Improving Dementia Support for People with a Learning Disability

Successes and Learning from MacIntyre's Dementia Project

April 2016 - October 2018

Foreword

MacIntyre was established in 1966 by the parent of a disabled child and has grown to become a leading national charity, setting standards and increasing choice for people who have a learning disability and/or autism. Our vision is for all people with a learning disability to live a life that makes sense to them. We encourage the people we support to be ambitious and to achieve their dreams – and as an organisation we too strive towards ambitious goals.

For several years MacIntyre has been championing better care for people who have a learning disability who are developing or diagnosed with dementia. The Department of Health and Social Care allowed us to expand this work through an Innovation, Excellence and Strategic Development Fund award. Our Dementia Project helped turn our ambitions into reality, extending good practice throughout MacIntyre and beyond. We have moved move forward at more speed and scale than would otherwise have been possible.

This report shares some of our successes and learning. It is written in style to suit our teams and partners, based on rigorous independent evaluation.

In 2018 the National Institute for Health and Care Excellence (NICE) released a best practice guideline about healthy ageing for people with a learning disability. Our Dementia Project showcases how to implement such best practice, working with the people we support, staff and external partners to raise awareness, support a timely diagnosis and improve the quality of care. We have developed an online toolkit of resources that is freely available to all in the UK and internationally. We have embedded new ways of doing things at MacIntyre and helped staff become more confident to support people to live well with dementia.

Central to the way we do things is working alongside the people we support. The Dementia Project has been no exception. Our Keep Going ……. Don't Stop! group of people with a learning disability has helped us every step of the way: giving advice and helping to create easy read resources. Two people we support became Dementia Project Assistants, showcasing what we can achieve by working together. More than 420 people we support, family members and members of the wider community took part in 'Memories and Miles' events in autumn 2018 to celebrate the successes of the Project and raise awareness.

We have worked with partners to help increase understanding across health, social care and the voluntary sector about how to consider learning disability and dementia together – something that had seldom been done before. Our innovation and impact was recognised through a 2017 Dementia Care Award and two awards at the 2018 National Learning Disability and Autism Awards.

We would like to thank everyone at MacIntyre and others who have been part of the Dementia Project for their hard work, dedication and passion. We are making a difference and we call on you to help us continue the momentum.

Emma Killick
Director of Adult Services

Sarah Ormston
Dementia Project Manager

Key messages

What did we do?

As everyone ages, our physical and mental health is likely to decline. People with a learning disability may experience health inequalities and not always get the support they need. MacIntyre wanted to lead the way around high quality care and reducing health inequalities for people with a learning disability, including as they age.

MacIntyre is a national charity providing learning, support and care for more than 1,500 children, young people and adults who have a learning disability, autism or both. There are more than 150 MacIntyre services across England and Wales, including supported living, registered care homes, outreach, accredited training and a residential special school.

Between April 2016 and October 2018, MacIntyre tested new ways to help the people we support and our staff learn more about healthy ageing for people with a learning disability. We hoped that if the methods worked well, other organisations would use them too. The Department of Health and Social Care supported the Project through an Innovation, Excellence and Strategic Development Fund award.

The MacIntyre Dementia Project aimed to:

1. help **raise awareness** of dementia among people with a learning disability, their families and professionals
2. help people with a learning disability receive a **timely diagnosis** of dementia
3. train our workers to provide **better care** for people with a learning disability living with or at risk of dementia

To achieve these aims, we:

- developed **142 resources** including a toolkit of online resources with 32 eLearning modules and booklets, 13 easy read documents and 9 films; 26 case studies of good practice and a folder of 22 resources to help staff better record people's health and track changes over time
- provided **183 formal training sessions** for MacIntyre staff, particularly support staff
- took part in **143 internal awareness raising and 31 external promotional events**, meetings and conferences
- were involved in **92 blogs, articles, newsletters**, radio interviews and similar, plus 1,476 tweets to 650 followers

The Project had a team of two full-time and three part-time staff, two of whom had a learning disability. We also had a group of people with a learning disability providing advice; a Steering Group and internal and external helpers.

To test whether we made a difference, all MacIntyre services supporting adults in three regions were given access to the eLearning, booklets and training sessions for a year before others. This meant we could compare awareness of dementia, diagnosis rates and the quality of care in regions that did and did not have access to the resources and training. We worked with an independent organisation to evaluate our successes and learning.

What did we achieve?

Supporting culture change

The Dementia Project had many benefits. It helped to raise the profile of MacIntyre as an innovative organisation and showed other organisations that it is possible to **work side by side with people with a learning disability** to make positive changes. Every month, the Project team worked with a group of people with a learning disability to develop resources and plan approaches. From 2018, two people with a learning disability were employed as part-time Project Assistants. These people presented at conferences, helped with training and did media interviews alongside other members of the Project team.

"Sharing stories and working together can help staff make a difference for people with dementia. Being part of the Dementia Project means people can see our point of view and hear how small things can make a big difference."
(Dementia Project Assistants, supported by MacIntyre)

Other organisations said that they learnt a great deal from the way that MacIntyre involved people.

"I think the range of people who were involved was brilliant. We heard from people with learning disabilities, professionals, academics,… carers, paid workers equally. … The story told by a disabled person and her mum blew us all away. Such a powerful example of inclusion, creative solutions, communication, understanding, equality… Having a 'chairperson' who has a learning disability sets the scene from the start and maintains throughout that people with learning disability are in control."
(External organisation representative attending Dementia Congress workshops run by MacIntyre)

Raising awareness of dementia

The MacIntyre Dementia Project **succeeded in raising awareness about dementia** and dementia care. Feedback from people we support, MacIntyre staff and other organisations suggested that they knew more about dementia as a result of the Project. We surveyed MacIntyre staff at the beginning of the Project in mid-2016 and at the end in October 2018, after resources had been available for one to two years. By the end of the Project, 100% of staff surveyed said they knew what dementia was, 91% said they knew quite a bit about dementia, 98% said they knew the symptoms to look out for and 89% said they were more confident looking out for dementia than one year ago. All of these proportions were significant improvements compared to when the Project began.

The MacIntyre team and representatives from other organisations felt that the Project had started to shift the way that people with a learning disability are considered when thinking about dementia and dementia services. Some health, social care and voluntary sector organisations said they had never thought about learning disability and dementia together before. This impact was recognised nationally, with MacIntyre winning a 2017 Dementia Care Award and two awards at the 2018 National Learning Disability and Autism Awards.

MacIntyre partnered with a number of organisations to achieve the aims of the Project, including the Alzheimer's Society and Dementia Action Alliance to create a range of resources and approaches to raise awareness across other organisations. All resources developed for the Dementia Project are being made **freely available online** so other organisations, health professionals and families can use them.

More timely diagnosis of dementia

The Project **improved the processes MacIntyre uses** to help people receive a diagnosis of dementia. We trained staff about the signs and symptoms to look out for and introduced new simplified 'health recording' documents to keep good records about people's health and track changes over time. These records may help alert staff when something is changing which may in turn prompt referral for assessment and help with timely diagnosis.

The Dementia Project could not easily change how promptly people were diagnosed with dementia because diagnosis depends on health professionals outside MacIntyre. At the start of the Project, 2% of adults supported by MacIntyre (25 people) were diagnosed with dementia and this proportion did not increase by the end. The absolute numbers increased but due to people dying or moving away the overall proportion did not change.

Although the proportion of people diagnosed did not alter, staff and managers thought that staff were more aware of what to look for and when to refer people for assessment. By the end of the Project 91% of staff said that they were more confident looking out for the signs and symptoms of dementia than one year ago compared to 49% at the start of the Project. Correspondingly, the **number of people officially recorded as suspected of dementia rose from 24 in 2016 to 33 in 2018**. This was only an increase from 2% to 3% of the total number of adults supported by MacIntyre, but is a tangible demonstration that signs and symptoms of dementia are being officially noticed and recorded.

