



## Embolden: Evaluation Report

August 2019





## **Contents**

### **Headlines**

- 1. Introduction**
- 2. Evaluation**
- 3. The Five Outcomes**
- 4. Impact on Family Carers and Case Studies**
- 5. Impact on Staff**
- 6. Impact on Professionals**
- 7. Legacy**
- 8. Conclusion**

### **Appendices**

## **Acknowledgements**

OxFSN wants to thank Jan Suman who created Embolden and lead the project in its first year, and after her retirement supported it as a volunteer. Jan's vision made this work happen.

This report is dedicated to the 215 family carers who brought Embolden to life. Working alongside older family carers was a pleasure and a privilege for the Embolden team.

## Headlines

### The numbers

- 215 family carers in total were supported by Embolden over 3 years
- 95% of these made contact through meetings and events
- Over 100 younger family carers also attended the countywide events
- 250+ professionals also benefitted, 140+ professionals attended the countywide events
- OxFSN held 28 events across the County for older carers and 440 came in all, so some of the same people came back more than once
- 18 coffee mornings attracted 30% of the older family carers, countywide events on key topics such as health, finance and housing attracted 65% and 5% got involved via other routes
- 124 people came to *The Better Together Event*, November 2018 and this included over 40 older family carers and 55 professionals

### Highlights

- Two films were made with *Get the Picture* featuring older carers challenging decision makers and supporting each other; they were shared nationally and are on the OxFSN website
- Older carers from Black Asian Minority Ethnic (BAME) communities shared their life stories with OxFSN and these are being used in research bids to the National Institute for Health Research (NIHR)
- *Life Long Caring* - is a photographic portrait exhibition of eight older family carers curated and created by OXFSN family carers. In June 2019 it featured in the Guardian online and it is touring health and social care public spaces during 2019-2020
- Ten older family carers coproduced detailed research on the impact of cuts to health and social care services, using the Health Equalities Framework, which was given to commissioners
- Evidence about the numbers of older carers in Oxfordshire was presented to Oxfordshire County Council and now informs its housing strategy and the Joint Strategic Needs Assessment (JSNA) used by commissioners
- Social media, radio and press coverage featuring older carers' stories was local, regional and national
- OxFSN represented older carers voices and interests at the Transforming Care Partnership Board, Coproduction Board and Oxford Health Learning Disability Programme Board
- OxFSN responded to countywide consultations on Disability Related Expenditure (DRE) as part of the County Council's new Client Contributions Policy

- Resources requested by older carers on the Care Act, jargon busting and planning ahead were created and made available and are being used by older carers

## **1. Introduction**

### **1.1. Embolden and OxFSN**

In July 2016, Oxfordshire Family Support Network (OxFSN) began a three-year project, *Embolden*, to support, advocate for and empower older family carers aged 60+ years who care for a family member with a learning disability.

Embolden was generously funded £116K for this work by Comic Relief over three years; funding officially ended in July 2019, though legacy events are planned for Autumn 2019. It was delivered by a small team of three part-time staff.

OxFSN is a unique organisation based in Oxfordshire. It provides independent information, advice and support by families for families of people with learning disabilities. Set up as a charity 12 years ago, by family carers who wanted to use their experience to help others in the same situation, it strives to improve the lives of people with learning disabilities and their families.

### **1.2. Purpose of this report**

This self-evaluation report was commissioned by Embolden Steering Group to assess the impact of Embolden, on family carers, professionals and the Embolden team; answering the key questions,

*“What difference did Embolden make?”*

*“What can OxFSN do to support older family carers, when Embolden stops?”*

The purpose of this self-evaluation for the Embolden project is

- To enable OxFSN to assess the impact of Embolden on all those involved in delivering and benefitting from the project, and to disseminate headline findings to those people.
- To plan for the legacy of Embolden for older carers, as the funding stops, but older carers continue to care and grow older

Headlines from this report will be shared with family carers and other organisations working to support people with learning disabilities and their families, and professionals via the OxFSN website, mailing lists, social media and face to face at a legacy event in Autumn 2019.

### **1.3. Embolden**

Embolden was created by OxFSN from the legacy of a previous OxFSN and Comic Relief funded project called *Changing Scenes*. Both projects focused on the needs of older family carers, i.e. 60+ years who supported family members with learning disabilities.

*Changing Scenes* provided emotional support and a social network for a group of older family carers, whereas *Embolden* as its name suggests, aimed to give a stronger voice to older family carers, to influence decision makers and hold them to account in order to improve health and social care services for themselves and their family member.

National and local data showed and continues to show, that the numbers of carers (both children and adults) are rising as is the ageing population in Oxfordshire, against a background of austerity where national and local provision of health and social services are shrinking. According to Age UK's recent research, there are now over two million carers aged 65 and over, 417,000 of whom are aged 80 and over.

OxFSN suspected from *Changing Scenes* that the numbers of older carers age 60+ years of people with a learning disability in Oxfordshire were under-reported and therefore unknown to social and health care services and also increasing. They also knew from *Changing Scenes* that older family carers in Oxfordshire were not aware of their rights and entitlements, and furthermore unable or unsure of how to ask for them.

### **1.4. Embolden Outcomes**

Embolden had five outcomes shown below.

- 1 Older carers and their families understand their rights and have confidence to challenge and hold key public bodies to account
- 2 Older family carers and their relatives are empowered through building effective group advocacy
- 3 Strong expert by experience networks are created
- 4 Engagement between local services and families is significantly improved
- 5 Impacts of health and social care cuts on people with learning disabilities and older families are better understood and shared in order to influence change

### **1.5. Family carer**

The term 'family carer' used throughout this report, is a person who cares for an immediate member of their family with a learning disability. In most cases this is a parent, though it is sometimes another relative, often a sibling, aunt or uncle or grandparent. OxFSN use family carer to identify and respect the lived experience of an unpaid family carer as opposed to the professional and paid relationship of a carer e.g., a support worker, personal assistant.

### **1.6. Professionals**

The term 'professional' used throughout this report refers to paid support workers (often called carers or paid carers) working for care provider organisations, paid workers in statutory and third sector organisations, and other paid workers, social workers, psychologists, physiotherapists, behaviour support staff and speech and language therapists in statutory health and social care organisations.





## **2. Evaluation**

### **2.1. Scope**

Whilst this evaluation will provide additional assurance to the funders Comic Relief that OxFSN has delivered on Embolden's five outcomes, OxFSN have already provided fully evidenced six monthly reports to the funder throughout the project and this self-evaluation will not replicate these or provide additional data for them.

