WELFARE REFORM AND LEARNING DISABILITIES

Reflecting on the achievements and lessons of Transforming Day Services at Chapeltown Citizens Advice Bureau

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Executive Summary

This report was commissioned by Chapeltown Citizens Advice Bureau and funded by the Higher Education Innovation Fund via Leeds Social Sciences Institute. Under the auspices of a Postgraduate Research Fellowship, an independent researcher is exploring how current and forthcoming welfare reforms will impact on households affected by learning disabilities. More specifically, this report reflects on the achievements and lessons of Transforming Day Services – a generalist advice service established to ensure that those affected by learning disabilities receive the correct benefit and health and community care entitlements.

Since the inception of the project and the commissioning of this research, a growing body of evidence has revealed that there are significant institutional and service failures to fulfil welfare rights and meet provisions under Section 7 of the Local Authority Services Act (1970). Adult Social Care Services are not pro-actively accounting for disability-related expenditure when assessing the level of community care charges for service and client users. In addition, Leeds City Council is not consistently providing advice about entitlement or helping with completion of benefit claims. To some extent, Transforming Day Services has responded by securing over £250,000 for clients in social security payments. The service has also secured a great deal of respite care, discounts and subsidies for clients. Given Leeds City Council’s breach of statute, a number of lessons can be learnt from the Transforming Day Services project and how Leeds City can best equip itself to meet the needs of the most vulnerable and deal with the current and forthcoming welfare reforms.

There are a number of issues and themes arising out this study that have informed a set of actionable recommendations to be discussed shortly. Firstly, some of the key research findings from this study are outlined below. This serves to provide some context:

- There are currently no official statistics detailing the number of people with learning disabilities in the UK or Leeds. It is believed that the Leeds Learning Disability Strategy 2009-2012 underestimates the prevalence of learning disabilities.
- Though undeniable linked, there is no simple causal relationship between learning disabilities and deprivation. Rather, a range of potent demographic and institutional factors coalesce to propagate the experience and severity of deprivation and social exclusion faced by people with learning disabilities. This affects the health, education and employment outcomes of people with learning disabilities and their surrounding support networks.
- Leeds is not performing as well as other local authorities in the delivery of Adult Social Care Services. Those in receipt of care in Leeds seem to be less satisfied than those in receipt of care nationally in a number of respects: they are more likely to be unhappy with the way they are helped by staff; more likely to rate their quality of life as bad on the whole; and
- The number of enquiries regarding benefits and tax credits has risen significantly since the economic crisis and recent austerity measures of the Coalition Government. Chapeltown Citizens Advice Bureau witnessed a 19% increase in enquiries related to benefits and tax credits between 2008/09 to 2010/11. As a proportion of all enquiries, this was an increase from 31% to 38%.

- The condition of having a learning disability means that many individuals with learning disabilities and those with caring responsibilities incur extra costs as a result of the condition. Owing to the extra costs that this can incur, many more households affected by learning disabilities are likely to face poverty than is officially projected. Due to significant caring responsibilities, poor financial incentives, high marginal tax rates and poor flexible working options, the majority of carers did not work or only worked part-time. The significant costs associated with learning disabilities, poor employment opportunities and the residual level of many benefits mean that many households affected by learning disabilities are faced with the prospect of restrictive living and caring conditions. This is detrimental to the well-being and finances of the household as a whole. In addition, it threatens the autonomy of the person with learning disabilities as their own benefits are often subsumed into the running costs of a house that can no longer financially support itself due to the aforementioned challenges.

- Owing to the aforementioned conditions, participants are heavily reliant on the social security payments they receive from Central Government and the discounts and subsidies delivered via Leeds City Council. Understanding of benefits is mixed amongst carers and those with learning disabilities. In some cases, understanding was extremely poor with people unaware of their benefit and welfare entitlements for more than twenty years.

- The care, advice and support available from Leeds City Council plays a vital role in safeguarding the well-being of households affected by learning disabilities. Not only for those with learning disabilities, but also carers. All participants were positive about the integrative potential of Day Centres.

- There were mixed reactions to the support provided by Leeds City Council. Some participants felt that they didn't receive any or sufficient support from Adult Social Care Services. It was felt that support and social workers were not always sufficiently present to be able to adequately monitor the condition and situation of those with learning disabilities and those with caring responsibilities. Other participants felt that the interaction that they did have with Adult Social Care Services was unsatisfactory. It was felt that support and social workers did not always spend a sufficient amount of time assessing and understanding their needs.
Many clients are more concerned with ‘getting by’ and coping with day-to-day life rather than speculating about the future and what might be available to them. Reflecting on this situation, one cannot rely on clients to contact and access resources, particularly if they have low levels of understanding. Rather it was suggested that Adult Social Care Services need to take a more proactive role in assessing the needs and capabilities (financial or otherwise) of households affected by learning disabilities.

The trust and rapport developed between the specialist caseworker at Chapeltown Citizens Advice Bureau, Leeds City Council, the client and potentially their carer has proven crucial in implementing the new generalist advice service. Without this trust and rapport, the specialist caseworker would not have been able to access so many clients and secure their welfare and care entitlements.

If Leeds City Council and Chapeltown Citizens Advice Bureau want to improve the experience and satisfaction of clients, both institutions need to account for the extra time that is very often necessary when dealing with households affected by learning disabilities.

The continuation of Transforming Day Services will enable clients to understand and proactively engage with the forthcoming welfare reforms. A Universal Credit will be introduced over the coming years and Personal Independence Payments are set to replace certain components of the Disability Living Allowance. Concerns have already been raised about the value of current benefits. As the CASE report data and interviews illustrate, the benefits people are presently entitled to, do not always sufficiently cover the costs incurred by those affected by learning disabilities. Worryingly, the value of Universal Credit and Personal Independence Payments is anticipated to fall in real terms over the course of their implementation. This will make the lived experience of learning disability even more challenging for those with the condition and those with caring responsibilities. Households affected by learning disabilities are already struggling on the residual level of benefit that they currently receive. With forthcoming changes to welfare entitlements that include benefit and housing caps, it is increasingly important for Adult Social Care Services to approach the Financial Assessments and Benefits process rigorously and methodically. In doing so, Leeds City Council can ensure that disability-related household costs are accounted for in community care charges and households affected by learning disabilities receive a full assessment of their needs and capabilities that includes advice and assistance in securing the maximum care and welfare entitlements one is eligible for.

Welfare caseworkers within Citizens Advice Bureau are experiencing an increasing workload with fewer resources. This is against a backdrop of significant shifts in welfare policy and social security implementation. The problems faced by benefit claimants more generally are intensified for those households affected by learning disabilities. When changes are made affecting households affected by learning disabilities; a greater level of support in welfare and care transitions is needed as clients require more time
to understand and deal with changes. By continuing *Transforming Day Services* Leeds City Council and Chapeltown Citizens Advice Bureau can ensure that the most vulnerable are protected from cost-saving measures that endanger the well-being of many individuals and households across Leeds.

Based on these research findings, a number of recommendations are outlined below at different institutional levels. Each institution has the capacity to affect the lives of those affected by learning disabilities. As such, the following actionable recommendations are made in the hope that Leeds City Council and Citizens Advice Bureau can become better equipped to deal with the significant upheaval and changes that are anticipated with forthcoming welfare reforms.