> *"Staff are more aware of the symptoms and what to look out for so are more likely to see a change in behaviours and get people referred to specialists."* (Regional manager)

Improving the quality of care

The Dementia Project **achieved its goal of training staff** to provide better care for people with dementia. Between April 2016 and October 2018 the Project ran 183 training sessions for MacIntyre teams. The Project team also visited services to provide advice and support about ways to improve care for people with dementia. During the Project, the 32 available modules and ebooks were **completed a total of 6,377 times** by MacIntyre staff.

MacIntyre frontline staff gave examples of things that they had done differently as a result of Dementia Project training sessions and eLearning, including:

- keeping good records to monitor changes in people's health and behaviour over time
- using red, yellow or blue plates to make them easier for people to recognise
- using healthy eating guidance and tools to help people manage their weight
- taking people to memory cafes where they had a chance to talk about the past
- using life story tools to help people remember things that are important to them

MacIntyre already has good quality of care so there were not major improvements to make. However the Dementia Project identified that there **remains room for improvement** in the way that best practice care is recorded. Audits of the records of people at risk, suspected of or diagnosed with dementia at the beginning and end of the Project found no improvement in whether people's records fully described the type of dementia people had or the support they needed. This may be partly because the information is not made available by health professionals. There a noticeable improvement in the extent to which life story work was recorded on people's care plan, and this was a major emphasis for the Dementia Project. However even so, no more than one in five relevant people's care plans recorded life story work or other aspects of good practice. This suggests that more work is needed to turn awareness raising and training into tangible changes in care outcomes and reporting.

What did we learn?

The Dementia Project achieved all its main goals and learnt many lessons along the way:

- The Dementia Project found ways to **involve the people we support** which may be feasible for other organisations. A group of 12 people MacIntyre supported met with the Project team each month to provide advice and develop easy read versions of resources. Two people that MacIntyre supported were hired as part of the Project team and gave presentations at external conferences. People with a learning disability also volunteered to help with Project administration and data entry. The people MacIntyre supported were asked for feedback about the Project's benefits in groups and using surveys. These activities took time and resources and none were formally funded by the Project grant, but were key to success.

- The team needed to **prioritise activities** to avoid focusing more on awareness raising than making tangible change. The team learnt that it is important to build in development time for resources, to have a process for updating resources and to have all content reviewed by experts. Having a broad range of people in the Project team helped to provide 'fresh eyes' and a reminder about priorities. In addition to the small core team working on the Project day-to-day, the Project drew on help from many others including web designers, communications experts, dementia experts and evaluators. A director of MacIntyre had overall responsibility which maintained support at senior level.

- **The way that resources were presented** influenced how they were used. Placing the toolkit online rather than on MacIntyre's internal servers, making eLearning modules no longer than 15 minutes and using interactive components, bright colours and images all helped to engage MacIntyre staff and other organisations.

- Merely **making resources available was not enough**. Frontline staff have many other commitments and must take part in the mandatory training needed to run a safe and effective service so may not prioritise looking at other resources. Running face-to-face sessions to introduce topics or answer questions sparked interest about dementia and built relationships. Sustainability was built in by providing a toolkit and videos and by training local champions to run ongoing training in local areas. There was most interest in the resources when managers promoted them and when services used them as a team. For example, one service completed all the e-modules together as a team, which led to good discussions.

- There is wide interest in the resources, but **health and care teams may need encouragement** to use them. Only seven out of 35 health and care professionals explicitly asked to test the resources did so (19%) due to competing priorities on frontline staff and manager time and barriers created by having to log in to access resources. This made it difficult to see what adaptations might be needed for wider rollout. However since MacIntyre made the Toolkit available online, there has been good uptake, with about 400 downloads or visits to the resources in four months.

The MacIntyre Dementia Project has been a success and the organisation is committed to continuing its focus on healthy ageing. The Project succeeded in raising awareness of dementia amongst MacIntyre staff and others and has taken steps towards improving processes to support timely diagnosis and good quality care for people with dementia. The work will be sustained, with a small team continuing to have responsibility for promoting dementia awareness, all resources produced made freely available online and ongoing partnership work with other organisations to spread the learning.

Contents

Acknowledgements

Memories and Miles event, Bedford

Overview

Key points

This section provides background information about the MacIntyre Dementia Project, including what the Project aimed to achieve and how MacIntyre would know if it was having an impact. The key points are:

- MacIntyre is a national charity that supports people with a learning disability and/or autism. People with a learning disability are more likely than others to be at risk of dementia, but it can be difficult to ensure that people receive a timely diagnosis or access to primary or secondary care services. MacIntyre wanted to do something about this.

- The MacIntyre Dementia Project ran from April 2016 to October 2018. The Project aimed to increase awareness of dementia amongst MacIntyre staff and the people supported by MacIntyre, help people receive a more timely diagnosis of dementia and train staff to improve the quality of care MacIntyre provides for people with dementia or at risk of dementia.

- The people MacIntyre supports were heavily involved in the Dementia Project. A group of people with a learning disability met monthly to help shape the Project. Two people we support were hired as Dementia Project Assistants and spoke at conferences and internal events to motivate others. Easy read versions of materials were produced for our toolkit. Easy read surveys and discussion groups were used to help get feedback from the people we support and the people we support and their families were part of key events.

- As part of the Dementia Project, MacIntyre developed a toolkit with eLearning modules, booklets, easy read documents and films. MacIntyre also ran training and awareness raising sessions for staff, visited individual services to provide support, took part in conferences and promotional events, tested resources with health and care professionals and developed new processes and documents to make sure people's health was recorded well.

- To test whether the toolkit, training and support made a difference, staff were surveyed at the start of the Project, after the first phase and at the end. People's support plans were audited at the start, after the first phase and at the end. The number of falls and other incidents were tracked over time as was usage of the toolkit resources. This helped to compare whether staff knowledge and confidence and the quality of care changed during the Project. One group of services had access to the resources for a year before others to see whether services that had the resources and training improved more than services that did not.

Setting the scene

Around 1.4 million people in the UK have a mild, moderate or severe learning disability. Someone with a learning disability may find it takes longer to understand new or complex information, communicate, learn new skills or live independently. A learning disability occurs when a person's brain development is affected before they are born, during birth or in early childhood, but sometimes there is no known cause.

MacIntyre is a national charity supporting more than 1,500 children, young people and adults with a learning disability and/or autism in England and Wales. MacIntyre has about 150 services including supported living, registered care homes, outreach, alternative education and a residential special school. Support workers, nurses and education specialists help people with a learning disability to live as independently as possible in their own homes and in their local community.

As we age, it is expected that our physical and mental health may deteriorate and that is no different for a person with a learning disability. Dementia is a term used to describe a group of conditions characterised by impairment in brain functions such as memory and judgment. A person with a learning disability is at higher risk of dementia, but recognising the signs and symptoms of dementia in someone with a learning disability can be much harder. The symptoms of dementia include forgetfulness, impaired social skills and issues that interfere with day to day functioning, making activities such as writing a shopping list or paying a bill difficult. Someone with a learning disability may already need support with these activities so it might be harder to recognise if dementia is developing.

Very little is known about how to help care teams recognise and support someone with a learning disability who may develop dementia. Recognising this gap, in 2016 the Department of Health and Social Care awarded MacIntyre an Innovation, Excellence and Strategic Development Fund grant to explore ways to upskill staff, particularly support workers, to recognise and help people with a learning disability with or at risk of dementia. It was hoped that, if successful, the approaches developed and tested by MacIntyre might be able to be spread to other health and care organisations. Funding was provided to hire staff and develop and test resources over a two and a half year period, from April 2016 to October 2018.

This report describes the successes and learning from the Project. It focuses on impacts rather than describing all of the activities undertaken in detail. It is written in a style suitable for our teams and partners but is based on robust independent evaluation.

This section describes what the Project aimed to achieve and how MacIntyre would know if the Project was a success. The next section describes the benefits of the Project. The final section describes lessons learnt as MacIntyre implemented the Project and factors that contributed to success.

