12 months down the line I'm still awaiting assessment at a spinal injuries unit'.

Others expressed dissatisfaction with the support received,

'Was advised during a care assessment for my husband, in the social workers own words, that it doesn't matter if he cannot wash his back or legs as he doesn't really get dirty, this was their reason for our not meeting the criteria'.

Some respondents felt the support was not appropriate to their needs:

'he is depressed about living in supported living with no one like him in the house , the others have completely different disabilities and can't communicate with him. We cannot access any psychological help for him as he has the 'wrong type of head injury!'.

Others provided very positive feedback about some third sector services such as Headway, Forest Sensory Services, Gloucestershire Deaf Association and other local services.

'I get support from the Community Centre I attend regularly. I have also received equipment to assist with my hearing impairment: telephone amplifier, doorbell announcer and wireless fire alarm system'

'I have had good support from local services for mobility aids and rails within the home'.

This range of personal experiences was borne out by the focus group discussions, with a high value consistently placed on support received from family and friends. Some clearly considered that they were fully involved in their care and support and their experiences were really positive. For others there was an impression that practitioners did not understand their specific and particular needs.

Therefore the standard of care and support received by people varied considerably and according to individual circumstance, illustrating a lack of consistent quality of experience.

A common theme across age and services from children to older people was the lack of available information and advice from practitioners regarding the range of support and opportunities provided within local communities, alongside a high value placed on attending peer support groups. Where people were directed to an organisation, for many, they frustratingly experienced being signposted from one agency to another.

The perceptions of respondents from the survey and focus groups regarding the quality of care and support received largely correlated with the extent of involvement in the planning of their care and the choice and control they experienced in their life;

thereby reinforcing the need for a personalised approach to planning and delivering support.

Feedback was also received that practitioners carrying out assessments, in both health and social care, tend to ask a person (child or adult) to repeat their life or condition history. This left people feeling frustrated and out of control in planning their support.

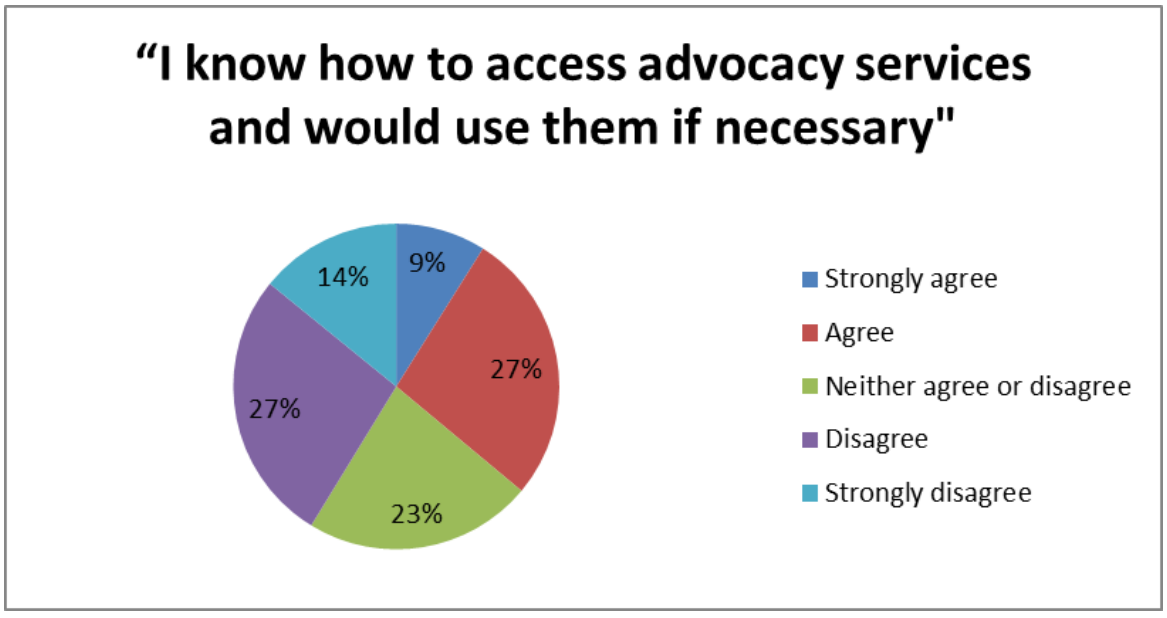
Recommendation: There is a need to improve information sharing within, and between, provider organisations, specifically health and social care practitioners, so a person only needs to tell their story once.

4.2 Advocacy, Information and Advice

An advocate is an independent individual who can help the wishes and views of someone to be heard. This might include accessing information or accompanying him / her to meetings or interviews, in a supportive role. Some advocates can also make decisions regarding your care in your 'best interest' if you do not have the capacity to make the decision yourself. GCC commissions a number of organisations to provide advocacy services to residents of Gloucestershire. GCC also funds 'community connectors', paid staff and volunteers in a local area who can signpost people to sources of support and information and enable them to access community resources. A review of these services is currently underway to improve delivery for the future.

Respondents to the survey were asked about their knowledge of advocacy services. There were a range of themed responses to the question.

Figure 30: Illustrates survey respondents' knowledge of advocacy services.



Many statements were received illustrating a lack of knowledge of formal advocacy services,

> *'I do not know how to access this service - if I did know how to I would use them'*
>
> *'My son would not be able to contact advocacy services on his own to use them. I don't even know what advocacy services would be available to him'*

Others expressed a tendency to use a range of support organisations and/or family and informal networks,

> *'I have an effective and eloquent friend'*
>
> *'I have to speak on my sons behalf'*
>
> *'Not heard of 'advocacy' unless referring to support agencies such as Headway'.*

It is not clear whether these statements relate to formal advocacy or informal advice. Only one comment was received about a formal commissioned advocacy service. In the main the comments received illustrate that the concept of advocacy and knowledge of formal, independent advocacy services are not familiar to many from this group of people. In addition, for some, signposting results in being passed on from one agency to another with little material outcome or benefit.

> *'I'm not sure what that means. I have been to Village Agents, CAB, Shelter, Green Square, Glos Law Centre & others about housing but only Shelter had any advice, the others just passed me on to another advice line because they didn't have experience of the situation I am in'.*

Recommendation: Frontline practitioners must be better informed about the local community opportunities providing low level support, and specifically advocacy services, in line with the requirements of the Care Act 2014.

Recommendation: GCC commissioned information and advice services should be more broadly promoted, for example through GPs, to reach those who are not in receipt of GCC services

4.3 Equipment

The majority of people responding to the survey agreed or strongly agreed that the equipment they use is effective in maintaining independence and wellbeing.

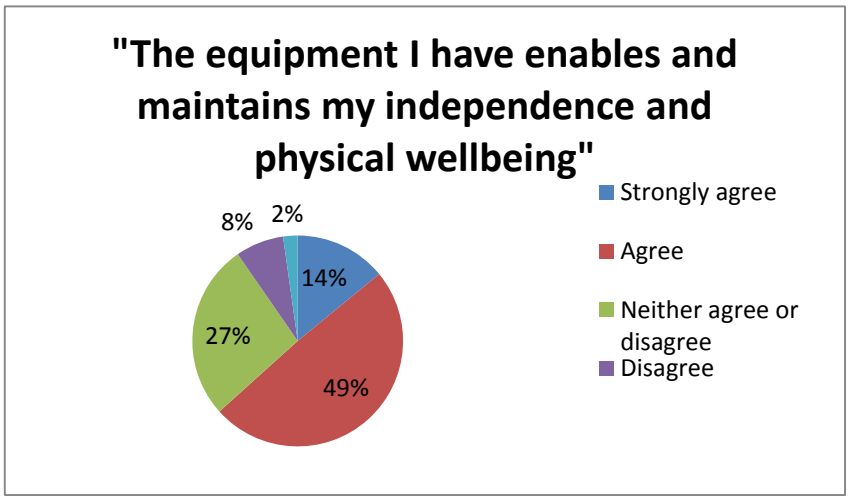
Some comments really illustrate the importance of their equipment in reducing dependency on support services.

'Powered wheelchair is absolute lifeline. Without it would need carer/PA support'

'We have been well provided with excellent equipment and support'

'Stair lift and bathroom adaptations have been essential, could not cope without them. I am getting new wheelchair in next few weeks as I can no longer use self-propelling one. Used to have mobility scooter but cannot now walk as far as garage (40-100 yards) to get at it and it was too big too get it in and out of mid- terraced house. Air conditioner helps a lot and I could not do without it'.

Figure 31: Illustrates survey respondents' views regarding the equipment they use.



For others additional or different equipment would make a difference to their quality of life.

'Wheelchair options limited - don't cater for inside and outside needs - used to like walks in countryside but off-road 3 wheelers too expensive'

'.... lacks some of the equipment which will enable her to be more independent & less frustrated with herself. We are constantly fighting for more help to increase her independence'.

For some, equipment which identifies their impairment was perceived to be beneficial – for others, not.

'One of the most useful things I have is the white stick I have from social services as it flags up to people I have an impairment and this makes them more helpful. Also helpful crossing the road'

'I have a walker but am too embarrassed to use it'.

These opinions were largely reinforced by the focus group discussions. Those that were most vocal were people who had significant mobility needs and made use of a range of equipment. Most people were satisfied with their current equipment whether that was through funded means or self-funded and were positive about response times for provision and repair.

Equipment and technology were given as examples of how independence was maintained; "*through the use of a power wheelchair, mobility scooter or Motability vehicle – 'My car. This is an adapted Motability vehicle which carries my electric wheelchair'*.

Additional equipment and assistive technology would help a number of those who attended our focus groups. Voice activated technology was suggested as a useful option by members of a young focus group. Some who attended our focus groups already used the swipe and type functions on their mobile phones and iPads to communicate. This reinforces the recommendation in Section 3 to further explore new and emerging technologies to increase the uptake of assistive technology in the interests of prevention and promotion of independence.

5. HEALTH

This section considers risk factors which may result in impairment and summarises survey and focus group responses to questions about their health.

5.1 Health conditions which may result in impairment

There are a range of different risk factors which could contribute to a person developing a physical or sensory impairment over their life time. In Gloucestershire, the general diagnosis rate for conditions or risk factors which can lead to impairment is below the national average. These risk factors are discussed in further detail below. Some of these can affect people at any age, however for a chronological approach; they are described under the life period when there is a higher risk or when conditions are most prevalent. It is not an exhaustive list.

5.1.1 Pre birth and Congenital impairment

Prior to or during birth a congenital anomaly can leave a child with long term impairment. These are medical conditions that can be developed during the foetal stage of development or because of genetic reasons. Although approximately 50% of all congenital anomalies cannot be linked to a specific cause, some factors are known to increase risk of anomalies. These include advanced maternal age, genetic mutations, maternal infections, maternal nutritional deficiency and maternal exposure to harmful substance (in particular tobacco, alcohol and drug use) during pregnancy. Some of these factors can lead to premature labour and low birth weight having detrimental effects on the growth and development of a baby.

- **Smoking during pregnancy.** In Gloucestershire, the number of women who smoked at delivery fell, from 987 to 726, between 2010/11 and 2014/15. The percentage of women who smoke at time of delivery in Gloucestershire also fell, and was similar to that of England in the latest year.

