

Embolden 2: Evaluation Report

September 2025



Table of Contents



Introduction	1
The Project	2
Data	4
Embolden 2 Outcomes	6
Headlines	7
Evaluation	8
The Outcomes	15
What we are pleased about	23
What we have learned	24
What are we concerned about?	25
Case Studies	27
Embolden 2 Legacy.... what needs to happen next	31
Acknowledgements	35

Introduction

In September 2022, Oxfordshire Family Support Network (OxFSN) began a three- year project, Embolden 2, to support older family carers who have a family member with a learning disability or a learning disability and autism to plan ahead for when they are no longer able to care for their relative. The project provided older carers with the information and knowledge needed to find a provision that would support their family member's needs.

Embolden 2 was generously funded £148,000 over three years by The National Lottery Community Fund, the largest funder of community activity in the UK. Funding officially ended in August 2025, with one presentation to the Association of Directors of Adult Social Services (ADASS) still to take place in September 2025. The project 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 18 years ago, by families 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.

Purpose of this report

This self-evaluation report assesses the impact of Embolden 2 on family carers, professionals and the Embolden team: answering the key questions,

“What difference did Embolden 2 make?”

“What can OxFSN do to continue to support older family carers to plan ahead when the project stops?”

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

- To demonstrate to The National Lottery Community Fund that OxFSN met the outcomes that they set out to achieve.
- To enable OxFSN to assess the impact of Embolden 2 on all those involved

- To plan for the continuation of OxFSN's work with older carers after the current funding ends as the need for this work remains.

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 conference in July 2025.

Embolden 2

Embolden 2 was created by OxFSN from the legacy of two previous projects, Changing Scenes and Embolden funded by Comic Relief. All three projects focused on the needs of older 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. *Embolden* gave a stronger voice to older family carers, to influence decision makers and to hold them to account in order to improve health and social care services for themselves and their families. Embolden 2 aimed to help older family carers to plan ahead for when they were no longer able to provide the care and support to their relative in their own home.

National and local data showed and continues to show, that the number 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 2.1 million carers aged 65 and over in the UK including 420,000 aged 80 and above.

OxFSN suspected from Changing Scenes, that the number of older carers age 60+ years of people with a learning disability in Oxfordshire was under reported and therefore unknown to social and health care services and also increasing. As a result of the first Embolden project, adult social care began to record the ages of family carers of people with a learning disability.

OxFSN also knew that older family carers struggled to plan ahead, and were unable or unsure of how to get support to do this often resulting in a crisis situation for their relative. They wanted to support these family carers to start the planning ahead process whilst also encouraging other younger family carers to start the planning ahead process much earlier.



" I know I would look into it (planning ahead) more and maybe look into the prospects for her, because I feel now that I've been thrown in at the deep end in many ways.

- Pat aged 84 on what she would do differently

Tiers

Family Carers were grouped in to Tiers dependent on the age and level of support needed for each family carer

Tier 1: primarily younger family carers who benefitted from attending the larger information events

Tier 2: family carers who were actively starting to think about the next steps and benefitted from the smaller coffee and chat groups

Tier 3: family carers who needed more intensive one to one support, usually in the home. This also included siblings whose parents were struggling to continue to care for their brother or sister.

Not Known: it was not always possible or appropriate to get the age of the family carer. It is worth noting that there were a high number of Tier 2 family carers who were in the planning stages for their relative.

Definitions

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 or a learning disability and autism. In most cases this is a parent, though it is sometimes another relative, often a sibling, grandparent or aunt or uncle. OxFSN use family carer to identify and respect the lived experience of an unpaid carer as opposed to the professional and paid relationship of a carer e.g., a support worker, personal assistant.

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, occupational therapists and speech and language therapists in statutory health and social care organisations.



The Numbers Benefitting

359 family individuals and 180 professionals benefitted from the project over 3 years.

People benefitting directly were counted as people who made direct face to face contact by coming to a coffee morning or an event and who made enquiries by phone. The target number benefitting directly over the three years was exceeded in Year 1. This was partly due to the project focus on making contact with family carers from the Embolden 1 project but also the importance of this information to families to help them with planning ahead for a person with a learning disability.

Data

Beneficiaries	Target lifetime of grant	Target first 12 months	Year 1 actual	Year 2 actual	Year 3 actual	Total
People benefitting directly <ul style="list-style-type: none"> • Family Carers, siblings & close relatives of people with learning disabilities • People with learning disabilities 	125	60	155	138	66	359
Frontline workers benefitting <ul style="list-style-type: none"> • OxFSN project workers & volunteers • Social workers • Social Care Staff • Support Workers • Voluntary organisation staff we partner with 	25	10	55	76	49	180
Other people benefitting <ul style="list-style-type: none"> • Carers who receive information online • Attendees of the event, including online information • Younger family carers, who may not have reached this stage yet 	125	75	155	138	66	359

Direct/Indirect Beneficiaries

OxFSN did not differentiate between people benefitting directly and other people benefitting as it can be hard to determine information of those who are accessing information online. Younger carers also attended events but because it is not always appropriate or possible to ask for age or ethnicity the data does not reflect a true representation of those who benefitted from the project.

Social Media

Whilst it is not possible to accurately measure numbers reading each post on social media OxFSN has:
1677 followers on Facebook
138 followers on Instagram.
Many of the posts are often shared across social media networks.

Data

Family Carer by Age

Age	Total
21-30	3
31-40	8
41-50	5
51-60	32
61-70	42
71-80	27
81-90	12
91-100	3
Not Known	220

Family Carer by Tier

Tier	Total
Tier 1	47
Tier 2	103
Tier 3	62
Not known	142

Embolden 2 Outcomes

Embolden 2 a three year project, designed to support older family carers of relatives with a learning disability to focus on future planning for their loved ones had five outcomes:

	Reduce Isolation by bringing families together
	Better informed by providing information, advice and support
	Reduce anxiety by demonstrating what good can and should look like
	Feel supported..... by supporting families to think and plan ahead and support them through the process of obtaining future support
	Start planning earlier by encouraging younger family carers to start the planning ahead process earlier

Headlines



We supported 359 people in total across the whole project

- 318 family carers
- 25 siblings
- 6 grandparents
- 5 people with learning disabilities
- 5 extended family members

- 34 families received more intensive support (Tier 3)
- 9 of these were siblings
- we connected with 180 professionals



Planning Ahead

All About Me Folder

- we ran 39 events
 - 16 online
 - 23 face to face
- we developed resources to help families plan ahead including
 - Crisis Care Planning Ahead Checklist
 - All About Me Planning Ahead Folder

Evaluation

Methodology

The Embolden Programme Lead and Embolden Project worker have contributed to this report. Both are Experts by Experience as both are family carers of adults with learning disabilities and have either gone through the planning ahead process of moving their family member in to supported living or are in the process of, thus giving them first hand understanding of what is involved.

External Evaluation

OxFSN planned to employ an experienced independent evaluator to help with the self evaluation. However, they were unable to find someone who was able to commit to this so were guided by both the **OxFSN Trustees** and the **Embolden 2 steering group** all of whom have experience of caring for or working with family carers and people with learning disabilities. This final report is a culmination of the three year Embolden 2 project.

Steering Group

The independent Steering group was set up to oversee the work we do and to provide guidance and support over the lifetime of the project. Members were external to OxFSN and included:

Dr Sara Ryan:	Professor of Social Care, Manchester Metropolitan University
Doug Amos:	Older Family Carer
Jacqui Gilbert:	Team Manager Community Connexions Team, Oxfordshire County Council
Clare Kassa:	Chief Executive, SIBs UK
Jon Hyslop:	Academic, Oxford Brooks University

Steering Group Meetings were held quarterly and provided guidance and direction. The steering group members were able to offer advice and support based on their experience and expertise and ensured the project stayed on track.

Working Group

A Working Group was established with statutory services and learning disability support providers to ensure awareness of the project and the ability to refer into Embolden stages 2 and 3. These meetings were held quarterly but members of the working group were available to be contacted at all times establishing a good working relationship over the life time of the project. It gave the Embolden team direct access to key decision makers within adult social care and Oxford Health Learning Disability Teams.

The working group included:

Gail Hanrahan:	OxFSN Project Manager
Kathy Liddell:	Embolden 2 Project Lead
Oona Bannister:	Embolden 2 Assistant
Jacqui Gilbert:	Team Manager Community Connexions Team, Adult Social Care, Oxfordshire County Council

Evaluation continued

Sam Harper: Interim Learning Disability Lead, Adult Social Care, Oxfordshire County Council
Sue Giles: Social Worker, Community Connexions Team, Adult Social Care, Oxfordshire County Council
Emma Short: Team Manager, Nurse Consultant, Learning Disability Team, Oxford Health NHS Foundation

Quantitative Data

The numbers who benefitted were collected and recorded throughout the project by OxFSN and were:

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

OxFSN also collected where possible

- detailed profile data on all family carers who contacted OxFSN for support and came to Embolden events, i.e. those under 60+ years of age, in terms of age, gender and living situation

Qualitative Data

was obtained through

- The National Lottery Community Fund reports
- OxFSN publications including *The Planning Ahead Folder*, *Questions to ask Support Providers*
- Event Feedback from family carers who attended 39 engagement and information events through written, verbal, formal and unsolicited means.
- OxFSN Surveys after online and face to face events with family carers
- OxFSN photographic stories of older family carers
- OxFSN film - *Planning Ahead*
- Interviews with key health and social care professionals

Publicity

The team used social media and newsletters where possible to initially launch the project inviting all those who were part of the Embolden 1 project both family carers and professionals to attend. The Embolden Team were aware that older carers were less likely to use social media so were contacted by letter or a phone call. Information was sent to all local radio and TV stations.

Information about the project was also disseminated by key leads across the adult social care and learning disability health care teams. This resulted in a high number of referrals of family carers not previously known to OxFSN, especially Tier 3 families who needed face to face support.

Evaluation continued

Newsletters

OxFSN produce a quarterly newsletter sent out to over 500 subscribers. Information about the Embolden 2 project, including upcoming events was included in every newsletter. The team also established an independent data base specific to Embolden 2 family carers to keep them regularly updated on topics relevant to the Embolden 2 project.

Social Media, Facebook, Instagram and X

were increasingly used through out the project to advertise events and disseminate information to professionals and other organisations who had contacts with older carers. It was a good way to highlight the importance of planning ahead. It also helped reach a wider and younger audience and there was a noticeable increase in younger family carers getting in touch and attending events wanting to know more about planning for the future. Social media and the newsletter was regularly used to let family carers know about the Tools that OxFSN had developed to help them in their planning ahead.

Eventbrite was used for advertising and booking events. Family carers from outside of Oxfordshire started to attend both online and face to face events feeding back that there was no other organisation that provided this type of information.