Objectives

In 2018, the National Institute for Health and Care Excellence (NICE) released a guideline about supporting healthy ageing in people with a learning disability. The guideline noted that it was essential to raise awareness about dementia, to train health and care staff about how to support people and to tackle issues with diagnosis and care. Although the MacIntyre Dementia Project began before this guidance was launched, the Project was very much in line with the best practice promoted by NICE and the evidence on which the guidance was based.

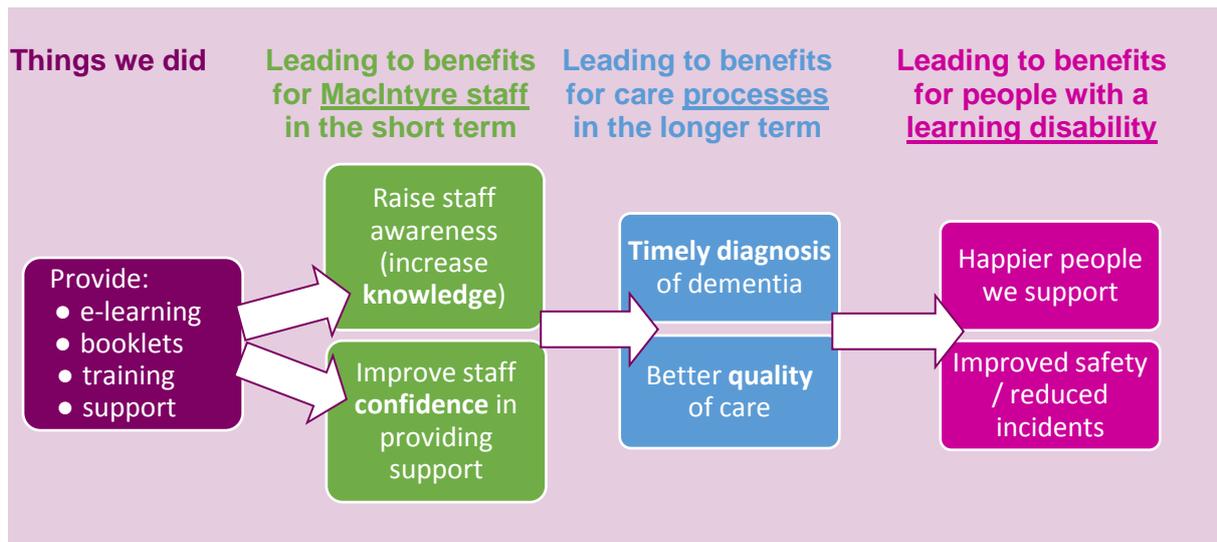The Dementia Project aimed to

1. help **raise awareness** of dementia among people with a learning disability, their families and professionals
2. help people with a learning disability receive a **timely diagnosis** of dementia
3. **train workers to provide better care** for people with learning disability living with or at risk of dementia

Photo: Raising awareness at an event for health professionals

The Project's 'theory of change' was that offering resources and training would increase MacIntyre staff members' knowledge about dementia and confidence supporting someone with a confirmed diagnosis of dementia, suspected of dementia or at risk of developing dementia. The Project hoped that if staff had more knowledge and confidence, staff would know the signs and symptoms to look for and how to raise issues with health professionals to help people get a diagnosis of dementia in a more timely manner. It was also hoped that increasing staff knowledge and confidence would improve the quality of care available for people with dementia using MacIntyre services (see Figure 1).

Figure 1: Outcomes that the Dementia Project hoped to contribute to

Things we did	Leading to benefits for MacIntyre staff in the short term	Leading to benefits for care processes in the longer term	Leading to benefits for people with a learning disability
Provide: • e-learning • booklets • training • support	Raise staff awareness (increase **knowledge**) / Improve staff **confidence** in providing support	**Timely diagnosis** of dementia / Better **quality** of care	Happier people we support / Improved safety / reduced incidents

MacIntyre was realistic that these outcomes may take more than the two and a half year Project timeline. The main focus was on seeing benefits in the short-term (coloured green in Figure 1), with the expectation that these would lead to other benefits in the longer term (coloured blue and pink in Figure 1).

For example, health professionals are responsible for diagnosing dementia so the timeliness of diagnosis is not within MacIntyre's control. Therefore instead of influencing diagnosis rates directly, the Project aimed to strengthen MacIntyre's internal processes to give staff the documents and confidence they needed to identify when people should be assessed by health professionals. In this way, the Project aimed to take steps in the right direction towards more timely diagnosis, even though this outcome may be unlikely to be achieved within a short period.

Activities

To achieve the Project aims, MacIntyre:

- worked with a group of people MacIntyre supports to help plan and deliver the Project
- developed 142 resources including a toolkit of online resources with 32 eLearning modules and booklets, 13 easy read documents and 9 films; 26 case studies of good practice and a folder of 22 resources to help staff better record people's health and track changes over time
- ran 183 training sessions for staff, particularly frontline support staff, to raise awareness about dementia and develop new skills such as using new documents for recording and tracking people's health over time
- participated in 143 MacIntyre team meetings, service visits and support sessions, including visiting services to provide services with advice about areas for development
- took part in 31 external meetings and conferences to raise awareness
- was involved in 92 media interviews, blogs, articles, newsletters and similar
- posted 1,476 tweets to 650 followers
- audited people's care plans to identify areas for development
- worked with organisations such as the Alzheimer's Society and Dementia Action Alliance to develop resources and share learning

Some of these activities are described briefly here to give a flavour of what the Project did.

Project team

The Project was run by a full-time project manager, a full-time staff member experienced in working with people with a learning disability, a part-time administrator and two part-time assistants that had a learning disability who were heavily involved in awareness raising. The team was overseen by a MacIntyre Director. Two external helpers provided support when needed: a specialist in dementia and a specialist in evaluation. Other MacIntyre team members helped with activities, such as designing the online eLearning platform and developing and implementing communications plans. A group of people with a learning disability helped to test ideas and develop materials. A group of people with a learning disability tested all easy read versions of resources. A steering group made up of internal and external supporters met quarterly to review the workplan and make strategic decisions.

Photo: The MacIntyre Dementia Project core team

Working with people we support

An important part of the Dementia Project was showcasing within and outside MacIntyre how to involve people with a learning disability in improvement initiatives. The Project highlighted that people with a learning disability can be fully involved in planning and implementation.

"Involving people we support is a key value for us and something that we always do. It has also helped us connect with our audience – including external people. They see us as credible and they admire working together. Real stories and real people – this is what people want to hear about." (Senior manager)

The Dementia Project ensured that the voice of people with a learning disability was heard in all aspects of the Project. This was not explicitly written into the initial Project plan or funding allocation, but is an underpinning part of the way MacIntyre does things. An advisory group of people supported by MacIntyre was set up. The group met monthly during the Project and were recognised with vouchers. They developed a name for themselves and this was used as a strapline for the Project: "Keep Going…….Don't Stop!" The group helped to create an image used as the Project logo, which was placed on the eLearning toolkit and all resources. They also helped to develop 13 easy read resources for people with a learning disability. Box 5 provides more information about this group.

The processes that the Project used are being embedded for future use in MacIntyre. For example, when two people supported by MacIntyre were recruited as Project assistants, the job application, supporting letter and contracts were prepared as easy read documents and they went through a job interview. The Project assistants wrote the foreword for a Voluntary Organisations Disability Group report: 'Developing dementia-friendly care and support for people with a learning disability'.

People supported by MacIntyre were also involved in volunteering their administration skills at one of MacIntyre's offices, helping to input information, type reports and photocopy and organise resources.

All external events at which the Project team presented included someone that MacIntyre supported as a presenter, including at events such as the Royal College of Psychiatrists and UK Dementia Congress. The Project also included training sessions where the people supported by MacIntyre learnt side-by-side with staff.

Photo: Dementia Project Assistants at an external awareness raising event

The MacIntyre "Keep Going…….Don't Stop!" group met every month during the Project, keeping in touch by telephone and Skype in between. The aim was to develop easier to read materials that help people with a learning disability understand what is happening as they grow older and how their health needs may change. Each member was recognised with praise and vouchers.