### **2.2. Methodology**

A member of the Embolden team who is also an experienced independent evaluator was employed to co-ordinate this self-evaluation, guided by and accountable to, the Embolden Steering Group and OxFSN Trustees. The Embolden Programme Manager and Embolden Project workers have all contributed to this report.

Steering Group members are external to OxFSN and are as follows:

Alison Giraud-Saunders – Health & Social Care, Independent Consultant  
John Hutchinson- Older Family Carer and Chair of Friends of Abingdon Day Centre  
Chris Ingram – Chief Executive Style Acre  
Neil Morris – Together 4 Change  
Larry Saunders – Health Spokesman for the Green Party (England & Wales)

### **Quantitative data**

The numbers who benefitted were collected and recorded throughout the project by OxFSN as required by Comic Relief and were:

- People who benefited directly i.e. family carers, and people with learning disabilities
- Frontline workers, i.e. professionals
- Others

OxFSN also collected:

- Social media analytics
- Detailed profile data on *all* family carers who came to Embolden events, i.e. those under 60+years as well as 60+ years, in terms of age, gender and living situation survey (n=125 responses)

- Geographical mapping data on older carers who are living in Oxon (n=128)

#### **Qualitative data**

- Comic Relief 6 monthly and annual reports by the Embolden Programme Manager
- OxFSN publications *The Numbers of Older Carers in Oxfordshire*, *Care Act Guidance*, *Guidance on Disability Related Expenditure*, *Jargon Buster*
- OxFSN 6 month and 18 month Embolden independent Evaluation reports
- Event feedback from family carers - who attended over 28 engagement and information events - written and verbal, formal and unsolicited
- Health Equalities Framework data – from OxFSN research with family carers (n=10)
- OxFSN seldom heard communities reports and life story work (n=5)
- OxFSN photographic portraits and life stories of older carers (n=8)
- OxFSN films – *Peace of mind* and *What will happen when I am no longer around?*
- Interviews with key health and social care professionals
- Interviews with OxFSN Steering Group, Project Manager and Embolden staff team
- Workshop feedback from professionals who came to Working with Families training





### 3. The Five Outcomes

#### 3.1. Evidence for outcomes

The evidence for how OxSFN has met each of the five project outcomes is set out below. The five outcomes are linked, so that evidence for one often serves another, but to avoid repetition the evidence is only recorded under one 'best fit' outcome. Success in one outcome will therefore impact positively on others and likewise challenges in one outcome will also affect others.

#### 3.2. Outcome 1: Older carers and their families understand their rights and have confidence to challenge and hold key public bodies to account.

*"Knowledge is power." (Embolden, Older Carer)*

The Embolden team set up a series of events including 18 Big Coffee mornings open only to older family carers over two years in locations across the county. (See Outcome 2)

- 109 older family carers aged 60+ years in total were supported by Embolden over 3 years
- 95% of these made contact through meetings and events
- OxFSN held 28 events across the County for older carers and 440 came in all, so the same people came back more than once

Having identified issues important to and important for older family carers, they set up a series of countywide events, for older family carers, but open to younger family carers and professionals.

Major countywide events were: meeting decision makers and holding them to account, the Care Act, health, finance and housing, which between them attracted 65% of the older family carers who took part. All the 140 professionals who were involved as frontline workers were attendees at these events. Over 100 younger family carers also attended these events.

The most successful event in terms of attendance was *The Better Together Event*, Nov 2018 when 124 people came and this included over 40 older family carers and 55 professionals. As a result, OxFSN were commissioned by the County Council to run this event annually for 3 years.

All events had decision-makers present and key speakers from external organisations. Family carers had opportunities to speak to decision makers directly and challenge them as well as gain update accurate information and good personal contacts.

Table 1: Attendance numbers for the countywide key events

<b>Event</b>	<b>Total Numbers</b>	<b>Older FC attending for first time</b>
Care Act Workshop with HFT, Oxford HFT, Oct 2016	37	17
Meet the Decision Makers, Oxford Nov 2016	52	10
You Said We Did, Oxford Jan 2017	38	3
Housing and Support, Didcot, Jun 2017	61	15
Health, Didcot, Feb 2018	42	9
Finance, Abingdon, Mar 2018	53	10
Better Together, Oxford, Nov 2018	43	28



At the *Meet the Decision Makers* event which was held in Oxford in November 2016, key issues, quotes and comments were written up on ‘speech bubble’ templates and displayed at this and subsequent events for decision makers to see. This was followed by *You Said We Did, Oxford* in January 2017 at which we presented the findings including a simple, easy to read guidance on the Care Act which older family carers said would help them challenge decisions they felt were unfair and to help inform them of their and their relatives rights.

### **3.3. Outcome 2: Older family carers and their relatives are empowered through building effective group advocacy.**

*“Sibling input is important.”* (Embolden, Older Family Carer)

*“I think we have quite an active group in Abingdon. That just gives you a bit more, to keep on challenging as you have another tool to use at your disposal.”* (Embolden, Older Family Carer)

The project started with nine issue-based focus groups - Big Coffee Mornings in Year 1. Followed by nine in Year 2. These were held across the County and the team developed a questionnaire with family carers to identify their concerns. These were well attended, and older carers were highly engaged. Coffee Mornings attracted 30% (n=60+) of the older family carers. Key issues they raised are in Appendix 1 and were used to focus a series of events and actions for Embolden, ensuring that all activities related back to what older carers needed to be addressed.

Older family carers showed they are less inclined to set up their own initiatives and networks without substantial support. The purpose of Coffee Mornings in Year 2 was to encourage older family carers to meet again and set up their own groups. However, they were less well attended than in Year 1 – in a few cases no older carers came at all.

*“After 40 or 50 years of full time caring it’s hardly surprising that they don’t have the energy or inclination to set up and run these groups” (OxFSN Programme Manager)*

Notable exceptions are where the group exists for a clear purpose or is extremely well established already, e.g. a Friends of Abingdon Day Centre and a group in Witney, who despite dwindling numbers remain determined to see change happen. They reported that support from Embolden staff regularly attending their meetings with updates is helping with this, however they were invaluable sounding boards and focus groups for responses to consultations and supported detailed research.

### **3.4. Outcome 3: Strong ‘expert by experience’ networks are created**

*“I learnt a lot that I can pass on to other people.” (Embolden, Older Carer)*

*“The meetings have enabled me to learn a lot from other parents.” (Embolden, Older family carer)*

*“The older generation are picking up from other families.” (Embolden, Older family carer)*

#### **Experts by experience**

Whilst older family carers have decades of experience, the oldest family carer who took part in Embolden was Brenda who is aged 93 years, their experience is not often valued by themselves – they do not choose the label ‘experts by experience’, regarding themselves as having no choice but to get on with it. Creating strong networks was challenging and limited by the ability and energy of older carers to get involved and stay involved. Therefore, OxFSN decided to extend its reach and include younger family carers and utilise the media, social media, film and photography to get the message across that older carers are experts in life-long caring.