- **Alcohol and drug use during pregnancy.** There is no locally available data on the prevalence, however the NHS estimated that around 1% of pregnant women consume alcohol regularly and that around 1 in every 5,000 births may be affected by Foetal Alcohol Syndrome. The number of births in Gloucestershire averaged around 6,500 per annum, so the number of babies affected by alcohol could be around 1 each year.

- **Low birth weight** increases the risk of childhood mortality and developmental problems for the child. In Gloucestershire, numbers of babies with low birth weight saw a rise in the past 10 years, from 146 to 177 between 2005 and 2014. By 2014, Gloucestershire had the same percentage of live births with low birth weight as England.

- **Premature live births** are births with gestational age of less than 37 weeks. There is substantial evidence that smoking during pregnancy and exposure to second-hand-smoke can lead to premature birth[29]. Premature babies have a high risk of disabilities. During the period 2010-12, there were a total of 1,431 premature births in Gloucestershire, and the rate of premature births was lower than that in England.

Several national studies examining the trend of babies with congenital anomalies who are subsequently identified as having disabilities suggest that the expansion of and improvements in antenatal screening have offset an increase in congenital anomalies resulting from rising maternal age over recent decades. At the same time, however, increasing survival rate of preterm infants has been a contributing factor to the rise in childhood impairment.

5.1.2 Childhood

For those under 16, according to DLA data, neurological diseases make up the highest recorded condition for claimants and again can be linked to problems in gestation or complications during child birth. Diabetes affects people of all ages including children, and in worst cases lead to a loss of limbs. The condition is increasing at a gradual rate in Gloucestershire and is linked to being overweight or obese. Obesity is a risk factor in itself for ill-health and impairment. The numbers of obese 4-5 year olds in Gloucestershire has been higher than the England average since 2009/10. For 10-11 year-olds, the numbers classified as obese or over-weight has fluctuated but the overall trend was upward since 2008/09. The percentage of obese or overweight 10-11 year-olds, however, was lower than the England average in 2014/15. Studies tracking child obesity into adulthood found that the probability of overweight and obese children becoming overweight or obese adults increases with age.[30,31,32]

GCC is currently prioritising the promotion of healthy lifestyle choices through a range of commissioning projects.

5.1.3 Early Adulthood

People can acquire impairments at any age from accidents, illness or poor working conditions as well as attempted suicide. However there are certain factors putting young adults at higher risk that other age groups.

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[29] http://bmaopac.hosted.exlibrisgroup.com/exlibris/aleph/a21_1/apache_media/GR3GIR2QERK3

[30] Guo SS, Chumlea WC. Tracking of body mass index in children in relation to overweight in adulthood. The American Journal of Clinical Nutrition 1999;70(suppl): 145S-8S.

[31] Serdula MK, Ivery D, Coates RJ, Freedman DS, Williamson DF, Byers T. Do obese children become obese adults? A review of the literature. Preventative Medicine 1993;22:167-77.

[32] Starc G, Strel J. Tracking excess weight and obesity from childhood to young adulthood: a 12-year prospective cohort study in Slovenia. Public Health Nutrition 2011;14:49-55.

Road traffic collisions are a major cause of morbidity. For children and for men aged 20-64 years particularly, mortality rates are higher in lower socioeconomic groups. The trend of serious injuries or deaths from road traffic collisions has been fairly static since 2009. In the period 2012-14, 692 people in Gloucestershire were seriously injured or killed in a road traffic collision. This number represents 38.1 per 100,000 population in Gloucestershire, lower than the rate in England (39.3 per 100,000 population).

A number of GCC's highest cost care packages for adults with complex needs are a result of injuries sustained in road traffic collisions. Social care data suggests there is a peak in those with care needs as a result of a road traffic collision or attempted suicide in the age group from late teens to late 20s – the majority of which are young men. Data regarding the number of attempted suicides which result in physical impairment is not recorded.

5.1.4 Adulthood

Conditions such as cancer or coronary heart disease which can lead to physical impairment affect people of all ages however risk increases in later adulthood. Steep increases in cancer rates in Gloucestershire are in line with the national average and rates of heart disease are relatively stable. In Gloucestershire, the number of people recorded with diabetes increased from 28,502 to 31,547 in the 5 years to 2014/15, and the percentage of people recorded with diabetes was lower than England. People with diabetes have excess risk of a range of complications, e.g. cardiovascular, kidney, foot and eye diseases, which can result in considerable morbidity. Obesity in children can lead to impairment in adulthood. In Gloucestershire, the data available refers to the period 2012-14 when 23.5% of adults in were classified as obese, similar to the rate for England.

Arthritis is the most prevalent condition recorded by DLA data and can affect people of any age, however more often starting when a person is 40-50 years old. Numbers diagnosed with the condition in Gloucestershire are relatively stable year on year. neurological diseases make up a large proportion of DLA claimants In Gloucestershire. This includes multiple sclerosis diagnosed aged 20-40 on average and the motor neurone disease with highest incidence occurring between the ages of 50 and 70. As people age, their risk of stroke increases, leaving some with paralysis, mobility difficulties or high levels of pain. Anecdotal evidence from the Stroke Association in Gloucestershire suggests they are seeing higher levels of younger adults who have suffered stroke. Levels of stroke have been increasing in Gloucestershire since 2009 and this is slightly above the England average.

5.1.5 Older age

Conditions such as osteoporosis become more prevalent into older age causing brittleness of bones. Prevalence of the condition is falling in Gloucestershire in line with the rest of England. Further analysis of impairment in older age is beyond the

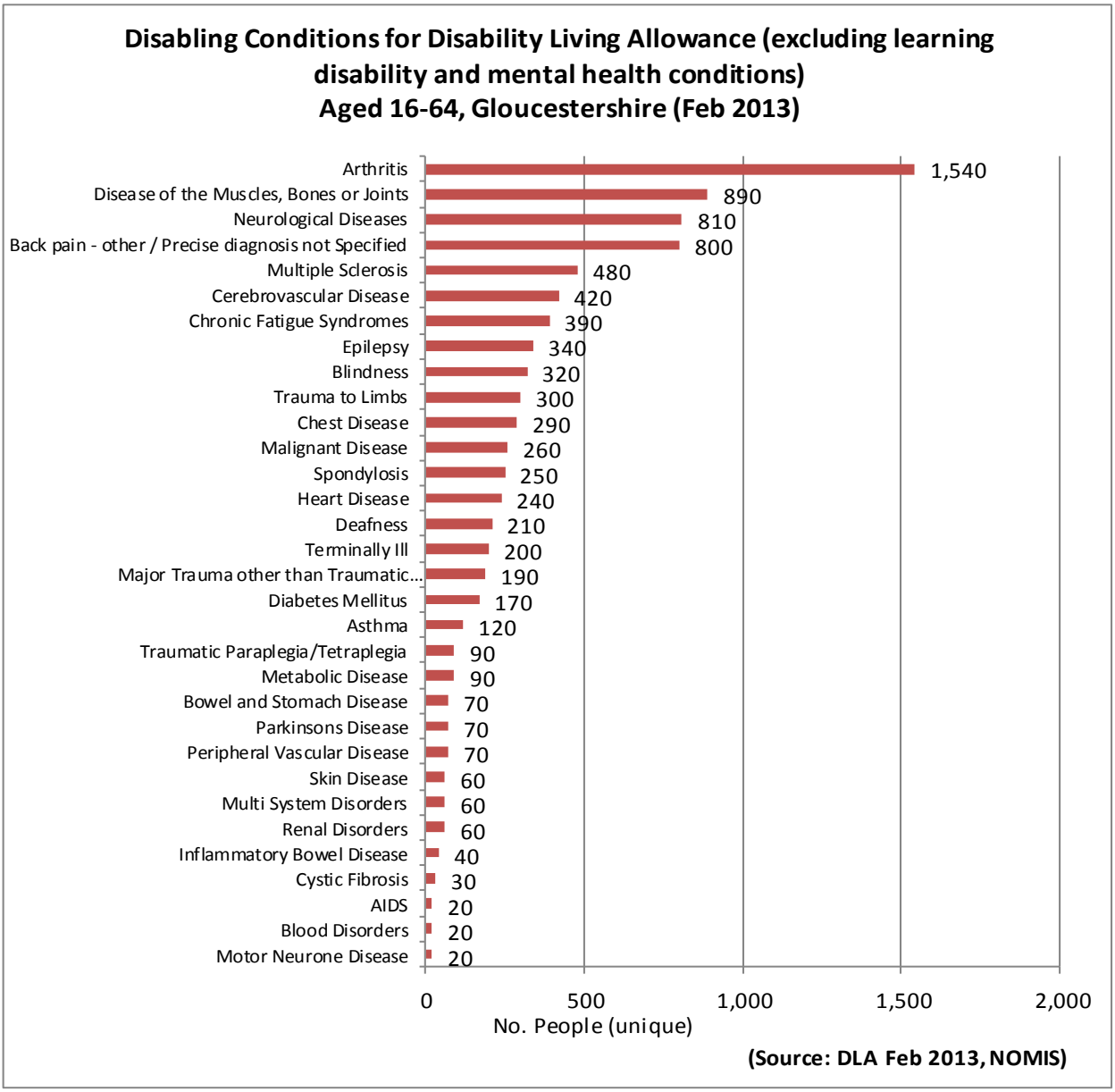
scope of this work however, it is an area that deserves further consideration in the future.

Recommendation: The Partnership Board should work with commissioners of health services to identify further support in pregnancy and early assistance for parents and carers of children and young people with disabilities.

5.1.6 Further trends

It is difficult to identify a comprehensive list of conditions among the population in Gloucestershire. However, data from DL A, and GP Profiles provide an indication of the prevalence of impairments and/or health conditions which result in physical impairment in the county.

Figure 32: Highlights the health conditions of people have accessed DLA in 2013



Neurological disease is the most common physical health condition in childhood for claiming DLA whilst arthritis is the most common condition in adulthood, followed by 'disease of the muscles/bones or joints' and 'neurological diseases' (excluding learning disability and mental health conditions).

5.2 Long-Term Physical Conditions from the GP Profiles

The following table depicts the number and prevalence of long-term physical conditions which can result in a physical impairment in Gloucestershire[33]. The incidence of long term conditions increases along with an ageing population. The condition increasing at the fastest rate is cancer, followed by COPD, whilst the highest prevalence rate is arthritis, reinforcing the DLA claims data above. However, diagnosis of condition does not necessary result in a disabling impairment.

