



**The number of older family carers of people  
with a learning disability in Oxfordshire**

A report by Oxfordshire Family Support Network for the Embolden project.  
Funded by Comic relief

**Angeli Vaid**

7/1/2017



## Contents

1. Introduction
  2. Embolden
  3. Definitions
  4. Approach and assumptions
  5. Headline Findings
  6. How many people with LD nationally?
  7. How many people with LD in Oxfordshire?
  8. How many carers of people with LD nationally?
  9. How many carers in Oxfordshire?
  10. How many older carers of people with LD in Oxfordshire?
  11. Older carers of people with LD known to Embolden
  12. What we don't know
  13. Future numbers
  14. Moving forward: what we need to know
  15. Questions
- Appendix 1
  - Appendix 2
  - Appendix 3

## References and Bibliography

## 1. Introduction

This report sets out the current knowledge on the numbers of older family carers in Oxfordshire, caring for an adult relative or friend with a learning disability (LD).

It aims to make the case for increasing current knowledge in health and social care services – both statutory and independent of the numbers and profiles of older carers of people with learning disabilities in Oxfordshire, in order to meet their needs and plan support for their futures.

It does not discuss in detail the needs of the family carers or the person they are caring for. Nor does it discuss in detail the numbers of people with LD with comorbid conditions eg autism or genetic disorders.

## 2. Embolden

OxFSN through Embolden, is committed to and funded by Comic Relief for 3 years, to improve outcomes for older family carers in Oxfordshire, which includes being able to ask for and get services across social and health care. In order to do this all agencies involved need to know the numbers of older carers in Oxfordshire who care for people with LD, and who may need support and access to services now and in the future.

[For more information on Embolden please visit our website: <https://www.oxfsn.org.uk/older-carers/embolden/>]

## 3. Definitions - who are we talking about?

The definition of an older carer of person with a learning disability for the purposes of the Embolden Project is; a person aged over 65 providing unpaid care to a family member or friend who has a learning disability. This is based on common definitions below.

**Older carers:** Older carers of people with learning disabilities are people who are 60 years or over, caring unpaid, for a family member or friend who has a learning disability. (1)

**Learning Disability:** “A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.” (2)

**Carer:** “A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.” (3)

**Older People:** Older people are defined in terms of social care needs as being aged 65 and over. (4)

#### 4. Approach and assumptions

Currently there is no one data source either nationally or in Oxfordshire which tells us how many older carers of people with LD are in the county.

The approach in this report is to look at the data in two areas:

- the numbers of people with LD nationally and locally, and,
- the numbers of carers nationally and locally.

Then, using this data making calculations based on assumptions and additional research to arrive at a working number of older carers of people with LD.

Using these estimates and data collected by OxFSN in year 1 of the Embolden project, we are gradually building up a picture of the numbers and profile of older family carers in Oxfordshire.

#### 5. Headline Findings

**Our findings are that there are at least 2940 older carers aged 65+ living in Oxfordshire caring for a family member or relative in their own home.**

Paragraphs 6-11 set out how we came to this conclusion.

#### 6. How many people are there with LD nationally?

The National Learning Disabilities Observatory says,

“There is no definitive record of the number of people with learning disabilities in England. No government department collects comprehensive information on the presence of learning disabilities in the population and learning disabilities are not recorded in the decennial Census of the UK population.” (5)

The Observatory also says, three approaches can be taken to estimate the numbers of adults with learning disabilities in England (and therefore Oxfordshire). These are based on:

- number of people **using** learning disabilities services
- number of people **known** to learning disabilities services or known to GPs
- **estimated** number of people with learning disabilities in the population.

Health and Social care agencies in Oxfordshire currently use these approaches to estimate the numbers of people with LD in Oxfordshire, but not the age of their carers.

Research by Emmerson and Hatton, says that many adults with LD do not use specialist LD services (6). People with moderate difficulties but significant needs may not qualify to get services- which means a picture based on service use is likely to be an underestimation.

## 7. How many people are there with LD in Oxfordshire?

*The Oxfordshire Big Plan for Adults with Learning Disabilities, 2015-2018, (7)* estimates that there are 11,100 adults with LD in Oxfordshire. In 2010 it was estimated that around 900,000 adults aged 18 and over in England had a learning disability, of whom 191,000 (21%) were known to learning disabilities services. In 2010 Oxfordshire was home to around 1.2% of England's adults aged 18 and over. On a proportionate basis, this suggests that around 11,100 adults in the county might have a learning disability.