Evaluation continued

Partner Organisations

A major objective of Embolden 2 was to build on and develop good working relationships with key professionals and organisations. OxFSN are aware that the lack of trust in statutory services, often long held, by this group is a major barrier, which has resulted in a failure to plan ahead leading to significant crisis, where the person with learning disabilities can find themselves in emergency accommodation, sometimes miles from their own community and networks, while also dealing with the ill health or death of a parent.

Our planned approach enabled the charity to act as a bridge into statutory services. Because of our lived experience we were able to engage with family carers and deliver effective, person-centred planning. In this way, OxFSN were able to access families who may not initially have felt comfortable engaging with services, but who were in need of support and long-term plans.

Adult Social Care - Oxfordshire County Council



“The Embolden Project has been a fantastic example of what can be achieved through strong partnership working and collaboration. It has been brilliant to hear of the wonderful outcomes that have been achieved for people and their families, and I am grateful to OxFSN for leading on this and working so closely with us.”

Karen Fuller - Director of Adult Social Care (July 2025)

OxFSN has built up a good working relationship with key professionals within the Adult Social Care team despite a high turn over of professionals which has been instrumental in helping raise issues directly and identify gaps in services. What OxFSN found was

- Older carers in particular were increasingly worried about ‘rocking the boat’ and opening up to professionals about the challenges they were facing or being identified through the project in fear that they would lose support they currently received for their relative. This has prevented them from coming forward or starting the planning ahead process. Regular meetings with the working group and direct access to the Community Connections team meant that issues families felt unwilling to raise themselves with a social worker could be raised by the Embolden Team. By the end of the project, we saw more increased collaboration between Adult Social Care, OxFSN and families.
- Working within GDPR requirements, both Adult Social Care and OxFSN were able to raise awareness and identification of families needing some support to continue their vital caring role. In total, OxFSN provided intensive support to 34 Tier 3 families over the life time of the project which was more than originally planned.
- Social workers would come and go, often without any notice which left families not knowing what was going on and frustrated and anxious at the lack of continuity and information. The Embolden Team were often able to give an update providing families with the reassurance they needed.

Evaluation continued

- Due to time constraints and pressures, Social workers often struggled to commit the time to build positive and trusting relationships with families. Family Carers were also wary of professionals who they viewed as barriers to their relative getting a good life. OxFSN were able to work with both social workers and family carers to address the challenges that arose.
- One of the main aims of the project was to avoid Crisis Situations where a person would be moved in to supported accommodation in an emergency. The project highlighted the importance of social workers having long-term planning and contingency conversations in a sensitive and person-centred way which OxFSN were able to support practically through the events and person centred planning workshops. One of the key successes was an elderly carer in her 90's who supports her son aged 66 in her own home. Fiercely independent, she continually refused support from adult social care. As a result of the Embolden Team supporting her, the adult social care team now regularly 'check in'.
- Adult Social Care and the Embolden Team have worked closely together to try and make moves in to supported living as positive and well managed as possible. OxFSN know this has made a difference to those families who did not understand the process and felt daunted by the prospect.
- It cannot be underestimated how important it is to families having someone work alongside them who they can trust. Knowing that the Embolden Team had gone through this process meant that families felt confident in the support they were being given. Many social workers recognised this and would often ask the team to speak with families on sensitive or tricky issues knowing that families would be more understanding.

"It was nice to be able to offer a support service, focused at older carers, who understand and know the difficulties faced and options for support - it is important to share this with people we support . It feels more informal and relaxed, which often helps build trust" - Social Worker OCC

" I referred a couple of families- as they needed some additional support, and I thought they may interact better with someone who may understand their position and be able to explain a complicated system and build trust to have hard conversations. One family has felt let down in the past by professionals, so I thought they may connect better with OxFSN"

Social worker - OCC

Evaluation continued

Oxford Health NHS Foundation

Family Carers who care for a relative with complex health needs are often reluctant to consider supported living for their relative due to their fear that support providers might not adequately address their relative's specific health issues. Equally family carers feel a sense of loss of control over their relative's care and daily life.

- OxFSN have established a good working relationship with key health professionals specialising in learning disabilities over the years one of whom was a member of the working group. They also have a direct connection with Oxford Health's Learning Disability Health team and the Learning Disability Nurse's at the John Radcliffe Hospital which meant they were able to address some of these concerns and help navigate the transition to supported living.
- The learning disability locality health teams often worked with families not always known to adult social care and referred a number of older family carers whom they felt would benefit from more intensive support.
- Funding for those with a life long complex health need may come from a different budget depending on a person's diagnosis. Family carers find this process confusing and complex. The Embolden Team were able to run an online event on Continuing Health Care so that families had a better understanding of who funded what.
- Even with forward planning, there were families who still felt that they were not included in health decision's that were being made for their relative, especially once they had moved into supported living. The team were able to feed this back to both Oxford Health and support providers asking that a best interest meeting with family always take place.



SIBS UK

SIBS UK is a national charity dedicated to representing the needs of siblings of disabled children and adults. The Embolden team knew from their own experience that this can have a huge impact on other siblings in the family and felt that having the guidance of how best to support any siblings that they worked with would be helpful.

The CEO Clare Kassa was part of the steering group and the Embolden Team worked with the charity to run an online event for Siblings of the families they worked with. Feedback from the siblings involved who tended to be older, was that they found information events and advice more helpful than emotional support. Many had not been involved in their siblings day to day support, so were understanding for the first time exactly what their parents had to do.

Evaluation continued

Local and National Organisations

OxFSN despite being a small charity has a good network of contacts both locally and nationally with specialist knowledge across a whole range of topics that family carers need to know about when caring for someone with a learning disability.

- The Embolden Team were able to use these connections to run information events on topics including Wills and Trusts, Deputyships, Benefits, The Care Act, Mental Capacity, Continuing Health Care and Planning Ahead for Supported Living etc which family carers found invaluable, especially younger family carers whose relative was turning 18. These events gave family carers the opportunity to ask questions directly to professionals which they really valued.
- Often, the team would be asked a question that they did not have the answer to and were able to contact the professional on the families behalf to get the answers they needed. For example, one older carers relative who was still living in the family home was of pension age but the family did not know if they were eligible for a pension as the rules are complex and depend on individual circumstances. The Embolden team were able to contact the Department of Work and Pensions to get more information and help the carer navigate the system to apply.



Support Providers

Because of the process involved in finding supported living accommodation for someone with a learning disability in that it is for the most part, dependent on adult social care involvement, contact with support providers is often minimal until a possible house has been found. Support providers working within Oxfordshire also change and many family carers did not know who the support providers were, or who to approach. Families therefore did not know what to expect in terms of provision, what supported living looked like or what was involved.

OxFSN have an established relationship with a number of support providers locally and were able to bring family carers and support providers together. Because of their own experience of having a relative in supported living, the Embolden Team were able to provide a first hand insight in to what family carers needed to know when looking at a possible home for their relative. The team also created a Supported Living Guide with advice on what to look for and what questions to ask when visiting a supported living house.

The Outcomes

Evidence for how OxFSN has met each of the project outcomes is set out below. The outcomes are linked, so that evidence for one often serves another, but to avoid repetition, the evidence is 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.

1. Evidence of Reducing Isolation by bringing families together

The Embolden Team set up a series of 39 events including coffee mornings open to family carers over three years in locations across Oxfordshire.

- 87 older family carers aged 60 + years in total were supported by Embolden over 3 years.
- 220 family carers did not disclose their age
- 192 family carers were below the age of 60+

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

Meet ups and Information Events that were run across the county and on line were:

- Coffee and Chats - Abingdon, Banbury, Bicester, Witney, Oxford, Didcot, and online
- Person Centred Planning Workshops
- Money Matters Information Event
- SIBS online event
- The Care Act
- Maintaining Friendships
- Q & A with Adult Social Care
- Community Dentist
- Planning for Supported Living
- Office of the Public Guardian
- Planning Ahead Folder Filling
- Mental Capacity Act
- Wills and Trusts
- Continuing Health Care

“As well as being very informative the events also meant we got to speak to other parents to exchange experiences and were also able to speak to the professionals to ask questions. The general coffee and chat events are really great and we have also learnt information and facts from those too.

There is nowhere else, no other organisation like this that relates to our situation as older carers of an adult child. It is invaluable.”

The Outcomes continued.....

548 family carers and 162 professionals attended events over the duration of three years.

The most successful event in terms of attendance was the Supported Living Event, 8th June 2023 when 76 people came, the oldest of which was in their 80's. These events are invaluable to families in the planning ahead process as they provide the opportunity to hear directly from other families about their experiences as well as connect with others in a similar situation. Knowing that others have already successfully found a home for their family member helps family carers starting out on this journey feel less isolated.

All events had decision-makers present and key speakers from external organisations. Family carers are given the opportunity to speak to decision makers directly, gain accurate updated information, learn more about the process involved and make good personal contacts. Without OxFSN, these connections would not be possible for many family carers who are more isolated because of their caring role.

Many family carers often come to these events more than once (counted in the total attending) as not only are they a valuable source of information, for many they are also an opportunity to meet with others who have either gone through, or are going through a similar situation to themselves. However, despite efforts to encourage older family carers to meet up without support from Embolden staff, this did not happen. They valued the support they got from OxFSN and in turn were invaluable sounding boards and focus groups to the team.

"I find the events are encouraging and helping me keep going with the lifelong support."
Family Carer - Embolden

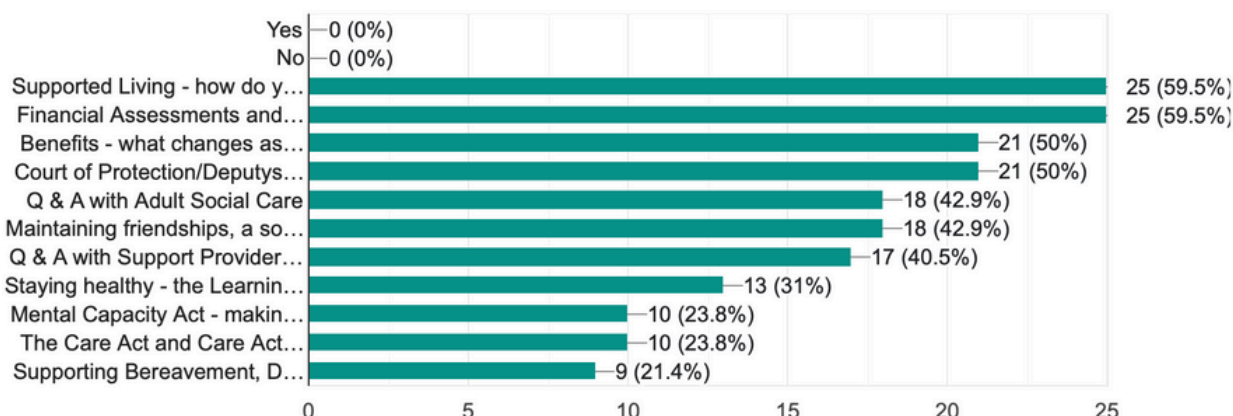
"Support, particularly local, is so important when people are facing the turmoil of caring for someone with disabilities. It is a huge responsibility and the right help can prop up the mental wellbeing of the family"
Family Carer - Embolden

The Outcomes continued.....