Figure 33: Conditions which may cause disability and trends according to GP Profile data for Gloucestershire

Condition	Age	Trend	Glos.	Eng. ave
Cancer	All	Increased by 20% from 13,606 in 2012/13 to 16,279 in 2014/15 in line with English trend	2.6%	2.5%
Coronary Heart Disease	All	Relatively stable around 20,000	3.2%	3.2%
Stroke	All	Increased by 4% from 11,559 in 2012/13 to 11,986 in 2014/15	1.9%	1.6%
Chronic Kidney Disease	18+	Increased by 10% from 29,811 in 2012/13 to 32,822 in 2014/15	6.5%	4.1%
Heart Failure	All	Increased by 6% from 4,324 in 2012/13 to 4,595 in 2014/15	0.7%	0.7%
Diabetes	17+	Increased by 3% from 30,682 in 2012/13 to 31,547 in 2014/15	6.1%	6.3%
Osteoporosis	50+	Increase from 698 to 1107 in 2012/13, sharp fall to 505 2014/15, mirroring English picture	0.3%	0.3%
Arthritis/long term joint problem	18+	Relatively stable	12.5%	12.6%
Rheumatoid Arthritis	16+	Increased by 2% from 4,139 in 2013/4 to 4,213 in 2014/15	0.8%	0.7%
Chronic Obstructive Pulmonary Disease	All	Increased by 20% over 5 years from 9,063 to 10, 848 by 2014/15 in line with England trends	1.6%	1.7%
Asthma	All	Increased by 5% over 5 years from 39,541 to 41,610 in 2014/15	6.6%	6.0%
Epilepsy	18+	Increased by 6% from 4174 in 2012/13 to 4,414 in 2014/15	0.9%	0.8%
Blindness or severe visual impairment	18+	Increased slightly from 1.0% to 1.2% from 2013/14 to 2014/15	1.2%	1.5%
Deafness or severe hearing impairment	18+	Increased slightly from 3.9% to 4.1% from 2012/13 to 2014/15 in line with English trend	4.1%	4.1%

[33] This data refers to all people with the indicated condition in Gloucestershire, rather than only those who have a physical/sensory impairment

5.3 Multiple/Overlapping Impairments

The information below outlines the most common overlap between conditions using national data. Significantly, people with a visual impairment have a 34% likelihood of also having depression or a mental health condition. It is a similar picture for people living with chronic physical health conditions. This reinforces the discussion above regarding people with complex needs who access social care services.

Figure 34: Common overlapping impairments for people with physical/sensory impairment.

Overlapping Impairments					
	Hearing impairment	Visual impairment/Sight Loss	Mobility	Dexterity	Chronic physical health conditions
Long-term pain	33.8%	32.2%	50.9%	54.2%	
Mobility		50%		Significant overlap	
Visual impairment/Sight loss	Significant overlap		Significant overlap		
Depressed/ Mental health condition		34%	Significant overlap		30%

Recommendation: The Partnership Board should explore how to influence practitioners to ensure people are considered holistically.

5.4 Experience of health and wellbeing and access to healthcare amongst survey respondents

The survey included questions to gain people's opinions regarding their health behaviours and their access to health care.

The majority of respondents reported they generally led a healthy lifestyle and numbers reporting they drank or smoked was low – we recognise that self-reporting of lifestyle behaviours are not always accurate and tend to be conservative. A significant number felt that keeping a healthy weight was made difficult due to the lack of access to appropriate exercise facilities, classes and equipment.

Having access to weighing facilities was highlighted as an issue for wheelchair users. Some have had to go as far as Oxford to be weighed as there are few facilities for this activity within Gloucestershire.

A number of reasons were cited for poor uptake of exercise activity:

- lack of appropriate exercise equipment
- difficulties using changing facilities
- cost of exercise facilities
- lack of accessible information about the local offer
- lack of support to engage in the activity.

> *'I am very overweight and so exercising would be beneficial in an accessible venue'*
>
> *'I am not very good at exercising at home and I am unable to go to classes or gym due to my sight'.*

Swimming is an exercise that many with mobility problems are able to enjoy when other exercise is difficult or not an option,

> *'Swimming… is the best exercise as its not weight bearing'.*

Hydrotherapy pools, which are warmer than standard pools, are well used, and many respondents would like to see more of them.

59% of respondents felt that they had good mental health and emotional wellbeing. However, a significant number also reported that they felt depressed, stressed or anxious and that this was often linked to their health condition, levels of pain, social isolation or lack of mobility.

> *'Is often depressed due to pain and the restrictions that his disability places on him'*
>
> *'In addition to his physical disabilities, my husband… is often highly anxious and distressed'.*

Equal numbers reported positive and negative experiences of mental health intervention from professionals including a number who experienced long waiting lists.

Social interaction was crucial to a good day for many respondents as well as having a sense of purpose or something constructive to do. We know that these are key to building a person's resilience. Comments included,

> *'discussing or resolving issues using sign language with friends'*
>
> *'going out to lunch with friends… where my needs are catered for'*.

A number of individuals wanted more groups in the community to be available which emphasised socialising rather than coming together due to a shared impairment.

> ‘*there is a lack of social groups for young people in our area. He doesn't want a group just of people that have the same conditions as him, he wants to socialise with people that have the same interests as him’.*

Others wrote about wanting to socialise rather than *‘being part of a self help group’.*

Almost 75% of respondents believe they have good access to healthcare. This included both primary and secondary care. Many also felt they had a good relationship with their GP, *‘*

> *Good support from surgery - we have an Asian GP who speaks my mother tongue’*

Other professionals were also commended*,*

> *‘We are very lucky to have a good support system in place and the school and school nurse very supportive’.*

The practical barriers to accessing healthcare, both making an appointment and getting were highlighted. These barriers have the potential to cause disparity in access between able-bodied people and those with a physical and/or sensory impairment. Alternative ways of booking healthcare appointments, for example by email, text or online were suggested by respondents. Some would also like health information to be shared with them in different formats, Deaf people in particular.

> *‘I have issues with medical appointment letters: they often ask that you 'phone to book/confirm/change appointments; I am DEAF! I cannot use a 'phone!!’.*

Lack of public transport to doctor’s surgeries and poor parking made getting to an appointment extremely difficult for some.

Levels of aftercare that people received following the onset of an impairment or condition largely depended on the hospital department. The multiple sclerosis nurses were highlighted as being good, and so were the county’s audiology departments whilst some of those who survived a stroke felt they had little aftercare following hospital discharge including advice on adapting to life with decreased mobility.

There was a general consensus at focus groups that the NHS was good at dealing with conditions that were more common, however members felt a complex health condition often meant there were delays in diagnosis, they had to travel out of county for care, or the NHS didn’t fund support for their condition. There was a view that this was because there weren’t the funds for specialist practitioners or treatments locally and specialist knowledge wasn’t shared. As an example, one respondent to the survey stated,

'I have had mixed experiences. I have an excellent relationship with high quality general practice services. It has taken 12 months to establish a formal diagnosis and only now have I been referred to a spinal injuries centre. I feel NHS services from therapists are inadequately funded or resourced to adequately support someone with my specific disabilities outside a residential or in patient care setting'.

Recommendation: The Partnership Board should influence the range of health settings to improve physical access and access to information

Recommendation: The Partnership Board should consider options for increasing access to weighing facilities for wheelchair users in Gloucestershire including for private providers to offer this service.

Recommendation: The Partnership Board should work with partners to improve access to public and private exercise and sport facilities and equipment. This should include access to hydrotherapy pools, evidenced in this report as a form of exercise many felt they could take part in.

6. EDUCATION

6.1 Provision

For primary and secondary education, GCCs guiding principle is that all children and young people are entitled to have their educational needs met in local mainstream settings, schools and colleges. Specialist provision is considered when a child or young person's outcomes cannot be achieved in a mainstream setting. As part of implementation of the SEND reforms arising from the Children and Families Act 2014, GCC developed a Graduated Pathway of support to enable early identification, planning and monitoring of support for children with SEND. This pathway is used across agencies to provide a child-centred and integrated plan of support to address needs e.g. My Plan or My Plan+.

Figure 35: Current GCC education provision for Children and Young People (CYP) of all impairments:

Type	**Number of places available**
Primary mainstream provision	246
Secondary mainstream provision	39
Specialist provision (all ages)	25

The council's schools accessibility strategy sets out the following aims to:

- increase the extent to which disabled Children and Young People can participate in the school curriculum

- improve the physical environment to increase the extent to which disabled CYP can take advantage of education and associated services

- improve the access to disabled CYP of written information which is provided to CYP who are not disabled and where necessary alternative communication to written information

All schools must have a designated Special Education Needs Co-ordinator (SENCo). Schools are required to have an accessibility plan and provide enough resources to achieve this plan. Children and Young people with sensory and/or physical disabilities are supported by the Advisory Teaching Service which is a countywide Special Educational Needs (SEND) teaching and advisory support service. The Advisory Teaching Service works in partnership with NHS colleagues, families and voluntary and community sector organisations at a local and regional level to ensure any problems are assessed, identified and managed as early as possible. The service work together to meet the needs of CYP, their families and their educational settings (aged 0-25 years) using the graduated pathway.

There are some key factors to a school achieving good provision which include:

- having the right kind of leadership
- encouraging the inclusion of children and young people with impairments with other pupils
- following a graduated pathway for early identification and intervention, empowering children to become independent and successful at the start of their life's journey[34].

6.2 Early Years Special Educational Needs (SEN) (pre-school)

The Early Years SEN Service provides a range of programmes that support pre-school children with additional needs (medical/educational) and their families. It incorporates the Gloucestershire Portage Service, a specialist teaching service offered to children aged 0-5 years, and the Gloucestershire Child Development Centre, a specialist early years centre for young children aged 0-3 years.

Children receiving the services are usually assessed as being significantly delayed (e.g. 2 levels below their chronological age) in at least three areas of development (motor skills, sensory, speech and language, self care, cognition and social communication) where other interventions are failing to meet their needs; having on-going complex medical or developmental concerns; having neuro-developmental difficulties – motor delay with additional learning needs; or having an identified syndrome or genetic disorder.

The demand for early years SEN services has increased substantially in recent years, from 14 in 2011 to 54 in the first five months of 2014. The increase is partly due to changes in the way the team works and an increase in staffing levels, which has allowed the team to increase its caseload. The type of conditions affecting children, however, was not recorded for the majority (26) of children receiving services in 2014. Among those whose conditions were recorded, 9 children had a physical delay, the most commonly reported conditions. This was followed by a cognitive condition (8 children).

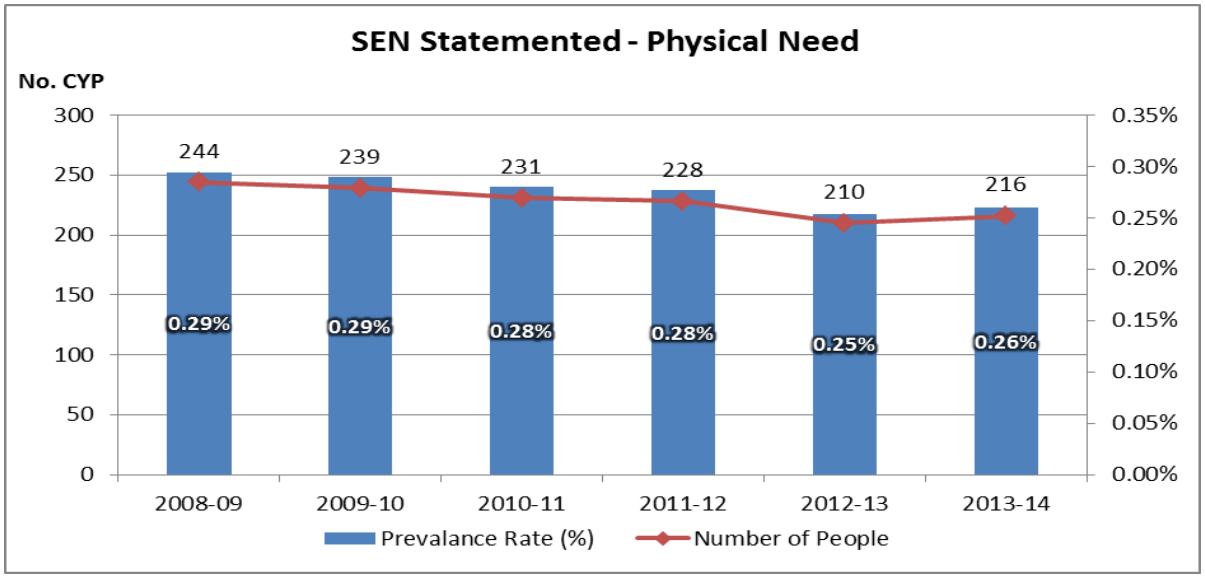
6.3 Special Educational Needs (SEN)