Of the approximate 11,100 adults with a learning disability in Oxfordshire, 2,600 have a learning disability that is moderate or severe

- In September 2014, 2,066 people received support from a social care learning disability team of whom 1,794 had a paid for service.
- The other 272 will be open to the teams for low level support and monitoring, including concerns over safeguarding.
- There were 2,311 eligible for health support, and 820 service users with a current open health referral. The health and social care service users overlap.

Of the 1,794 people who received a paid for service:

- 469 people are receiving a direct payment and of these 48 people are using their direct payment to pay for a care home or direct payment place
- 659 are currently in supported living
- 282 are currently in a care home (190 outside Oxfordshire)
- 54 people are in long term shared lives placements
- 75 people are in short term placements with shared lives
- 429 people are getting day care
- 82 people are receiving home care
- 6 people using hospital services. About half of the people using assessment and treatment hospital services do so for mental health reasons.

*The Family Resources Survey for the UK in 2014-15* estimated that around 20% of the UK’s population was disabled, experiencing physical, mental, cognitive, learning, social, behavioural or other types of impairment. (8)

Applying this regional rate to Oxfordshire implies a total of 128,800 with a disability living in the county including 8,800 children aged 0-15. This is well above the 89,800 people in Oxfordshire in the Census 2011 as having activities limited by health or disability (9).

The difference may be due to the definition of some impairments in the Family Resources Survey which may not been seen as “limiting” by people responding to the Census, or as a result of applying a UK prevalence rate or both.

The total number of people aged 0-65+ with a learning disability in Oxfordshire is given as 16,800 as shown in Table 1.

**Table 1: Estimate of number of people in Oxfordshire by impairment type and age from UK prevalence data (2014-15) (10)**

Impairment type	Children (0-15)	Working age adults (16-64)	State Pension age adults (65+)	TOTAL
Vision	700	8,100	9,600	18,400
Hearing	700	5,900	12,800	19,400
Mobility	1,900	33,100	36,800	71,800
Dexterity	900	19,100	19,200	39,200
<b>Learning</b>	<b>2,800</b>	<b>10,300</b>	<b>3,700</b>	<b>16,800</b>
Memory	900	11,800	9,600	22,300
Mental health	1,600	22,100	3,700	27,400
Stamina/ breathing/ fatigue	2,700	25,000	24,500	52,200
Social/behavioural	3,100	5,200	500	8,800
Other	1,700	12,500	6,400	20,600

*The Quality and Outcomes Framework* provides a count of GP-registered patients by health condition and from 2014-15 this includes patients of all ages with a learning disability. (11)

- 2,561 patients were registered with a learning disability in 2014-5
- 2,599 patients had registered in 2015-16

## 8. How many carers of people with LD are there nationally?

Local and national data on carers provides a valuable picture of the likely number of carers in Oxfordshire. But there is no one data source on the age of people caring for people with LD.

*The Carers Trust* (12) estimates that,

- 1.2 million people in England and Wales over 65 are carers
- 14% of carers care for people with LD/autism
- No. of carers aged 85 and over grew by 128% from 2001 to 2011
- 9% fewer carers over 75 are being offered services following carers' assessment than 7 years ago

## 9. How many carers in Oxfordshire?

According to the most recent Census 2011 61,131 people are providing unpaid care in Oxfordshire. (13) At the time of the 2011 Census, around 61,100 people in Oxfordshire said they provided some level of informal care to a relative or friend, representing 9.4% of the county's population (up from 8.8% in 2001). This proportion was slightly lower than in the South East (10.2%) and England overall (9.8%).

The largest group of carers in the county are between 50-64 years old, but the number of young carers referred to their services increased by 81% in 2015-2016. (14)

A larger proportion of unpaid care in Oxfordshire was provided by female residents. This was particularly the case for higher intensity care, 60.2% of which was provided by female residents. The group most likely to provide unpaid care was aged 50-64. In Districts more carers are in the Vale than in Oxford.