**Leeds City Council**

- **Adult Social Care Services** should *proactively* rather than *reactively* engage with service users and clients. In such a capacity, Leeds City Council must follow provisions issued under Section 7 of the Local Authority Services Act (1970). Essentially, Leeds City Council is obliged to take account of disability-related expenditure when assessing the level of community care charges for service and client users. Leeds City Council must also proactively provide benefit advice and information to ensure that clients are receiving what they are currently entitled to.
- Develop and issue training to the Leeds City Council’s Financial Assessments and Benefits Team to ensure that assessment officers are providing a consistent service to clients.
- Exploit the significant data sources generated by organisations such as Mencap, Leeds Carers, CAB, etc, to identify and contact those individuals and households affected by learning disabilities that are not currently known to Leeds City Council.

**Citizens Advice Bureau**

- As part of the open Call for Evidence exploring the impact of welfare reform on learning disabilities, CAB should scope out the extent to which other local authorities are failing to provide the care and support that are legally required to. As part of the *Valuing People Now* strategy, each local authority has had to implement a set of objectives and there may be a significant gap in provision nationally.

**Chapeltown Citizens Advice Bureau**

- Develop a training session for Gateway staff and volunteers to establish and judge whether a client has learning disabilities.
- Given the significant level of dependency generated through the service, CCAB should ensure that a minimum notice period of three months is written into the next contract of the caseworker to be part of the *Transforming Day Services* Project.
- Given the important role of trust and continuity, CCAB should endeavour to provide a managed transition from one caseworker to another.
Introduction

Recent work undertaken by the Citizens Advice Bureau (CAB) in Chapeltown suggests that benefit claimants with learning disabilities are not receiving their full entitlement in spite of advice, provision and support from the adult social care community. On the 8th March 2012, the Welfare Reform Act received Royal Assent. As a result, a Universal Credit will be introduced to replace a significant number of mean-tested benefits such as Employment and Support Allowance, Housing Benefit, Income Support and Jobseeker’s Allowance. Components of Disability Living Allowance will also be replaced with a new benefit; Personal Independence Payments. These flagship policies and the structure and funding of the adult social care community will significantly impact upon the lived experience of benefit claimants with learning disabilities.

To fully understand the implications of the Welfare Reform Act and recent changes to the structure and provision of welfare services, it is important to understand the situation as it currently stands. With this in mind, this study will attempt to explain why benefit claimants with learning disabilities are not receiving their full entitlement in spite of advice, provision and support from the adult social care community. In addition, this study will explore how under-provision and under-payment of benefit claimants with learning disabilities affects their overall well-being, finance and health. Reflecting upon this, I hope to explore how the current and forthcoming welfare reforms are likely to impact upon benefit claimants with learning disabilities.

This project aims to validate the collective experience of households affected by learning disabilities. The study also aims to inform the strategic direction and work of the Citizens Advice Bureau in supporting enhanced provision for individuals with learning disabilities. There were three key stages to this research: a consideration of existing research; a summary of CASE report data for 172 cases; and a series of in-depth interviews with individuals from households affected by learning disabilities.

Learning Disabilities: the situation as it currently stands...

There are currently no official statistics detailing the number of people with learning disabilities in the UK. Administrative records are collected by local authorities, educational institutions, Primary Care Trusts and Central Government Departments. However, the data is piecemeal and research suggests that there are often inconsistencies in the collection and use of information. For example, the recorded prevalence of learning disabilities amongst children aged 0-17, is much higher than in the adult population. The administrative records of education, health and social care institutions are more comprehensive and systematic in recording the learning disabilities and needs of children aged 0-17. Within the adult population, the recorded prevalence of learning disabilities drops quite significantly. Given that these statistics are only based on people currently in receipt of care or using support services, this figure in reality is likely to be much higher; ‘it is clear that the majority of adults with learning disabilities simply do not use
learning disabilities services\textsuperscript{1}. With this in mind, there have been a number of attempts to project and estimate the number of people with learning disabilities in England. According to research commissioned by the Department of Health\textsuperscript{2}, it is estimated that 2.29\% of the population or 1.2 million people in England have learning disabilities. Grossing this up, it is estimated that 1.4 million people have learning disabilities in the UK\textsuperscript{3}.

Whilst this is currently the most robust method of estimating the prevalence of learning disabilities, it is often not possible to offer a categorical means by which to identify people with learning disabilities. The World Health Organisations defines a learning disability as a ‘state of arrested or incomplete development of the mind’, moderate to severe learning disabilities are generally those recorded by public regional and national agencies. A broad spectrum of needs faced by individuals make it difficult to identify and quantify the prevalence of learning disabilities. In addition, it is worth noting that there is a significant amount of regional variation in the number of people known to be using learning disabilities services or in receipt of learning disabilities support or care. The Leeds Learning Disability Strategy 2009-2012 applies national projections to the prevalence of learning disabilities in Leeds. However, unique demographic characteristics suggest that the prevalence of learning disabilities could be higher in Leeds than that nationally.

The ethnic composition of Leeds suggests that there may be a higher proportion of people with learning disabilities in need of support, services or care in the local area. There tends to be a higher incidence of learning disabilities in South Asian and Black Caribbean ethnic groups. Recent population estimates released by the Office for National Statistics, suggest that 7\% of the population in Leeds are Asian or Asian British, compared to 6\% in England overall. Within this, there is a particularly high proportion of Pakistanis in the Leeds. This represents demographic changes in the Leeds population over the last decade. Between 2001 and 2009, Leeds witnessed a bigger proportionate increase in the number of Asian or Asian British individuals than London. In 2001, 4.5\% were classified as Asian or Asian British in Leeds but this figure rose to 6.9\% in 2009: a 2.4\% increase. The proportion of Pakistanis grew from 2\% to 3\%, Bangladeshis grew from by 1\% and there was also a minor increase in the proportion of Black Caribbeans during the same period. Whilst, the Leeds Learning Disability Strategy 2009-2012 estimates that around 14,000 people currently have learning disabilities in Leeds, this figure is likely to be higher given the demographic make-up of the area. It is also anticipated that an ageing population will also increase the prevalence of learning disabilities nationally and in Leeds.

\textsuperscript{2} Ibid.
\textsuperscript{3} This figure is based on population projections in England and the UK for 2010.
Learning Disabilities: Deprivation and Social Exclusion

Research indicates that there is a strong relationship between learning disabilities, deprivation and social exclusion. It is important to understand the extent of this relationship. A recent study\(^4\) suggests that disabled people are almost twice as likely to experience poverty: 16% of non-disabled people live in relative poverty as compared to 30% of disabled people. Individuals with learning disabilities are faced with extra costs as a result of their impairment(s): extra expenditure owing to specified or extensive needs, necessary adjustments to their home, the cost of buying support and care services, extra costs of transport services, and so on. When these extra costs are accounted for it is estimated that well over half of all disabled people live on less than 60% of median national income.\(^5\) From this, it is possible to argue that over 50% of people with learning disabilities ‘lack the resources to obtain the type of diet, participation in the activities and have the living conditions and the amenities which are customary or at least widely encouraged or approved in the society to which they belong.’\(^6\) In other words, these individuals face social exclusion; they are unable to effectively participate in day-to-day life because they lack the necessary resources.