The number of children and young people with a SEN statement because of a physical impairment (including physical disability, hearing impairment, visual impairment and multi-sensory impairment) fell in the past 5 years from 244 to 216 (down 11.5%). This is in contrast with those who had a learning disability, which saw a sharp rise in the same period (up 23.5% from 1,316 to 1,625). However reports from the Advisory Teaching Service suggest that there are in fact increasing numbers of children and young people with complex physical and sensory

[34] http://www.gloucestershire.gov.uk/schoolsnet/CHttpHandler.ashx?id=61267&p=0

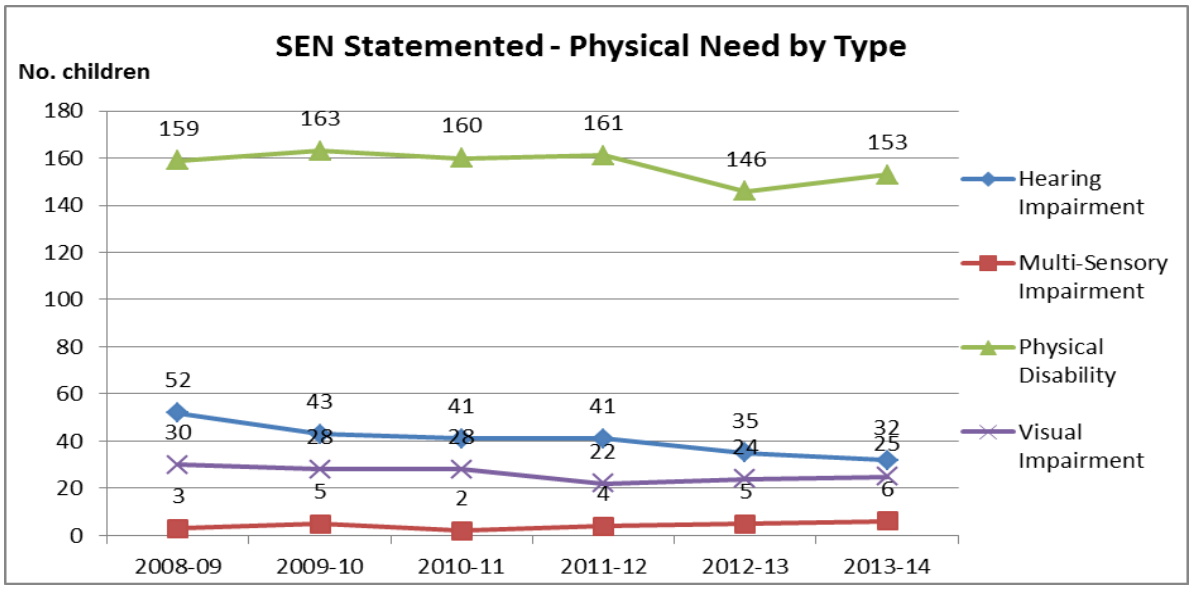
impairment accessing their services, possibly due to the increased life expectancy and birth survival rates of children born with congenital impairment detailed previously. The difference between these reports and the numbers who are statemented can be largely explained by the numbers who have been transferred to an Education, Health and Care Plan (from September 2014) and numbers for whom support is provided by the graduated pathway detailed previously. This is a robust support programme to coordinate targeted support from across agencies without the need to resort to a more traditional administrative route of statementing a child.

Figure 36: The trends of children and young people with a SEN (2008-14)



Physical disability is by far the most common condition (70.8% in 2013/14), followed by hearing impairment (14.8%), visual impairment (11.6%) and multi-sensory impairment (2.8%).

Figure 37: A breakdown of SEN by need (2008-14).



6.4 Education, Health & Care Plans (EHCPs)

Education, Health and Care Plans replaced the Statement of Special Educational Needs in September 2014, and cover children and young people aged 0-25 years with complex special educational needs and disabilities. The aim of these statutory plans is to identify additional resource needed to meet individual needs across health, education and social care in an integrated manner and building on the non-statutory graduated pathway that has been put in place.

The latest data shows that as at 31 January 2016, a total of 296 children and young people had a statement or Education Health & Care Plan (EHCP) whose primary need was physical, which includes hearing impairment, multi sensory impairment, physical disability, and visual impairment. Physical disability was the most common condition, followed by hearing impairment and visual impairment.

Figure 38: Numbers of Pupils on with an EHCP according to impairment

Type of Physical Need	**Number of children with a statement or a EHCP 31 January 2016**
Physical Disability	222
Hearing Impairment	37
Visual Impairment	32
Multi Sensory Impairment	5
Total	296

Recommendation: Gloucestershire's Local Offer (through the Family Information Service directory) should be further promoted. This provides information about provision across education, health, social care, private, third sector and community sectors for children and young people who have SEND and is in line with the move towards the offer of further non-statutory support.

Recommendation: We need to plan for and better understand children and young people transitioning between childhood and adulthood. This is to allow parents to explore options available to them post 18.

6.5 Further and Higher Education

Research undertaken to determine the accessibility of education for physically and sensory impaired students at the county's further education colleges and university suggest there are a number of schemes that are intended to support students. These include benchmarking exercises to measure levels of attainment for impaired students against able-bodied students.

Learning support units in further education colleges and at the University of Gloucestershire provide advice to departments on adaptations to ensure their courses are accessible and it is common practice for learning support practitioners to make contact with a prospective student to explore options of support when they submit an initial application to study at that place of learning.

A freedom of information request made to the University of Gloucestershire indicates that students with a physical or sensory impairment originate from 17 different, mainly neighbouring, counties. This appears to mirror where students without an impairment also originate from, suggesting a positive picture that a student with an impairment is not necessarily deterred by travelling outside of their home country for their higher education. However, total numbers of students recorded as having a declared physical or sensory impairment is low – just 0.6% of the student population.

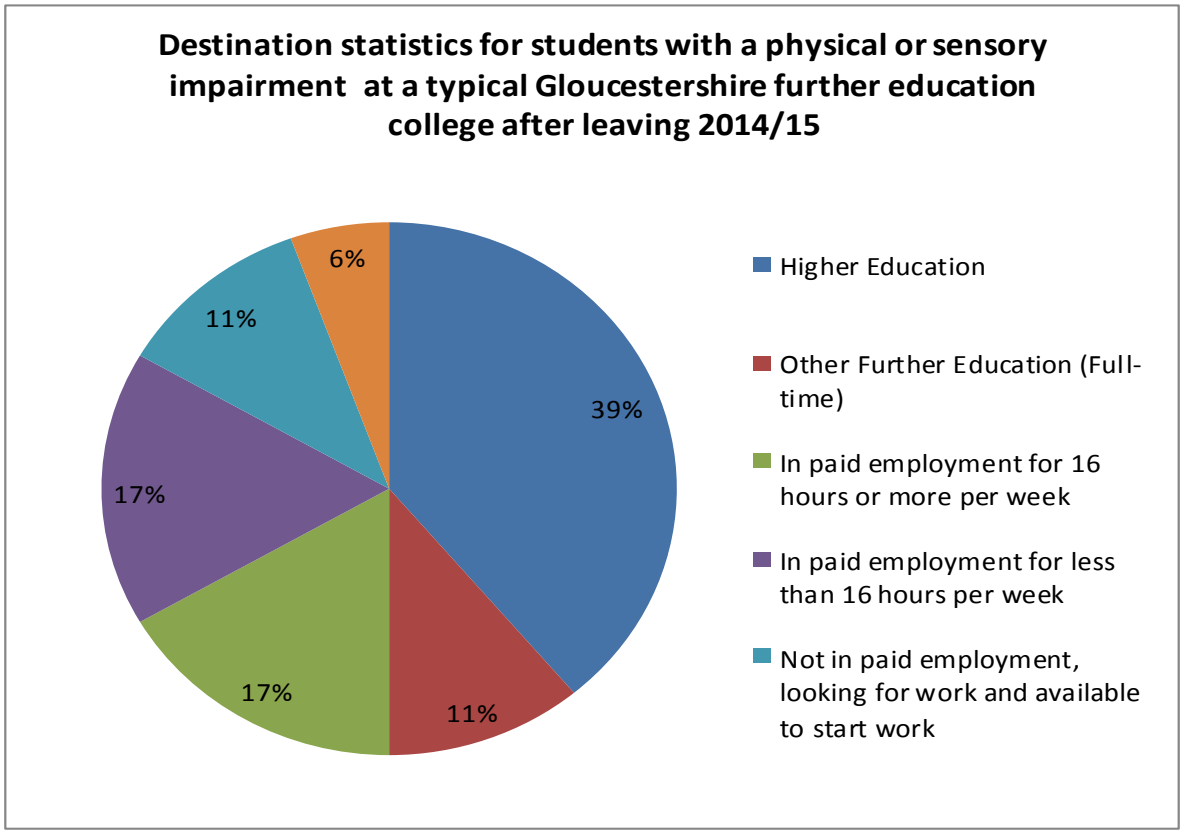
The information below shows the numbers of students who have declared a physical or sensory impairment at three Gloucestershire providers of further education for the academic year 2015/16.

Figure 39: Comparisons of student numbers by impairment at 3 further education colleges in Gloucestershire

Declared disability	**GlosCol (Gloucester, Cheltenham and Forest of Dean Campuses)**	**Stroud College**	**Cirencester College**
Visual impairment	34	16	<5
Hearing impairment	32	26	6
Disability affecting mobility	52	28	<5
Other physical disability	25	12	10

The following graph suggests a positive picture indicating that 83% of students with a declared physical or sensory impairment at a typical further education college in Gloucestershire continue onto further studies or employment.

Figure 40 Destination statistics for further education students with impairments in Gloucestershire



6.6 Experience of Education in Gloucestershire

25% of respondents to the survey have been in education in the last three years across a range of educational settings and of these 77% agree that they had a positive experience. The quality of support on offer appears variable when comments are analysed. Comments include:

'Very supportive, and tailored teaching to suit… needs'

'She attends Battledown Centre in Cheltenham. It is a fantastic place for our daughter'

'At College I have been able to do things I would not have been able to do somewhere else'

'Developing trusting bonds with my lecturers'

'There was no extra assistance and I had to ask for help – not conducive to learning. Felt a nuisance'

‘Daughter is excluded and segregated from others on a frequent basis and has not had the same opportunities to participate in school activities as others’

‘1-1 hours too low then fighting for everything he is entitled to makes having a child with disabilities even harder and meaning he is even more disadvantaged’.

When comments are categorised the main themes that emerge are the emphasis placed on receiving the right specialist support e.g. from a teaching assistant or from a learning support service in a college or university. Feeling excluded from the activities of their peers was also a comment recorded a number of times.

Recommendation: The Partnership Board should work with Gloucestershire mainstream further education colleges and the University to improve the support for those with higher level needs in the same way that those with lower level needs are supported.