### **Younger family carers**

Significant numbers (n=100) of carers aged under 60 years old also attended the countywide events on housing, health and finance and Better Together because although they were aimed at older carers the information had an equal value to younger carers. This had a number of benefits: older carers issues were championed by younger carers, as they saw this could be them in the future if things do not change; and older carers feel more supported and empowered to challenge. Older carers reported that they drew strength from having younger families influencing change and gaining information alongside them and this work has started to build a stronger, more supportive network in the county.

### **Press publicity**

The team also used local regional and national media to tell their tales, by identifying a number of family carers who were willing to share their stories with a view to inspiring others and providing positive evidence of successful challenges, but also showing how hard a lifetime of caring is.

The Embolden Programme Manager also featured stories about older family carers throughout the project on Oxfordshire TV, BBC Radio Oxford (x2), Jack FM, BBC South Today, for example on Red Nose Day, 24<sup>th</sup> March 2017. The story of older family carers supported by Embolden was shared through BBC South Today (8 June 2017). It showed them, caring for their 45 year old daughter (sadly now deceased), highlighting the need for family carers to have a stronger voice and lack of data and forward planning for this group of carers.

### **Staying in touch**

Newsletters for the project were sent out to older families, to Carers Voice, Carers Oxfordshire and Oxfordshire Association of Care Providers and others and shared on social media and OXFSN website in December 2016, March 2017, June 2017 and June 2018 and July 2019.

### **Photography**

The Embolden team requested that the Oxfordshire Festival of the Arts in June 2017, should feature an OXFSN older family carer with South Asian heritage and her son in *Gratitude a* portrait photographic exhibition. The Festival reported that the exhibition was extremely well received by the public. It was then exhibited outside the Said Business School, Oxford in front of Oxford train station in view of thousands of daily commuters.

*Life Long Caring* opened in June 2019 a photographic portrait exhibition of six Embolden older carers, photographed by family carer and activist Dr. Sara Ryan. Currently on exhibition in County Hall Oxford, in the corridor leading to the Council Chamber - it was picked up by the Guardian online and shared via social media Facebook and Twitter. OXFSN

were delighted by the coverage and response from individuals who saw it and said how moving they found it.

*'I just wanted to let you know I think the exhibition at County Hall is really great. Beautiful photos and I think they convey such a warm and important message, Robyn Noonan, Area Service Manager, 14 June 2019*

*"Your embolden project is fantastic, the case studies and photos online are really important in highlighting the needs and experiences of older carers." Frances Danylec, Development Officer –Adult Siblings, SIBS UK, 10 June 2019*



## Social Media

Social media, Facebook and Twitter, were increasingly used throughout the project to advertise events and disseminate information to professionals and other organisations who had contacts with older carers. The Embolden team were aware that older carers were less likely to use social media, however many younger family carers and professionals do, so it was a good way to highlight issues that older family carers were dealing with such as Disability Related Expenditure.

**Appendix 3** has more details of the social media statics for *Life - Long Caring* and shows the impact that social media can have in terms of spreading news very quickly to high numbers of people.

## 3.5. Outcome 4: Engagement between local services and families is significantly improved

*"All the information provided has been a great help" (Embolden, Older Family Carer)*

*"I get good advice." (Embolden, Older Family Carer)*

### **Fears of institutional living**

OxFSN discovered through early meetings with older carers that views of supported living are often based on the old institutional care settings of the past and their fear of handing over the support to others is compounded by horror stories in the media. This stops them planning for the future when they are no longer around. They often only seek support when in a crisis. OxFSN used films, podcasts and written articles to share positive success stories to inspire and allay fears.

### **Film**

The Embolden team used film to not only increase the presence and visibility of older carers, in the public arena, but as a way of voicing their concerns and having their voices heard.

Working in partnership with *Get the Picture* an Age UK Comic Relief funded project, two films were made with Tom Skinner a community film maker. The first was aimed at decision makers; older carers decided on the issues they wanted raised with decision makers which was 'what will happen when I am longer around?' – the fear of incapacity and death for an older carer is very real and present. The film was called: *What Will Happen?* It was shown to older carers and professionals at the *Meet the Decision Makers Event* and to the Oxford Health NHS Foundation Trust Board. Professionals then responded directly to family carers.

A second film *Peace of Mind* was also made in partnership with *Get the Picture*, this time with three older carer families who have found supported living for their older family member and who shared the positive impact that it has had on all their lives. This was sent to all key commissioners in Adult Social Care and Health. Home Farm Trust, a national charity, have used it as a resource on their own national website. It is available on the OxFSN website.

### **Support providers**

The Embolden team fed back these concerns to supported living providers (Style Acre and SeeAbility) and Style Acre is now offering further reassurance. Meanwhile from 2017 OxFSN offered staff training and support to individual families through its mediation and support service. This is a service commissioned and paid for by the Providers themselves and has become a small income stream for OxFSN which developed as a result of this project.

### **Clear and jargon-free information offline**

It became clear from conversations and requests for information at events, that older family carers are less likely to access the internet and social media, themselves but their children (i.e. siblings) do, and it is where many younger families get their information.

OxFSN developed *A Guide to the Care Act*, available in hard copy, which was requested by family carers. This was followed up with a presentation at the Housing and Support Event. A short *Jargon Buster* in hard copy was also produced.



By Year Two the *Care Act Guide*, was being shared in other areas of the country; a workshop on the *Guide* for nine older family carers was held in Hampshire instigated by older carers from Hampshire who had attended the Oxfordshire event.

### **Training professionals**

In 2018 *Working with Families* training (separately funded) was delivered by OxFSN to 80 professionals working with families of people with learning disabilities in health and social care in Oxfordshire County Council and Oxford Health. This provided an excellent opportunity for sharing the issues affecting older family carers identified by Embolden with them. Professionals said in written feedback they now have a better understanding of the older family carer's journey and the impact this can have on relationships with them, e.g. not asking for help or being 'difficult' to engage with.

### **External networking**

Networking with partner organisations via key supportive individuals was extremely helpful and is reflected in the high number of professionals who came to the Better Together Event and were involved in the project over all.