Further research\(^7\) indicates that the relationship between learning disabilities and deprivation is particularly strong and immovable. Families who have a child with a learning disability are significantly more likely to be unemployed and experience poverty than families who do not have a child with a learning disability. In addition, the transition into employment and out of poverty for these families is much rarer than for families with children with no learning disabilities. Not only because of fiscal resources, but also because of resources such as time, energy and support, families who have a child with a learning disability struggle to obtain sustainable and flexible employment that accommodates their family needs and also sufficiently remunerates them.\(^5\) The experience of deprivation and social exclusion then is pervasive for a significant proportion of those with learning disabilities but also, those that care for those with learning disabilities.

This is likely to explain why there is a higher prevalence of people with learning disabilities in the most deprived areas of the UK (Please see Figure 1). Indeed there is a very strong linear relationship between area deprivation and the incidence of learning disabilities.\(^9\) There is little difference between


\(^5\) Ibid.


the poorest and the richest areas of England in terms of the incidence of severe learning disabilities. However the incidence of mild learning disabilities gradually increases according to how deprived an area is.

**Figure 1: Prevalence of Learning Disabilities in each decile of IMD**

![Prevalence of LD](image)


Sustainable and flexible employment for people with learning disabilities can often prove challenging and as a result, the experience of deprivation within a given area can intensify. Also, people with learning disabilities are more likely to live in areas with high social housing which are more likely to experience higher levels of deprivation.

In terms of employment, people with learning disabilities are much less likely to engage in the paid labour market when compared to the overall population. Statistics recorded by the National Audit Social Care Intelligence Service suggest that 6.2% of people with learning disabilities were employed in 2010-2011. This compares to 70.3% of the overall population. In Leeds, 69% of people were employed in 2010-11, but only 5.6% of adults with learning disabilities were employed. In Leeds this represents a rise, with 4.6% of adults with learning disabilities previously employed in 2009-10. As already noted, not all those with learning disabilities are known to Adult Social Care services and as a result, the employment rate may well be different for the adult population. Indeed, statistics from the Labour Force

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11 That is, adults aged 18-69 with a learning disability that are known to Councils with Adult Social Services Responsibilities
Survey\textsuperscript{12} suggest that the employment rate may be much higher; with 50% of employed people identifying as having some form of disability and 20% identifying as having some form of learning disability. Perhaps then, the figures from the National Audit Social Care Intelligence Service may be misleading. Irrespective of the measure used, it is reasonable to conclude that there is a stark contrast between the employment status of the overall population and that of adults with learning disabilities and in spite of recent improvement, this contrast becomes even more pronounced when we look to the case of Leeds.

Though undeniable linked, there is no simple causal relationship between learning disabilities and deprivation. Rather, a range of potent demographic and institutional factors coalesce to propagate the experience and severity of deprivation and social exclusion faced by people with learning disabilities. Along with the aforementioned conditions, this affects the health, education and employment outcomes of people with learning disabilities and their surrounding support networks.

\textbf{Welfare and Care: mapping experiences}

As a result, a complex system of benefits exists to support those with learning disabilities and those with caring responsibilities for such individuals. The amount of entitlement available to each individual and carer depends on the level of need and severity of condition. Alongside, adult social care services, this system of benefits intends to play an important role in improving the quality of life and overall well-being of those that may face barriers to effective participation within society. In spite of such provision however, 6% of all those that receive disability benefits are still below the relative poverty line (Please see Figure 2). Moreover, the proportion of people receiving disability benefits below the relative poverty line has increased over the years from 2% in 1995/96, rising to 8% in 2006/07 for a number of years and falling to 6% in 2010/11. In addition to this, the care and support provided by adult social care services does not always seem to effectively safeguard and improve the well-being of individuals with learning disabilities and those with caring responsibilities for such individuals.

\textsuperscript{12} Labour Force Survey 2007, ONS, \textit{HMSO?}
Undoubtedly, such services play a vital role in the lived experience of households affected by learning disabilities. However, according to the Personal Social Services Adult Social Care Survey for 2010-2011 (Please see Table 1), 11% of people in receipt of support or care still rate their quality of life as bad on the whole. Those in receipt of care with learning disabilities varying in a number of respects to those in receipt of care more generally: they are less likely to rate their quality of life as bad on the whole, less likely to feel that they have adequate social contact with people and also less likely to find it difficult to find information/advice about support, services or benefits. With this in mind, it would appear adult social care services at a national level are succeeding in a number of respects to meet the needs of those with learning disabilities, but more needs to be done to provide opportunities for social integration.

Looking to the case of Leeds, the available data cannot give further details about the experience of care users with learning disabilities in Leeds. Looking more generally at care users of Leeds City Council’s Adult Social Care Services though, it is possible conclude that Leeds is not performing as well as other local authorities. Those in receipt of care that receive adult social care services in Leeds seem to be less satisfied than those in receipt of care nationally in a number of respects: they are more likely to be dissatisfied with the care and support services they receive; more likely to be unhappy with the way they are helped by staff; more likely to rate their quality of life as bad on the whole; and also more likely to find it difficult to find information and advice about support, services and benefits.
Table 1: Summary of Results from the Personal Social Services Adult Social Care Survey for 2010-2011

<table>
<thead>
<tr>
<th></th>
<th>England</th>
<th>Leeds</th>
<th>Learning Disability</th>
<th>White</th>
<th>Asian or Asian British</th>
<th>Black or Black British</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dissatisfied with care and support services received</td>
<td>3.6</td>
<td>4.0</td>
<td>3.7</td>
<td>3.4</td>
<td>5.8</td>
<td>8.6</td>
</tr>
<tr>
<td>Unhappy with the way they are helped by staff</td>
<td>2.2</td>
<td>7.0</td>
<td>2.3</td>
<td>2.2</td>
<td>4.1</td>
<td>2.4</td>
</tr>
<tr>
<td>Rate my quality of life as bad on the whole</td>
<td>11.0</td>
<td>13.1</td>
<td>4.9</td>
<td>11.4</td>
<td>14.7</td>
<td>16.4</td>
</tr>
<tr>
<td>Have adequate social contact with people</td>
<td>35.6</td>
<td>35.4</td>
<td>29.9</td>
<td>35.7</td>
<td>35.7</td>
<td>30.4</td>
</tr>
<tr>
<td>Found it difficult to find information/advice about support, services or benefits</td>
<td>19.2</td>
<td>24.9</td>
<td>17.6</td>
<td>18.6</td>
<td>26.9</td>
<td>25.5</td>
</tr>
</tbody>
</table>

Care users from BME groups are also less likely to be: satisfied with the care and support services received; the way they’re helped by staff; their quality life on the whole; and feel it is particularly difficult to find information and advice about support, services or benefits. Given the ethnic diversity of Leeds, particularly in area of Chapeltown, this may come some way to explain why benefit claimants with learning disabilities are not receiving their full entitlement in spite of advice, provision and support from the adult social care community.

According to recent data, those with learning disabilities are also less likely to receive community care assessments in a timely matter. In 2010-11, the length of time between a first contact and completed assessment was much higher for clients with learning disabilities as compared to all client groups. For all client groups, 62% of clients had a completed community care assessment within two weeks of the initial contact. For those with learning disabilities this figure dropped to 47%. Whilst this is a worrying disparity in need of redress; it is already an improvement on previous years when only 41% of those with learning disabilities had a completed community care assessment within two weeks of the initial contact in 2008-2009. In 2010-2011, only 6% of all new completed assessments took over 3 months; for clients with learning disabilities, this figure rose to 17%. Again, this is an improvement on previous years when it was 20% for those within learning disabilities in 2008-2009. Nevertheless, this would suggest that care recipients with learning disabilities are not receiving their assessments in a sufficiently proactive manner as compared to other client groups.