7. EMPLOYMENT

7.1 Provision of employment support

Evidence shows that the right job with the right support is beneficial for people able to work. Regardless of the type of impairment, people benefit, in terms of their wellbeing, social inclusion and financially, through doing some kind of work.

Gloucestershire County Council commissions the Forwards employment service which provides a range of support for people with impairment to find employment. These include;

- One to one support for people to help them find work including supported internships
- Forwards Work Clubs for anyone who has impairment. These are often based in community library drop-ins
- Support to help people retain their job by providing advice and support on Department of Work and Pensions Access to Work Schemes and liaison with Jobcentre Plus to access other programmes
- Forwards offers advice to employers on employing people with impairment and work with other partners to provide expert advice and help

6.2 Experience of employment in Gloucestershire

20% of respondents to the survey of working age (17-64 years) are employed. Of these, 10% said they work full time, 8% part time and 3% are self employed. 6% of all survey respondents volunteer, with focus groups participants being higher, particularly for those living in residential or supported living.

Work was an area some felt they made a positive contribution to and others felt this was missing in their lives,

> *'I would love to return to work but there are many jobs I cannot do due to loads of time on foot or distance and I can't drive. It would be nice to have help to return'*

> *'I can't get a job - employers are permitted to discriminate when making "reasonable adjustment" for an interview, so if they don't feel like interviewing me they just have the interview in an inaccessible building. That is before I have to tackle the perception that the wheelchair affects my brain!!!'.*

For those wanting to access employment, support such as a PA, interpreter or job coach were identified as being of value to support with CV writing or with a job search. For others they felt the biggest challenge came from the attitude of employers and fellow colleagues. Some require further training and qualifications whilst others find the physical accessibility of work environments an issue.

Comments included:

'He has not been able to access training or exams so has no chance of getting any employment. There would have to be some sort of training and education to happen first that was acceptable to any employers'

'The job centre told me to volunteer... [the charity] refused to consider me as "their corridors might be too narrow for a wheelchair'.

Some felt they were able to give back to the community through volunteering, in turn gaining a sense of purpose and sense of achievement from doing so,

'I help out at the girl guides and this gives me a sense of helping others and social connections'.

From focus groups and responses in the survey there was a real sense that people with an impairment felt they could support one another – this in itself represents a potential community resource.

Further work could be initiated within GCC to influence positive attitudes to disability at an organisational level targeting management in particular. Opportunities for work experience and paid work for people with impairment are already offered by the organisation.

Recommendation: The Partnership board should encourage employers to be more disability friendly through provision of Disability Awareness training and promote the benefits and skills people with impairment can bring to an employer.

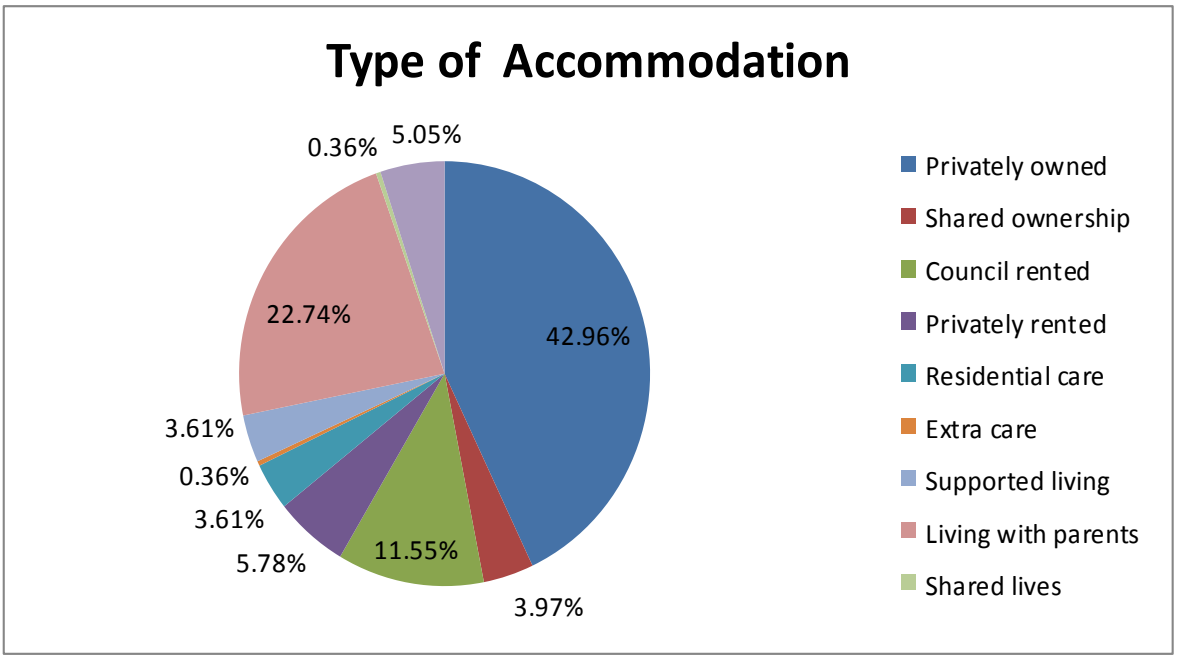
Recommendation: We need to ensure there is a consistent offer of employment support to people regardless of the type of disability or impairment.

Recommendation: The County Council could lead by example, helping people with a range of impairments to access work within GCC to improve employment opportunities.

8. HOUSING AND ACCOMMODATION

Survey respondents were asked to indicate their type of accommodation to try to identify issues or themes arising in this area. The greatest number live in privately owned accommodation or with their parents.

Figure 41: Type of accommodation of survey respondents



8.1 Provision of housing support

GCC has a Housing and Brokerage function for people of all ages with all types of impairment. It includes:

- A housing working group which meets quarterly. Members include district and borough councils, parent carers, housing providers, GCC disability operations teams, 2gether NHS (mental health trust) representatives, and service users.

- A GCC employed housing broker. This role is concerned with developing housing options for people with impairment, offering housing support and advice, reviewing housing need, working with landlords to develop housing that is required.

- A Specialist Multi Service Brokerage Team which supports the individual contracting process for those needing support to secure accommodation with providers. The new frameworks aim to cause a separation between care provider and landlord to ensure service users have security of tenure and can change their provider without an impact on their housing.

Building Better Lives has a focus on housing and there is an action card to direct the work of the housing working group. Pathways into different housing options are being mapped which will be a positive tool for service users and professionals.

Work with district and borough councils is underway to test their new Homeseekers system (the online website where people can bid for social housing) with service users to ensure the system is appropriate and accessible.

8.2 Social Housing

Evidence suggests that people living with impairment in Gloucestershire are more than twice as lively to live in social housing compared to those who have no impairment[35]. Research was carried out into the levels of social housing which are suitable for people with physical or sensory impairment. The majority of social housing stock in Gloucestershire is no longer owned by district or borough councils, but managed by individual housing associations.

All providers of social housing, operating in Gloucestershire, were contacted to build a picture of available housing for people with physical and sensory impairments. The majority of housing associations were unable to detail numbers of adapted properties in their portfolios, instead stating if resident required adaptations these would be considered. Cheltenham and Gloucester councils still retain some ownership over their social housing stock (at arms length).

Cheltenham Borough Homes advised they did not know how many wheelchair accessible properties are available in total, although they recorded 49 in in the year 2013/14. A further 101 properties completed in this year were of a 'lifetime' standard[36]. Gloucester however was able to give detailed information regarding the number of adapted properties it had in its portfolio:

Figure 42: Social housing stock in Gloucester for people with a physical impairment

	Total	**Percentage of stock and explanatory notes**
Total affordable housing stock (Registered Provider properties)	8240	
Number of Wheelchair adapted properties	142	2%
Number of Lifetime Standard Homes	478	6%
Number of medically adapted homes	80	Less than 1%

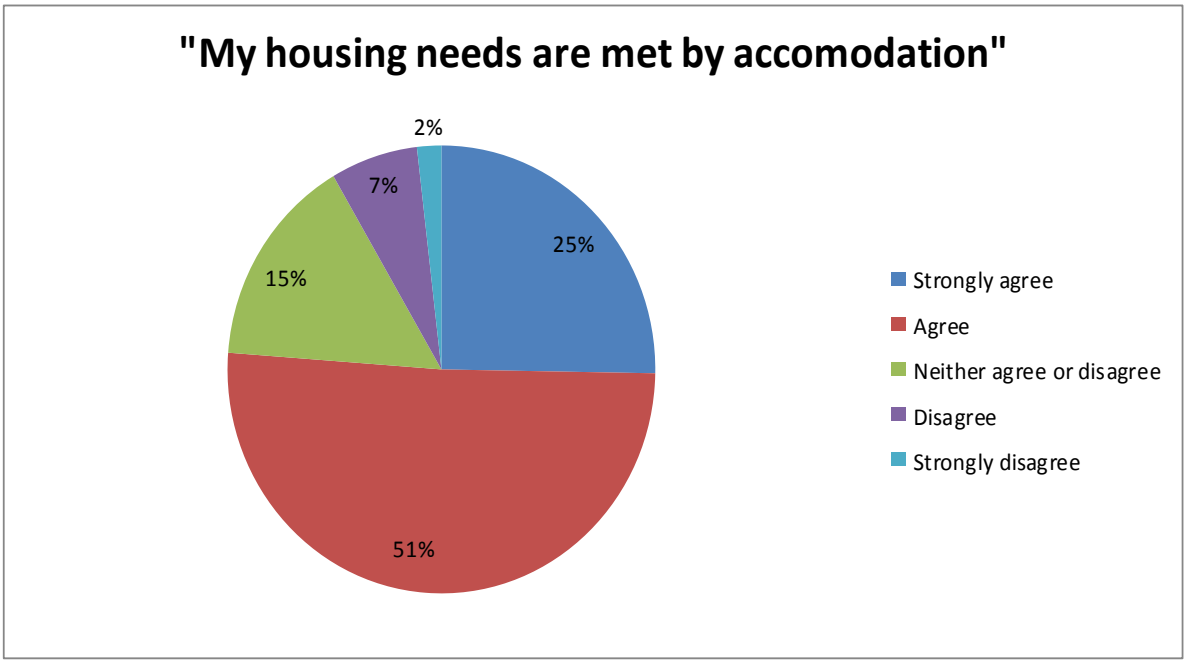
[35] http://www.barnwoodtrust.org/images/uploads/docs/Living_with_Impairment_Summary_v07-web.pdf

[36] A set of 16 design criteria set by a foundation of support charities that provide a model for building accessible and adaptable homes

8.3 Satisfaction with housing and accommodation

Over 75% of respondents to the survey agreed or strongly agreed their housing needs are met by their accommodation.

Figure 43: Depicts the satisfaction of survey respondents towards their accommodation.