Being part of the group had positive impacts for members and showcased how people MacIntyre supports can be involved. All members of the group developed their skills, abilities and confidence.

"A has really flourished attending the group. I can see how much his confidence has increased being part of the group and I think he likes that sense of belonging to something that's raising awareness and doing good work." (Frontline manager)

"The change in this lady over the past two years is phenomenal. She's chatty and funny and she really looks forward to seeing her friends and being part of something that is so important." (Frontline manager)

As the Project progressed, the group became more confident and took on more responsibility for running the group. This is an important outcome given the starting point of each person, their self confidence and self advocacy experiences. One member of the group shares her story here: https://www.macintyrecharity.org/louise-tells-us-why-the-keep-going-dont-stop-group-is-important-to-her/

From working in this way, MacIntyre and the group learned that it is important to organise time well so the sessions run smoothly and stay focused. Each meeting had an agenda and each member of the group had responsibilities throughout the day, such as clearing waste paper bins and making lunches.

There were some challenges working in this manner. The topics covered by the group could be sensitive or upsetting, such as end of life care. Enough time needed to be allowed to explain all the topics clearly, with room for the group to share worries and feedback.

MacIntyre also learnt that it takes time to create meaningful materials so easy read resources were produced at a slower pace than initially planned. The group developed 13 easy read resources about dementia and healthy ageing.

Online toolkit

A toolkit of 32 modules with e-learning, booklets and easy read resources was developed. The modules were split across six topic themes (plus introduction) as listed in Box 2. Nine of the modules were interactive and 23 were eBooks. All modules also had other downloadable documents, a printable A5 booklet and easy read documents and some had films associated with them.

The 'Wellbeing for Life' toolkit was made available to MacIntyre staff through the intranet, where other eLearning is housed.

From September 2017 onwards the resources were made available in full to all staff supporting adults in three MacIntyre regions. In the year since their release at least 54% of all staff supporting adults at MacIntyre in those regions have completed one or more of the six topic themes or introductory material. This is not mandatory training, so the fact that more than half of all staff have accessed it is a success.

From April 2018, the Toolkit was made available to all staff supporting adults at MacIntyre. In the seven month period to October 2018, at least 40% of staff completed one or more of the six topic themes or introductory material.

During the Project, the 32 available modules and ebooks were completed a total of 6,377 times by MacIntyre staff.

In mid-2018, MacIntyre began making modules freely available to all via its website. The modules were released one by one, to allow tweets, blogs and other promotion of each component of the resources. In the four months since MacIntyre made resources available online, the Toolkit webpages / resources were accessed by 398 unique visitors.

Photo: Examples of easy read resources developed by the Dementia Project
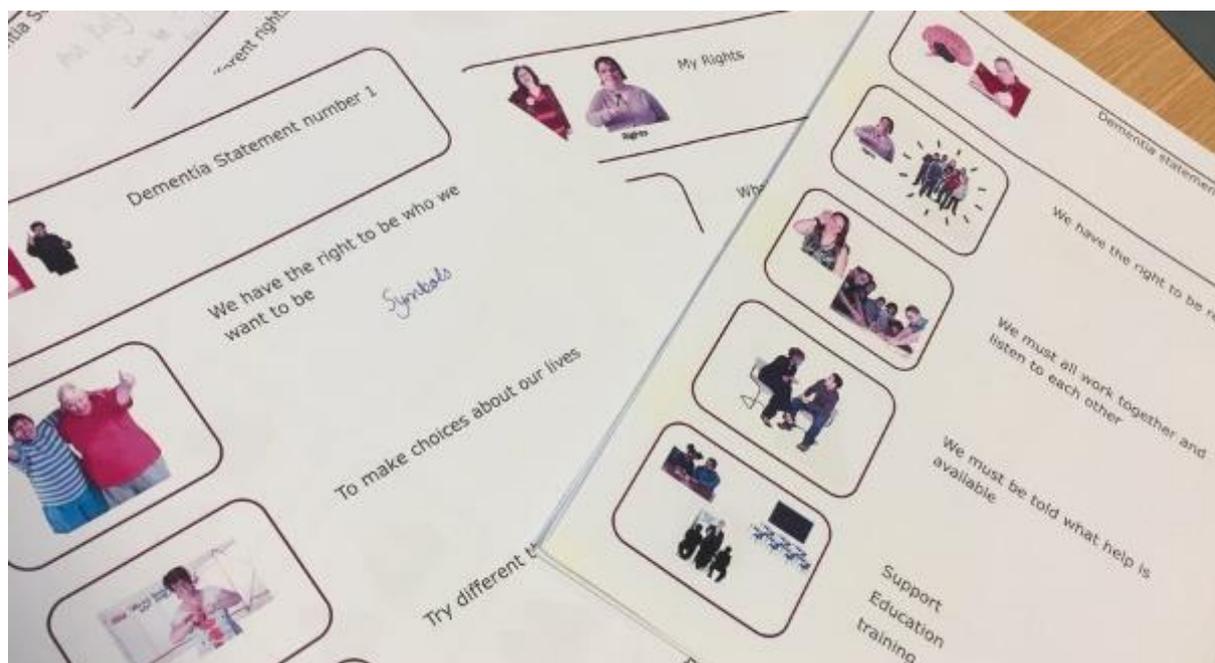
Wellbeing for Life – an introduction

Theme one: Fit for the future
   Wellbeing (interactive learning and additional documents)
   Eating and drinking (interactive learning)
   Challenging discrimination and stigma (eBook)

Theme two: Person-centred approaches
   Person-centred care and support (eBook and additional documents)
   Life story (eBook)

Theme three: Health and wellbeing
   Access to healthcare (eBook)
   Epilepsy in later life (interactive learning)
   Reducing the risk of falls (eBook)
   Safer swallowing (eBook)
   Pain and distress (interactive learning and additional documents)

Theme four: Good support
   Dignity and respect (eBook and additional documents)
   Promoting independence and safety (eBook)
   Who else can help? (eBook)

Theme five: The dementia pathway
   Learning disability and dementia (interactive learning)
   Signs and symptoms (interactive learning)
   Timely diagnosis (interactive learning and additional documents)
   Supporting peers and friends (eBook)
   Living well with dementia (eBook)
   Emotional impact of dementia (eBook)
   Treatments (eBook)
   Validation and reality orientation (eBook)
   Dementia friendly environment (interactive learning)
   Changed behaviours (eBook with 11 additional booklets)

Theme six: End of life care
   Introduction to end of life care (interactive learning)
   Exploring end of life care (eBook)
   Loss, change and grief (eBook)
   Talking about death and dying (eBook and additional documents)
   Providing the best support (eBook)
   Care in the last days and hours (eBook and additional documents)
   Continued care and support after death (eBook)
   Advance care planning (eBook)

   22 documents are available to download to help staff record health status and changes

   8 films are also part of the package

Health recording documents

In order to develop resources to support timely diagnosis of dementia, the Project first sought to define a 'timely' diagnosis. The team audited the records of 30 people diagnosed or suspected of having dementia. This information was used to identify common actions and challenges. The audit found that MacIntyre staff knew the people they supported well, but there was relatively poor record keeping about people's health and healthcare appointments. There appeared to be long gaps between health appointments, poor information about people's health history, limited records about the outcome of health appointments and few letters written by health professionals that were copied to the person using MacIntyre services. The audit found that staff were responsive to meet the changing needs of people they supported and once a diagnosis was made staff actively sought help.

The audit also found evidence of poor communication between health professionals and MacIntyre staff. Some health professionals were not willing to make a diagnosis or assessment when requested by MacIntyre staff unless family were present and there were records of professionals perceived to be blocking solutions requested by MacIntyre teams. In many cases health professionals did not involve people supported by MacIntyre in the diagnosis process in a way they could understand. In other instances, there was no handover of information when a health professional left or the person's health history was not shared with MacIntyre staff.