In recent years, Adult Social Care Services in Leeds have suffered a reduction in the level of investment and financial support. Expenditure on

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13 The response rate to this survey was 40% for England, but the response rate for Leeds was only 33%.
14 Community Care Statistics via the NHS Information Centre for Health and Social Care 2010-2011
Residential personal social services has dropped significantly, from £28.6 million to £22.5 million between 2008 and 2011. Gross expenditure for residential personal social services per 1,000 people with learning disabilities has fallen from 17.91 to 12.64\(^{15}\) during the same period. This may come some way to explain some of the disparities in the experience of care recipients in Leeds, those with learning disabilities and point to potential differences in the community care assessments received by those with learning disabilities and other client groups in Leeds.

The Leeds Learning Disabilities Strategy 2009-2012 does endeavour to ‘work beyond the traditional boundaries of social care such as housing, benefits, leisure…’ and also recognises that self-directed support can only work when those with learning disabilities ‘know how much money they are entitled to spend on their support.’ However, the reality is that many carers and individuals with learning disabilities are not aware of their welfare and care entitlements. In this sense, Chapeltown Citizens Advice Bureau plays a crucial role in offering advice and information to carers and individuals with learning disabilities who may not be aware of their current entitlements. In many respects, CCAB can be seen as a crucial player in ensuring that Leeds City Council delivers on its high level action plan to meet the Valuing People Now Strategy.

**Chapeltown Citizens Advice Bureau and Transforming Day Services**

Citizens Advice Bureau is the largest advice provider in the UK, dealing with 7.1 million problems every year. The largest proportion of these enquiries is related to debt, then benefits and tax credits and then issues of employment. The number of enquiries regarding benefits and tax credits has risen significantly since the economic crisis and recent austerity measures of the Coalition Government. Between 2008/09 to 2010/11, CAB witnessed a 26% increase in enquiries regarding benefits and tax credits rising from 1.7 million to 2.2 million. As a proportion of all enquiries nationally, this represents an increase from 28% to 31% (Please see Table 2). Chapeltown Citizens Advice Bureau witnessed a 19% increase in enquiries related to benefits and tax credits between 2008/09 to 2010/11. As a proportion of all enquiries, this was an increase from 31% to 38%. There has been a particular rise in enquiries related to Disability Living Allowance; both the carers and mobility component, Carers Allowance and Employment and Support Allowance. There has been a reduction in enquiries related to Incapacity Benefit but this is to be expected given the transition from IB to ESA provision since January 2011.

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Table 2: Percentage difference in the number of enquiries received about selected benefits and tax credit from 2008/09 to 2010/2011

<table>
<thead>
<tr>
<th>Component</th>
<th>CAB: National</th>
<th>CCAB: Chapeltown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incapacity Benefit</td>
<td>-57.7%</td>
<td>-68.4%</td>
</tr>
<tr>
<td>DLA-Care Component</td>
<td>+29%</td>
<td>+31.6%</td>
</tr>
<tr>
<td>DLA-Mobility Component</td>
<td>+29.5%</td>
<td>+36.5%</td>
</tr>
<tr>
<td>Attendance Allowance</td>
<td>+9.8%</td>
<td>-25.2%</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>+29.8%</td>
<td>+11%</td>
</tr>
<tr>
<td>Employment Support</td>
<td>+714.2%</td>
<td>+1236.6%</td>
</tr>
</tbody>
</table>

Between 2010 and 2011, 690,000 clients were helped with a range of issues related to benefits and tax credits by Citizens Advice Bureau and half of all advice concerned client’s eligibility to entitlements to unclaimed benefits or tax credits. In addition to this, enquiries regarding Health and Community Care nationally have risen by 12% between 2008-2009 and 2010-2011, and have risen by 26% during the same period at CCAB. A growing number of the enquiries dealt with by CCAB are indisputably related to benefit, tax credits and health and community care. This is in part due to the economic crisis and recent austerity measures of the Coalition Government. In addition though, this is due to new programmes run by Citizens Advice Bureau such as Transforming Day Services that are raising awareness of welfare and care entitlements amongst vulnerable and challenged groups of the Leeds community.

As part of the Leeds Learning Disability Strategy 2009-2012, Leeds City Council is committed to ensuring that people with learning disabilities will have a choice about what they do during the day, evenings and weekends. As a result, Day Centres are being modernised and ‘transformed to offer meaningful activities based on individual choice’. In addition, the activities of day centres have been designed so that they are more community-centred – enabling the customer with learning disability to engage with the activities and facilities that their local community has to offer. This is part of a broader shift to empower people with learning disabilities to pursue the life they want to lead and also integrate them into their local community, thereby tackling the social exclusion of many vulnerable groups within the Leeds community. To assist with the transition, Leeds City Council commissioned Chapeltown Citizens Advice Bureau in May 2010 to run a service that has been developed as an integral part of the modernisation of day services for people with learning disabilities. It is a generalist advice service to ensure client needs and concerns regarding their benefit and health and community care entitlements are proactively dealt with by a dedicated caseworker. The service has been running from CCAB office but a significant amount of outreach work has also been done across Leeds.

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16 Extracted and summarised from CASE report data.
This service has been well-utilised by customers across Leeds with individuals with learning disabilities, carers, social and support workers, nurses, adult social care services and even social enterprises utilising the service. Drawing upon the knowledge, skills and expertise of the dedicated caseworker, this has served to ensure that any individual or household affected by learning disabilities receives the welfare, benefit and care entitlements that they are due in both fiscal and non-fiscal terms. As a result of this service over £250,000 of monetary gains for customers have been made so far. In addition, a significant amount of care and respite care has been secured for households and individuals affected by learning disabilities. CCAB is providing a particularly crucial service for vulnerable individuals that may not be aware of their welfare rights and entitlements as a carer or individual with learning disabilities. The service is currently funded until March 2013.

Having read through the CASE report data and notes for 172 enquiries arising out of this service, I have coded or used existing codes to summarise the key demographic and advice information under Transforming Day Services. Out of the 172, two thirds (66%) of enquiries were regarding benefits. A further 13% were regarding health and community care. It should be noted, that many of the enquiries were not necessarily mutually exclusive, an enquiry principally regarding benefits for example, may also be related to other issues related to debt, employment, and so on. In comparison to the enquiries that CCAB normally deals with, enquiries related to benefits and health and community care are grossly over-represented. Normally, around 29% of enquiries that CCAB deals with are regarding benefits compared to the 66% of enquiries arising out of Transforming Day Services. Similarly, only 1% of enquiries are normally regarding health and community care at CCAB, compared to 13% of enquiries arising out of Transforming Day Services. Perhaps this is not surprising given the demographic and institutional factors that coalesce to shape the lived experience of people with learning disabilities. But of course it also reflects the remit of Transforming Day Services.