There were high levels of satisfaction with residential care, supported living, shared ownership and living with parents whilst more concerns were raised by respondents living in privately owned, council rented and private rented homes. For example, one respondent living in rental accommodation stated,

> '*It's not always ideal, in several respects, but the rental market doesn't always offer everything one wants at a price one can afford!'*

These lower levels of satisfaction could be due to the levels of adaptions required to be undertaken by the owner in privately owned/rented accommodation. A number of respondents reported difficulties in accessing the right advice in order to make adaptations when applying for Disabled Facilities Grants (DFG) or sourcing advice from occupational therapists. One respondent commented,

> *'I needed hand grips on the stairs. I was told I was a priority as I had fractured my femur. They rang and spoke to me and said would come to the house to look at the stairs. They never came. I subsequently bought handrails from a disability shop and these were fitted by my husband.'*

Members of a motor neurone disease (MND) support group reported that the rapidity of degeneration left people struggling to meet needs and the delays in getting adaptations severely compromised their resilience.

> *'I have a degenerative condition therefore my needs are constantly evolving so the help and adaptions I need to remain independent constantly change.'*

The MND group called for a fast track assessment period so that adaptations could be made before their condition deteriorated further to maximise their changing levels of independence.

The numbers of bungalows countywide, especially those accessible to a wheelchair user, are particularly limited. Respondents to the survey reported bungalows being at a premium and one commented,

> *'I have had adaptations made to my housing association home to make it usable, I was advised a bungalow would be best but there are no bungalows available in forest and I would have to move my children out of there schools to move to an area where they are available. I feel this is not an option as my disability impacts my family enough.'*

Comments received suggest bungalows are hard to source on the private market and there are long waiting lists for them on social housing lists.

Recommendation: The Partnership Board should work with partners to centralise information about adapted properties so those who need access to social housing are more easily able to source properties suitable for their needs.

Recommendation: The Partnership Board should work with partners to improve information to aid access to appropriate housing, to include advice to private landlords and how to access Disabled Facilities Grants.

Recommendation: The Partnership board should work with partners to explore opportunities to create countywide best practice guidance to encourage house builders to build to Homes for Life Standards.

9. ACCESS

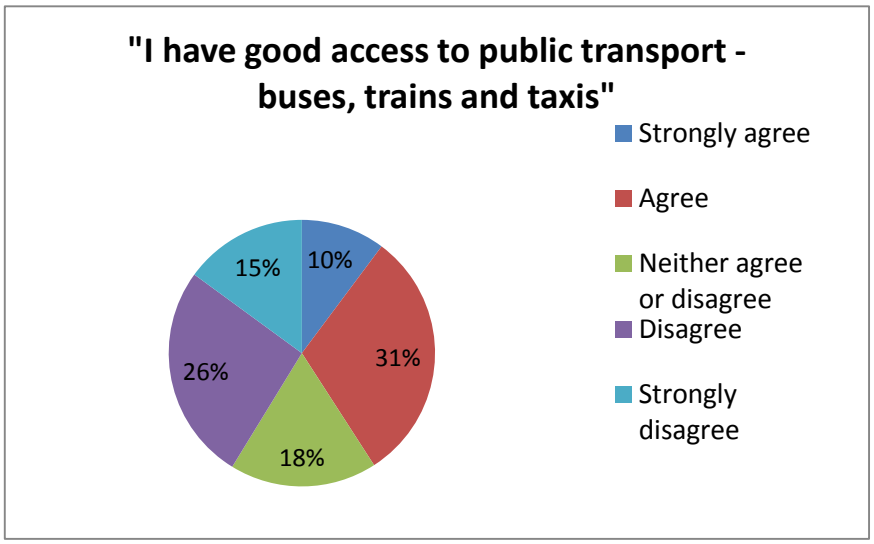
Access is a longstanding issue for people with a physical and/ or sensory impairment and was a major concern for survey respondents and focus groups participants. It was the theme that recorded the most responses. People were asked their views about transport, the accessibility of the outside environment and public facilities. Ease of access in daily life was something that could make the difference between a good or a bad day for someone and on occasions people felt discriminated against when a problem with access acted as a barrier.

9.1 Transport

GCC holds contracts with a variety of suppliers to provide people in Gloucestershire with a public transport system. The main provider of public buses is Stagecoach. The council also have a number of contracts with community transport providers that serve the county's 6 districts. A public transport accessibility forum comprised of people with a range of impairments and council officers, meet with local transport providers twice yearly. The aim is to hold these companies to account and raise any issues that people with impairments have in accessing public transport (including buses and train services).

9.1.2 Public Transport

Figure 44: Highlights survey respondents' views regarding access to transport



The responses to the survey evidenced a wide range of opinion in people's experiences of public transport.

Feedback regarding poor access was correlated with certain geographical locations. Comments revealed that the Forest of Dean, Stroud district, Cotswold district and rural areas scored poorly for accessible public transport.

'I live in the Forest of Dean so I would be lost without a car'

'One bus every hour to Stroud…no direct route to Gloucester from Eastington'

'Living in a Cotswold village, public transport is available but limited'.

Residents living at a purpose built, extra-care facility near Cirencester have been waiting for an agreed connection to the local bus service since the development opened in 2011. Residents advised that they "felt trapped" at the development without a bus service and cannot access the train service from Kemble 4 miles away.

A recurring theme throughout the focus groups and survey comments was the limited space on buses for wheelchairs and mobility aids. Many respondents cited the space available for a wheelchair is often taken up by pushchairs and buggies, and usually a first-come-first served/one wheelchair only process, operates on bus services. Respondents at focus groups described how this fragmented their travel arrangements and inevitably broke up groups on social and shopping outings.

'Space on buses for my Walker are limited'

'Can only take one wheelchair so have to wait for next bus - may miss it - can't rely on it'

'If pushchair already on, driver can insist that pushchair be moved out of space, but drivers don't often do this'.

Feedback on access to bus services was endorsed by responses from some of the focus groups who suggested that bus drivers

'Don't always assist by putting ramps out for wheelchairs'

'Sometimes appear to lack basic training in practical assistance' and

'… cause frustration by speaking to the carer rather than the person concerned.'

People at focus groups and through the survey reported higher satisfaction with train services than with the bus service, especially when support was booked in advance.

Taxis are used by a number of respondents to the survey and by members of focus groups when public transport is not accessible, available or appropriate. There is a variable level of service from taxis across the county with greater availability in Cheltenham and Gloucester. 'Dial a cab' was mentioned by various members of

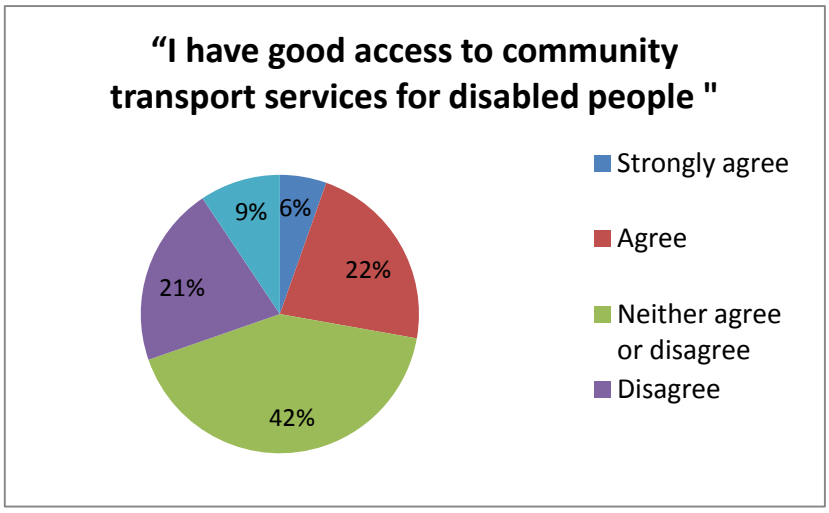
more than one focus group as offering a good service that could accommodate a larger than average wheelchair. The company describe themselves on the Healthwatch website as one that specialises in disabled access. However many found taxis prohibitively expensive, with some reporting increased fares for adapted vehicles. A Deaf respondent to the survey reported that some taxi companies offer a text booking service.

Recommendations: Partnership Board members should report their experiences and feedback to the Building Better Transport links forum to highlight issues with public transport providers and highways issues.

Recommendation: The Partnership Board should encourage the use of alternative booking methods (e.g. via text) to increase the accessibility of taxis for a greater number.

9.1.3 Community Transport

Figure 45: Survey respondent views regarding access to community transport.



Responses suggest a varied experience of community transport around the county. Respondents cited cost and/or lack of flexibility of the service which discouraged them from accessing it. The survey revealed a lack of awareness of available services and the perception they were only intended for older people:

'Community transport proved so unreliable I gave up using them also they are only 20p cheaper than taxis - without taxi time flexibility'

'Dial-a-Ride is brilliant, but only for specific times. (half hour wait each way). No evening service; No Sunday service. I use Bream Voluntary Car Service'

'Have never thought of using this as I feel it is for older people'

"Never accessed these - no idea how I would access them'

'I do not know how I might access these services. If I were to, I would imagine I would be able as long as my mobility aid could come with me. The problem is the lack of spontaneity and need for forward planning'.

The most positive feedback was given by respondents who use the Dial a Ride service in Newent, *'Newent dial-a-ride offer me all transport requirement needed.'*

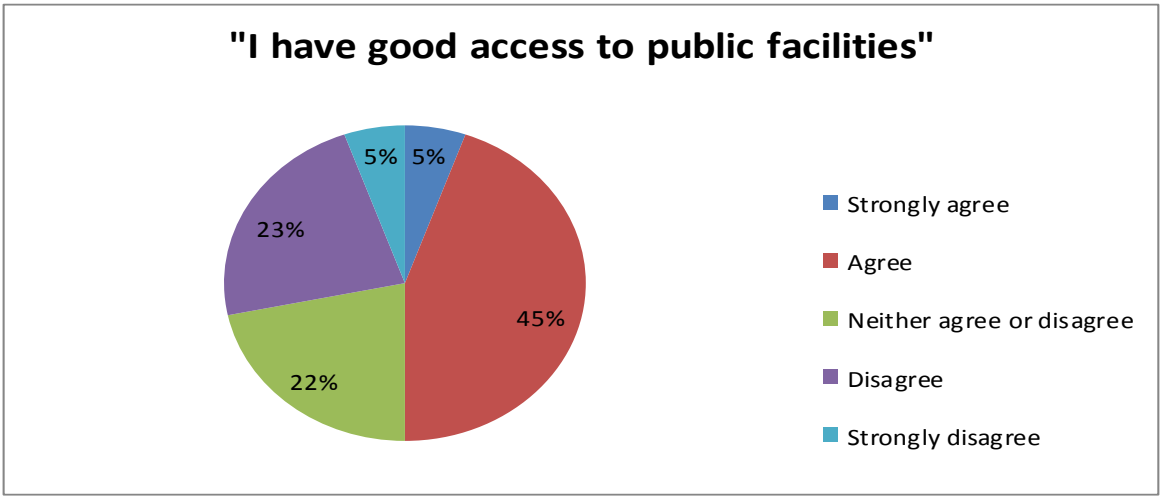
Recommendation: The Partnership Board should better understand the reasons why community transport is under used by people with a physical and/or sensory impairment in some areas and explore what makes some providers more successful than others.

9.2 Buildings and Environment

9.2.1 Access to buildings

Gloucestershire is a county with two main urban centres (Cheltenham and Gloucester) surrounded by the more rural often hilly areas of the Cotswolds and Forest of Dean. The historical nature of the county is what makes it so appealing to many, however this can cause obvious problems for people with particular impairments with access.

Figure 46: Depicts survey respondent views regarding access to public facilities.