2. Evidence of Better Informed Families

At the start of the project, we set up a series of coffee and chat sessions across the county to gain insight on what families felt they needed the most. Families told us that they really valued the information sessions. We conducted an online survey across all family carers who were currently on our database to find out which topics were of most interest. We also asked them to complete a Planning Ahead Check List which in turn helped us prioritise what information events to run over the next three years.

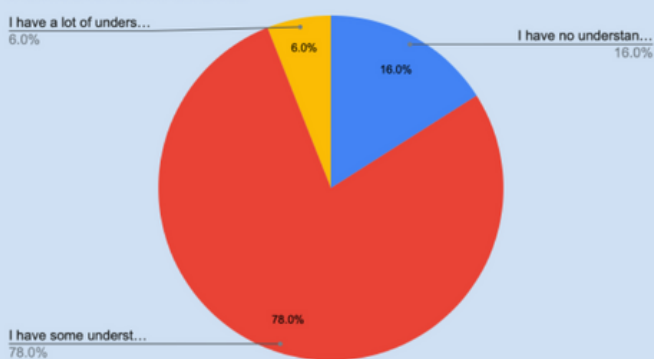
Information Events Survey



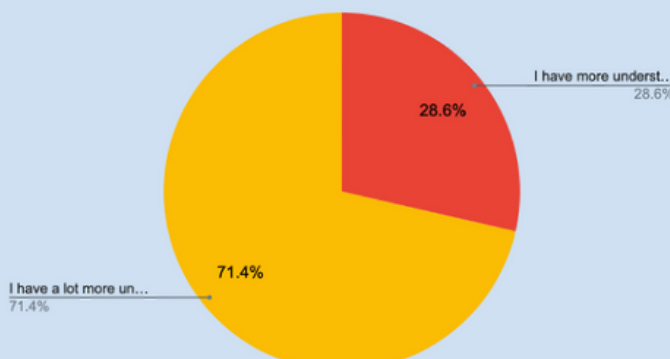
Collecting evidence

At the start and end of our information sessions we asked those attending to complete a poll so we could measure how informed people felt.

Poll before the events



Poll after the events



The Outcomes continued.....

We know that for many family carers, these events are often the main source of information on many of the topics they need to understand when supporting someone with a learning disability. They are also an opportunity to ask questions directly of key professionals. OxFSN, are able to bring in speakers with specialist knowledge on topics family carers need to help plan ahead. The Office of The Public Guardian for example had never run information sessions until OxFSN approached them. They now do yearly sessions for OxFSN as well as online sessions open to people across the UK giving Family Carers starting out on this process a much greater knowledge and understanding of the process.

3. Evidence of Reducing anxiety

Family carers caring for a relative with a learning disability are life long carers. With that comes a huge amount of anxiety at any stage of life, but none more so then when thinking about the future and what will happen to their relative when the family carer is no longer able to care for them. Family carers often tell OxFSN that the worrying keeps them awake at night and for some, their wish would be for their relative to die before them.

This was particularly noticeable with the older family carers in their 80's who were often isolated, having spent a life of caring for their relative, regarding themselves as having no choice but to get on with it and who did not want to be a burden to their other family members.

Fears of institutional living

OxFSN knew from the first Embolden project that views of supported living amongst older carers are often based on 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 from planning for the future when they are no longer around. They often only seek support when in a crisis.

Because the Embolden team had direct experience of supported living with their own relatives, they were able to give a more accurate insight in to what good supported living could look like. On occasions they were able to take family carers to see the house where their family member lived which made the process of what supported living looks like more tangible and help reduce anxiety about the unknown.

The team were able to show family carers who had access to the internet the film **Peace of Mind** made during the first Embolden project where three older family carers talked about the positive impact that finding supported living for their older family member had on all their lives.

The Outcomes continued.....

At the supported living events, OxFSN brought in family carers who had gone through or were going through different routes in to finding supported living to talk about their own experiences, highlighting the pros and cons and giving families starting the planning journey an opportunity to ask questions.

The Embolden team also invited **support providers** (Style Acre, Brandon Trust, Kingwood, Fitzroy, and You and Me Supported Living) to the information events. This gave family carers the opportunity to meet with and ask questions about any worries or concerns that they may have about the support provided.. OxFSN also created a **Supported Living Checklist** with a list of questions to ask Support Providers when going to look at potential houses.

Feeling overwhelmed

Many older family carers found the process of planning ahead emotional and overwhelming. They needed help prioritising what to do first otherwise, many would just bury their head in the sand, and in some cases expect the extended family to sort it out when they were gone.

Meeting with Tier 3 family carers in their home on a regular basis helped reduce their anxiety as the Embolden team were able to go through the Planning Ahead checklist and help prioritise what needed to be done first. By having a clear plan, family carers felt more in control and less overwhelmed.

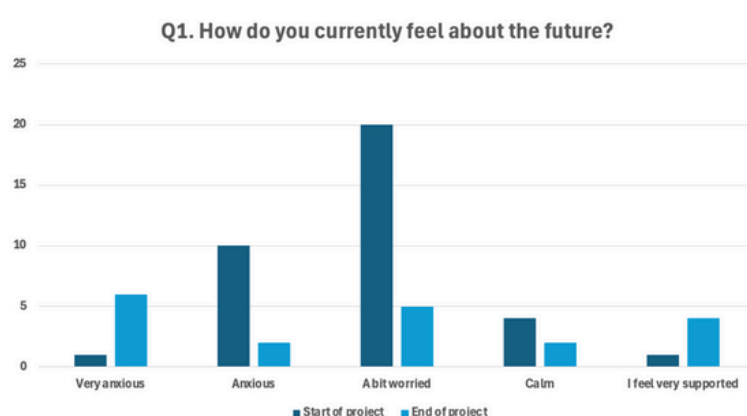
I'm still anxious, but I don't feel completely lost. It is so valuable to know that there are people who are there to support me as well as my son.
Family Carer - Embolden 2

"To have an organisation such as this is unique and the fact it is run by people who are not only knowledgeable but understand emotionally the difficulties and processes involved is pretty rare"
Family Carer - Embolden 2

The Outcomes continued.....

We ran a baseline survey at the beginning and end of the project to gauge how family carers felt about the future. Not surprisingly, the results showed that there were some who still felt very anxious although they felt much more supported. For family carers any change of circumstances for their relative, especially a move in to supported living when they hand the care over to someone else brings with it a whole set of new worries so the anxiety never goes away.

What difference did it make?



4. Evidence of feeling supported

The Embolden team know through their own personal experiences that raising a child with a learning disability can be a lonely journey. This becomes more so as their child becomes an adult. They no longer have the support of the education system and have to carve out their own networks. This is more difficult to do, as their caring role means that they do not have the time or the energy to make this happen. At the same time, they are having to navigate a system that is constantly changing, and whilst statutory organisations such as Adult Social Care or Health Services provide support to their relative, family carers often feel they have to ‘battle’ to get the right support. No continuity of staff and information not always easy to find or transparent means family carers are often left, not knowing where to go to get the help and support they themselves need.

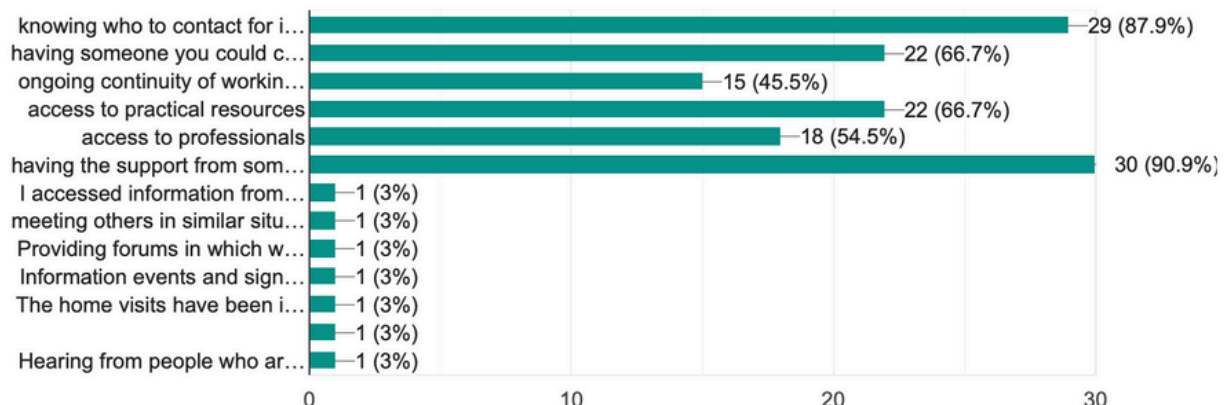
The Embolden 2 project helped families to think and plan ahead and support them through the process of obtaining future support. They did this through the information events which were open to family carers of all ages. Significant numbers of younger carers aged under 60 years attended these events because although they were aimed at older carers, the information had an equal value to younger carers.

The Outcomes continued.....

Younger carers could draw on the experience of older carers many of whom advocated the need to plan ahead earlier and older carers felt more supported and empowered to move forward with the planning ahead process. Older family carers reported that they drew strength from having younger families gaining information alongside them which has started to build a stronger, more supportive network in the county.

Many of the older carers in Tier 3 found the process of planning ahead overwhelming and exhausting. The Embolden team were able to make more frequent and shorter visits which made the process much more manageable and whilst there were still things that the team could not do, they were able to help move the process along completing paper work, or acting as the main liaison with adult social care or health. Families told us that this made a difference as they knew who to contact to get the information they needed and they valued having support from someone who understood the system.

Some older carers were dependent on the Embolden Team for emotional support, especially when it involved an actual move of their relative out of the family home in to supported living. This was a very emotional time for them, especially if they were also dealing with the loss of a spouse which usually triggered the move in the first place. Many did not want to burden other family members preferring to get on with it themselves, but finding the idea of not being the main carer after so long very overwhelming. The Team were able to offer a lot of reassurance but also make the social workers aware of how important it was to support older carers through this process.



"Every mother that has a child or an adult like we have, experiences the same difficulties (we) all have the same worries...and from the very start...I felt I had someone that I could tell all my troubles to Professionals are 'really nice' but they can't feel like I do unless they have someone like I have"

Tier 3 Family Carer

The Outcomes continued.....

5. Evidence of planning ahead earlier

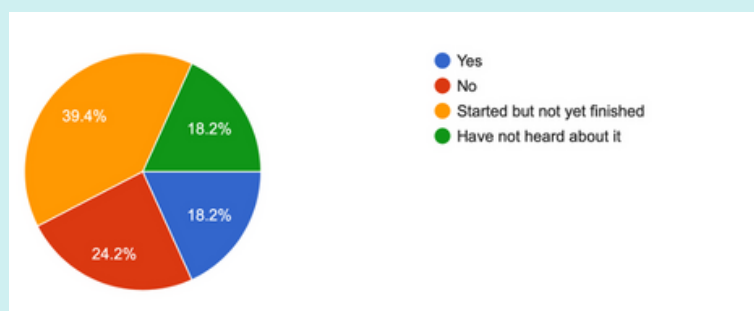
OxFSN know from previous work with older carers that the reluctance to plan ahead often comes from their view of supported living being based on old institutional care settings and a fear of handing over the support to others. This has often stopped them planning for the future only seeking support when in a crisis.