Under the project, the demographic profile of clients tended to be older than the clients normally seen by CCAB, with 28% of clients aged 65 or over compared to only 7% normally. Principally, there were fewer people that were between 17-34, with only 7% of this age range, compared to 34% normally. There was an over-representation of females also with 65%, whereas normally there is an equal split between males and female seeking advice provision from CCAB. In many cases, the carers of clients with learning disabilities are enquiring about the benefit entitlements of an individual with LDD but also about their benefit and care entitlements as a carer themselves. A disproportionate number of these carers are female.

Unsurprisingly there is a significant over-representation of those with learning disabilities: 45%, compared to 1% normally. Only 10% of clients

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18 This is looking at case data available for enquiries within the financial year 2010-11.
were employed, as compared to 29% normally which supports the suggestions previously made about the employment outcomes of households affected by learning disabilities. 22% were carers of someone that was elderly or disabled as compared to 1% normally. 50% were permanently sick or disabled as compared to 4% normally. 12% were retired as compared to 7% normally. Normally, only 26% of clients visiting Citizens Advice Bureau in Chapeltown are white, but this figure rises to 80% for those clients receiving advice via Transforming Day Services. This may well be something to do with the referral process and also who attends previously open Day Centres such as Moorend.

**Research Findings**

As stated at the outset of this report, this study aims to explore some of the potential impacts that current and forthcoming welfare reforms will have on households affected by learning disabilities. Exploiting the rich set of information that has come out of the Transforming Day Services project, qualitative interviews have been taken up to understand:

- the mechanisms and processes by which individuals with learning disabilities and their carers can come to secure their care and welfare entitlements;
- the personal and organisational barriers to this process;
- how under-provision of care and under-payment of benefit claimants with learning disabilities affects their overall well-being, finance and health.
- the institutional and practical lessons to be learnt at the level of Central Government, Leeds City Council and Chapeltown Citizens Advice Bureau.

In addition to analysis of the CASE report data, seven in-depth interviews with individuals with learning disabilities and/or carers have been conducted, an informal observation of a community-centred activity, a visit to a day centre, informal discussion with day centre manager and a visit to a resource centre. These activities were undertaken all over Leeds with a mix of genders, ages and ethnicities. The severity of learning disabilities varied, only two of the interviews were undertaken with LDD clients themselves and these individuals had mild learning disabilities. In situations where a client had more severe learning disabilities, the carer was interviewed in conjunction or on their behalf. Each of the in-depth interviews lasted between an hour and an hour and a half. The interviews covered areas of interest such as; understanding of welfare entitlements; the impact of previous and current welfare and care arrangements; Adult Social Care Services and the support and care made available; and finally, understanding of the current and forthcoming welfare reforms. Due to the significant amount of data collected and the time constraints of this study, it has been necessary to be pragmatic in the analysis and presentation of the data. The issues arising from analysis of the CASE report data and qualitative fieldwork are dealt with thematically. Whilst they may follow on from one another this may not always be the case. Each of the issues arising out of the primary research will now be discussed in turn.
The lived experience of learning disability

The needs and challenges faced by those with learning disabilities vary according to the severity and qualities of their condition. Those with mild learning disabilities will have very different life experiences to those with severe learning disabilities. The role of carers and care support also differs accordingly. Those with learning disabilities often live with relatives for prolonged periods of time and relatives often serve a crucial function as principle care-givers. As such, it is useful to explore the impact of learning disabilities not just on individuals and carers but also families and households. Respondents with mild learning disabilities were generally coping with the day to day running of their lives. However, they often described ‘crisis points’ that occurred due to a lack of support or help. Whilst they acknowledged the importance of this support and guidance, they were also keen to emphasise their own independence. In addition, respondents with mild learning disabilities expressed some frustration with the time it took to do things and get them resolved. This was often blamed on inflexible institutions, practices and services.

Having spoken to only two people with learning disabilities, it has not always been possible to ascertain the experience of this group directly. In many instances though, it has been possible to speak to the principle carers and relatives of those with learning disabilities. In all cases where a client had a severe learning disability, the vast majority of affairs have been dealt with by the principle carer. Invariably this tended to be a relative. The affairs dealt with by a principle carer included activities such as daily grooming, bathing, financial management, nutritional intake and so on. According to many of the carers interviewed those with severe learning disabilities would not be able to identify the impact of their condition as they were born with it:

“He don’t know any different…”

In contrast, carers were much more likely to be able to identify the impact of the learning disabilities for themselves and their household. Many suggested that it had caused significant stress and fatigue owing to the level of care that severe learning disabilities necessitate:

“He can’t make a meal, I do everything for him. I do all of his medication with him. And the bathing and grooming for him… I run the bath and I have to wash him and I can’t leave him on his own…there is no chance of him making financial decisions…he doesn’t know the value of money…you have literally got to watch him all the time.”

Not only does this involve a greater amount of work for the carer, it often involves increased costs to the household overall. The condition of having a learning disability means that many individuals with learning disabilities and those with caring responsibilities incur extra costs as a result of the condition. According to one case, a client sweats excessively both night and day and as a result has to change their day clothes, night clothes and bedding frequently which results in additional laundry with the washing
machine used at least once per day. The client also uses an excessive amount of toilet tissue (1 roll per day) partly because of a lack of understanding on his part and also because he 'eats constantly' and has to use the toilet more often than normal. The client also uses a lot of tissues (1-2 boxes per week) as he takes far more than he needs each time. He occasionally soils himself requiring bathing and laundry. He uses excessive amounts of toiletries in the shower - shower gel (1-2 bottles per week) and deodorant (1 can per week). His excessive and constant eating means a great deal of extra food shopping as well. Cases such as this illustrate the significant and mounting costs that having a learning disability can incur. Some of it is routine aspects of life such as washing, laundry and heating:

“He can go through a wardrobe of clothes in a day so…I can have basically 10 pairs of underwear over two days easy…I don’t want this to sound awful but the amount of toilet roll we go through is unbelievable…his bed can be changed two or three times a week.”

Other more significant costs are associated with replacing or fixing damaged furniture and white goods such as washing machines, dryers, freezers, sofas, and televisions:

“The dryer’s just gone again so need a new dryer. James rocks on the beds so you got to buy a new bed about every 12 months and I don’t know how he does it but he seems to pull draws apart. So you get him the big heavy ones thinking they’ll last longer and they don’t. Televisions as well: he goes through a telly like nobodies busy…he seems to break electrical things.”

In some instances, these extra costs are incurred due to behavioural problems or compulsive habits such as repeatedly performing a task. In other instances, a client has little concept of space or ‘being careful’ or just being ‘heavy-handed’. The root cause of this though is a poor level of understanding. Owing to the extra costs that this can incur, many more households that are affected by learning disabilities are likely to face poverty than is officially projected (Please see Figure 2)\(^{19}\). A number of the families and carers that were interviewed stated that their opportunities for financially rewarding employment\(^{20}\) were limited due to their caring responsibilities. Having to juggle paid employment and looking after or assisting those with learning disabilities meant it was a challenge. As a result, financial situations were always tight and often bad with people getting into debt:

“We’ve got more going out than coming in…it really is a struggle.”

“At the moment I haven’t got a sofa cos I’ can’t afford to buy a new one.”