50% of respondents agreed they had good access to public facilities. 23 individuals advised they experience poor or no disabled access to their local shops, many citing they felt this was due to buildings being old or listed. Banks were consistently highlighted as having poor access with some respondents forced to carry out their banking ‘on the street’. The listed status of many banks was often given as a reason for why they have not been made more accessible.

‘Too many listed buildings 'protected'… no ramps, lifts, automatic doors, hand rails’

‘Shops very poor mainly because they are listed buildings’

‘There are many places difficult to access in Tewkesbury. all entertainment is upstairs .I understand it's due to the buildings being old or listed.’

“2 steps up at the front and the disabled ramped access being a long way around the back of the bank”.

Shops in Cheltenham, Stroud and the Forest of Dean were highlighted by the survey as being poor for access.

‘There are few places in the Forest area which are accessible to electric wheelchairs - or manual, for that matter - as the majority of shops have at least one step’.

‘*Some shops especially Stroud do not have access or the room for me to access with my Walker or wheelchair*.’

Comments from the Deaf community revealed that intercom or any voice controlled access systems in public buildings excluded residents with a hearing impairment, as follows:

‘Intercom systems are awful! I cannot hear the person on the other end. I was terribly embarrassed when I had to visit the court building in St. George's Rd, Cheltenham; I had to stand there saying hello, hello until a security guard came and let me in’.

“’f there is an intercom, as a deaf person, I cannot see and therefore cannot hear what the person in reception is asking or saying. I find these inaccessible’.

Survey and focus group respondents reported access to accessible toilets was variable with particular problems in Cheltenham. Where they were available they were sometimes poorly designed or ‘out of order’ due to being used for storage. A number of respondents, especially parents responding on behalf of their children, suggested a need for changing facilities in public places.

Recommendation: The Partnership Board should work with our partners to identify a suitable location for a 'changing places' toilet/changing room and share knowledge of capital grants available to fund this scheme.

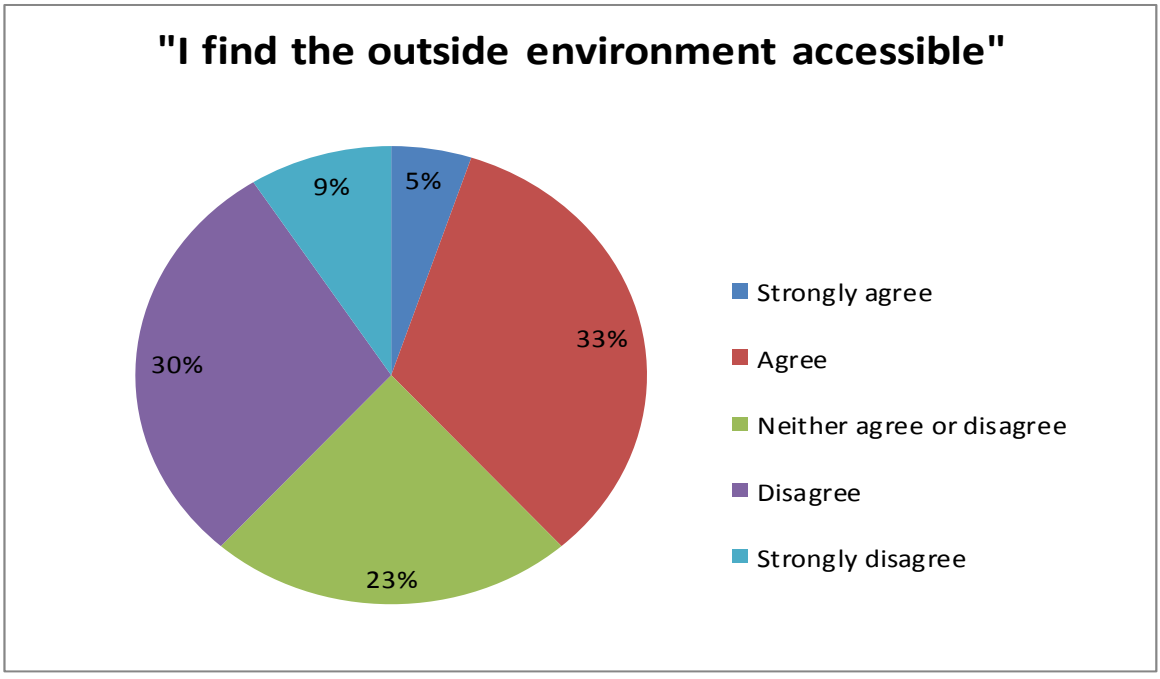
Recommendations: The Partnership Board should review the provision of accessible toilets across the county with district and borough partners and private businesses.

9.2.3 Access to the outside environment

GCC is responsible for maintaining some of the county's roads, streets and pavements. As stated previously Gloucestershire is a historical county with a natural and built landscape that cannot be easily adapted.

There was less satisfaction with the accessibility of the outside environment than with access to public facilities. Only 38% agreed that the outside environment was accessible.

Figure 47: Illustrates the percentages of respondents who found the outside environment accessible



43 survey respondents identified their experience of dropped kerbs as being problematic; either they were too high or poorly positioned. People reported that drop kerbs are not near disabled parking or not opposite each other on roads. 39 respondents, identified the condition of pavements caused them access problems. Comments covered rough, uneven, cracked and unrepaired pavement surfaces. A number highlighted that sloping pavements, particularly towards roads, causes access problems. Parents at the Allsorts Focus Group advised that;

> *'many of the pavements in Stroud are angled sideways which can make access with a wheelchair awkward'.*

People cited traffic speeds as causing confidence and safety concerns for them whilst members of a residential focus group in Cheltenham suggested that more speed bumps would slow traffic down. The issue of the length of time to cross at push button crossings was a concern for some who used a wheelchair or impaired mobility with members of focus groups highlighting 'Boots Corner' in Cheltenham as being particularly problematic.

9.3 Improving independence by improving access

Access to transport and the outside environment was something people felt inhibited their independence. Some wanted more information on available public transport options; others gave practical solutions to making the outside environment and buildings more accessible. Access could improve independence by an increase in changing facilities at venues and increased seating in banks or shops and one respondent said;

> *'do not disallow ramps and handrails 'because of listed status' or other rules that put buildings ahead of people.*

The perspective of many respondents with different impairments was such reasonable adjustments are not necessarily costly but there appears to be a lack of will or understanding to accommodate.

Recommendation: The Partnership Board should feed highways issues to the Building Better Transport links forum as above.

Recommendation: The Partnership Board should explore ways in which issues affecting access to the built environment can be fed back to district and borough councils.

10. INDEPENDENCE, CHOICE, CONTROL AND QUALITY OF LIFE.

The Barnwood Trust report (2013) into the wellbeing of people in Gloucestershire suggested that people living with impairment have lower levels of overall life satisfaction and mental wellbeing compared to the general population. They were also less likely to feel satisfied with their social lives and a sense of connection with their neighbours[37]. 22% of respondents with impairment were living alone compared to 12% of respondents who had no impairment. Research by the Barnwood Trust and GCC suggests that living alone is negatively associated with overall life satisfaction and mental wellbeing[38].

Responses to the survey and our focus groups highlight the need for meaningful occupation for all people regardless of impairment. Over 50% of respondents agreed they were able to make a positive contribution in their lives. 74% of respondents who agreed they had good emotional wellbeing also agreed they make a positive contribution in their lives. They were able to contribute in a number of ways; through their support networks, wide range of hobbies and interests, community groups and through sport and exercise. Many stressed the importance of information technology and social media to communicate and keep a grasp on current affairs when leaving their home environment was difficult or unobtainable.

Some felt their impairment limited the contribution they could make and for others it was the responses of other people that restricted them,

> *'People's perceptions of disability prevent me from making a contribution as my abilities are constantly underestimated'*.

The unhelpful response of some strangers on a daily basis frustrated a number of people. People reported feeling patronised or having their capabilities misjudged.

Social and support groups help many make a positive contribution.

> 'I go to lip-reading classes at GDA - I like it because it allows me to socialise with other deaf people whilst also learning'. (Gloucestershire Deaf Association)

This opportunity for networking, building relationships and offering support to one another would fill a need for many increasing emotional resilience and independence from other services.

Results highlight a need for information about available community groups to be increased and made in an accessible format. As an example, one parent felt there was not enough on offer for their child,

> *'It is important for us to find activities that my daughter can participate in... but it's quite hard because of her limitations and disabilities'.*

[37] http://www.barnwoodtrust.org/images/uploads/docs/Living_with_Impairment_Summary_v07-web.pdf
[38] http://www.gloucestershire.gov.uk/inform/index.cfm?articleid=119817

There are many groups available in the community however information is not always accessible when needed.

GCC and the GCCG commission community support to put people in touch with support groups and offer information and advice in order to reduce social isolation create active and supportive communities. Work is currently being undertaken to assess and improve these services for the future

10.1.1 Quality of life

Almost 75% of respondents agreed they felt safe in their daily routine and environment. There was no significant difference in numbers reporting they felt unsafe when categories of conditions were compared, however a number of Deaf people added comments regarding feeling vulnerable. Some made the distinction between feeling safe in their own home compared to being away from it and the fear of falling was commonly reported.

'at home [I feel safe] - I feel scared when I go out, especially if I'm on my own'.

The support that strangers offer when away from home often contributed to whether people felt safe. Members of focus groups sometimes used disability aids, not so much as a way of helping with their mobility but as a way of signalling to others they had a disability. This was especially true of those who felt they did not appear to 'look' physically impaired.

Recommendation: The Partnership Board should further explore options with a range of community, condition-specific and third sector organisations to give practical support for people in their day-to-day lives. A card could be created and shown when required to explain to a stranger a person's impairment. Some support organisations already offer this service.

Recommendation: The Partnership Board should work with partners to promote the range of social, community and support groups on offer in the county to help combat social isolation; a real determinant of both emotional and physical wellbeing.

10.1.2 Choice and Control and Resilience

Almost 65% of respondents agreed they have choice and control over their day-to-day lives; some reported they needed support in making decisions; however did have control over any final outcome.

Parents of children and young people with impairments often reported they tried to empower their children to make decisions for themselves;

> *'we encourage decision making and follow through the decisions made'*.

For carers who supported adults, choice and control also seemed to be encouraged demonstrating a proactive approach by the majority to give the people they support as much autonomy as possible in making decisions for themselves.

Several respondents commented they had come to understand their capacity to carry out day to day activities fluctuated; this was often due to their health condition and level of pain.

> *'Within the boundaries of the things I can't always control; how much pain I'm in at any given moment, what my responsibilities are that day - then yes I have as much control as anyone else. Recognising what I can control and what I can't is a key part of my strategy'.*

Independence was achieved in a number of ways and meant different things to different people; however for many an active network of family and friends was crucial to maintaining independence. Where this is lacking in people's lives community and social groups have an even greater role to play.

Independence coaching was suggested as something that would benefit, especially young people, to build independence. The National Star College's LIFT scheme, which trains young people to use public transport independently, was highly valued by younger members of our focus groups. It had enabled them to get out and see friends at the weekend, or to take part in volunteering. Parent respondents to the survey suggested their child's independence could be improved practically if they were given food preparation training and this would also help them lead a healthier lifestyle.