As a result of this audit, the Dementia Project developed a comprehensive approach to keeping health records. Guidance and folders containing new record-keeping templates were developed and began to be implemented as part of routine practice. The Dementia Project team visited services to provide training about how to use the new resources. The templates provided a simplified and standardised process for keeping records about people's health, their behaviour and visits to health professionals. This included a monitoring tool to show any changes in health which may aid timely diagnosis (known externally as the Anticipatory Care Calendar). The Project developed easy read versions of documents and encouraged staff to use these as the main record where a person is independent and able, rather than having a separate version for staff and an easy read version for the person supported. The documents were designed for use with everyone, not solely those at risk of dementia. The health calendar and a baseline health assessment was introduced as mandatory for MacIntyre services supporting people with their health, with the rest of the health recording documents available for services to 'pick and mix' as they wished. All staff that provided 24-hour support were required to take part in a two hour workshop about using the health records system.

Internal training and awareness raising

The Dementia Project ran more than 200 internal training and awareness raising events. One of the formats was 'roundtable' sessions. These brought staff together in regional locations, with pre-chosen topics, to provide peer support for each other within an informal learning environment. Each roundtable session lasted three hours and was facilitated by the Project's external consultant alongside a Dementia Project team member. Topics were based on the Wellbeing for Life toolkit, with area managers selecting topics that their teams might find most useful. This meant that every topic had at least one corresponding eLearning module that staff could complete before or after the session to reinforce what they learnt. One to two topics were covered at each session. An important part of the sessions involved asking every participant to set themselves an action plan that they would follow through on after the session. The workshops also provided practical examples of how to do things.

"Workshops bring our resources to life. We wouldn't have the same uptake if we didn't do workshops. We provided examples of how to create a good baseline for health recording so it made more sense to people. This worked well and now we have staff sending through their baseline examples to have us check them. It's a good way of engaging people." (Project team member)

Photo: A dementia training session for MacIntyre teams

External awareness raising with organisations

The Dementia Project team undertook significant promotional work outside MacIntyre. For instance, the team ran a full-day of workshops at the 2017 UK Dementia Congress. Learning disability had never been presented at the Dementia Congress previously. About 4,000 professionals, carers, people living with dementia and academics attended.

Other examples of external awareness raising included presenting at the Royal College of Psychiatrists conference (attended by 50+ people) and the Dementia Action Alliance roundtable event at the Royal College of Nursing (attended by 20+ people and available here: http://www.macintyrecharity.org/macintyre-at-the-dementia-action-alliance-roundtable/)

The team released a number of blogs and published articles to raise awareness about dementia in people with a learning disability. Examples include: http://www.huffingtonpost.co.uk/beth-britton/a-tale-of-two-worlds_1_b_18564628.html and https://www.macintyrecharity.org/achieving-amazing-things/.

The Dementia Project worked with others to produce a film about learning disabilities that was released to over 600 care homes. Other, internally produced, films included poignant stories and feedback from people supported by MacIntyre and a series of films from a regional manager.

MacIntyre worked with the Alzheimer's Society to create the resources that now support accessible Dementia Friends sessions for people with a learning disability.

In 2017 the Dementia Project won 'Outstanding Dementia Care Innovation' at the National Dementia Care Awards. A team member from Warrington won the 'Dementia Carer Award' at the Great North West Care Awards and a service team from Milton Keynes won the 'Palliative Care/End of Life Award' for their support of a lady who lived with a learning disability and dementia. In 2018, the Dementia Project won 'The Team Award' at The National Learning Disability & Autism Awards and a service team won 'The Supporting Older People with Learning Disabilities Award' at the same event.

Photo: Raising awareness externally at Dementia Congress 2017

External awareness raising with the public and families

The Project team undertook a number of activities to raise awareness about dementia and healthy ageing amongst people with a learning disability, their family members and community members. For instance, in 2018, as a celebration of the achievements of the Dementia Project, MacIntyre ran four 'Memories and Miles' events whereby participants were encouraged to walk or go in wheelchairs or by other means around a fully accessible one mile course, sharing their memories and taking part in activities along the way, including stands set up around the route with easy read resources. Participants that completed the route received a medal at the end.

"We decided to formally name these events Memories and Miles, as not everyone that is supported by MacIntyre is able to walk, we have a lot of people that use Wheel Chairs, and most of all, we wanted the route to be fully accessible for anyone to take part. We learnt that a fully accessible Memory Walk can be achieved, it takes a lot of hard work and communication between many different teams to run smoothly on the day, but these events have been so successful so far that staff, people supported and families are already saying they should be annual events." (MacIntyre team member)

The events were open to anyone in the community and there was good participation. About 420 people attended, spread across four events. The events were advertised on radio and via social media and local newspapers. Journalists took photos and did interviews, further helping to raise awareness about both dementia and the support that MacIntyre provides.

Staff and members of the public were very positive about this awareness raising strategy, which not only had benefits for individual participants, but also increased the visibility of dementia, healthy ageing and learning disability in local communities.

"I'm really pleased to say that the person I care for DID make it round Lodge Lake. Thank you so much for your help. We arranged extra support in three places on the far side of the lake to help her get round - and for her completing the circuit has been a massive achievement. She had a good time and now is very proud of her medal. We noticed others very proud too, and this has all created great memories. Oh - and putting out rocks for everyone to find while on the walk was an inspiration!" (Carer of person with a learning disability and dementia)

"It's been a pleasure and rewarding in so many ways to work on the Memories & Miles events - the walks have brought many members of the community together in a way that would not have happened without the MacIntyre Dementia Project. It's been a fantastic way of sharing the wonderful work, resources and knowledge that the MacIntyre Dementia Project team have worked so hard on over the last 2.5 years." (MacIntyre team member)

Memory Cafes are another example of an activity serving both a support and awareness raising function. Four Macintyre Memory Cafes have been set up based on enthusiasm and support from the Dementia Project. Four more are due to start over the next six months. These Cafes are open to the entire community, not solely people supported by MacIntyre. They are often attended by family members and health and care professionals. They have acted as a stepping stone to building sustained relationships between MacIntyre and other organisations such as Admiral Nurses.

Making a difference

To test whether the Project made a difference, MacIntyre audited people's records and collected feedback from MacIntyre staff, people supported and families.

To get an even clearer idea of whether the Project made a difference, services in three regions were given access to the resources one year before others so MacIntyre could compare whether those with access to resources had better outcomes. This is called a cluster quasi-experimental design.

The three regions that were given first access to resources and training were chosen because they included a mix of staff groups and services, because they were in different parts of the country and because they supported a reasonable number of people diagnosed with or suspected of dementia. At the start of the Project there were 15 people diagnosed or suspected of dementia using MacIntyre services in these areas and 503 staff supporting adults. In all other areas there were 24 people diagnosed or suspected of dementia and 865 staff supporting adults.

The Project used a range of methods to see whether the Project made a difference including:

Assessing knowledge and confidence
- anonymous surveys with 743 MacIntyre staff supporting adults, people supported by MacIntyre and families (before, during and after the Project)
- tracking use of the Toolkit available online and through the staff intranet
- online feedback form completed 6,377 times after staff used eLearning modules

Assessing timely diagnosis
- audit of records of 30 people diagnosed with dementia
- log of comments and quotes about health recording documents and training
- tracking progress of everyone suspected or diagnosed with dementia over a 2.5 year period

Assessing training staff to improve the quality of care
- analysis of 658 copies of MacIntyre's annual customer satisfaction survey
- audit of 150 care plans of people diagnosed, suspected and at risk of dementia
- analysis of annual records of safety incidents such as choking and falls
- telephone interviews to follow up staff who took part in training sessions
- telephone interviews and survey with 7 health professionals who tested resources

Reflecting on lessons learnt
- log of successes and lessons, with feedback from meetings, emails and social media
- telephone calls and online survey with 37 members of the Project steering group, management and other key stakeholders
- group reflections sessions at Project steering group and core team meetings

Training teams about new processes for recording health

Impacts

Key points

This section describes the benefits of the MacIntyre Dementia Project. The main points are:

- **The Dementia Project achieved its goal of increasing awareness of dementia amongst staff**. At the start of the Project, 63% of MacIntyre staff surveyed said they knew quite a bit about dementia. By the end of the Project this had increased to 91%. At the end of the Project 89% of staff surveyed said they knew more about dementia than one year ago, up from 43% in 2016. The more eLearning modules and training sessions that staff had accessed, the more likely they were to say they had knowledge and confidence about dementia.