In many instances, respondents with caring responsibilities wanted to earn more money and take on more work to try to cope with extra costs. However, many expressed frustration, that they wanted to work more but were unable to do so. A number of challenges and barriers presented


\(^{20}\) Note that there was no reference to employment being self-fulfilling
themselves to people. First and foremost was the challenge of balancing significant and demanding caring responsibilities with paid employment. Then, there was a concern with the quality and level of care available for people with learning disabilities and the significant costs that this care might incur. Concerns were also raised that wages were not high enough and concurrently that working or working more hours might result in benefit insecurity. As one respondent with caring responsibilities noted:

“I got a part-time job I go on a night. I only do a little cleaning job. I get £110 a week but that doesn’t affect my Carers [Allowance]. Anything I earn over that they take off me then in tax because I’m only allowed to do so many hours which is really annoying... I still got my mortgage to pay... because of them restricting me doing my work they have to pay me more – when you explain it to them they don’t seem to understand that.”

Balancing caring responsibilities with paid employment means that many respondents with caring responsibilities struggle to find flexible enough employment opportunities:

“See Joe [LDD client] is at the Centre during the day so I could get a job during the day but I’d have to get something where I could get in after 9:30 and be back home for Joe by 3:30 so it’s finding a job in them hours. It’s a disincentive to work more if you wanted to...oh definitely.”

In spite of the significant activities involved in caring, many carers were keen to take on paid work to offset the rising outgoings of their household. However, due to significant caring responsibilities, poor financial incentives, high marginal tax rates and poor flexible working options, the majority of carers did not work or only worked part-time. The significant costs associated with learning disabilities, poor employment opportunities and the residual level of many benefits mean that many households affected by learning disabilities are faced with the prospect of restrictive living and caring conditions. This is detrimental to the well-being and finances of the family, carer and person with learning disabilities. In addition, it threatens the autonomy of the person with learning disabilities in many respects as their own benefits are subsumed into the running costs of a house that can no longer financially support itself due to the aforementioned challenges:

“Richie ends up paying a little more than he ought to really but what can you do?”

**Importance of Benefits**

Owing to the aforementioned conditions, participants are heavily reliant on the social security payments they receive from Central Government and the discounts and subsidies delivered via Leeds City Council. Participants receive a wide range of benefits for various reasons. For those with learning disabilities; entitlement to Disability Living Allowance components, Employment and Support Allowance, Attendance Allowance, Income Support and Tax Credits vary according to the severity of the condition and
financial income and capital of the claimant. For those with caring responsibilities; entitlement to Carers Allowance varies in a similar capacity. Other mean-tested benefits including Housing Benefit, Council Tax Benefit, Direct Payments and Pension Credit all serve a crucial function for households affected by learning disabilities. All respondents emphasised the significant impact these benefits have on their daily lives, increasing their capacity to lead a ‘decent’ life.

Whilst all participants, were keen to emphasise the important role social security payments and local discounts and subsidies played, many were not able to articulate why they receive the amount and components that they currently do. Understanding of benefits is mixed amongst carers and those with learning disabilities. In some cases, understanding was extremely poor with people unaware of their benefit and welfare entitlements for more than twenty years. Until interventions involving CCAB, these individuals were unaware of the financial support and care available to them. This has greatly improved the quality of life of many individuals with learning disabilities and carers. In this capacity, benefits are helping cover the extra costs incurred by running a household affected by learning disabilities. These benefits provide a vital baseline for many households affected by learning disabilities. This is illustrated in the comment of participants reflecting on the absence of such financial provision:

“If we didn’t receive this? Basically Olivia wouldn’t be able to do half of what she does now because she would rely on us and to a certain extent she’s still fortunate that she’s got us, because I know she works with people that don’t have the family support.”

“I don’t think we’d be able to cope at all because you know to feed him as well because he’s such a big lad… so I would never cope cos I’m just retired myself no we wouldn’t be able to manage at all without the benefits that we get right now.”

For one participant with learning disabilities, benefits enabled them to lead a fulfilling life and not feel socially isolated or excluded, which is a key objective of the Valuing People Now Strategy:

“I like going out, Gemma [carer] takes me fun places – the bowling is fun and Charlie [a friend] comes too”

A number of participants were also concerned about the low level of benefit that they were currently entitled, stating that this was not enough to cover the significant costs of caring for someone with learning disabilities:

“Carers [Allowance] money is a joke, it really is – it don’t even touch nothing. I don’t know what it’s supposed to do honestly I really don’t. I think you should get more carers money and that’s for somebody who needs a lot of care.”
Importance of Care, Advice and Support

The care, advice and support available from Leeds City Council and Adult Social Care Services plays a vital role in safeguarding the well-being of households affected by learning disabilities. Not only for those with learning disabilities, but also their carers. Commenting on the care provided by Day Centres, one carer noted how this care creates space and time to get things done for those who rely on the ‘free time’ to undertake paid employment or undertake household chores or errands.

“I can get stuff done that I need to get done, whilst he’s at the Centre.”

All participants were positive about the integrative potential of the Day Centres that often enable those with learning disabilities to undertake activities and interact with people that they would otherwise not be able to. For some participants, the transition from Moorend Day Centre to the smaller centres has not been a wholly pleasant or successful experience. Some clients were particularly hard hit by the transition with a number feeling unsatisfied with the level of support.

A number of carers suggested that they would like to know more about what was happening on a day to day basis at the Day Centres as the person they cared for was unable to communicate with them. The same participants also remarked that the level and consistency of communication has deteriorated since the transition from Moorend to other Day Centres. One participant speculated that this was caused by under-resourcing, with the same number of staff but a greater number of clients in each Centre. In spite of this, participants tended to be positive about the care provided by Day Centres and were worried what they would do without such a service and the repercussions that this could have:

“He’d be stuck in the house 24/7 if he didn’t have the activities and I’d be stuck in house with him… I do find it very stressful, he was at home for nearly 8 month before they set all this up and it were very hard.”

“I don’t how I would cope [without the care from Day Centres] because I need some time for me don’t I? … I don’t think he would like it at all…staying at home all the time wouldn’t do him good.”

“He’d deteriorate I’d imagine, if he didn’t go to the centre.”

There were mixed reactions to the support provided by Leeds City Council. Some participants felt that they didn’t receive any or sufficient support from Adult Social Care Services. It was felt that support and social workers were not always sufficiently present to be able to adequately monitor the condition and situation of those with learning disabilities and those with caring responsibilities:
"We just rang in and had the name changed. Nobody asked any questions... nobody came out to assess us. Nothing. That was it, just a phone call 15 years ago."

Other participants felt that the interaction that they did have with Adult Social Care Services was unsatisfactory. It was felt that support and social workers did not always spend a sufficient amount of time assessing and understanding the needs of clients and carers. This is something reflected in the results from the Personal Social Services Adult Social Care Survey in the differences between National satisfactions scores and those of Leeds (Please see Table 1). It is also reflected in some of the comments participants:

“I get upset when they don’t listen...always rushing in and out.”

“He’s been going there just over a year and still hasn’t settled because you know he was going to Moorend for twenty years before. He was settled there. You can’t really sit him down and explain any situation to him... it was really tough on him. We all knew about this change for a long time you know and erm we as a family tried to say to the people who were really in charge of the moves and everything how to cope with this thing with Joe you know... what to do to try and introduce him but they did nothing whatsoever. They did not listen they took it for granted that they can just pick him up and put him down.”