As of the end of September 2015, around 17,200 adult carers were known to Oxfordshire County Council's social care teams. This figure has been increasing over time. It includes all carers whose needs have been assessed, some of whom will also have received a service from the council.

However, only 11,039 of these are registered as a carer with their GP. (15).

## 10. How many older carers of people with LD are in Oxfordshire?

Estimating the number of older carers of people with LD is based on research by Emerson and Hatton in 2008, which showed nationally that two thirds of adults with a learning disability live with their families, the majority with their parents ie 66%. Of these, 40% live with a parent aged over 60 years and 33% live with a parent over 70 years old. (16)

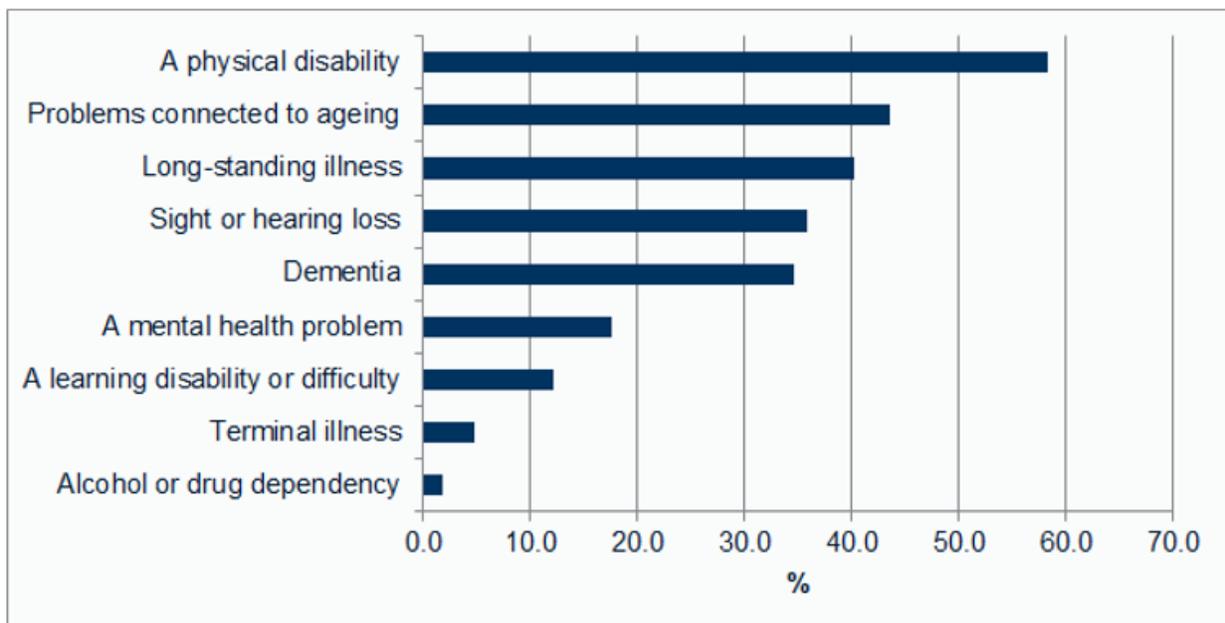
The *Personal Social Services Survey of Adult Carers in England* is carried out every two years and took place for the second time in 2014-15. (17). It focuses on carers' needs and outcomes, and supports the finding about housing, in fact finding that 75% of those interviewed had the person living at home with them.

715 carers in Oxfordshire responded.

The results in Table 2 show that:

- 18% (n128) of the carers in Oxfordshire who responded to the survey, the person they cared for had a learning disability.
- About three quarters were living with the person they cared for.
- More than one in three had been caring for more than ten years.
- Slightly under half of respondents (44%) reported providing 100 or more hours of care per week.
- Nearly two thirds of the carers who responded (65%) were retired

**Table 2: Carers in Oxfordshire, by health condition of the person they care for (2014/15)**



This pattern broadly reflected that at national and regional levels, although carers in Oxfordshire were more likely than nationally to be caring for someone with problems connected to ageing. This is likely to be linked to the fact that many care for a partner. (18)

In 2016 the Papworth Trust (19) research found that:

- At least 50% of all adults with a learning disability live in the family home - meaning that many don't get the same chances as other people to gain independence, learn key skills and make choices about their own lives.
- 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 25% of these cases have a Local Authority planned alternative housing.