To change this conception for younger families coming through the system and to encourage them to start the planning ahead process earlier, OxFSN used the film **“Peace of Mind”** from Embolden 1 and written articles to share positive success stories to show what good looked like and to allay fears.

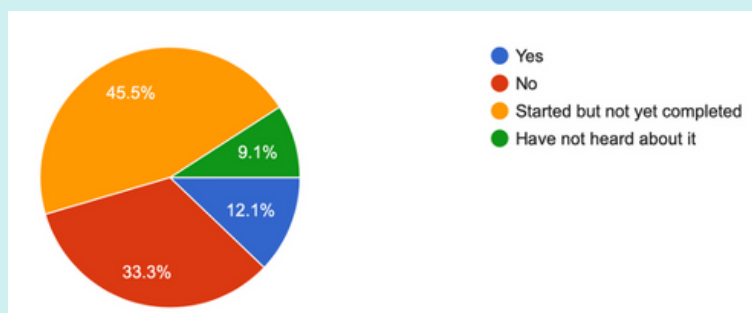
To help people start planning for the future, OxFSN created a **Planning Ahead Checklist** which they used with all the older family carers they supported and circulated at all their face to face events, including in all their newsletters and on social media. This checklist helped younger families start to prioritise what they could put in place. This is especially important when planning ahead financially when someone lacks capacity as it can lead to complications in managing their finances when someone becomes an adult.

OxFSN also developed an **All About Me Planning Ahead Folder**. Feedback from family carers was that they needed some guidelines on what to include so the team put together templates that families could fill in that included key information about their relative that would help anyone stepping in in an emergency or short notice. These are available to download from the OxFSN website.

Survey results at the end of the project showed that 57% of the family carers who responded had completed or started to complete a **crisis care form**.



Survey results at the end of the project showed that 56% of family carers who responded had completed or started to complete an **All About Me Planning Ahead Folder**.



“OxFSN has motivated us to act upon long postponed intentions, and helped us to finally work towards a good future for our son”
Family Carer - Embolden 2

84% of family carers who responded to our survey have started to make plans for the next stage of their relative's life.

25 people with a learning disability have moved from their family home into supported living or plans are underway.

What we are pleased about



- The difference we have made to individual families. We know it has helped because they have told us it has.
- The seemingly small steps are actually huge. Some family carers were previously reluctant to engage with social workers but having a member of the Embolden team work alongside them gave them confidence to start the planning ahead journey.
- We developed a good working relationship with key professionals particularly in adult social care. This meant we were able to keep family carers informed of the process of their relative in a system that often alienates families.
- Provided structure to family carers who have gone through education and the moving in to adulthood stage. This was particularly important to those older family carers who did not have a named social worker and were unsure of how to start the planning ahead process for their relative.
- Developed resources and ran events that helped all family carers. These resources helped younger families think about planning ahead even though they had not yet reached the stage when they were ready for their relative to move out of the family home.
- We have worked with some older family carers previously not known to us through the project. A big push promoting the Embolden 2 project amongst Adult Social Care and Oxford Health resulted in a steady number of referrals especially of older carers. These carers are often isolated with no access to social media and their only contact with adult social care was often at the annual review of their relative when it was recommended that they contact us for support.
- The involvement of siblings was far more than we anticipated. By the end of the project we had worked with 25 siblings, most of whom were unknown to OxFSN.
- Feedback from all Tiers has been extremely positive and we know that family carers appreciate the opportunity to learn more about what they need to do when planning ahead.



“ The home visits are just so relaxed, and we have been able to grasp the situation with our daughter going into supported living so much better. We were really overwhelmed with the whole business and desperately needed someone to help. OxFSN has been an essential lifeline help. I cannot express how important their input and guidance has been. ”

Family Carer - Embolden 2

What we have learned

- Working with older carers requires more time. They often have their own health issues to deal with and many feel overwhelmed by the amount of planning that has to be put in place. The team found that frequent visits for a shorter period of time worked better for many of the older carers.
- Meeting with the Tier 3 families in their home on a regular basis helped reduce their anxiety. By the end of the project, many looked forward to these meetings as it gave them a timeline to work towards and a sense of accountability.
- Many family carers found the process of planning ahead emotional and overwhelming. For many it meant coming to terms with accepting that they were no longer able to provide the care for their relative which for some was over 60 years. They also needed help prioritising what they needed to do first otherwise many would just bury their head in the sand.
- Building relationships, building trust and getting to know each other has been the key to this project. Family carers valued talking to someone who had “already walked in their shoes”. Knowing that the team knew the system, having experienced it themselves meant that family carers were more trusting of the information they were being given.
- Attending face to face events gave family carers the opportunity to meet with other parents to exchange experiences and to speak directly to professionals to ask questions. Families valued hearing from others in similar situations as they could relate to many of the issues and concerns raised and provide suggestions to help.
- Sibling/Parent carer relationships could sometimes be difficult to navigate. Some family carers did not want to burden their other children with looking after a sibling. However, this often meant that the siblings had no idea what was involved and when a parent died were like a ‘deer in headlights’ as they attempted to navigate a complex and confusing system. In some cases, siblings got in touch as they were concerned that their elderly parent was no longer able to provide the care and support to their sibling and wanted to know how they could get involved. Some parents were receptive to this. Others were resentful which meant the team often had to navigate some tricky relationships.
- Some Tier 3 families were still reluctant to start the planning ahead process even though they knew they needed to. The team spent a lot of time getting in contact with and chasing some family carers knowing that they needed the support but found that despite an initial positive reaction to support, then failed to engage.

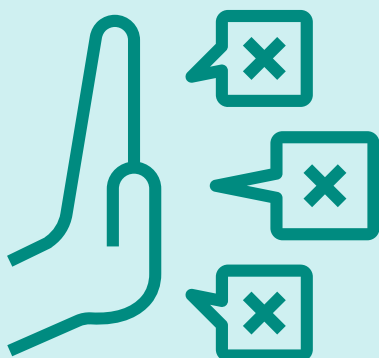


- An appreciation of how complicated some family situations can be and how much social workers have to juggle. No one family situation is the same, yet their situation had to ‘fit’ in to systems which though they professed to be person centred, often proved to be inflexible. This meant that both the Embolden team and Social workers at times found it difficult to provide the outcome that the family were looking for.

What are we concerned about ..

...what difficulties did we encounter?

- The team could prepare and plan with the family carer but reached a point where they could not move any further forward usually without adult social care involvement. This was due to either no social worker being allocated to that family or a lack of appropriate supported living opportunities for their relative.
- Many of the older carers were not on the internet so a lot of the support had to be face to face or over the phone. As older family carers tended not to initiate, the team had to continually reach out to move anything forward. Meetings with elderly carers took a lot longer than anticipated as they got tired. Many were dealing with their own health problems and could only manage two-hour meetings, so progress was slow.
- Despite giving family carers the tools and support needed, some still found it difficult to move forward with the planning process.
- The team had to tread carefully in some situations to navigate family circumstances when siblings were involved.
- The process of finding somewhere appropriate to live took a long time as families often wanted their relative to live locally to them. Opportunities offered were either not appropriate or too far away from the family.
- Many family carers had no idea what supported living looked like so found it difficult to imagine their relative moving. Their first encounter was usually when the social worker contacted them to say they had found a 'suitable opportunity'. Families were then given the chance to look around but often had nothing to compare it to.
- Shared Lives was often presented as the only option to families, so they had to go through the hoops of rejecting it before being offered a shared supported living house. Whilst some families saw it as a step towards independence for their relative, they did not see Shared Lives as their 'forever home'. Older family carers wanted to see their relatives settled in a setting with support providers trained to provide the right support and felt that living with another 'family' would only confuse their relative.
- Some social workers were more willing to work alongside OxFSN than others, despite the project having support from senior management. This meant the team struggled to get the answers they needed for the families.



- Social workers came and went, often without notification so families had no idea what was happening. In one situation, a family had worked with 7 different social workers over three years. The family carer had to repeat their story each time and felt it impacted any progress moving forward.
- Family carers who would have benefitted from having an 'eye' kept on them were often having their cases closed as quickly as possible usually due to staff pressures. A change of circumstances would have to be reported in order to reopen their case and get a social worker.

What are we concerned about ..

...what difficulties did we encounter?

- Families were sometimes promised things would be put in place which then did not happen which lead to disappointment and mistrust. The team would spend time trying to manage the situation, knowing this was the only way to maintain good relationships.
- Oxfordshire County Council's systems and processes were too inflexible to support older carers, who although not yet in crisis, a crisis was clearly pending. Yearly reviews were not frequent enough to enable monitoring of those family carers whose circumstances were changing daily.
- The team struggled to engage with Oxford Health when it came to health concerns especially when the relative had moved out of the family home in to supported living. Older family carers who had a relative with ongoing health needs sometimes felt sidelined when health decisions were being made. The Team fed this back to Oxford Health, and asked that best interest meetings take place to include families.



Embolden: Some Families Have Shared Their Stories



To capture family carers views of the planning ahead process and the support they received through OxFSN, the team interviewed a number of families who were willing to share their story about their own journey and the impact that caring for a relative with a learning disability had on them. The video can be found on [OxFSN's You Tube](#) page

Case Studies

Janet and Nichola's Story

Janet: Aged 85, Nichola: Aged 54

About the Family

Janet comes from a large family of fourteen brothers and sisters! She is the last living member of her family. Janet and John have two daughters, Julie and Nichola, and Julie is six years older. They have many cousins. Nichola loves little babies and finding presents to give them. The family used to live in Jericho in Oxford before moving to the Cowley area.

Nichola attended mainstream schools when she was small until she was diagnosed with Autism with moderate learning disabilities and she attended the Ilffley Mead school.

After leaving school Nichola worked in a Health food shop for a time which she really enjoyed, but sadly another person who worked there started to tease her a lot and she decided she didn't want to work there anymore. Nichola has always lived at home and enjoyed going to the shops and 'people-watching' as she has a friendly personality and says hello to everyone. This also makes her very vulnerable. Janet was able to continue working up until retirement age, but she says that the family was never able to be spontaneous. Everything revolved around Nichola. Holidays were at caravan sites and Nichola's needs were always put first. Janet felt rather lonely as friends didn't really understand her situation. Janet did the bulk of the caring and she found she was able to manage.