One carer commented on what they feel is a lack of social work support, over many years. This particular carer was offered respite care in the past, but was unsure about what this entails and was concerned about not knowing where their relative with LDD would be placed and who with. Another carer also mentioned that her brother has had little support from Adult Social Care Services and last had a care assessment over 3 years ago. In contrast to these cases, two participants felt that the care and support provided by Adult Social Care Services was of a very high standard. It is noteworthy that these two participants were carers and were particularly proactive in their engagement with Adult Social Care Services. This may say something about the necessary approach to services and support targeted at those with learning disabilities and those with caring responsibilities. This will be discussed shortly.

**Resources and Information**

Firstly though, it’s important to reflect upon the availability and accessibility of resources for those with learning disabilities and those with caring responsibilities. There are currently two Resource Centres in Leeds open to the general public but also targeted at households affected by learning disabilities. Speaking with a member of staff in one of these Resource Centres, it is apparent that the information and advice available for those with learning disabilities and those with caring responsibilities is under-utilised. As previously stated, some people’s understanding of their welfare and care entitlements is particularly poor. In a number of instances, this
inhibits participants from seeking out the resources and information that may help them:

“If I had to set about trying to sort Rachel’s’ benefits out again, I don’t really know where I’d go because I know it sounds daft … I didn’t know I had to go to HMRC for Tax Credits... I wouldn’t have thought in my head that that’s where I’d go to sort out Tax Credit... so I don’t know off hand where I’d go to start looking at her benefits... I don’t know.”

There are inconsistencies in access to and provision of resources and information. The two participants that were particularly engaged were also the most inclined to feel that enough information was available to them:

“Yes there’s enough information provided. Right now we got to a point where Olivia now gets the maximum support... I don’t think there’s anything else there that we can claim...”

“They send me newsletters every so often so I can get in touch with them if I need to.”

Other participants were less positive and stated that they would like more information and advice on resources and support available. Some stated that they had received no information or guidance in years. Perhaps it is reasonable to conclude that those with learning disabilities and those with caring responsibilities need to be more proactive in accessing the resources and information that is already available.

Proactive engagement with service users and clients

However, speaking with a Day Centre manager it was suggested that Leeds City Council should not expect those with learning disabilities and those with caring responsibilities to proactively seek care, advice, support and information. According to the Day Centre manager, many clients are more concerned with ‘getting by’ and coping with day-to-day life rather than speculating about the future and what might be available to them. Reflecting on this situation, the manager felt that Leeds City Council cannot rely on clients to contact and access resources, particularly if they have low levels of understanding. Rather it was suggested that Adult Social Care Services need to take a more proactive role in assessing the needs and capabilities (financial or otherwise) of households affected by learning disabilities. It was felt that this was the most effective and appropriate means by which Leeds City Council could allocate and provide care, advice, support and information. In support of this, a number of carers and participants with learning disabilities felt that Leeds City Council could do more to check in with people and ensure that they’re okay:

“Nobody checks... I coulda done Richard in the day he came to live here and nobody would have known... obviously you do it but nobody ever checks to see whether you’re taking him to the dentist or optician...”
For those with significant caring responsibilities or those with particularly severe learning disabilities, Adult Social Care Services then must proactively rather than reactively engage with service users and clients. A particularly important objective is to identify and contact those individuals and households that are not currently known to Leeds City Council. In addition the council must take sufficient steps to ensure that households affected by learning disabilities are receiving the correct welfare and care entitlements. In many ways the generalist advice service provided by Chapeltown Citizens Advice Bureau under Transforming Day Services fulfils this role. Prior to this however, speaking with clients and assessing CASE report data, it would appear that Leeds City Council has been in breach of provisions issued under Section 7 of the Local Authority Services Act (1970). Re-affirmed in Guidance on Fairer Charging Policies for Home Care and other non-residential Social Services released by the Department of Health, it states that:

*Councils should ensure that appropriate benefits advice is provided to all users of non-residential social services and carers services at the time of a charge assessment... any charge assessment should be focused on the user's overall finances and personal needs. It will normally need to be carried out by personal interview in the user's own home by appropriately skilled staff. The service should include advice about entitlement; help with completion of benefit claims and follow-up action, if the user wishes.*

Essentially, all local authorities with social services responsibilities are obliged to take account of disability-related expenditure when assessing the level of community care charges for service and client users. The local authority must also proactively provide benefit advice and information to ensure that clients are receiving what they are currently entitled to.

Analysis of CASE report data and interviews reveals that there have been a significant number of cases of excessive community care charges, whereby disability-related household costs have not been accounted for. In addition, complaints from various clients and service users suggest that the Financial and Assessment Benefits process is being conducted inconsistently across Leeds with some clients receiving a great deal of support and help whilst others are completely unaware of the FAB process in itself, let alone the advice and provision that should feature as part of it. To some extent, the level of support and information received seems to vary according to the relationship between the client, carer and social worker. One participant who had quite regular and consistent contact with a social worker said:

*"I trust her [social worker] to make decisions about benefits and keep me informed about what's what."*

This participant spoke with a member of staff from Adult Social Care Services at least once a month and knew who to contact and how to go about it if she had any queries. Unsurprisingly, this participant was satisfied with the level of support received during the Financial Assessment and
Benefits process. In contrast, other participants had never had any help or support with benefit and care entitlements.

Those who had received an assessment also found that the level of support received varied according to who undertook the assessment and the amount of time allocated for their appointment. In one assessment for example, one carer felt that the assessment was ‘rushed’ and the person undertaking it did not ask many questions about the client’s learning disability and the expenses related to it. With this in mind, a concerted effort needs to be made to ensure that the Financial and Assessments Benefits process is consistent for all clients and service users. Adult Social Care Services need to adequately train staff to approach and offer advice to clients. Failing that, staff should be consistently referring clients to the Transforming Day Services advice provision to ensure that the welfare and care entitlements of clients and carers can be protected.

**Continuity and Contingency**

Whilst interviewing participants, it became apparent that the individual biographies of those with learning disabilities and those with caring responsibilities inevitably shaped the care and support that they needed. Some participants emphasised the importance of continuity when interacting with Adult Social Care Services and any advice provision and support. Many of the clients known to Adult Social Care Services are greatly dependent upon their carers and the staff employed by Leeds City Council. With this dependency, comes a certain level of trust. Often an implicit agreement exists between Leeds City Council, the client and potentially their carer. All three parties tacitly cooperate to safeguard the well-being of households affected by learning disabilities. A trust and rapport between all three parties is developed over a prolonged period of time. The trust and rapport developed between the specialist caseworker at Chapeltown Citizens Advice Bureau and all three parties has also proven crucial in implementing the new generalist advice service. Without this trust and rapport, the specialist caseworker would not have been able to access so many clients and secure their welfare and care entitlements. With this in mind, there needs to be some level of continuity between the specialist caseworker and their interaction with all three parties.

As such it is important that caseworkers are employed for a sufficient amount of time to be able to develop and nurture the links between CCAB, Leeds City Council, clients and carers. In addition, CCAB needs to develop some sort of contingency plan in the event that the specialist caseworker leaves or there are significant changes to the services offered by Leeds City Council. Gaps in advice provision and ruptures in the continuity of services threaten the compact between all parties and have the potential to damage any trust and rapport developed over time, further isolating households affected by learning disabilities.
**Time**

If Leeds City Council and Chapeltown Citizens Advice Bureau want to improve the experience and satisfaction of clients, both institutions need to account for the extra time that is very often necessary when dealing with households affected by learning disabilities. As an illustration; for enquiries handled between 2011 and 2012, the average amount of time dedicated to each in CCAB was 99 minutes. Under *Transforming Day Services*, the average amount of time dedicated to each enquiry was 121 minutes. For general queries where a client had some form of learning disability, the caseworker has dedicated 177 minutes on average to the enquiry. In addition, a significant minority of these individuals also had more than one enquiry/issue to be dealt with.