### **3.6. Outcome 5: Impacts of cuts to health and social care services, on people with learning disabilities and older families are better understood in order to influence change.**

*"It's important to get together as it sparks a conversation"*

*"As I get older I get more isolated so the meetings offer a chance to get together"*

*"I have been helped by sharing information"*

### **Health, Equalities Framework**

Ten family carers from the Witney area supported detailed research work to highlight the impact of austerity measures and cuts to social care services in Oxfordshire. The Embolden team used the Health Equalities Framework and held four Health Equality Framework meetings which produced detailed individual data for each family and overall results were fed back to Oxfordshire County Council commissioners. The average age of the group was 80 years and quotes from what they said are above.

### **Scared to challenge**

Older family carers also said that the increasingly tight budgets in social care meant they are worried that if they speak up or can be identified through Embolden work, that they will lose support they currently receive for their relative. This has prevented them coming forward. Families with non-traditional white British backgrounds felt even more concerned and were very reluctant to even engage with OxFSN as intermediaries.

OxFSN worked very hard to identify and encourage older carers who felt able to speak up at key events with professionals. The Embolden team also focussed significant amounts of time and energy on raising issues with decision makers directly and pursuing them for evidence of actions and impact after the events. The July 2019 Better Together Event Update being a primary example of this. Additional actions to raise issues and influence change are below.

### **Spreading the word**

- Spoke at Care Matters Conference run by Carers Oxfordshire, 30<sup>th</sup> November 2018
- Presented at Healthwatch Oxfordshire conference, 21<sup>st</sup> May 2018
- Spoke at Transforming Care engagement event run by Oxfordshire Transforming Care Board, October 2016
- Jan Sunman, OxFSN older carer and volunteer spoke at a conference for Dying Matters Awareness May 2017 giving a powerful and moving presentation about her daughter which has been shared widely on social media and LDOX website.
- OxFSN's Programme Manager, Gail Hanrahan became Co-Chair (with a person with learning disabilities) of the Oxfordshire Transforming Care Partnership Board in 2017 in order to provide stronger links and greater opportunities to raise older carers' issues at the highest decision making levels in the County, across health and social care.
- A report by OxFSN in Year 1 *The Numbers of Older Carers in Oxfordshire*, published by OxFSN received favourable reviews from the County Council and is informing the County Council's social care Housing Strategy.
- Embolden data on the number of older carers was passed on to the Oxfordshire Joint Strategic Needs Assessment in 2017. The County Council are now logging data of people supported by older carers and now know there are at least, 60 people supported by family carers over the age of 80.
- A Project Worker is on the County Council's Co-production Board with the Head of Adult Social Care and Commissioner for Children's and Adult Social Care - older family carers' issues are being recognised and included in projects.
- OxFSN put out a call for evidence on proposed cuts to personal budgets, March 2018 and fed this back to the County Council.
- OxFSN challenged proposed changes to Disability Related Expenditure which it believes will disproportionately impact older carers and researches and publishes guidance for family carers.

## 4. Impact on Family Carers

### 4.1. The numbers benefitting

215 family carers and over 251 professionals benefitted over the life of Embolden.

This section summarises the numbers who benefitted; the categories are those set by Comic Relief.

*Table 2: The numbers benefitting by year*

Beneficiaries	Target	Year 1	Year 2	Year 3	Total
<b>People benefitting directly</b> Older Family carers, siblings and close relatives of people with learning difficulties	125	107	34	74	215
<b>Front line workers benefitting</b> OxFSN project workers and volunteers Learning Disability Nurses Occupational Therapists Intensive Interaction Support Staff	25	102	86	63	251
<b>Other people benefitting</b> Carers who receive information online and by other means. Attendees at the final conference including professionals working with older families	125	75	302	7568	7945

### 4.2. People Benefitting Directly

The number of people benefitting were counted as people who made direct face2face contact by coming to a coffee morning or an event and who made enquiries by phone. The target number benefitting directly in Year 1 were exceeded after the first 6 months. This was due to the project focus on finding and meeting older carers through the Big Coffee Morning events. The numbers stabilised in Year 2 as family carers who made contact in Year 1 still stayed engaged and returning to successive events. The increases in Year 3 were due to attendance at events.

#### 4.3. Front line workers

Front line workers benefitting was an underestimation, as OxFSN recorded those who came to events only, and not for example those who made enquiries on behalf of a third party, or who regularly shared the OxFSN Facebook information with other professionals.

#### 4.4. Other people

377 people in total in this group were known to OxFSN staff.

The reason for the very significant increase in Year 3 is due to the addition of social media statistics. As the Embolden project evolved the team got better at capturing statistics on other people benefitting.

OxFSN did not capture statistics via social media Years 1 and 2; the team also had less time to focus on the data collection and interpretation due to other issues during Year 1. In Year Two they redesigned data collection processes and collected more detailed information from family carers e.g. whether they have other caring responsibilities and the impact of caring on their own health. Evidence from both social media and the Guardian statistics for the Life Long Caring exhibition in Appendix 3, is very positive and shows that Other People Benefitting has been under calculated and underreported in Year 1 and Year 2.

#### 4.5. Profile of family carers who were involved in Embolden

OxFSN collected data from family carers involved in Embolden via surveys. The results are in the tables below; a full and detailed analysis is beyond the scope of this report.

Table 3: older family carers by gender

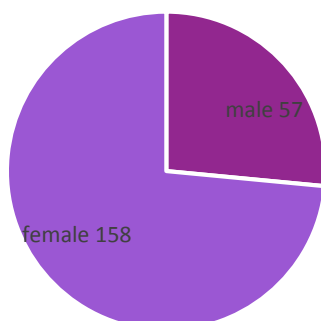


Table 3 shows more women caring for a family member were involved in Embolden, than men, and this is in line with national data which shows more women are carers than men.

Table 4: Age of family carers involved by number

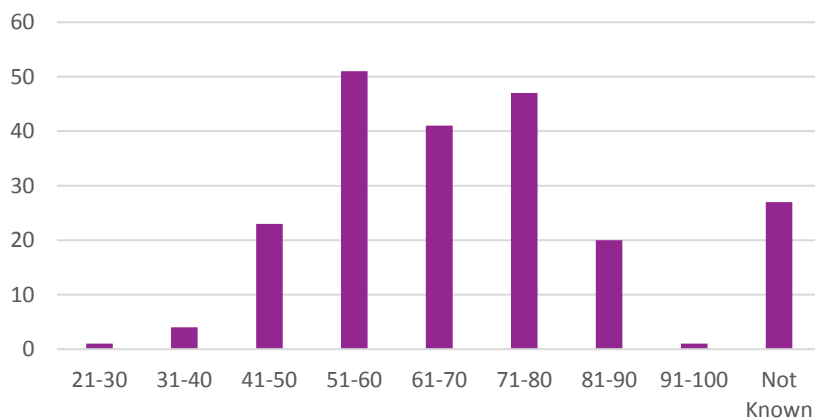


Table 4 shows that family carers in their 40s and 50s were significantly involved in Embolden events, and this group offered support and encouragement to their older peers.