When Nichola turned 50, her behaviour suddenly changed and Janet found this really challenging. She is very addicted to scratch cards which can cause problems when she runs out of money, and she also stopped being able to sleep at night. She became too difficult for Janet, and circumstances forced her to reassess where Nichola should live. Janet and John felt they couldn't cope with having Nichola at home any longer as John was having some health issues himself. The family had not had any support from Social Services previously, but it was at this point that they rang for help.

Their situation at the start of the project

When we first got involved Nichola had been taken into the Warneford Hospital for several months where unfortunately she put on a large amount of weight due to the medication which upset the family as it wasn't good for Nichola's health. She has asthma and became more breathless. Everyone close to Nichola noticed her personality had changed and it was difficult for them to see. After several months Nichola was moved into emergency respite at Saxon Way.



How we supported them

Janet had not heard of OxfSN. It was her Social Worker that recommended us to get in contact with the family. We met Janet at home and supported her through this difficult time. Nichola stayed at Saxon Way for fifteen months, visiting Janet twice a week by travelling on the bus with her carers to Cowley, until a Supported Living home became available in Abingdon. Some adaptations needed to be made to enable Nichola to be more independent.

During this time we provided Janet with information on finances, (LPA and setting up a Bank account in Nichola's name), emotional support, and we helped Janet in putting together a Planning Ahead Folder with a one page profile. We also liaised with the Social Worker and Oxford Health. Nichola moved into a Supported Living home in January 2025. This was a difficult time as she takes a long time to settle into a new environment and Janet was very concerned. Nichola's behaviour deteriorated and a new Social Worker was brought in to assist, along with the Intensive Support Team at Oxford Health. We supported Janet through this time, liaised with the Social Worker and with the Dynamic Support Register Team. We enabled Janet to attend the online meetings and she was therefore able to express her concerns. This was really important and meant she could be involved, as she doesn't have easy access or feel confident with digital technology and had not attended previous meetings.

What difference did we make?

Janet says she found the help from OxfSN very supportive. She found the information and home visits useful, and "just being able to ring up and speak to someone about any problems or queries was reassuring when I needed". Looking back, Janet would have liked to have had Nichola settled into a Supported Living home earlier "but up until Nichola was 50 she was fairly easy to care for". Janet has recently felt very stressed about the Supported Living Home as things are not running particularly smoothly. To begin with she felt the one to one care hours allocated were not sufficient for Nichola even though this had been raised with the previous Social Worker before the move. For instance, for many years Nichola has had the routine of going out daily on the bus, to sit and 'people watch' and have a cup of coffee. Initially the carers had not understood how important this was. With more one to one care now in place there have been improvements which has been positive.

OxfSN have been an advocate at meetings for Janet as she has sometimes felt overwhelmed by the situation and did not wish to attend.

After each visit, Janet's parting sentence has always been the same,

"I don't know what I would do without you!"

Janet, Derek, Julie, Andrea and Susan's Story

Janet: Aged 85, Derek: Aged 88 (died October 2024), Julie: Aged 58

Janet:
"You carried on doing it (caring), you didn't sort of worry about things... I just took each day at a time"

Andrea:
"They (Mum and Dad) just both presumed they were going to carry on for ever"

About the Family

The family have always lived in West Oxfordshire and have very strong ties to the area. Julie, who is the middle daughter of three siblings lived, up until the age of 57 at home with her Mum and Dad. She attended both the local primary and secondary school but at the age of 11 became a weekly boarder at Wood Eaton Manor School as she was bullied at the local school and needed extra support. This was hard for the family, but Julie enjoyed it. She then went on to Banbury college where she did a life skills course.

After leaving college Julie tried working but found it hard to maintain so for most of her life has attended the local day service three days a week. She also went to April Cottage in Witney for respite. At no point were Janet and Derek given the option of Julie moving in to supported living. It was only when both parents ended up in hospital at the same time and Julie's siblings became involved that they started to think about the future. The family home of 60 years was sold in July 2024. Julie moved into a shared house in her local town and her parents moved into a retirement flat 5 minutes away. Sadly, Derek passed away shortly after the move, so having Julie nearby has been even more important for Janet who she is able to see on a regular basis.

Their situation at the start of the project

The family weren't known to OxfSN at the start of the project. Andrea, Julie's younger sibling got in contact after she heard about the charity through another family carer. Both her and her sister Susan were concerned that their parents were struggling to care for Julie at home as both had been ill and in hospital at the same time. On this occasion the immediate family stepped in but knew that it was not a sustainable option and that they needed to start thinking about the future for Julie. Janet had always been the main carer for Julie and organised everything, so the extended family had very little understanding of what they needed to do.

Julie's life had also become quite limited. "It got to a point where they (Mum and Dad) didn't really want Julie to go anywhere so Julie, apart from going to the (day service) or April Cottage wasn't really going out very much. He (Dad) just wanted her to stay at home all the time".

For Andrea and Susan, starting the process was difficult as they knew it was important to balance their own involvement with Janet's wishes, recognising that it was an emotional journey for her.

How we supported them

The process of planning ahead felt overwhelming to Susan and Andrea who had no idea of what needed to be put in place, and had never looked into it, so we began by meeting with Janet and her three daughters to go through the Planning for the future check list to help them prioritise what they felt they needed to focus on first. We knew the need to find a suitable home for Julie, preferably close by in the community she had always grown up in was a priority, but there was also a lot to sort out around managing her finances. We met several times face to face as a group and Andrea was in frequent contact either through phone calls or email.



Julie did have her own bank account which had been set up years ago by the local bank manager who "knew the family" yet Janet did not have Appointment, only third party access, even though Julie wasn't able to manage her own money. The social worker completed a mental capacity assessment which then enabled the family to apply for deputyship for finance and property and one of the sister's was able to take on appointment for Julie's benefits with the DWP.

We spent a lot of time doing person centred planning to identify what was important to and for Julie and using this information worked closely with the social worker to look at suitable supported living options. Yet again, Shared Lives was offered as the first option even though the family had said this wasn't the route they wanted to go down, and with OxfSN's support, the family were able to work with the social worker to identify a shared house as the best option. Andrea completed an All About Me Folder for Julie which the support provider was able to use when it came to moving.

What difference did we make?

Having the support of OxfSN through the journey made a big difference to the family as "we really didn't know an awful lot". Working with someone who understood the process because they had gone through it themselves "gave us more confidence" and they appreciated hearing personal experiences from a family carer which were more relatable. Both Andrea and Susan did attend an online SiBS event but felt that being older they were in a different situation to those of younger siblings, as they have each other for emotional support, and at this stage needed more practical information.

When the family home was put up for sale, finding a suitable place to live for Julie became a priority. We were able to alert the Community Connections team within Adult Social Care, who were able to find a home that was suitable quite quickly as they were already aware of her requirements because of our involvement with them.

The family feel a lot happier now than they did before OxfSN first became involved. They feel a lot more confident that Julie is getting the support that she needs and they themselves feel much more supported.

Would you do anything differently?

Janet: "I've always been a person never to worry about the next day". The only thing she thinks she would have done differently is move herself. She enjoyed having Julie at home because she was company and when she did move, she missed her terribly.

Andrea: Would have recommended that Julie move in to supported living a long time ago to give her more independence. Her parents did everything for Julie so "she has never had to learn to do stuff on her own" and now "we always wonder...if she'd have had that kind of support then, that she gets now, how different it would have been".

Case Studies

Enid and Tracy's Story

Enid: Aged 83, Tracy: aged 58

About the Family

Enid and her five elder brothers grew up in Oxford. When Enid was only eighteen her mother passed away very suddenly. She and her brothers and father have lived in Oxford all their lives.

Tracy is Enid's only child, and she was born with Cerebral Palsy. She also has Learning Disabilities, and her sight is badly affected. Enid "always thought that she would support Tracy for as long as she was able", and so she didn't think about Tracy living anywhere else except at home.

Tracy went to several Special schools but Enid was always her full-time Carer. During the holidays she did not receive any help. The school provision ended when Tracy was sixteen, then she was at home for three months and during this time Enid was also caring for her father who had had a stroke. Enid looked after her father for a further ten years up until he passed away whilst continuing to care for Tracy. Her father received some respite every other week which gave Enid a "little break". Tracy attended the Day Centre for five days a week which allowed Enid some time to herself in the day time.

Enid said she found it very restrictive looking after Tracy. She needed to be very organised and always had to take Tracy with her in the wheelchair if she went to the shops. "In some ways having to be so organised was a good thing." Later, Enid's partner Ken became involved with Tracy's care which was a great help to Enid and made it easier to manage.

In 2017/2018 Ken and Enid visited a few Supported Living Homes as Enid had had some health issues herself and they were both getting older. The homes were not suitable however as Enid was a wheelchair user, and the properties had steps so they decided not to pursue it.

Situation at the start of the project

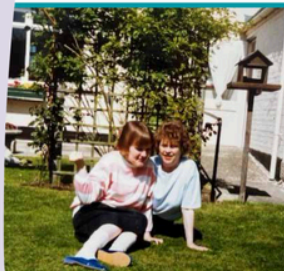
Ken became ill in May 2023 which was the reason why Enid first contacted Social Services for help as she then knew that she definitely would not be able to look after Tracy on her own. From November 2023 Tracy was in emergency respite all week and came home at the weekends. Ken was going to many hospital appointments and Enid knew she couldn't care for Tracy whilst she needed to be there to support Ken.

Enid had seen OxfSN advertised in the back of the Carer's Oxfordshire booklet but it was the Day Centre that Tracy attended, who mentioned the Embolden 2 project to her. She had already decided that Supported Living would be the best option for Tracy.

How we supported them

In December 2023 shortly before Christmas, Ken passed away and after that time Enid not only had to cope with grieving for Ken but also with the thought of Tracy leaving home to be looked after by other carers. Although there was nothing available at that time, it was a stressful period for Enid and when I visited her either on my own or sometimes with the Social Worker, she was often close to, or in tears when she was talking about Tracy.

We talked about Money Management being an option as Enid didn't have any relatives who could look after Tracy's finances, and she didn't want to be responsible for the money side of things any longer. Enid had already made a Folder with all of Tracy's important documents and Health information.



What difference did we make?

We helped by attending meetings and liaising with the Social Worker, making sure the Care Needs Assessment had the correct information, contacting Money Management, ringing various charities and companies trying to get transport for Enid and delaying Tracy's move date to allow Enid to get items needed for her new home. We assisted in shopping for the bed linen, duvets and towels, and put together a one page profile for the Support Provider and created a list of all the songs for Carers to sing with Tracy. She said she found OxfSN very supportive and "I felt less isolated because I could ring up and knew that you would pick up the phone." She could then ask us questions and if we didn't know we would find out and get back to her with the information. "You got things moving somehow". Enid said. She also found she was able to find out more information from us.

Tracy moved into Supported Living in May 2024. Initially it was difficult as there was no transport provided (which had been a condition on which Enid had accepted the Supported Living Home as it wasn't in Oxford City and would involve three different buses). Enid had to rely on the kindness of staff from the respite centre to take her to visit Tracy every week. Now a year on, things are gradually running more smoothly and very importantly transport for Enid has been provided. Enid feels much happier and Tracy is more settled. She feels her "stress levels have gone down and the last things that need to be sorted out are beginning to be put in place."