As previously noted, a number of clients feel that social and support workers often rush them without fully considering disability-related expenditure during the Financial Assessment and Benefits process. In addition, a number of participants felt that Adult Social Care Services did not completely understand their needs and capabilities as a person living in a household affected by learning disabilities. Given the greater amount of time that it takes to deal with these enquiries, Leeds City Council and CCAB may need to factor this into the implementation of their services and advice provision, particularly with forthcoming welfare reforms.

**Individualisation and independence**

As part of the *Valuing People Now* Strategy, Leeds City Council is encouraging a certain level of independence and individualisation when it comes to the provision and design of Adult Social Care Services. This reflects a broader trend towards empowering those with learning disabilities. Rather than viewing clients as passive recipients of welfare and care, there is a shift in policy rhetoric to enable clients to be active citizens and consumers by part-taking in community-centred activities. The provision of Direct Payments and the proposal for Personal Independence Payments suggests that those with a learning disability are no less capable of deciding and defining the services and care they receive than any other client. Whilst all participants thought that this was a positive step in principle, a number of participants raised concerns about the concept of independence and its principles:

“It would be lovely if he could do it, if you weren’t as affected as Olivia it’d be lovely – but for Olivia she hasn’t got any idea.”

“He couldn’t manage to live independently – he couldn’t; he always needs you know lots of support.”

“Independence? But everybody is so different you know everybody does not fit into a mould and I don’t think it’ll suit everyone…”

Whilst participants with caring responsibilities recognised the importance of client empowerment, they were not always convinced that those with
learning disabilities had the capacity to make the decisions that served their own interests.

“[Commenting on Day Centre staff] They don’t understand his condition very well sometimes… he’s got rights, but come on. I mean he’s got a right to cross the road but if you let him do it… he would hurt himself.”

Whilst there were concerns about the independence agenda, all participants were positive about the prospect of Leeds City Council involving welfare and care recipients in the design and delivery of Adult Social Care Services. In many respects, this can be seen as fulfilling attempts to empower clients to not accept things at face value and take ownership of their own affairs. Several participants felt that advice provision from Chapeltown Citizens Advice Bureau had enabled them to do that.

Conclusion

Transforming Day Services currently provides crucial assistance to households affected by learning disabilities. The provision of advice, guidance and support to these households has had a number of positive outcomes. It has;
- Enabled some individuals with learning disabilities to enter the workplace for the first time with better financial outcomes.
- Enabled some carers to balance paid employment with caring responsibilities.
- Encouraged Adult Social Care Services to assess the needs and capabilities (financial or otherwise) of households affected by learning disabilities more systematically.
- Supported and empowered individuals to make informed decisions about their finances and affairs.
- Secured over a quarter of a million pounds in welfare and care entitlements.

More generally, CCAB’s specialist advice provision has come some way to address a series of institutional problems within Leeds City Council’s Adult Social Care Services. These problems principally concern clients not receiving the correct community care charges for non-residential care services and not being given sufficient advice and information regarding their welfare and care entitlements during the Financial Assessments and Benefits process. To this end, Transforming Day Services has ensured that Leeds City Council follows Guidance on non-residential care services released by the Department of Health, and also meets the provisions under Section 7 of the Local Authority Services Act (1970).

Arguably the most important but least tangible outcome of Transforming Day Services is the experience of support in its fullest meaning. During fieldwork, all participants spoke very highly of the services and help they had received from Chapeltown Citizens Advice Bureau. Many participants found comfort in the idea that a specialised service was available to them when they needed it. With the transition to community-centred activities and the
forthcoming changes to welfare and care entitlements, this service will become even more important. In this sense, *Transforming Day Services* has the capacity to equip clients and Leeds City Council to deal with the forthcoming welfare reforms.

All participants that were aware of the forthcoming changes to welfare and care entitlements expressed concern over the future and the prospects for the well-being of their household affected by learning disabilities. Others who learnt of the proposed changes during the interview also expressed great concern:

“I know there may be people out there that choose to play the system but people like my son do not play the system – that’s how he is. He has been this way from birth and there’s nothing he can do about it… if they’re threatening to take away any benefits anyway… I dread what’ll happen to us.”

The continuation of *Transforming Day Services* will enable clients to understand and proactively engage with the forthcoming welfare reforms. As previously stated, a Universal Credit will be introduced over the coming years to replace a significant number of mean-tested benefits such as Employment and Support Allowance, Housing Benefit, Income Support and Jobseeker’s Allowance. In addition, Personal Independence Payments are set to replace certain components of the Disability Living Allowance. Concerns have already been raised about the value of current benefits. As the CASE report data and interviews illustrate, the benefits people are presently entitled to, do not always sufficiently cover the costs incurred by those affected by learning disabilities. Worryingly, the value of Universal Credit and Personal Independence Payments is anticipated to fall in real terms over the course of their implementation. This will make the lived experience of learning disability even more challenging for those with the condition and those with caring responsibilities. Households affected by learning disabilities are already struggling on the residual level of benefit that they currently receive. With forthcoming changes to welfare entitlements that include benefit and housing caps, it is increasingly important for Adult Social Care Services to approach the Financial Assessments and Benefits process rigorously and methodically. In doing so, Leeds City Council can ensure that disability-related household costs are accounted for in community care charges and households affected by learning disabilities receive a full assessment of their needs and capabilities that includes advice and assistance in securing the maximum care and welfare entitlements one is eligible for.

Welfare rights workers and caseworkers within Citizens Advice Bureau are experiencing an increasing workload with fewer resources. This is against a backdrop of significant shifts in welfare policy and social security implementation. As one caseworker commented on the current and forthcoming welfare reforms:

“There’s so much to read – it’s difficult to keep up. They’re changing too much too fast for us and for them [clients].”
The problems faced by benefit claimants more generally are intensified for those households affected by learning disabilities. When changes are made affecting households affected by learning disabilities; a greater level of support in welfare and care transitions is needed as clients require more time to understand and deal with changes. By continuing *Transforming Day Services* Leeds City Council and Chapeltown Citizens Advice Bureau can ensure that the most vulnerable are protected from cost-saving measures that endanger the well-being of many individuals and households across Leeds.

It is a telling reality in itself that we cannot definitively identify the amount of people with a learning disability. As previously stated, there is a discrepancy between the number of children recorded with learning disabilities and those known to Adult Social Care Services. To a great extent, this report is about people that are already known to Leeds City Council and receive some form of care or support. What is also of interest though is those that are absent from this report; the vast majority of those with a learning disability are unknown to local authorities; they receive little care or support and are not necessarily receiving the correct welfare and care entitlements. If Leeds City Council is committed to *Valuing People Now* and their own three year Strategy, it needs to invest in provisions that will help protect some of the most vulnerable to current and forthcoming welfare reforms. Those with learning disabilities are likely to be amongst the hardest hit and Leeds City Council needs to develop a new strategy that sufficiently prepares for this.