Table 5: Age of family member with learning disability being cared for, by number

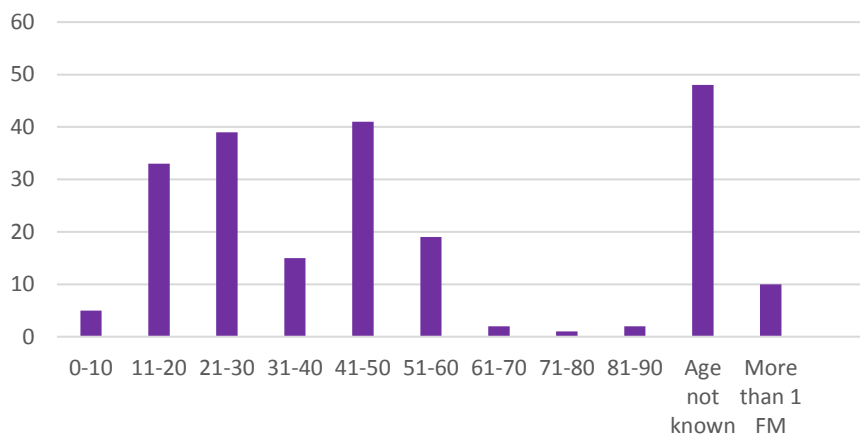


Table 5 shows that family carers involved in Embolden look after family members from childhood to very old age. Siblings are caring for family members in their 80s.

Table 6: Gender of family members with a learning disability by number

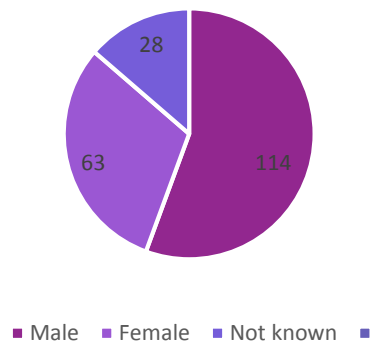


Table 6 shows that more men than women are being cared for, which again accords with national statistics.

10 families said they were also caring for more than one family member with a learning disability or other disability.

Table 7: By living situation of family members with a learning disability

Family Member Living Situation	Number of Family Carers
Deceased	3
Residential - in county	3
Assessment Treatment Unit	3
Sheltered Accommodation	4
Living independently	10
Out of County	19
Supported Living	30
Not Known	45
Living at home	93

Table 7 shows a minimum of 93 family carers have a family member with a learning disability living at home with them.

Five families had more than one family member with learning disability or a disability, living at home.



**Case Study 1**

Mrs A is 76 years old. She has eight children, the youngest of whom has Downs Syndrome and is 32. Mrs A is in poor health. She has cardiomyopathy and breathing difficulties. Her son lives at home with her and her husband, who has rheumatoid arthritis.

She is also aunt to a niece who has moderate learning disabilities, who also has a daughter, her great niece who is now 18 and also has learning disabilities. Mrs A has supported her niece over many years, as she requires support with financial matters, and lacks the skills to manage her own affairs well. Mrs A has had to support her when dealing with interviews or meetings with professionals as she can misunderstand information and sometimes reacts aggressively.

Her great-niece's care package, which was provided as a Direct Payment, had been stopped in May 2016. She found out that this should not have been stopped, pending a re-assessment of her great-niece's needs. The problems arose when her great-niece was moving from disabled children's services to adult services at 18. An assessment was carried out and the social worker informed her niece that *"this is the last time you will get anything from social services."* Her niece ended up over £1,000 in debt as she tried to find money to pay support workers.

**What we did**

Mrs A attended a workshop OxFSN held on the Care Act, as well as other sessions OxFSN held to enable carers to speak directly with key decision makers from health and social care services in the autumn.

Mrs A did not know how best to challenge this until she attended the workshops that Embolden held, informing her of the rights that family carers have under the Care Act 2014

**Outcomes**

As a result, she felt more confident that she could challenge the decision to stop her great niece's care.

Happily, the appeal was successful, as the care package was re-instated by the adult social care team, who assessed her great-niece.

She is now working on finding agencies that can support her great niece and again has sought information from the Embolden project team for this.

## **Case Study 2**

These parents are in their 60+ years and have a son, A, aged 30 with profound and multiple learning disabilities and complex health needs.

It became apparent that the family had a number of issues that were intertwined;

- A negative relationship with professionals, who saw them as controlling
- Needing help to understand Benefits
- A disqualification for Continuing Health Care (CHC) funding due to changes in eligibility criteria.
- They were worried they might lose the family home if their son moved out, as they were living in social housing that was adapted for disabled people
- Lack of respite and family support, which lead to many stressful calls to the team and to the GP.
- Worry about son moving into residential care

## **What we did**

The work we did with the family took over one year.

- They were supported to put their case to all agencies involved
- The case was built by working with the family and agreeing with them the information for the complaint and appeal.
- The independent complaints officer working for the Trust advised that they also challenge the CHC decision after he met with the family and supporter.
- Supported them with information about what supported living could be like and sought advice about the families living situation should he move out
- Supported them to seek help with Benefits

## **Outcomes**

- Apologies were received from the Social Care Services and the Health Trust.
- The family finally won their CHC appeal, they were able to provide key information to the CHC assessor and challenge in an effective way at the assessment meeting.
- With encouragement they decided to try residential care and A is now happily settled, 30 minutes from family home. The family have a good relationship with staff and the provider and remain very much part of his life.
- A's benefits have been sorted and family will be reimbursed for the Community Care Charges.
- With support they were able to put their case to the Housing provider. To remain in their family home, so their son could visit at weekends.
- A Direct Payment to cover support for the weekend visits was agreed, as a result of a challenge to have the right to a family life.

## 5. Impact on Professionals

*“The Embolden project has provided a valuable voice to many older family carers who may find it difficult to express their needs for many different reasons. We would welcome the expansion of this approach to all ages as it enables our own staff to learn and to have informal contact in an environment where we can learn together.” (Kate Terrioni, Director, Adult Social Care, Oxfordshire County Council, Dec 2018)*

### 5.1. The professionals involved

A major objective for Embolden was to identify and build up good working relationships with key professionals and decision makers, to ensure the right people heard and saw what older carers were saying and that older carers had access to them.

251 individual professionals were recorded as either attending OxFSN Embolden events or making contact by phone, email and social media and this represented more than 54 organisations. A full list of the organisations represented is in **Appendix 2**.

The numbers of professionals who attended each event are shown in the table below.