Mencap said in 2015 the majority of people with a learning disability *known* to local authorities live in one of three types of accommodation: with family and friends (38%), in a registered care home (22%) or in supported accommodation (16%). 12% live as tenants in accommodation provided by a local authority or housing association and 3% in privately rented accommodation. (20)

There are an estimated 11,000+ adults in Oxfordshire with an LD - and assuming that each person has one surviving parent this would give 11,000 carers. Some may have no surviving parent, but others may have two parents alive that they live with. Based on Emmerson's research that 66% are living at home this would equate to 7260 carers (21). 40% of those are living with a parent aged over 60 - 40% of 7260 who are older carers ie a figure of **2940 older carers of people with LD in Oxfordshire.**

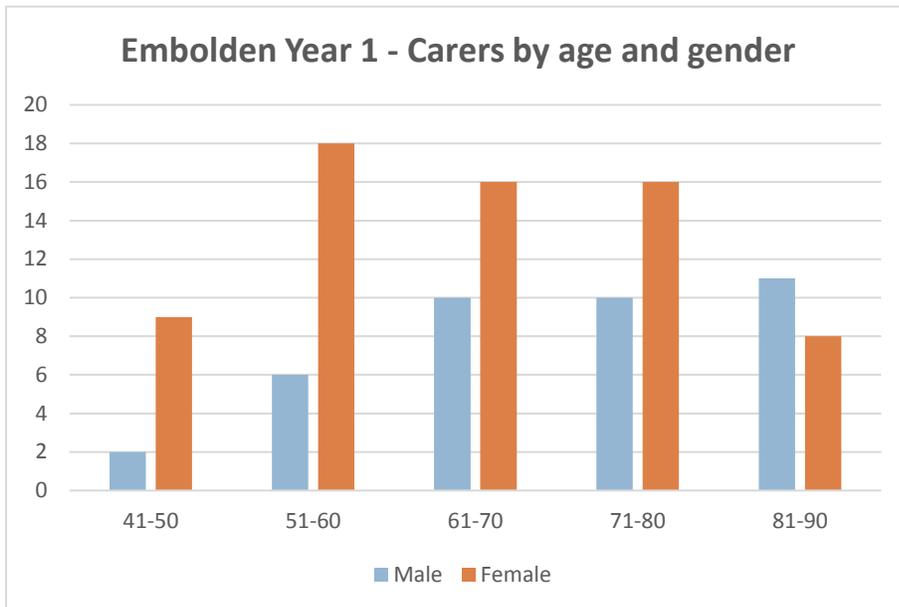
## **11. Older carers of people with LD known to Embolden**

Embolden is required by its funders to collect data on the number of direct beneficiaries and indirect beneficiaries and to report these figure annually. The project has a target to make contact with 125 older carers in Oxfordshire as direct beneficiaries.

At the end of year one 107 carers aged 40-90 had made direct contact, through attending an event, emailing, or speaking to a staff member. Of these 107

- 40 carers were men and 67 women
- 4 were siblings
- 50 of them had their relative living at home with them ie just under 50%

The ages of the carers were reasonable evenly spread from 41-90+ years – this suggests a life time of caring.



More information on the Embalden data can be found in **Appendix 3**

## 12. What we don't know

The estimate of 2940 carers is based on data, research and assumptions which whilst robust in terms of methodology, uses current available data which is mostly national datasets, and then applies the finding to Oxfordshire. The danger is that local nuances which impact on people with LD and their carers are lost, for example, that the need in Oxford City with its 20% BME populations is thought of as the same as a small Oxfordshire market town. (22)

We know the numbers of people using LD services in Oxfordshire in health and social care, but very little about those who qualify but don't take up services

We also know little about the number of carers supporting people with mild or moderate LD for now but who may need more support as they age.

“The level of support someone needs depends on the individual. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need fulltime care

and support with every aspect of their life – they may also have physical disabilities. People with certain specific conditions can have a learning disability too. For example, people with Down’s syndrome and some people with autism have a learning disability.” (23)

We know little about the needs of BME communities in Oxfordshire – in spite of detailed Census 2011 data; this is a community predicted to grown significantly nationally by Emmerson and Hatton.