We have continued with visits after Tracy's move to help iron out any problems and kept in contact providing a bridge between the Social worker, Enid and OxfSN which Enid found reassuring.

What would you have done differently?

Enid feels that the advice she would give to her younger self would be "to speak out" more. "If I knew then what I know now, I wouldn't have just sat there and listened!" Tracy has taught Enid to speak out and say things now that she never would have done all those years ago when she needed more support.

Enid always wanted to look after Tracy for as long as she could, and it is clear that she was, and still is, a devoted parent, keeping up a constant stream of conversation by describing what she was doing, singing favourite songs to her, and cooking her delicious food which she loved! Now Enid enjoys her Saturday visits to see Tracy in her new home, and she feels much less anxious about the future.

Christina and Lorne's Story

Christina: Aged 67, Lorne: Aged 57

About the Family

Christina has an older sister and brother. Her younger brother Lorne, was born with Down's syndrome and Autism when Christina was 10yrs old.

"Lorne was a joy as a baby and had lots of nieces and nephews to play with". He always lived at home with his parents. Since the late 1990's, Christina had been assisting her mother with her brother's care. She would support her by attending the various meetings and appointments. It was between 2000 and 2002 that it was decided that Christina would be the family member who would take over Lorne's care when the time came.

"My parents never really believed that anyone other than them would be able to care for Lorne as well as they did and could never let go. They, particularly my mother, could not fully trust anyone else's judgement and they were extremely overprotective of Lorne. It was assumed that the family would take over from them when the time came, and other alternatives were discounted."

Christina took over Lorne's care in 2008. This had its difficulties in that Christina lost the freedom to do things with her own family because she had to get back for Lorne by a certain time or could not go out in the evening without first arranging alternative care for him. She had to always be there in the mornings to do his personal care even if she was ill. Holidays could only be arranged if respite was arranged well in advance. Lorne would not settle or join in on any holidays or family events as he got older. The thing she found most difficult was the fact that it was only her that could attend to Lorne's main needs, and it was becoming a worry as to who would be able to do this if she could not. Respite was the only other place he would actually sleep but his time there was limited and not guaranteed. Christina was never able to really relax as she was always looking at the time and thinking she must get home soon to be there when he arrived back.

The situation changed dramatically in 2020 due to lockdown, after which Lorne's behaviour became more challenging, and things never returned to how they were before Covid. Christina's husband had also had health problems in recent years which were only likely to deteriorate, and she had to face the fact that she would also have to care for him. "The prospect of being a carer for 2 men has been a worry". It also played on her mind that even though she did have a support network, at the end of the day she was the only person that could look after Lorne, and there was nobody that would be able to step in to take over in a crisis.

Christina began to suffer with her mental wellbeing, and it was suggested by many people that maybe she should consider looking at a Supported Living home for Lorne.

She heard about the Embolden 2 project because she was already on the OxfSN mailing list, having attended some support group meetings for carers some years ago in Oxford/Cowley.

The situation at the start of the project

When we first met with Christina at her home in Banbury, she was caring for Lorne and he was attending Redlands Day Centre five days a week and having a few nights at respite. Lorne also had a PA that he was very familiar with but she was getting older and was hoping to retire. Christina did not really have a plan for his long-term future. She had come to terms with her situation in that she had taken on the role of her parents.

She said, "In the beginning I managed quite well. I had a lot of support from my family. I managed to carry on working and had a support network of family, day service, respite and paid Personal Assistants".



What difference did we make?

We discussed options for Lorne and the aims of the Embolden 2 project and encouraged Christina to think about planning ahead for Lorne's future care and her own well-being. We encouraged her to come to our Supported Living Face to Face Event and the importance of having a Folder containing all the necessary information about Lorne so that someone would be able to step in in a crisis. Christina was already very organized and chose to create her own Folder. We suggested Christina attend the Person-Centred Planning course to help with this, and we kept in regular contact by email and home visits. When Christina had decided that Supported Living was the best provision for Lorne, we advised her how to go about trying to find a Supported Living home and making a request for a Social worker.

Christina says, "Embolden 2 came at just the right time" and we advised her to see what sort of Supported Living properties there might be in Banbury that would be suitable for Lorne. She had it in mind to maybe find somewhere by the time she was 70, "but it happened much quicker with the help of OxfSN."

Before Christmas 2024 Lorne moved into a Supported Living home in Banbury with three others who Lorne knew from the Day Centre. It took some time for the Carers to understand his needs and routines, but within six weeks or so Lorne appeared to be happier and more settled.

Christina says,

"Without the help of OxfSN, I may not have got to the stage I have reached today and would still be struggling to work things out. For many years now I have always known that OxfSN were there for support and the Embolden 2 project came at a perfect time to help me along the way. It enabled me to explore the different options available and meet and speak to people in a similar situation to me."

Case Studies

Pat and Yvonne's Story

Pat: Aged 84, Yvonne: Aged 63

"I love Yvonne to bits, and I really want her to be able to be without me, but it's going to be a big thing for me as well. Even now at my age, I'm still worried about...how she's going to be settled"
"I need social services, the day centre and everyone to really help me now, because I can't do it. I am literally worn out. I was trying to be brave, but I am really tired now"

About the Family

Originally from Ireland, Pat moved to the UK when she was newly married in her early 20's. Yvonne is the eldest of three siblings, and it wasn't until she was a toddler, and she had her other children that Pat felt Yvonne wasn't reaching the milestones of her peers. Yvonne was eventually given a diagnosis from a professional who told Pat bluntly that "Yvonne would never attend a normal school" but didn't offer any advice on what support there was for her, leading Pat to cry for the first time. Yvonne subsequently attended Mabel Pritchard, a specialist school when she was 5. At 16, Yvonne went to a new educational facility which was open for only a year. She was then given the opportunity to do some paid work for several years, but this stopped after a few years and since then she has attended the local day service 5 days a week. During the early years, Pat was not offered any respite or support and felt that there was an expectation on her to look after Yvonne at home.

Looking back, she reflected that she felt very isolated. She didn't know anyone else who had a child with learning disabilities, and she had no family close by to help her. Gradually she began to build up a network, but she feels that she has sacrificed a lot of personal freedom and social activities to care for Yvonne who was very anxious especially around transitions. Pat and her husband never took a holiday alone – always taking Yvonne with them and she always had to be home by 3.00 o'clock. There was limited support and information about respite care and services available and it wasn't until Yvonne was 21 that Pat was aware that she could apply for benefits for her. Yvonne still lives at home cared for by Pat.

The situation at the start of the project

Pat was part of the first Embolden Project that gave older family carers a stronger voice and to influence and hold decision makers to account within health and social care services. It gave her the knowledge and confidence to become a stronger advocate for her daughter Yvonne.

It has really been in the last ten years that she has found being an older carer more stressful. After her husband passed away 20 years ago she "made Yvonne her life" but when she started to have her own health issues she knew she needed to "start thinking about (planning ahead) in a big way" OxfSN reaching out at a time when she was really struggling "was the best thing that happened to me" and the prompt that she needed. She has support from her family but has always felt strongly that they have their own lives to lead and did not want to burden them.

How we supported them

Completing the Planning for the Future check list with Pat at the start of the project revealed that Yvonne did not have her own bank account, and that Pat had no will. Leaving money to someone with a learning disability requires careful planning and for Pat, in her 80's, putting everything in place felt daunting and overwhelming. However, with the support of other family members, not only has Pat set up a will and discretionary trust, but she has also put into place power of attorney for herself, set up a separate bank account for Yvonne and handed appointment of Yvonne's benefits over to one of her relatives. We also completed both a person-centred profile and an All About Me folder for Yvonne, key information to help with planning for the eventual move in to supported living.

What difference did we make?

The biggest difference to Pat of having someone from OxfSN involved in their Planning Ahead journey was the reassurance of having someone alongside them who has "experienced the same things as I have. Every mother that has a child or an adult like we have, experiences the same difficulties (we) all have the same worries...and from the very start...I felt I had someone that I could tell all my troubles to — Professionals are 'really nice' but they can't feel like I do unless they have someone like I have". As a family carer ourselves, we understand the anxiety and worry that often comes with the thought of 'letting go' of our son or daughter and can reassure them, that they aren't in fact 'letting go' but just stepping aside and will continue to be involved in their relative's lives.

For Pat, she knew that for her, this planning ahead journey would ultimately mean Yvonne moving in to supported living. She had given a lot of thought to what would work best for Yvonne and felt a shared house with people of a similar age, near to family and in the community she has grown up in would be the right option. In preparation for the move, she wanted Yvonne to spend some nights at a local respite service to help her get used to nights away. We worked closely with adult social care to put this in place.

At times, Pat has felt very frustrated. The process has been long due to changes in social worker, the need by adult social care to explore Shared Lives as an option, despite Pat being clear this would not work for Yvonne, and the lack of suitable supported living opportunities in the right area has meant that Yvonne is still living with Pat. However, our close connections with Adult Social Care has meant that we have been able to regularly update Pat on what is happening, even when nothing has moved forward, which has helped alleviate some of her anxiety. A suitable home has now been found which Pat really likes and Yvonne is now in the process of moving in with our support.

Her advice to her younger self and other family carers

When asked if she had any advice for her younger self, Pat reflected that she should probably have been more proactive about looking into what support was available for Yvonne from an earlier age. At times she has found caring for Yvonne very stressful which is why she feels so tired now, but she has no regrets and is trying to be optimistic. She feels that with the right people looking out for Yvonne she will be happy in her new home. "I would love to have that peace of mind, but I haven't got it yet. With a bit of luck, with your help, the people at social services, the day centre and my family, we will get there".

Her advice to younger family carers: To sort out the planning for the future for their relative earlier.

"That way you can be part of the process and see them settled and you would know they were happy"

June, Sue and Michelle's Story

June: Aged 92 (died September 2024), Michelle: Aged 58, Sue

"Mum chose not to go down that route...I was always pushing...to get Michelle established where she could be, where she could run...but it was always no, no, no...it was very difficult for me because...we did have some arguments"

About the Family

The family have always lived in Oxfordshire and were well known in their local community. Michelle grew up in north Oxford and led a relatively independent life. After leaving education, she attended Kidlington Blenheim Road Day Centre before going onto doing volunteer work at Oxfam and M&S and then at Wholefoods distribution depot where she attended Kidlington Blenheim Road Day Centre before going onto doing volunteer work at Oxfam and M&S and then at Wholefoods distribution depot where she worked for ten years, travelling on two buses to get there, until it closed in 2009. She then volunteered at Oxfam, which she did not enjoy, finally finding subsidised work through the council at Cutteslowe Garden Centre which she could walk to until it closed in 2023. This had a big impact on Michelle who enjoyed meeting with friends at the centre. Michelle's Dad passed away in 1997 and Sue moved to Devon in 2016 so Michelle and her Mum spent a lot of time together especially in the later years until June passed away in September 2024. Sue would visit them every eight weeks. As June's health started to deteriorate, she became housebound and began to depend on Michelle more to keep her company.