*Table 2: Attendance numbers for the countywide key events*

<b>Event</b>	<b>Total Numbers</b>	<b>Professionals</b>
Care Act Workshop with HFT, Oxford HFT, Oct 2016	37	7
Meet the Decision Makers, Oxford Nov 2016	52	12
You Said We Did, Oxford Jan 2017	38	13
Housing and Support, Didcot, Jun 2017	61	20
Health, Didcot, Feb 2018	42	20
Finance, Abingdon, Mar 2018	53	12
Better Together, Oxford, Nov 2018	43	55

Statutory health and social care organisations i.e. Oxfordshire County Council and Oxford Health and Oxford University Hospitals NHS Foundation Trusts are only listed once. However, their services are wide ranging and contact was made with the following teams:

Oxford Health: included the Learning Disabilities Support Teams comprising, intensive communication support, behaviour support, speech and language, physiotherapy, psychology and patient & public involvement.

Oxford University Hospitals NHS: included the Learning Disability Liaison Nurse, and Patient Advice and Liaison Service (PALS).

Oxfordshire County Council: included Adult Social Care, learning disability teams, co-production, and commissioners for housing and social care.

## **5.2. Engagement from professionals in Year 1**

The OxFSN Programme Manager said that by the end of Year 1

*“Providers, Professionals from Health and Social Care and key decision makers (Commissioners) know about Embolden and are actively engaged and supportive of the project”.*

There was positive response and engagement from the then new Director of Adult Social Care at Oxfordshire County Council and quarterly 1.5 hour meetings were scheduled throughout the project. As a result, the Oxfordshire County Council Commissioner for Vulnerable people has been tasked with exploring how data for future planning can be captured.

The new lead for Learning Disabilities at Oxford Health had been to all but one event by the end of Year 1. Oxford Health are now including older family carers of people with learning disabilities as well as those they care for in their Dementia Strategy

## **5.3. Engagement from professionals in Year 2**

Positive engagement with professionals, through events and attendance at meetings and networking and recommendations continued. OxFSN was invited to be part of many more Boards and Groups. While this allowed Embolden work to feed in and feedback issues to decision makers, it placed additional pressures on the limited workforce of the charity. Staff at the County Council and Oxford Health started using the information posted on the OxFSN Facebook page to update staff internally.

More staff attended the events, in particular the Working with Families training (see below) and are as a result having more face to face contact with older family carers.

## **5.4. Engagement from professionals in Year 3: Better Together Event Feedback**

The Better Together event in Dec 2018 was the most successful at attracting high numbers of professionals as 55 attended. The attraction was the chance to meet such high numbers of family carers and to network with other professionals from different organisations working with children and adults with learning disabilities and their families.

Professionals were asked to publicly sign up to a series of actions to improve their services. OxFSN have followed them up after six months sharing via newsletters with family carers the results of the professional's actions (or not!).

*“The County Council have heard the fact that we need to be having a different conversation with people who need support and their families to have better shared*

*experiences and better shared decision making and listening to what is most important to people. This means changing the culture and the way we do things. It means valuing relationships over process and refocusing on being person centred. This is a journey that has just begun and needs to include people we work with as well as our partners. The journey is about how we change our practice from focusing on diagnosis and what people can't do to putting strengths-based approaches at the centre of our social care practice in Oxfordshire. This means building on what people are good at and the things that give them confidence to achieve their aspirations rather than focusing on what people can't do." (Robyn Noonan, Adult Social Care, OCC) 10 June 2019.*



### **5.5. Working with Families Training Year 3**

During Embolden OxFSN gained pilot funding for training professionals and successfully trained 80. This has led to another grant for three years from 2019 and OxFSN have already been commissioned to deliver 'Working with Families' workshops with talk of this becoming mandatory training locally. As mentioned previously a significant part of this one day training is understanding the family carers' life journey and how they have come to gain the experiences and views they now hold.

*"A great opportunity to think about everyone's perspective, the background/journey and barriers in place that could make relationships strained, and what I can do to help*

*make the relationship positive and ensure working together.” (Professional 11 Oct 2018 Working With families Workshop)*

#### **5.6. Involvement at Oxford Health NHS Foundation Trust**

A good example of the impact of working with professionals by the end of three years, is Rachel Miller, Patient Involvement Lead for Learning Disabilities at Oxford Health, NHS FT. Rachel invited and supported adults with learning disabilities whose families were older carers to the *Better Together Event*, to ensure their voices were heard during this event which would help feed into service improvements and coproduction. Rachel Miller has now asked OxFSN family carers to contribute to the creation of mandatory training films for Oxford Health frontline staff, including receptionists and cleaners. When requested she also contacted 80 staff in teams to advertise the Life Long Caring photography exhibition and feature in the Guardian online.

*“OxFSN’s work with older carers has made me realise the incredible wealth of knowledge and experience this group hold and services could learn so much from them. I am fortunate to have been able to speak to and work with many of these carers and they always remind me of the importance of communicating honestly. This is, in my view, the foundation for services working effectively with families.” (Rachel Miller, Patient Involvement Lead for Learning Disabilities at Oxford Health, NHS FT.)*



## **6. Impact on OxFSN and the Embolden Team**

### **6.1. Learning about older family carers**

The impact on the Embolden team centred on learning about the lives and needs of older family carers gained from working with over 215 individuals over three years. Key learning is themed and set out below

### **6.2. Limited data**

There is almost no mention of older carers of people with learning disabilities in key social and health care Oxfordshire strategies for carers and for those with learning disabilities. The team were not able to find published data on the number or profile of older carers, including those who would identify with the seldom heard groups. Therefore, a significant amount of work was done to simply identify the numbers of older family carers.

### **6.3. Learning Disabilities Mortality Review (LeDeR) and Whorlton Hall**

During Embolden the LeDeR report into the premature deaths of people with learning disabilities was published and has created greater anxiety amongst families, to which Embolden needed to respond.

This was followed in 2019 by another horrific expose by BBC Panorama, about the abuse of people with learning disabilities in an NHS hospital Whorlton Hall. Older Family carers were yet again frightened and angry about the continuing abuse. Again Embolden needed to respond and challenge those with reasonability whilst reassuring and encouraging family carers not to close ranks.

### **6.4. Consultation responses**

As a small charity, with limited capacity, OXFSN often has to respond to public consultations and changes to health and social care services at short notice and a quick response is needed. These consultations are complex and often confusing for everyone but, particularly difficult for older carers to deal with i.e. Oxfordshire County Council had a consultation on Client Contributions and Disability Related Expenses. OXFSN had to take the time to develop information to share with families to help them make sense of it, which reduced time needed on other planned activities for Embolden.