We know little about the sexuality of carers. This reflects a picture issue with data in these areas as people are rarely required to give this information to health and social care organisations.

People with LD may also have a primary diagnosis (rightly or wrongly) of a medical condition eg an Autistic Spectrum Condition, Down’s Syndrome, genetic disorders and mental health illnesses, meaning that the medical condition is the focus of treatment and the learning disability regarded as a secondary issue, thus masking the needs of the carers in these situations.

### 13. Future numbers?

Evidence shows that there is an increase in the number of people with LD and eligible for social care services. People with LD are living longer ie becoming older people with LD. They are living longer at home with their family who in turn are living longer and becoming more disabled or frail. This will lead to an increased need for social and health care services for adults with learning disabilities nationally and in Oxfordshire. This is reflected now in an increased take up of social services nationally and in Oxfordshire.

Three factors are likely to lead to an increase in the age-specific prevalence rates for adults with learning disabilities in England over the next two decades (24).

- (1) An increase in the proportion of younger English adults who belong to Bangladeshi and Pakistani South Asian minority ethnic communities (among whom evidence suggests there may be a two to three fold increase in the prevalence of more severe learning disability in children and young adults).
- (2) Increased survival rates among young people with severe and complex disabilities;
- (3) Reduced mortality among older adults with learning disabilities.

Mencap says (25)

- The number of people with a learning disability aged between 65 and 74 years is set to increase by 33.5% between 2011 and 2030.

- Likewise, by 2030 there will be an increase of 53% in the number aged 75 to 84 years and a 103% increase in the number aged 85 and older.
- In 2011, there was a 3% increase nationally in the number of people with a learning disability known to social services compared with 2010.

Given the increase in the ageing population the number of people with a learning disability living with a parent over the age of 70 will also rise. Many family carers are caring alone; others are caring for more than one person. (26)

National estimates predict that demand for services will increase at a rate between 0.6% and 4% per year between 2009 and 2026. (27)

In Oxfordshire there has been a steady increase in the number of people open to learning disability teams in recent years (from 1792 in March 2012 to 1923 in September 2013), the number of people in supported living and care homes increased between 2011/12 and 2012/13 but fell in the first 6 months of 2013/14. (28)

## 14. Moving forward: What do we need to know?

Moving forward, a more accurate picture based on local data and knowledge would benefit older carers, people with LD: there is of course strength in numbers. However, service providers; both statutory, private and charitable will plan more effectively with accurate data to meet needs in the short and long term.

Aside from statutory requirements and the demands of social justice to meet needs, the economic case is clear for all of us. The hours of care declared by Carers in the 2011 Census were multiplied by a cost of £17.50 per hour to replace that care, by the Carers Trust.

“We have found that the value of the contribution made by carers in the UK is now £132 billion each year.” (29)

Care providers, health and social services could actively collect profile data which ideally will include the basic facts below:

- Name
- Age
- Sex
- Sexuality
- Ethnicity
- Health of carer – including disability
- Marital status
- Employment status

- No of dependents
- No of years of caring
- Care for another family member
- Location/home address
- Time spent caring
- Lone carer

Sources of for social care data would include: getting profile data on carers who have relatives with LD

- receiving a direct payment
- using day services
- in supported living
- in long term and short term placements with *Shared Lives*
- receiving home care
- getting day care
- in a care home within and outside Oxfordshire

Finally it is important to note that the number of 2940 older carers is also not an indicator of carer need, which is beyond the scope of this report. As a group they share common characteristics: longevity of their caring role, increasingly poor health with age and they report poorer quality of life.

As individuals older carers ages range over 35 years (65-90+). Like all people older carers have multiple identities within a family, eg a mother, sister, wife, partner, aunt, niece, grandmother, sister-in-law, godmother which together with a multitude of other circumstances- many outside of their control – shape and define their needs and their desire and ability to perform their caring role.

## 15. Questions?

If you have suggestions, comments or questions about this report please contact the report's author.