- The Dementia Project seems to have had **some impact on increasing awareness of dementia amongst the people MacIntyre supports** but there was not enough data to say that this was true for people's families.

- MacIntyre has **improved internal processes** to help people who may have dementia be referred for a diagnosis. MacIntyre introduced a new system for health recording which helps staff keep good records about people's changing behaviours and symptoms. It is hoped that this might encourage staff to talk to health professionals if a diagnosis is needed. It is difficult to measure whether people are being diagnosed with dementia in a timely manner as a result, but there has been good uptake of the new health records documents and some are now mandatory for all MacIntyre teams. There has been no change in the proportion of people that MacIntyre supports with dementia over the 2.5 years of the Project (2%) but new health records were introduced less than one year ago and may take time to have an impact. Diagnosis rates are out of the control of MacIntyre teams because diagnosis is undertaken by health professionals such as general practitioners. However it is positive that **the number of people officially recorded as suspected of dementia increased from 24 to 33** during the Project (from 2% to 3% of people supported).

- **The Dementia Project achieved its goal of providing training for staff**. The Project provided 183 formal training sessions for staff and 143 visits to services and attendances at staff meetings and similar. It is uncertain whether the training helped to improve the quality of care for people with dementia. There were few incidents of falling, choking or safeguarding issues at the beginning of the Project so it was difficult to show improvements over time. Audits of people's personal care plans conducted in 2016 and again in 2018 found that there were few improvements in indicators of best practice in people's care plans. Life story work was more likely to be documented by the end of the Project, but still four out of five relevant care plans omitted this. Improving the quality of care was a longer-term goal of the Project, not necessarily something that might be achieved in the first 2.5 years, but this shows that there is more work to do to make tangible changes. The Project emailed services with targeted advice prior to reauditing. However the results suggest that more intensive support may be needed to ensure better recording of good practice.

Raising awareness

Activities to raise awareness about dementia

This section describes whether the Dementia Project helped to raise awareness of dementia among staff, the people MacIntyre supports and their families. Between April 2016 and October 2018, the Project undertook the following activities to raise awareness about dementia:

- took part in 143 internal awareness raising sessions, meetings and visits to MacIntyre services to talk to staff and observe care, with more than 1000 contacts with staff
- attended or presented at 31 external meetings, conferences and events, with more than 6,000 participants
- made eLearning modules and booklets available via the staff intranet and online
- published 92 blogs, social media posts, newsletters and articles, with distribution lists / views of more than 20,000 in total
- posted more than 1,000 tweets to more than 600 Twitter followers (https://twitter.com/DementiaLD)
- took part in four media interviews and films, including contributing to a film to be watched by over 600 care homes
- had more than 200 phone calls and email exchanges with stakeholders
- took part in promotional activities during Dementia Awareness Week / Dementia Action Week each year
- created 13 easy read resources for people that MacIntyre supports and for use by families and other organisations supporting people with a learning disability
- worked with the Alzheimer's Society to create an accessible Dementia Friends pack so people with a learning disability are included in the Dementia Friends Campaign
- attended or supported the set up of four 'memory cafes'
- released eLearning modules and trained staff

Photo: Spreading positive messages externally via interviews

Methods used to see whether awareness increased

To see whether there were any increases in awareness about dementia, the Project used these methods:

- An anonymous online survey was sent to all MacIntyre staff supporting adults at the start, part way through and at the end of the Project. Paper copies were also made available. 13% of all MacIntyre staff supporting adults completed the survey at the start, 21% part way through and 17% at the end.

- Everyone on MacIntyre's newsletter mailing list (a total of 2,331 people), including families of people supported and health professionals was sent a survey at the start and part way through the Project. The survey link was advertised in MacIntyre's newsletter and on Twitter to gain feedback from families. Sixty-eight people responded (3%).

- A survey was distributed online and in paper form to people supported by MacIntyre. Feedback from people in areas that had access to resources was compared with areas that did not. In 2016, 4% of all adults that MacIntyre supported provided feedback and 5% did so in 2018.

- Staff who completed eLearning modules were asked to give brief feedback online at the end of each module. Modules and electronic booklets were completed 6,377 times over a two year period.

- The Project team collected any comments made at meetings, on social media and via email and stored these in a success and lessons log. The lessons log was analysed for themes.

The response rates for all surveys were relatively low and cannot be generalised to all staff, people supported by MacIntyre or families. However the surveys aimed to track trends over time to supplement the qualitative feedback collected.

All analysis was undertaken by an independent team.

Photo: Memory café event for people supported by MacIntyre and families

Impacts on awareness of dementia

The Dementia Project increased people's awareness of what dementia is and how to support someone with dementia.

Increasing staff awareness

Using surveys before and after the Project helped to track changes in staff awareness over time. At the beginning of the Project 63% of MacIntyre staff supporting adults said they knew quite a bit about dementia. By the end of the Project, this had increased to 91% (see Figure 2).

The proportion of staff who 'strongly agreed' that they knew what dementia is increased from 71% at the start to 100% at the end. The Project aimed to see a 10% increase so this target was achieved.

The proportion of staff who said they knew more about dementia than the previous year increased from 43% at the start to 91% at the end. The Project aimed to see a 30% increase so this target was achieved.

Figure 2: Proportion of staff who agreed with statements in 2016 and 2018
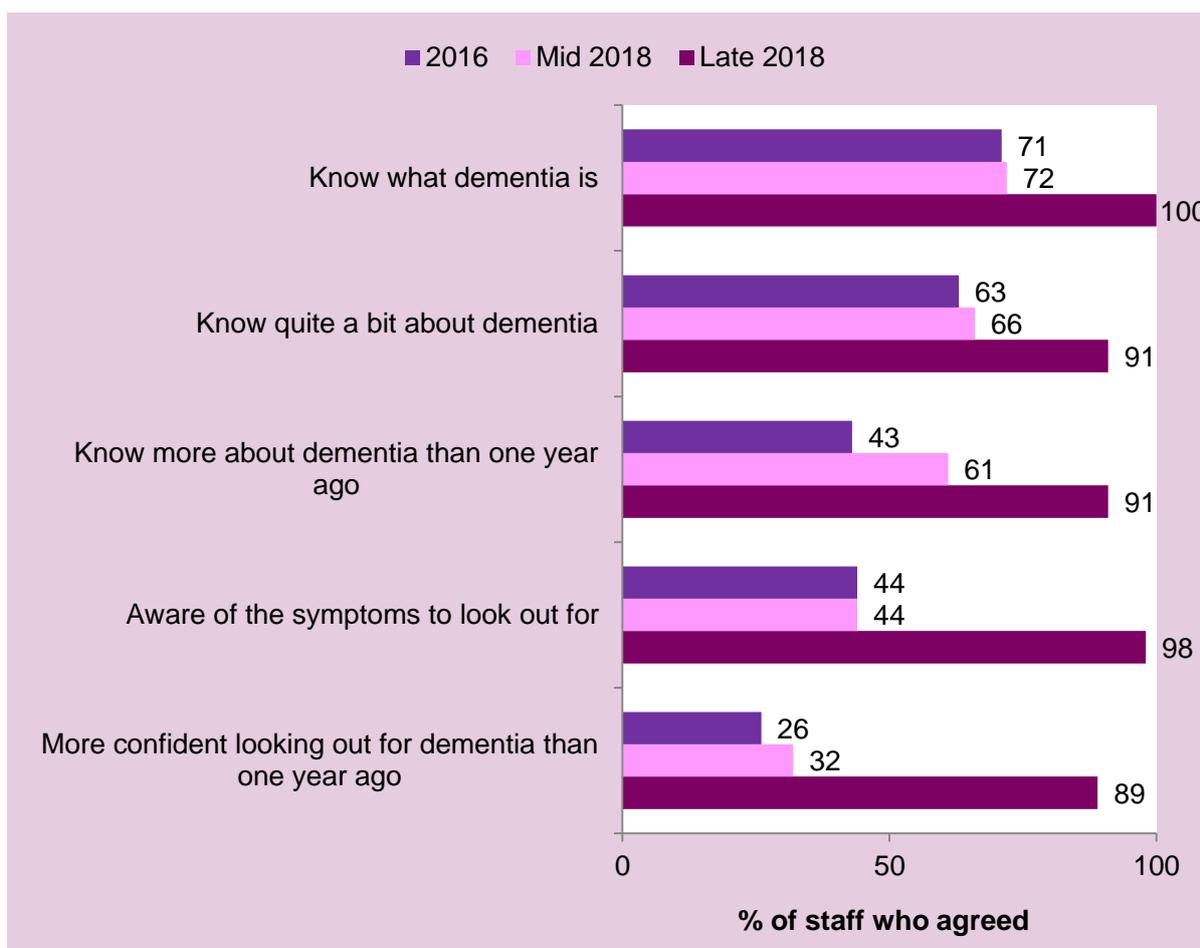
Note: A total of 174 staff gave feedback in mid 2016, 291 in early 2018 and 121 in late 2018.