Their situation at the start of the project

Sue first became acquainted with OxfSN when she attended a Supported Living event in 2023 which she found by searching online. At the time, both Michelle and June were receiving support at home through the same care organisation. However, as June's health began to deteriorate, Sue knew she had to step in and focus on Michelle's needs and start putting a plan in place, something that June did not like to discuss. Sue believes this was partly because of June's reluctance to be on her own as she began to limit Michelle going out, and partly, because she was worried that Michelle would move out and she would end up in a care home. Sue would often hear her Mum say to others when they asked her about Michelle's future, "Oh my daughter will deal with all that".

Both the staff at the garden centre and the community health team who were supporting Michelle at the time also expressed their concerns. Michelle was losing much of her independence as June's reliance on her increased, she was getting very little exercise and had limited social interaction with people she knew.

How we supported them

The support Sue needed changed throughout the time we worked with her. At the beginning, when June was still alive, Sue's priority was to get more one to one support for Michelle so that she could go out more so we met with Sue every time she came to Oxfordshire and helped her navigate the adult social care system, helping her understand what all the terminology meant and how direct payments and financial assessments worked. We then completed the Planning Ahead Check List with both Sue and June which helped Sue get a better understanding of all the areas that she then needed to focus on. Up until then, Sue had not really been involved in the day-to-day planning for Michelle, so she had no idea how the finances worked, what supported living options might be available to Michelle when she finally moved or how to go about finding her a place to live. It was all "a bit of a minefield".

After June died in September 2024, the priority was finding Michelle a suitable place to live. Initially Sue had talked about Michelle moving to Devon to live near her, but over time it became clear that what Michelle wanted was to stay in Oxford. We had done a lot of person-centred planning with both Sue and Michelle and what was important to Michelle was to live in an area she was familiar with so Sue with the support from adult social care was able to find an extra care home flat in Kidlington where she knew people.

What difference did we make?

Up until our initial contact, Sue had very little understanding of what was involved in planning ahead for someone with a learning disability who needed support. Coming across OxfSN and attending the supported living event was "brilliant" because "I knew there was a place to go" for support. After seeing everyone else at the event and hearing the questions being asked, she felt a huge relief that there were others out there "who seemed to be in the same boat". For Sue, the event was a positive experience providing a sense of direction and support even though everything still felt a bit "daunting".

A big plus for Sue was also the rapport and trust that was established between OxfSN and the family. She often found it difficult to get through to the right department or to speak to a named person to get the answers she needed. Yet, she knew that if she had a question or needed advice, she could ask us and we would come back to her with an answer. For her, OxfSN provided the continuity, whilst professionals came and went. The checklist and The All About Me Folder were helpful because it gave her something to work towards when she was dealing with the grief of having just lost her Mum and even though at times it felt "frightening (and) a bit scary...I knew I could always get in touch with (OxfSN) and get the guidance I needed". Sue now feels a lot more confident and a little more relaxed compared to how she felt when she started out on this journey.

Would you do anything differently?

Sue's advice to other siblings who are in the same situation as her is, that if their parents are receptive to it, "to get the ball rolling a lot quicker...otherwise it just builds up and up and you get to a point where you just don't know which way to go". She feels lucky that Michelle has found the right place in the right location and is already seeing the positive impact that the change in Michelle's living situation is having on her overall well-being.

Case Studies

Anne, Mark and Louisa's story

oxfsm Oxfordshire family
SUPPORT NETWORK



Anne: Aged 75, Mark: Aged 77, Louisa: aged 33

"I can't do this much longer, and it's not doing her any good... we won't last forever, and she needs to get out there and have fun with younger people while she's still young and gets used to being... independent"

About the Family

Louisa is the youngest of 2 siblings. Her older sibling lives abroad, so Anne and Mark are both full time carers for Louisa who was born with a rare chromosome abnormality, dyspraxia and nocturnal epilepsy. For many years, Anne was told that Louisa did not have epilepsy and that she was "overthinking things" and being a "fussy woman". Doctors also refused to do a genetic test but because of Anne's perseverance, Louisa finally got a diagnosis of 9p deletion syndrome at the age of 17.

At the age of 26, because of a severe reaction to a drug that Louisa took for her nocturnal epilepsy, she was on 13 years, Louisa's ability to function changed. She struggled with basic tasks and had trouble speaking clearly. Anne worked with a psychiatrist, the intensive support team and the community nurse to slowly wean Louisa off the drug but the result was that she refused to leave the house for over a year and developed strong obsessions. This was very different from when she was younger, when she loved being social, going on overnight trips and joining in activities.

They have no other support other than 10 hours a week from a personal assistant whom Louisa knows and trusts and are both thoroughly exhausted. They are keen for Louisa to establish her own life and Louisa herself is now very keen to move into her own home.

The situation at the start of the project

Anne and Mark were not aware of Oxfsm until the social worker they were working with made a referral and had relied on the information given to them by adult social care and health professionals. Their experience in the past and the effect it had on Louisa who wouldn't leave the house, and being told by the psychiatrist that "there's just nowhere she (Louisa) can go" meant that the thought of planning ahead just felt too "overwhelming".

However, a recent health scare combined with Louisa's nocturnal habits has been the catalyst for them to start planning ahead. Because Louisa has a fear of going to sleep at night in case she has an epileptic fit, Anne has to stay awake with her until 4.30 am every night. This situation now controls their day as by the time everyone gets up half the day has gone. They have no social life and the only break they do get is when Louisa goes out with her PA or when their daughter visits from abroad.

How we supported them

We met face to face regularly over three years. In the beginning it was just with Anne and Mark, but gradually Louisa started to join us which meant we were able to include her in the person-centred planning discussions and get a better understanding of the life she envisaged for herself. We did this slowly so that Louisa, who gets incredibly anxious with the idea of any change got to know and trust us and feel part of the planning process. The family completed the All About Me Planning Ahead Folder which they found daunting but very helpful "because it focused our minds on what we have to do".

Mark and Anne had already put in place a lot of the financial planning for Louisa so what they were keen to know more about was supported living and what that looked like. They had only been offered shared lives as an option but "you know, she's got her own family, she doesn't want to go and live with somebody else's family - she wants younger people her age living more independently". We took the family to visit a supported living house nearby. The change for Louisa was immediate. She finally had an idea of what all the talk had been about, she could visualise herself living in a similar situation, and she was able to relate to the things she saw which reassured her that there are people of a similar age in supported living that like the same things that she does. This gave Anne the encouragement to contact support providers and to push the social worker in to finding a suitable place for Louisa sooner rather than later.



Since Oxfsm's involvement, the family have met with 3 different social workers and each time, it has felt like they lost momentum. Louisa has been waiting for so long that "she doesn't really believe it's happening". We have been able to act as a go between with adult social care and keep them updated on the process which has given the family much needed reassurance.

What difference did we make?

"Until you came along, we were floundering... we've been struggling with all this for so long but you've pulled it all together... and given us huge reassurance"

Before Oxfsm became involved the family had met with "so many different people over the years... who sort of disappeared" and were finding the whole process "confusing". Having someone with the "information and experience with what happens... has been invaluable". The family appreciated the direction and experience that Oxfsm provided which they contrasted with the impersonal nature of social workers.

When we first started meeting the family, Louisa would choose to be out with her PA or stay upstairs so it took a while for her to feel ready to meet us. Three years later, she is very much part of the conversation, she is keen to move into her own home and wants to get a job. Whilst the family are still apprehensive about the future, they feel a lot more hopeful that Louisa will find a suitable home with the right support.

Would you do anything differently?

The family experienced so much trauma when Louisa was on medication that looking back, they don't think they could have done anything differently to prepare ahead. The issues they faced with medical care and support services and the lack of support and communication from professionals meant that for a long time, all they could focus on was Louisa's needs. What they would like to see is more joined up thinking between services and an understanding of the long-term impact of actions by professionals on families.

Malani, Sachi and Chandima's Story

oxfsm Oxfordshire family
SUPPORT NETWORK



Carer: Malani, Sibling Carer: Sachi (sister), Cared for: Chandima 59

About the Family

Malani and her son Chandima moved from South Asia to the UK in 2012. They moved after her husband passed away to be near to Sachi, her daughter. Sachi has her own family to look after and lives very nearby to where her mother and brother now live. Malani is a full-time carer for Chandima.

His sister keeps an eye on them and helps her mother with all the admin, care support, health and hospital appointments involved with keeping Chandima safe and well. He has very severe Epilepsy, a Thyroid condition and a Learning Disability. He needs 24/7 care and is extremely attached to his mother since his father passed away.

Chandima doesn't really understand what has happened - he just knows that his father has gone away for a very long time. Sachi says that her parents worked full-time when they lived in South Asia and they had helpers who came to the house to look after her brother when he was growing up. In those days his epilepsy was not well controlled and he would often fall and end up in hospital. Sachi remembers that although she was aware of all the care Chandima needed, she was not affected too much when he was younger as the family had relatives close by, but since coming to the UK she has taken over much of the responsibility.

The situation at the start of the project

Sachi had heard of Oxfsm through Carer's Oxfordshire, but it was their Social Worker who referred the family to Oxfsm. When we met for the first time it was easier for Sachi to be the spokesperson for the family as she speaks very good English. She has supported her mother with organising Chandima's care and continues to work full-time. During lockdown the family all lived together in Sachi's house and although her mother was always Chandima's main carer she had some extra support.

Two years ago, Chandima and his mother moved into a flat run by a Housing Association. As Malani has got older she has developed some health issues herself which means they have carers visiting two and sometimes three times a day to support her with looking after Chandima, as he really needs to have someone with him all the time.

How we supported them

While discussing the options for Chandima's future it became clear that Supported Living was not something the family wanted, as they thought he would find it very difficult being away from the family. His understanding of English is also limited and carers who speak his mother tongue Tamil, are rare. His mother would have found it very upsetting and Sachi didn't think it would have helped her either to be separated from him. Sachi works full-time, so visiting Chandima would have been difficult if he wasn't nearby. We looked at the possibility of being able to extend the lease with the Housing Association, which would be the best solution for the family so that Chandima could stay there in the future and be cared for at home. The Housing Association have said that this would be possible but Sachi would need to have Deputyship.



We gave her information on applying for Deputyship for Property and Finance with the Court of Protection so that she would be able to look after Chandima's finances and sign the tenancy agreements. She attended the online event that Oxfsm held recently with the Office of the Public Guardian which was very useful.

We have put together information into a Planning Ahead Folder for Chandima, including the Finance Form, Crisis Care Form, Health Form, and a one-page profile and good day/bad day chart, so that someone would be able to step in in an Emergency. His sister feels that having all the information in one Folder is very helpful for anyone stepping in in a crisis. We are providing on-going home visits and have encouraged the family to request input from the Community Physiotherapy service for Chandima. This input is important as he doesn't take much exercise unless his mother can also go with him. The family have tried to introduce some activities for him but this hasn't been very successful. We have also liaised with the Social Worker and attended meetings on the family's behalf.