Angeli Vaid

Family Advocate, Embolden, July 2017

[Angeli.Vaid@oxfsn.org.uk](mailto:Angeli.Vaid@oxfsn.org.uk)

## Appendix 1: Carers in Oxfordshire, Census 2011

### Proportion of carers in population by District

- Vale of White Horse 10.3%
- South 9.9%
- West Oxfordshire 9.9%
- Cherwell 9.4%
- Oxford 7.7%

### Age (yrs)

- 0 -24: 6%
- 25 - 49: 32%
- 50 - 64: 38%
- 65+ : 24%

### Time spent caring (hrs per week)

- 19 or less: 72%
- 20 – 49: 10%
- 50+ : 18%

### Ethnicity of carers

- White British: 89.6%
- Asian/Asian British: 3%
- Other white: 3%
- White Irish: 0.7%
- Black/African/Caribbean/Black British: 0.03%
- Other ethnic group: 0.03%
- Mixed/multiple ethnic group: 0.1%

### Gender

- Female: 58%
- Male: 42%

**Table 1: 2011 Census: Health and provision of unpaid care, local authorities in England and Wales**

	Provides 1 to 19 Hours Unpaid Care a Week	Provides 20 to 49 Hours Unpaid Care a Week	Provides 50 or More Hours Unpaid Care a Week
<b>Cherwell</b>	<b>9,216</b>	<b>1,452</b>	<b>2,686</b>
<b>Oxford</b>	<b>8159</b>	<b>1,468</b>	<b>2,098</b>
<b>South Oxfordshire</b>	<b>9,817</b>	<b>1,250</b>	<b>2,189</b>
<b>Vale</b>	<b>9,035</b>	<b>1,183</b>	<b>2,220</b>
<b>West</b>	<b>7,540</b>	<b>1,050</b>	<b>1,768</b>
<b>Total</b>	<b>43,767</b>	<b>6,403</b>	<b>10,961</b>

Source: Office for National Statistics, 2011 ,Table KS301EW

## Appendix 2: Accommodation arrangements for people with LD

Table 1: Accommodation arrangements for people with mild/moderate, severe and profound multiple learning disabilities				
	Mild or moderate	Severe	Profound multiple	All people
Private Households				
With parent(s)	48%	61%	60%	55%
With other relative	14%	11%	4%	12%
With partner	6%	<1%	<1%	3%
Alone	7%	2%	0%	4%
Sub-total	74%	74%	65%	74%
Supporting People funded	12%	8%	5%	10%
Residential Care Home	13%	15%	19%	15%
NHS Accommodation	<1%	2%	11%	2%
Total	100%	100%	100%	100%

As can be seen in Table 1, the majority of people with severe and profound multiple learning disabilities were living with a parent. The majority of people with mild/moderate learning disabilities were living with a parent or other relative. People with more severe learning disabilities were more likely to be living in Residential Care Homes and NHS accommodation.

(Emmerson people with LD report 2008)

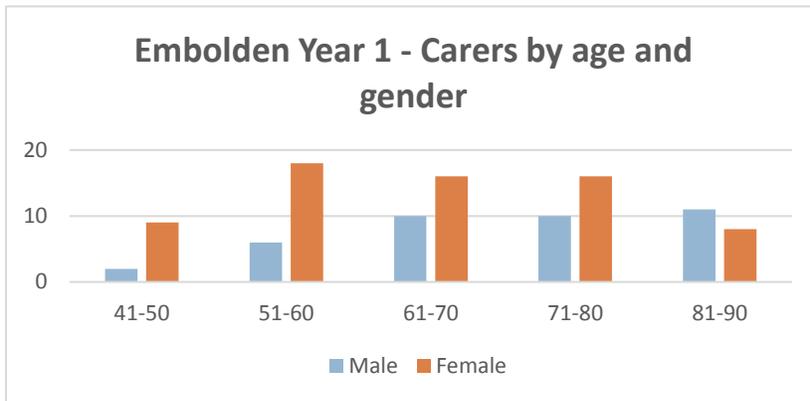
### Appendix 3: Embolden beneficiaries 2015-2016

#### 1. Collecting the data

These tables are based on the numbers of carers who were direct beneficiaries from Embolden, either by attending events or having direct contact with the Embolden team. The data was collected by hand with carers filling in a paper based form. The data was collected in year one of the project which ran from July 2016 - June 2017.