It might be suggested that other promotional campaigns or activities were responsible for the change in MacIntyre staff awareness, not the Project. To make sure it was the Dementia Project that made a difference, the Project gave three areas early access to resources and training and compared the outcomes in these regions with others. Staff in areas that had access to resources first were more likely to strongly agree that they knew what dementia was, knew the symptoms to look for and felt more confident supporting someone with dementia compared to staff who had not had immediate access to the resources and training (Table 1). This suggests that the Dementia Project resources, training and support made a difference.

In areas that did not have access to resources there was no reported increase in knowledge. However as soon as other areas were able to access resources and training, knowledge and confidence in these regions increased too.

In interviews and surveys, staff confirmed that they had learnt more about dementia and healthy ageing as a result of the Project.

"The Project has made our team know more about ageing. It's not only good for the people we're working with but also for our own families. We know more about what our parents and grandparents might go through." (Support worker)

"Staff are more aware of dementia, it is something which is talked about more within the services whereas before the Project it was not talked about as much and the services who had someone with a diagnosis of dementia felt more alone and isolated." (Frontline manager)

Staff that actively engaged with the training and resources were more likely to have increased knowledge and confidence than those who had not used the toolkit. In the survey, staff that said they had attended more events or completed more eLearning modules were most likely to say their knowledge and confidence had improved over the past year.

Table 1: Comparison of awareness of dementia before and after the Project

	Project start, mid 2016	Early 2018		Project end, late 2018
Staff		Early access to resources	Delayed access	
Number who gave feedback	174	130	161	121
Heard of dementia	90%	93%	93%	100%
Know what dementia is	71%	75%	70%	100%
Know quite a bit about dementia	63%	71%	63%	91%
Know more about dementia than 1 year ago	43%	80%	42%	91%
Aware of the symptoms to look out for	44%	49%	42%	98%
More confident looking out for dementia than one year ago	26%	53%	19%	89%
People we support				
Number who gave feedback	39	22	25	-
Heard of dementia	50%	82%	72%	-
Know more about dementia than last year	40%	50%	40%	-
Family and others				
Number who gave feedback	50	3	15	-
Heard of dementia	77%	100%	66%	-
Know what dementia is	52%	100%	40%	-
Know quite a bit about dementia	33%	33%	33%	-
Know more about dementia than 1 year ago	20%	33%	27%	-
Aware of the symptoms to look out for	22%	66%	40%	-
More confident looking out for dementia than one year ago	60%	66%	33%	-

Note: People supported by MacIntyre and family members were not surveyed at the end of the project as there was poor response earlier in the year and feedback was collected in other ways.

Increasing awareness in people supported by MacIntyre

The people supported by MacIntyre who were actively involved in the Project said their knowledge increased. The Project did not survey enough people that MacIntyre supports to draw conclusions about whether awareness of dementia increased across the board, but the trends were positive. About half of the people supported by MacIntyre who were surveyed at the start of the Project said they had heard of dementia compared to three quarters towards the end of the Project. This was backed up by interview feedback from people supported by MacIntyre and staff members.

"I want to stay healthy and keep doing what I like and be with my friends and stay living here. I know things now." (Person supported by MacIntyre)

"People know more about dementia now and that includes people we support. Easy read documents and films make the information available so we can have conversations about what dementia is. People with milder learning disabilities absorb a lot from TV and conversations so they might know there is a thing called dementia but think it is scary. A positive outcome from this Project is that people can now say the word dementia without crying when they say it." (Project team member)

Team members provided direct examples of how awareness raising visits from the Dementia Project team had made a difference.

"I would like to give you feedback from the people we support on their behalf on the brilliant workshop that you held … Everyone said that they really enjoyed it and it was lovely to see how much they had taken on board with the fantastic activities that you did. When I went into the kitchen the day after, everyone was sat around the table apart from D who has dementia, I sat at the table and we were discussing items that the people we support had requested to buy for their home. I suggested that perhaps we could do with a new tablecloth and everyone agreed. I asked everyone if they had enjoyed the training with you and they all said that they had, I asked if anyone could remember what it was about, J said 'dementia' and C said the brain. I then started to discuss the tablecloth again and suggested that it may be better to have a plain coloured one this time and not patterned as this maybe better for D. J asked 'why' and C replied because of D's dementia, I agreed and explained that a plain tablecloth would be better. Both C and J started to talk about the dementia training and the activity of placing the pictures on the brain and started to talk about how D can still do the things he does but needs more help." (Frontline team member)

The team also provided direct support for some individuals who were thought to have benefitted.

"The Dementia Project were asked to spend some time with a married couple who needed some support around a diagnosis of dementia. We spent time meeting and presenting the subject in an easy read way and the couple felt safe that they could talk honestly and openly to the team. We were also asked to be present when A was due to receive her formal diagnosis of dementia so if A or J wanted further support or reassurance we would be present right away. This was a long process and needed real commitment as each time we met we needed to go through what we had spoken about previously. J needed extra talks on his own as he found it very hard to talk openly in front of his wife and he didn't want to hurt her feelings if he was to say something that was on his I mind. J knows he can approach the team if he requires further support. He recognises that we are there in a bespoke way to support him in this area." (Project team member)

Increasing awareness in family members

Too few family members provided feedback in the survey to draw conclusions about whether their awareness was raised, but there were some positive trends. Family members were more likely to say that they knew what dementia was and knew the signs and symptoms to look out for as the Project progressed.

Increasing awareness of dementia amongst the family members of people MacIntyre supports is something that the Project may not have focused on as much as it could have. The Project did many things to raise awareness for family members, such as inviting family members to MacIntyre Memory cafes and Memories and Miles events where people walked, went in wheelchairs or travelled in other ways around a set course. The Wellbeing for Life Toolkit is now available online and family members of people with a learning disability (not necessarily supported by MacIntyre' have provided positive feedback about the impact this has had on them. Anecdotal feedback suggests that for some family members at least the Dementia Project has helped to raise awareness, however the Project was not able to measure numerically an overall change in awareness amongst the family members of people supported by MacIntyre.

Increasing awareness outside MacIntyre

Much of the work of the Project in the early stages focused on raising awareness amongst external health and care professionals about thinking about learning disabilities and dementia in a joined up way. This was complemented by an online presence with tweets and webpage content.

There were 3,148 unique page views of MacIntyre's general Dementia Project content online over the Project period (excluding repeated visits by the same person). This includes materials such as Project newsletters, films and updates. Releasing the Wellbeing for Life Toolkit online is also likely to have raised wider awareness. There were 398 unique page views or downloads of resources in the first four months after release, equating to about 100 downloads of resources per month.