### **6.5. Increased referrals for casework**

The success of the project in Year 1 of reaching more family carers increased the number of referrals and more complex individual case work. Through evidence provided as a direct result of Embolden, OXFSN were able to secure three year funding for a Family Support Service. A team of six family support workers/advocates are now supporting family carers of all ages. Referrals are logged, the issue, age of the carer and time spent to evidence need.

From the start of the funding in 2018 OXFSN has provided nearly 400 hours of support to 93 family carers.

#### **6.6. Partnership working**

As a very small charity OXFSN's strength is in networking and building partnerships. Embolden has given us the opportunity to work increasingly, not only with local families, who say they value the fact OXFSN are all family carers and independent of services, but also to work with learning disability support providers, the County Council, Health services, including the CCG (Clinical Commissioning Group), Oxford Health NHS Trust and other voluntary sector groups – locally and at all levels, e.g. Oxford Health NHS Foundation Trust.

#### **6.7. Good local knowledge and networks**

Embolden has increased OXFSN's local knowledge of services on the ground for older carers since the start of Embolden because they have worked across all agencies and have a good overview of their systems and processes. They are now even better connected and networked within services and have maintained good links with senior commissioners and leaders through this project. Consequently, they have very significantly raised their profile over the last three years especially for bringing people together through events and activities and sharing learning and resources.

#### **6.8. Supporting employment and volunteers**

Two family carers had the opportunity through Embolden, to return to work, benefitting from highly flexible working arrangements necessary to enable family carers to work and care. Two volunteers have also given highly skilled expert knowledge and support throughout.

#### **6.9. Value for money**

OXFSN was conscious of providing value for money throughout this project and used its resources cautiously. The recent partnership with Oxford Health NHS Trust provided free office space for Embolden, and the free use of parking, training and meeting spaces. They used free or low cost venues for events, and people brought their own lunches. They linked with other voluntary sector organisations to share resources, e.g. *Get the Picture*.

## 7. Embolden Legacy

### 7.1. Sharing the findings

The Embolden team began planning the legacy in Year 3 of the project and in October 2019 are holding an **Embolden Legacy Event** in Didcot to present the findings from the last three years, and more importantly talk about how OxFSN are going to continue to move the project forward.

A fundraiser will be recruited in September 2019 to enable OxFSN to apply for core funding and a continuation of the most popular events, such as Finance and Health issues, as well as smaller group workshops.

### 7.2. Extend the model

OxFSN recognised early on in the project the benefits to younger families who attended some of the events, and would like to build this and extend the model used to a wider group of families, across the age range through the Oxfordshire Parent Carer Forum. The running of an Oxfordshire Parent Carer Forum with a grant from the Department of Further Education via Contact (formally Contact a Family). The Forum started in September 2018 and is using the Embolden model of engagement i.e. giving a voice to family carers is now being used as model for parent carers of children and young people aged (0-25 years). This is an unexpected outcome and legacy for the Embolden project.

### 7.3. Advice, guidance and information

The advice on the Care Act and disability related expenditure, planning ahead checklist and the films, will all remain on the OxFSN website and are available for older family carers and their families to use. OxFSN are aware that for older carers there are barriers to finding and downloading information online, so these resources are more like to be used by younger family carers and professionals.

Future plans for 2020 include producing a range of themed, *Where to go for Help* guides on issues known to be of concern to older family carers, with supporting workshops e.g. consent and decision making, transition planning and financial assessments.

### 7.4. Research with Universities

Throughout Embolden the team has been regularly sharing information and findings with health and social care professionals, in the primary care but also in fields of research and academic. Historically research into learning disabilities is under- represented and underfunded. A committed group of academics in Universities across the UK are working in this area and invited OxFSN as collaborators or co-authors on the five projects to date.

OxFSN's primary role is PPI (patient and public involvement) to ensure that the voices and stories and experiences of older family carers is heard. This is new territory for OxFSN and extremely exciting as researchers acknowledge that finding and working with older family carers is challenging partly because they are invisible, but also researchers need to have built up trusted relationships with them to ensure coproduced outcomes and interventions and this often works better via a third party. Two current bids which have reached stage two with the National Institute for Health Research are: Right care, right place, right time for people with a learning disability in the last year of their life, for £2 million, led by Professor Irene Tuffrey-Wijne University of Kingston. OxFSN are collaborators. The second is Supporting family and professional carers to provide care for older people with learning disability and behaviours that challenge, led by Dr Sara Ryan University of Oxford, for £900k and OXFSN are co-applicants.

The pool of data collected at Embolden events for the under 60 year olds and those with learning disabilities is being put to good use with three additional bids.

#### **7.5. University Exchange with Japanese family carers and people with learning disabilities**

University of Oxford, Open University and OxFSN are taking part in a project with a Japanese University. One of the aims is for family carers and people with learning disabilities from Japan to meet with family carers in the UK and with self-advocates and to see how family carers support each other. In September 2019 they are meeting two older carers who took part in Embolden one of whom is Japanese and shared her life story experiences as part of Embolden to explore issues around what services for adults with learning disabilities look like in the UK.

The Japanese academic who is bringing the party over, is keen to show the visitors what happens in the UK, to learn about supported living and day services and the different ways that this can be set up.

#### **7.6. Life Long Caring**

The Life Long Caring portrait photography exhibition is touring Oxfordshire during 2019-2020. It leaves Oxfordshire County Council in Autumn 2019 and will be at the Churchill Hospital, the Oxford part of the OUH NHS Trust from November 2019. Other venues include public libraries across the county and local community centres.

#### **7.7. Better Together Event, Working with Families training**

OxFSN have secured three years additional funding from Oxfordshire County Council, to produce and host an annual *Better Together Event* and run *Working with Families* training for professionals in the County Council. There is talk of this becoming mandatory training locally.

### **7.8. Working with professionals**

Embolden has raised the profile of OXFSN as a small charity, and it is better connected to key commissioners in health and social care services. The Programme Manager still meets quarterly with the head of Adult Social Care at OCC and regularly meets with commissioners and other staff through a variety of learning disability related meetings. The impacts that any proposed changes may have on older carers are raised by professionals and are discussed with OXFSN in regular updates.

### **7.9. Here to stay**

While professionals come and go, family carers are in it for the long haul, so OxFSN is also in it for the long haul and has an 'institutional memory'. This comprehensive knowledge of local and national services – both current and historic - is now significantly enhanced by Embolden which OxFSN will continue to put to good use.