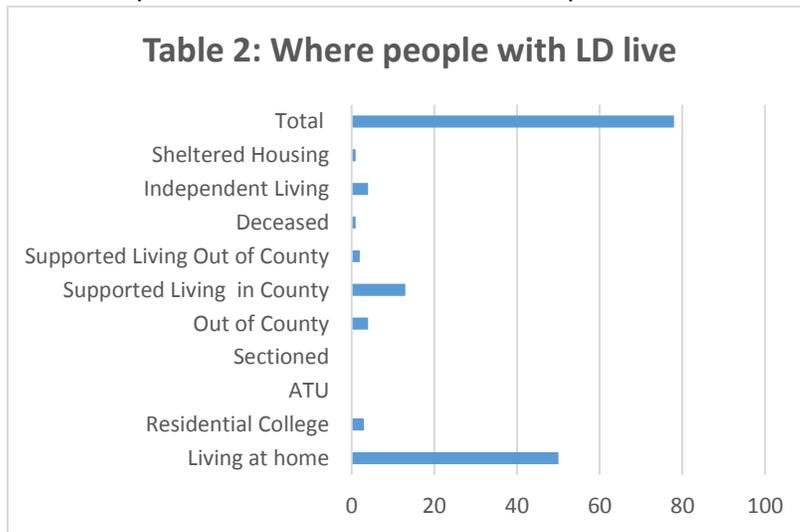
#### 2. Table 1: Older carers by age and gender.

36 men and 67 women benefitted across all age groups



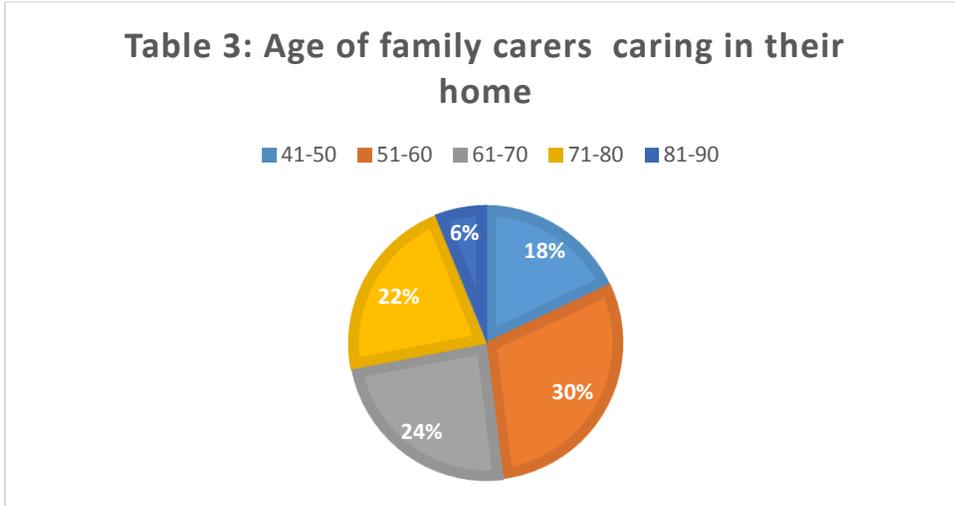
#### 3. Table 2: where people with LD live

Family carers told us that 50 of their family members with LD lived at home with them