High levels of resilience and self-reliance were explicitly communicated in the survey and by members of focus groups. People reported feeling fiercely independent due to their circumstance, necessity or character. These statements were particularly prevalent when respondents were asked about what keeps them independent

> *'Try to be self reliant – work hard at it', 'Strong willpower and discipline'*
>
> *'Belief in myself'*
>
> *'It is part of my attitude anyway'* and similar comments were often received'.

Recommendation: The Partnership Board should undertake work to better understand the factors contributing to the resilience of the many people with significant impairments who do not access formal support services.

11. CONCLUSION AND RECOMMENDATIONS FOR FURTHER WORK.

Conclusions and suggestions for further work following this needs analysis are categorised below.

Wider population

Prevalence data indicates a high number of people with a physical disability who require some support (14,640 with moderate disability & 3,329 with serious disability compared to 1,169 people receiving GCC funded services). Further work could be undertaken to map the support accessed by those who are not GCC funded and determine how effective it is. This could inform future targeted prevention and/or community funding. This could link to work in transport, employment and housing to help people maintain their independence and wellbeing in their community with recommendations to be progressed by the Partnership Board.

Provision

Commissioners may wish to consider further work to establish ways to increase the take up of assistive technology to improve and maintain independence for people with a physical and/or sensory impairment.

Demand

A third of the council's highest cost care packages are for acquired brain injuries. Further work could be undertaken to assess the effectiveness of related services and provision for this condition. This may include a market shaping exercise. With a large proportion of respondents to the survey aged over 55 years, further work to understand people aged 55 years plus with impairment may be useful. The higher usage of services amongst more deprived areas of the county may require further analysis.

Effectiveness of services

Further work is required to understand how effective services we fund are in meeting peoples' needs. This could start with further analysis on some of the complex cases, looking at needs and the services people receive. Commissioners may wish to start with a small cohort of services users with a physical disability in a particular geographic area i.e. Gloucester or Cheltenham, linking this with health data and user experience for further insight.

Recording/systems

We know there is a difference between a person's medical condition and their needs on a day to day basis. Two people with the same condition may have different

needs. Therefore a focus should always be on a person's needs and what is required to support them including to maintain their independence.

The high occurrence in recording of 'physical other' for a person's primary condition on GCC's social care database indicates staff may benefit from training to identify health/medical conditions. Commissioners and managers need to be clear about what they want to analyse from data so that it is recorded in the correct way in the first instance. The focus for anticipating future demand may be best placed on resulting needs and services rather than using trend data on conditions.

Following a review of the 50 highest cost care packages categorised by 'physical disability' it is evident there is no clear definition of this. We could therefore develop and refine a definition.

There are changes coming to our adult social care records database, so improving our recording in line for the new system is timely.

These findings will contribute to the development of a Market Position Statement for commissioning care and support for people with physical and / or sensory impairments in Gloucestershire in order to shape the market and increase the range and variety of support available.

Children and Young People

Data shows the numbers of children and young people on Special Education Needs statements or Education Care and Health Plans has decreased in recent years. However, Education services have seen an increase in children and young people (CYP) with complex needs. This may be due to increased life expectancy for children due to medical advances. These CYP are now being supported through more robust, informal support.

As commissioners we need to work more closely with social care and education services to better understand the needs of children and young people with increasingly complex needs.

An enhanced service for CYP aged 0-25 years aims to better support those transitioning between children and adult social care services. This will allow for better support and planning whilst increasing the information available to parents and carers to support their child post 18 years.

We suggest the Physical Disability and Sensory Impairment Board increase accessibility to the forum to parents and carers of children and young people, increasing the network through colleagues in education and social care teams to encourage representation.

Going Forward

The Physical Disability and Sensory Impairment Partnership Board will own and prioritise the recommendations, develop a plan and work with partners to progress the subsequent actions. These specifically include the recommendation for access, education employment and housing.

This is the first piece of work in Gloucestershire which has attempted to build a picture of general life as well as access to GCC care and support for children and adults with a range of physical and sensory impairments.

The co-production approach has ensured that areas of life important to this diverse group have been included which may not have been the case with a traditional quantitative piece of work. This has been ambitious and aspirational in taking a quality of life, holistic standpoint in the consideration of need.

The broad scope of the work is such that it highlights many areas where further work is required but it does provide a foundation for this work to develop.

Some of the challenges and limitations include the lack of coherent all-age data nationally, at a county level and from within our own organisation. A key strength of the work is the collaboration and engagement with the numbers and range of stakeholders throughout with whom we are able to continue the dialogue to inform our strategic thinking.

Glossary

Advocate	An advocate is someone who is independent who can help your wishes to be heard.
Building Better Lives (BBL)	Gloucestershire County Council's policy to improve our services for people with disabilities through an all-age, all-disability approach.
Carer	A family member or friend providing unpaid care and/or support
Census	A census is a complete population count for a given area or place taken on a specific date. The last government census was in 2011.
Commission	To understand what is needed and to plan, purchase and evaluate services and support designed to meet those needs.
Congenital	An impairment present from birth.
Demographic	A particular section of the population e.g. people with a physical impairment.
Direct Payment	Money given by a local authority to someone with social care needs to organise and fund their support themselves.
Disability Living Allowance (DLA)	Money from the government if you have a disability to help fund mobility or care costs. This has been replaced by the Personal Independence Payment in the majority of cases.
Education Care and Health Plans (EHCP)	An education, health and care (EHC) plan is for children and young people who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.
Eligibility Criteria	The level of need someone must have to be considered for funding to provide support for that need.
ERIC	Gloucestershire County Council's Adult Social Care records database.
Gloucestershire Clinical Commissioning Group (NHS GCCG)	The organisation responsible for commissioning most services funded by the NHS in Gloucestershire. They replaced Primary Care Trusts (PCTs).
Gloucestershire County Council (GCC)	The local authority responsible for commissioning some public services in Gloucestershire including social care and public transport.
GP Profile	Data collected by GPs on health conditions.
Impairment	An injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physical function or

	mental wellbeing.
Market	The range of providers that offer services / support. These can be from the private or third sector (including charities and community providers).
Methodology	A system of procedures used in carrying out research.
National driver	Legislation and/or policy which applies to the whole of England and with which Gloucestershire County Council must comply
Needs analysis	A piece of research, which identifies and evaluates the needs of a target population (in this case people with a physical or sensory impairment).
Personal Assistant (PA)	A support worker employed by people who need social care to enable them to live as independently as possible.
Personal Independence Payment (PIP)	Money from the government to help with some of the extra costs caused by a disability or long term ill-health. It has largely replaced the Disability Living Allowance.
Projecting Adult Needs and Service Information system (PANSI)	National data on health conditions which may require social care support for those aged 16-64.
Projecting Older People Population Information System (POPPI)	National data on health conditions which may require social care support for those aged 65+.
Partnership board	Members of the public, public sector, third and community sector organisations working together for joint solutions to common problems experienced by certain groups of people e.g. those with a physical or sensory impairment.
Personal Budget (PB)	An amount of money, determined by a person's needs, which is agreed by social services to fund support for an individual.
Physical disability	An impairment which affects a person's physical functioning, mobility, dexterity or stamina and can result in the loss or limitation of opportunities to take part in society.
Projection	An estimate of a future situation based on the study of information that is currently available.
Scope	The extent of a study. What is and what is not investigated in the research.
Service User (SU)	A person who receives support from social services including financially.

Social housing	Housing provided by government agencies or non-profit organisations.
Statement(ed)	Legal assessment of a child as having special educational needs. This is now largely replaced by Education, Health and Care Plans where they are deemed appropriate.
Support	Assistance. It may be provided by a carer or in the form of professional and financial help or through the use of equipment.
Trend	A direction in which something is developing or changing.

Appendix 1

Methodology

A co-production approach has been adopted to the work in general and in particular to the stakeholder engagement and qualitative elements. It was considered that the quantitative analysis of prevalence, need and projected demand should be balanced by the experiences of people with a physical and/or sensory impairment to increase our understanding of what it means to live with these impairments in Gloucestershire.

The intention was to go further than passively collecting information from people to more fully engaging them in the whole piece of work. Therefore, a virtual working group of people with a range of different impairments were involved, along with Inclusion Gloucestershire (formally Physical Inclusion Network Gloucestershire) to develop a survey and themed questions to be carried out with focus groups and to actively participate in the analysis and subsequent recommendations and actions.

This has also resulted in the development of relationships with a significant number of individuals and groups of people with whom we now have a better dialogue and the opportunity for further collaboration in the planning and commissioning of services and support.

The quantitative element of the research has relied on a number of secondary data sources outlined below as well as the GCC adult social care database known as ERIC to provide specific information regarding people receiving support from GCC.

Appendix 2

Data Sources

1.1 Primary Data Sources

The survey was aimed at all ages of the target population. A carer version was also produced to enable information to be obtained on behalf of those not able, or willing to respond which includes children of all ages.

The virtual reference group decided the scope of the topic areas identifying the quality of life indicators for them, which extend far beyond the receipt of care and support. Each was written as an "I" question so that they could be responded to from the perspective of a wide range of people of all ages and impairments and therefore interpreted and assessed from an individual's own judgement.

Respondents were able to rate each question and add narrative to clarify and expand where they felt appropriate. The same themes were used for the focus group discussions. The survey was produced in a range of versions including on-line, hard copy and large print. In addition to improve access for specific groups, a number of third sector organisations worked with us to engage people, particularly with sensory impairment to complete the survey and attend focus groups. It yielded 279 responses and 140 people contributed to the focus group discussions

1.2 Secondary Data Sources

The closest available data on physical disability in Gloucestershire are from the following sources, each with their own strengths and limitations:

- *Census of Population (2011)* - Census data captures the state of health and disability of the whole population in Gloucestershire through self-reporting. It provides information on the number of people who reported having a disability or long-term illness.
- *General Practice (GP) Profile (2012-15)* - Information collected by individual GP practices on prevalence of certain health conditions.
- *PANSI*[39]*(2014)* - Information system developed by the Institute of Public Care which identifies the overall prevalence of people aged 18-64 years with physical disabilities in local authorities (and some conditions) using national prevalence rates from the Health Survey for England.
- *POPPI*[40] *(2014)* - Information system developed by the Institute of Public Care which identifies the overall prevalence of people aged 65+ years with physical disabilities in local authorities (and some conditions) using national prevalence rates from the Health Survey for England.

[39] Projecting Adult Needs and Service Information
[40] Projecting Older People Population Information

- *Disability Benefit claims (2013)* - The main non-contributory and non means-tested benefit that people aged 16-64 years might be able to claim due to disability. However, because of the transitional changes to the DLA to the Personal Independence Payment, it is difficult to obtain the latest DLA claimant numbers that provide a reliable picture of the current number of DLA claimants. Therefore data from February 2013 has been utilised.

All data sources therefore provide different information and are not necessarily comparable, partly because of the differing age ranges adopted. They do, however help to build a picture of the need, demand and experiences of people with a physical and/or sensory impairment in Gloucestershire.

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Carers UK 2014 “Caring and Family Finances Inquiry UK Report”
www.carersuk.org/for-professionals/policy/policy-library/caring-family-finances-inquiry

Disability Living Allowance (DLA) Feb 2013 NOMIS
https://data.gov.uk/dataset/disability_living_allowance_dla;
https://www.nomisweb.co.uk

Equality and Human Rights Commission http://www.equalityhumanrights.com

Gloucestershire Clinical Commissioning Group
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