## **8. Conclusion**

### **8.1. Outcomes 1, 4 and 5**

- Older carers and their families understand their rights and have confidence to challenge and hold key public bodies to account (Outcome 1)
- Embolden has significantly improved engagement between local services, families in the provision of locality-based support solutions (Outcome 4)
- Health and social care impacts of cuts on people with learning disabilities and older families are better understood in order to influence change (Outcome 5)

The target number of 125 has been achieved as over 215 were direct beneficiaries.

The Embolden project has also increased the visibility of older family carers in Oxfordshire – literally through images – photographs and films. Their stories have been heard on local and social media and their presence at meetings and events across the county means they have met each other and professionals regularly over the last three years.

Consequently, there is far greater clarity on the issues that older family carers are facing daily and in the future. The numbers of older family carers are now documented by the County Council - they now know they have 60 older carers in their 80s providing daily care for a learning disabled family member.

The needs and views of older carers are being championed through meetings with commissioners, face2face and at board level. Three years ago, this was not happening. Therefore, of the five outcomes Embolden set out to achieve, Outcomes 1, 4 and 5 (below) have been achieved.

### **8.2. Outcomes 2 and 3**

- Older family carers and their relatives are empowered through building effective group advocacy (Outcome 2)

Older family carers say they have found being together in groups very helpful and the presence of younger family carers has had a very positive impact. They have come in high numbers to key events and needed good support to do this. This outcome has been achieved, however, sustaining interaction outside of the key events has been much harder for older family carers and there are few active networks in Oxfordshire, even with significant support from OxFSN staff. This is unsurprising given the barriers they face daily;



frailty, immobility, caring responsibilities and their own mortality. Therefore Outcome 3 has been harder to achieve consistently.

- Creation of strong expert by experience networks (Outcome 3)

The legacy for Embolden is underway, taking on all the learning for the last three years. OxFSN will continue to support and empower older family carers and ensure they have a voice.



## Appendix 1: Embolden Older Carer Consultations: Autumn 2016

OxFSN held a series of meeting with older carers across Oxfordshire in community locations in: Abingdon, Banbury, Bicester, Didcot, Oxford, Wantage and Witney. Overall 50+ people attended and responded to six questions at a table-top discussion, they recorded their responses on paper at the event. These responses were collated and themed by question as set out below. A themed summary of what older carers of LD said they needed is below.

Support for mutual carers	Sibling carers	Getting respite	Managing money	Getting specialist services
Continuity of care between health and social care	Thinking & planning ahead for the death of the carer	Coping with challenging behaviour	Knowing you can challenge	Being judged as difficult parent
Template letters & FAQs to understand the system better	Closure of day services	Meeting the cost of health care	Having a choice of care providers	Crisis and emergency support
Support groups which give information	Clear policies from providers on what they offer	Housing options and funding- where to find information	Transport Access to day services especially	Finding care providers and support workers
Clinical information on LD and aging and dementia	Need for an advocate	End of life care & bereavement of family member with LD	Claiming Benefits: ESA, and PIP	Care Act., Mental Capacity and DDA legislation – understanding it
Direct payments and personal budgets	Social care assessments- understanding the process	Mental health and dementia	Need for a point of contact - an expert signposter	Oxfordshire Carers Strategy and policies – knowing about it

## APPENDIX 2: Professional Organisations who benefitted from Embolden

Abingdon & Witney College	Learning Disability England
Abingdon Community Services	Learning Disability Oxford
Action for Carers	Online Community
Advance	McIntyre
Autism Family Support Oxfordshire	Mencap
Alexander House of Joy	My Care My Home
Autism Oxford	My Life My Choice
Barnardo's	NHS - Leicester
BBC	Oxfordshire Association of Care Providers (OACP)
Botley School	Oxfordshire County Council (OCC)
Brandon Trust	Oxfordshire Clinical Commissioning Group (OCCG)
Care With Heart	OUH NHS Foundation Trust
Carers Oxfordshire	Oxford Brookes University
Comic Relief	Oxford Health NHS Trust
Connection Support	Oxfordshire Employment
Department of Work & Pensions	Parasol Project
Dimensions	Real Life Options
DOSH Financial Advocacy	Reside Housing
Flexicare	Resource Life
Frankwise School	RNU – Oxford Health
Freeths LLP	Special Educational Needs and Disabilities Information
Get The Picture	Advice and Support Service (SENDIASS)
Golden Lane Housing	Style Acre
Guardian	That's Oxford
Guideposts	Yellow Submarine
Healthwatch	
Holy Trinity School	
Home Farm Trust	
Ice Centre	
KEEN Oxford	
Kingwood Trust	

## Appendix 3: Social Media Statistics Embolden

### Facebook

Engagement on Facebook is when people perform actions on your Page. They may like a post, click on a link or comment on an image for example. With Facebook Insights, engagement is defined as post clicks, likes, shares and comments.

number of people who follow that twitter account. There is no guarantee that all followers would have seen the article however. The only way to find that out would be from each individuals persons account.

#### Photography Exhibition: *Caring for Life*

Facebook (OxFSN),

**25/6/2019**

Post: Final reminder to see the exhibition at OCC

Engagement (People reached): 779

Post clicks: 66

Reactions, Comments, Shares: 42

**11/6/2019**

Post Guardian link to unsung heroes

Engagement (People reached): 1.6K

Post clicks: 141

Reactions, Comments, Shares: 86

**10/6/2019**

Brenda's post (Carers Week)

Engagement (People reached): 551

Post clicks: 20

Reactions, Comments, Shares: 18

**5/6/2019**

Photography Project – First post

Engagement (People reached): 640

Post clicks: 33

Reactions, Comments, Shares: 27

### Twitter

Tweets are harder to count but retweeted by the following individuals and organisations. The followers are the

- Making Families Count (890 followers)
- Care for the Carers (3391 followers)
- Oxfordshire Parent Carers Forum (253)
- Sam Clark - Learning Disability England (2133 followers)
- Learning disability England (9137)
- SeeAbility (7110)
- Society Guardian (72.5K)
- Guardian Social Care (45K followers)
- Dr Sara Ryan (9179 followers) (63 retweets)
- Alicia Woods – Dimensions (5236)
- The Challenging Behaviour Foundation (4989 followers)
- Bringing Us Together (1955 followers)
- Saba Salman Editor/Writer/Freelance - The Guardian (4901 followers)
- OxFSN (644 followers)
- Stay Up Late (25.1K)
- Paul Richards – Director of Stay Up Late (3530)
- Liz Wilson – Dimensions (948)
- Gail Hanrahan – Project Manager OxFSN (904)

**The Guardian Photography online  
exhibition. 'Lifelong Caring'**

The Guardian only capture the figures for the first week of publication: There were 6,200 page views with 62% in the UK, 10% in the US, 10% in the rest of the EU, 7% in Australia and 10% in the rest of the world.