What difference did we make?

Sachi says we provided a "bridge" between the Social Worker, Oxfsm and herself which she found much easier, as we were able to ask questions and relay the answers back to her. She also liked the continuity of one person knowing the family's situation and wishes. This helped her considerably as people had been suggesting to her that Chandima and her mother should move out of where they currently live and that worried her. She now feels less anxious since we have been visiting her at home and providing her with the information she needs. She said, "to be honest I hadn't thought about plans for the future at all" and so when she was given the planning ahead checklist she found that it provided her with a way of starting to put things in place "step by step". Sachi says the biggest difference we made is "that I no longer felt alone, there was someone helping me."

She adds "Oxfsm really did prompt me to start thinking about the future and giving me the information I needed - so thank you."

What would you have done differently?

"I would have started to gather all the information earlier if I had my time again."

(The names have been changed in order to protect the families privacy)

Embolden 2 Legacy - what needs to happen next!

Sharing the findings

The Embolden Team began planning the legacy in Year 3 of the project and in July 2025 held an **Embolden 2 Conference** 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. At the Conference they asked those attending to highlight what they saw as barriers to planning ahead and what would help to alleviate some of those barriers including who needed to be around the table in future discussions. The project manager is focusing on fundraising in order for OxFSN to be able to develop the project as a result of the extensive learning from Embolden 2.

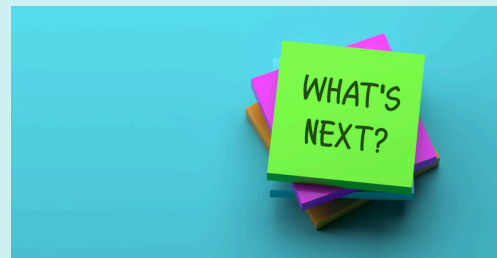
Extend the Model

OxFSN recognised early on in the project the benefits to younger families who attended some of the events, and would like to build on this and extend the model used to a wider group of families, across the age range in order to encourage younger families to start planning which will be less stressful and

overwhelming and something that older carers told us they wished they had done. OxFSN will use the Video created by the Team **“The Importance of Planning Ahead”** to reinforce the message of the need to start planning early.

The 3- tier model used in Embolden 2 proved highly effective and will be continued to provide

- intensive 1:1 support for families in greatest need
- a rolling programme of smaller workshops on practical topics
- larger events and gatherings to share information, connect carers and build community



Advice Guidance and Information



The advice on **The Care Act, Disability Related Expenditure, Planning Ahead Checklist, Crisis Care Form, Planning Ahead Folder** along with the recordings of the online events and **The Planning Ahead Film** will all remain on the OxFSN website and You Tube Channel and are available for older family carers and their families to use. OxFSN are aware that for older family carers, there are barriers to finding and

downloading information online, so these resources are more likely to be used by younger family carers and professionals.

Future plans will be to produce a range of themed guides on key topics on issues known to be of concern to older family carers, with supporting workshops. These will include consent and decision making, transition planning and financial assessments. Regular information events will be held as these are an important source of information.

Embolden 2 Legacy - next steps

Working with professionals

OxFSN builds trust and strong relationships with families by working as experts by experience who understand their situation and are able to act as a bridge between families and services, whilst also working directly with professionals to improve systems and processes. This, along with the three year funding that OxFSN receive from Oxfordshire County Council to run **Working with Families Training** for professionals in the county council enables OxFSN to highlight the need of working with this group of family carers in a certain way. These carers are lifelong carers which makes them a unique group with very specific and ongoing needs. Without the right support from professionals, daily life can become overwhelming and challenging. One of OxFSN's proposals from the project is the need for a specialised learning disability team within adult social care who understand the needs not just of this specific group of carers, but also between younger and older carers who are at different stages of their caring role. They would like to see within that a more specific team supporting older carers. Embolden 2 has also raised the profile of OxFSN as a small charity and it is well connected to key commissioners in health and social care services. The Programme Manager meets quarterly with the head of Adult Social Care and the team regularly meet 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 and vice versa.

Health inequalities

One of the findings from the engaging with the local health of health services OxFSN have had and need to build this back. a bigger focus on health not just person they support. The has major emotional and



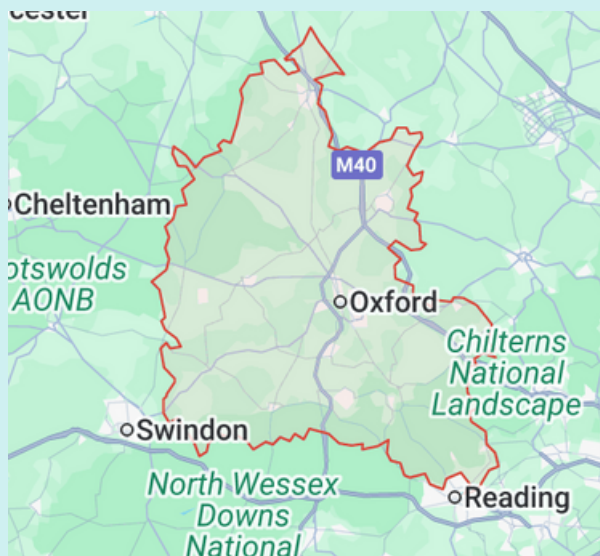
project was the difficulty of team. Since the restructuring lost the connections they once Going forward OxFSN will have on the family carer but the lifetime responsibility of caring physical impacts, with recent

research likening the experience to PTSD which can be ongoing and cumulative and is often overlooked or neglected by services (Affinity Trust, 2024). OxFSN will continue to aim to improve family carers mental well being through feeling connected, supported and informed by running regular meet ups.

OxFSN know that people with learning disabilities face stark health inequalities resulting in a poorer life expectancy than the general population and are twice as likely to die from preventable causes. Families need more support to navigate health systems and to be able to confidently advocate for their relative's needs, something that did not always happen once their relative moved in to supported living. Findings from the **LeDeR programme (Learning from Lives and Deaths of People with Learning Disabilities)** highlighted that families are often excluded from significant care decisions and whilst LeDeR is currently on hold locally which is a concern, the organisation will continue to address these issues by working with families, support providers and services providing more health related information events and resources.

Embolden 2 Legacy - next steps

Geographic expansion



Whilst OxFSN primarily supports families in Oxfordshire, events were attended by both family carers and professionals from out of county. Feedback was that there was no other organisation like OxFSN who provided this kind of service or information.

Going forward, OxFSN will continue to work primarily within Oxfordshire as current figures from OCC who now systematically log this data, has shown that there are currently 187 people with learning disabilities still living with carers over the age of 65 in the family home. However, OxFSN would like to start reaching in to neighbouring counties in line with the the new NHS boundaries which form the Integrated Care Board (ICB) and are comprised of Buckinghamshire, Oxfordshire and West Berkshire (BOB).

Supporting Siblings

During Embolden 2, more siblings became involved then originally anticipated and their involvement was shown to be a key factor in the project's success. For many siblings who had to step into the caring role as their parents aged, or were unable to continue with their caring role, they often felt unprepared and isolated. Some had to deal with the sudden death of a parent but had no time to grieve as they took on the mantle of caring for their sibling navigating a system they had no understanding of.

The next project will develop dedicated sibling groups and events, giving them the opportunity to be less isolated and connect with their peers, be more knowledgeable about their role and build confidence about their future responsibilities.



Broadening inclusivity



OxFSN worked with a number of families from diverse backgrounds through out the 3 year project, but are aware that overall, numbers were low. Going forward, OxFSN want to try and reach more families from more marginalised groups, those from ethnic minority communities and target support that will work for them, based on what they tell us they need. We know from the families we did support, that there is a need

for better understanding of cultural sensitivities both when planning for the future, but also when their relative moves in to supported living. OxFSN plan to work more closely with support providers to ensure services adapt to meet the needs of diverse families.

Embolden 2 Legacy - next steps

Systems and processes

Working with statutory organisations identified that the systems and processes needed to be more flexible to better support older carers. Many of them did not see a social worker until their relative's annual review. It was usually only then that they were referred to OxFSN for help with planning ahead, yet deteriorating health or the death of a spouse meant that their circumstances could change quickly without being picked up. Contact with older carers identified as needing more regular support needs to be put in place. There has been some progress in this area throughout Embolden 2 and OxFSN will continue to work with services such as Adult Social Care and support providers to encourage more flexible and responsive approaches.



Families also told OxFSN that the options available in supported living need to be more transparent so that families know what is available and what supported living looks like. OxFSN will plan to run specific sessions that bring families looking at supported living together alongside providers. Having looked at the barriers that prevent families from exploring this option, OxFSN believe these sessions will help with 'myth busting' and sharing what good supported living looks like. Through Embolden 2, 25 people with a learning disability moved from their family home in to supported living or plans were underway. This far exceeded the numbers anticipated. However, families still needed ongoing support from the team as they started to navigate a new situation with their relative.

Financial Impact - Benefits advice



As the OxFSN team know from their own experience, life long caring responsibilities for a person with a learning disability often limits a carers ability to work, leaving many reliant on benefits or reduced incomes. Research shows that for those caring more than 35 hours per week, the poverty rate is 43% compared with 18 % for non-carers (Carers UK 2024). Yet raising a child with a learning disability according to Scope UK and LDN London is significantly more expensive with families facing an average of £581 to £975 per

month in extra costs. Many families rely heavily on the disability benefits of their relatives to supplement their household income and this financial dependency creates extra complexities when discussing a relative's move out of the family home and into supported living. The organisation has supported families in these situations on a case by case basis finding practical solutions that work for them. However this can be time consuming so OxFSN are looking for additional funding for a benefits advice role, specifically to work alongside our carers

Infrastructure and future vision

OxFSN, after 4 years of remote working is in the process of securing a new office space with a multipurpose hub. This will provide a safe and welcoming environment where carers can attend regular workshops, coffee mornings and social activities which will enable stronger community connections and more consistent support.

Acknowledgements

Thank You



... to everyone who has supported this project in particular the National Lottery Community Fund for making the Embolden 2 project possible. Your generous support has empowered us to reach more people, strengthen our community, and create real impact. We truly appreciate your belief in our work

..... and to all the family carers, sibling carers and other family members who bought the Embolden Project to life. Their life long commitment to caring for their son or daughter, brother or sister, grandchild or friend knows no bounds.



In Memory.....

Eric Bird
Lucine Lewis
Ken Baxter

We remember with deep gratitude the older family carers from the Embolden projects who have passed, whose strength, wisdom, and care continue to inspire all we do.

Contact

OxFSN
30 Tamar Way, Didcot, Oxfordshire
OX11 7QH
<https://www.oxfsn.org.uk>
info@oxfsn.org.uk