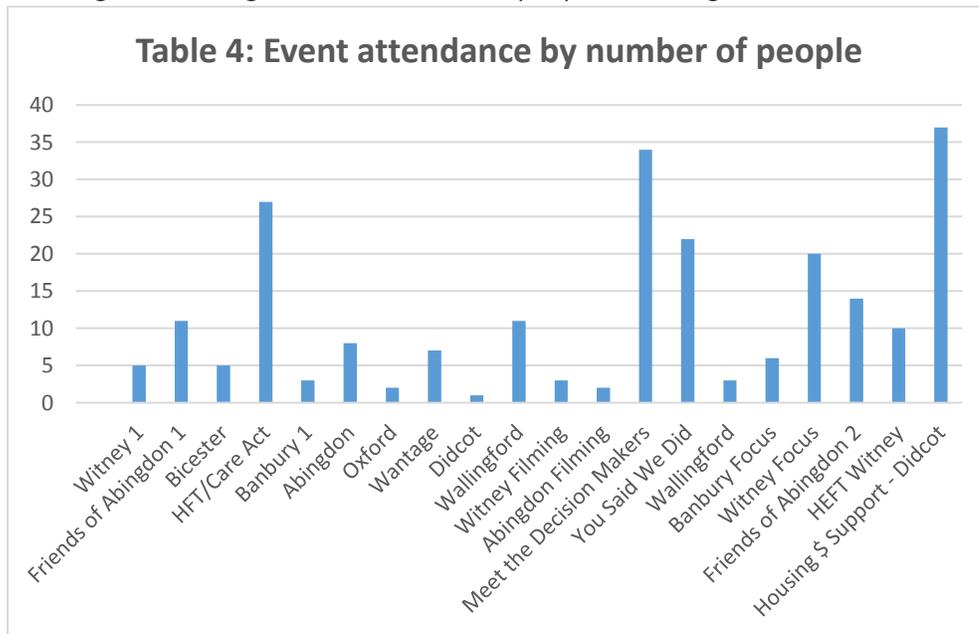


**4. Table 3: Age of Family Carers caring in their own home**

This table shows the age of the family carers who are caring for the 50 people with LD who are living at home. Interestingly the 50 people cared for at home are fairly evenly spread across the age groups from 51- 80 years, which suggests a static situation ie once the person is at home they remain at home. The % decreases for carers aged 81-90 which could correlate with the death of the carer.



**5. Table 5: Event attendance by number of people**, showing increased attendance at the 2 conferences and the popularity of the meet the decision makers meeting. Fact finding coffee mornings and filming were aimed at fewer people attending.



## References

- (1) Carers Trust: *Caring about older carers*: Carers Trust, 2015
- (2) Mencap - website 2017
- (3) Carers Trust – website 2017
- (4) Oxfordshire Older People’s Needs Analysis, March 2016
- (5) Learning Disabilities Observatory: *People with learning disabilities in England* 2015
- (6) Emmerson and Hatton, *People with Learning Disabilities in England*, 2008
- (7) Oxfordshire Big Plan for Adults with Learning Disabilities, 2015-2018
- (8) Joint Strategic Needs Assessment Oxfordshire 2017 Chapter 3.8
- (9) Census 2011
- (10) Extrapolation from Family Resources Survey 2014-15
- (11) Joint Strategic Needs Assessment, Oxfordshire 2017
- (12) Carers Trust: website 2017
- (13) Census 2011
- (14) Oxfordshire Draft Carers Strategy, 2017-20
- (15) Oxfordshire Carers Strategy, 2013-16
- (16) Emmerson and Hatton, *Future need and demand for supported accommodation for people with learning disabilities in England*. Housing, Care & Support 2005;8(4):17-22.
- (17) Personal Social Services Survey of Adult Carers in England, 2014-15
- (18) Oxfordshire Draft Carers Strategy, 2017-20
- (19): Papworth Trust: *Disability in the UK 2016, Fact and Figures*
- (20) Mencap: *Housing for people with a learning disability*: 2015
- (21) Emmerson and Hatton, *Future need and demand for supported accommodation for people with learning disabilities in England*. Housing, Care & Support 2005;8(4):17-22.
- (22) Census 2011
- (23) Mencap: *Learning Disability Explained*: website, 2017
- (24) Emmerson and Hatton, *People with Learning Disabilities in England* ,2008
- (25) Mencap: *Housing for people with a learning disability*: 2015
- (26) British Institute for Learning Disability :website, 2017
- (27) Emmerson and Hatton, *Estimating Future Need for services for People with LD in England* , 2008
- (28) Oxfordshire Joint Strategic Needs Assessment, 2014
- (29) Carers Trust: *Valuing Care* 2015

## Select Bibliography

- Carers in Oxfordshire a report on needs and services, Jan-March 2015 (Healthwatch with Guidepost Trust)
- Public Health Oxfordshire surveillance dashboards
- Report by the Oxfordshire's Commission on Health Inequalities (2016)
- Older People JSNA (2016)

**Table 3: summary of known numbers in this report**

	<b>LD people</b>	<b>Carers</b>	<b>Older carers</b>	<b>Older carers LD</b>
Nationally				
Locally	11,000 (Big Plan)	61, 000 Census 2011		

6. Mencap. The Housing Timebomb: The housing crisis facing people with a learning disability and their older parents. London: Mencap, 2002.