Many organisations and professionals said they learnt a great deal from MacIntyre's in person and online promotional work and ongoing partnerships were built with organisations such as the Alzheimer's Society and Dementia Action Alliance.

> *"The National Dementia Action Alliance (DAA) worked closely with MacIntyre on our From Seldom Heard to Seen and Heard campaign. They helped us significantly in our work on learning disabilities and dementia. The team supported us in putting together the agenda for our roundtable to discuss the issues involved and supplied us with videos and case studies. The roundtable was very successful and produced recommendations which DAA members could take back to their organisations and pledge to work with and support people with a learning disability and dementia. This has led onto joint work with the Foundation for People with a Learning Disability and the recommendations being included in their policy document. The DAA are now working with MacIntyre on simplifying the Dementia Statements so that people with a learning disability and dementia can engage with them. The Dementia Statements are a vital part of the DAA work, with our members actions plans being based on them. The Dementia Statements were devised by people living with dementia and carers and we feel it is vital people with a learning disability are also involved. Without MacIntyre's involvement, we could not have been able to do this important work."* (Dementia Action Alliance, organisation name quoted with permission)

Senior managers, steering group members and the Project team believed that the Dementia Project helped to raise the profile of MacIntyre as an innovative organisation and had emphasised that health and care services should consider the needs of people with a learning disability.

"One part of the Project that has definitely been successful is awareness raising in the external world that people with learning disability can and do live with dementia and there are lots of challenges with this. Learning disability services are much more person-centred and focus on maximising people's abilities. The Dementia Project has shown what is possible and has considerably raised the bar amongst other organisations." (Steering group member)

"When the Dementia Project began many professionals and the wider public had never considered the impact of dementia on a person with a learning disability. Once we started to share our knowledge and resources, it became clear that for many people this learning experience was a 'light bulb moment' that has changed the way they think about A) ageing with a learning disability and B) how dementia can affect a person with a learning disability." (Steering group member)

The Under Secretary of State for Health visited MacIntyre, and the Project team believed that this showed that the Project was putting people with a learning disability on the map in terms of wider conversations about dementia. Feedback from other health, social care and voluntary sector organisations suggested that they had never considered dementia in people with a learning disability and that this Project had significantly raised awareness across sectors.

Raising the profile of MacIntyre and helping other organisations understand the interlinkages between learning disability and dementia are positive outcomes from the Project, but also factors important for its success as it is hoped that wider awareness about learning disability will be a stepping stone to better communication and care.

The profile of the Dementia Project enabled MacIntyre to forge many mutually beneficial collaborations with high-profile dementia, learning disability and social care organisations and receive many other expressions of interest or requests for resources from individual health and social care professionals. This has enabled the Project to grow rapidly and have more authority, as well as ensuring that the legacy of resources and programmes developed alongside others will continue to be of use for many years.

Timely diagnosis

Activities to support timely diagnosis

This section focuses on how MacIntyre aimed to improve processes to support a timely diagnosis of dementia amongst people with a learning disability.

It sometimes takes a long time for people with a learning disability to be diagnosed with dementia after they begin experiencing changes in health, behaviour or mental processes. To help people receive a more timely diagnosis, the Dementia Project:

- audited records at the start and end of the Project to identify how many people using MacIntyre services had been diagnosed with dementia or were suspected of dementia
- visited a sample of services and reviewed the records of 30 people diagnosed and suspected of having dementia to examine their diagnosis journey
- visited services in the targeted areas to explore case studies of how people were supported with the diagnosis pathway
- reviewed the consistency of paperwork and record keeping to make it easier to follow up after people had appointments with health professionals, launching a new health calendar and simplified forms to record health issues
- ran more than 100 workshops about health recording with over 500 staff
- developed eLearning resources to increase knowledge amongst MacIntyre staff about how to support timely diagnosis
- presented at external organisations such as the Royal College of Psychiatry about the importance of receiving a timely diagnosis
- participated at a Dementia Action Alliance roundtable event, sharing three personal stories about how people faced challenges receiving a timely diagnosis
- presented at the Memory Service National Accreditation Programme conference about timely diagnosis, attended by about 200 professionals, mainly managers of memory clinics
- featured in a Community Care article with a focus on timely diagnosis (http://www.communitycare.co.uk/2018/02/02/myth-busting-importance-receiving-timely-diagnosis-dementia/)

Methods used to examine progress towards timely diagnosis

Following the audit of people's records and diagnosis journey, the Dementia Project concluded that it would not be possible to compare the timeliness of diagnosis before and after the Project because robust measures of the time to receive a diagnosis were not available prior to the Project. Instead, the Project focused on measuring the extent to which new processes and records were put in place to support timely diagnosis.

The Project used these methods to see whether there was any impact on processes to support timely diagnosis:

- A proxy measure of any changes in diagnosis rates was used: looking at the proportion of people who were suspected and diagnosed of dementia out of all adults supported by dementia. It might be expected that a higher proportion of people would gradually be diagnosed after the Project began. However such changes would not necessarily be expected within the Project timeline as diagnosis takes time.

- The Project collected feedback during training sessions, visits to services and follow up telephone calls to see whether staff were putting new processes and health recording documents in place. Staff were also surveyed about use of new practices, including health recording documents.

Photo: Dementia Friends session with people supported and staff

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Impacts on processes to support timely diagnosis

Improved health recording processes

There was some evidence of changes in care processes that may improve the likelihood of diagnosis (see Box 1 for an example). Staff that attended workshops about improving health recording provided positive feedback, including the following examples:

"I enjoyed the new health calendar as I believe it will improve good practice at work. Also new staff members will understand the people they support better. It was very interesting and easy to understand." (Support worker)

"I find the idea of the health calendar really exciting and I believe this will really help us with reducing unnecessary paperwork and just getting to the important bits." (Support worker)

In a 2018 survey sent to all MacIntyre staff, improving health recording to support more timely diagnosis was the most common thing that staff said they had done to improve care.

"Patterns of behaviour and health concerns are picked up much more efficiently and in a timely manner, which helps us to be responsive to the needs of the people we support… We do these with the people we are writing about, which has been a great way for our new staff to get to know the people they are supporting and vice versa, building relationships and learning about each other." (Frontline manager)

Photo: Training teams about health recording

A MacIntyre service began using new health recording documents in 2017. The Dementia Project team provided face-to-face workshops for all staff so they understood what each document was and could complete the eLearning that goes alongside it. This also gave staff a chance to share concerns and have their questions answered instantly in a group setting. The Project team visited on a number of occasions to provide a 'drop in' session, where staff could pop in to ask questions.

The frontline staff were initially excited to try using the documents because they thought they were simple and targeted towards the most important information. However staff needed ongoing help to use the documents in practice. It was not enough to make documents available. It helped to be able to discuss any concerns and work together to find a solution. Having eLearning available helped to reinforce how to use the tools.

Some staff missed the face-to-face training and so began using the tools without an explanation of how to use them. These staff had particular difficulty doing a baseline assessment, but once the tools were explained the staff became more confident.

The staff said that the new health records were a good way of recording a person's health. The health calendar helped to ensure that things were not missed. Staff thought that this would help a person receive an accurate and timely diagnosis of any health condition, including dementia. Staff reflected that the health calendar reduced duplication of paperwork and saved them time.

"Using the health calendar and its supporting documents has meant all our paperwork has been streamlined and flows in a more coherent and user friendly way. Recording is now part of the daily routine for the people we support as they are fully involved, which removes the complacency that can creep in ... We are therefore able to pick up positives and negatives as and when they occur and can respond straight away." (Frontline manager)

Diagnosis rates

The health recording documentation was implemented one year before the Project ended. The Project would not expect to have observed a change in patterns of dementia diagnosis in that time, but tracked changes in the overall proportion of people diagnosed with or suspected of dementia using MacIntyre services. Table 2 shows there was no significant change in the number or proportion of people diagnosed with dementia but there was an **increase in the number of people officially recorded as suspected of dementia** during this period. At the start of the Project 24 people were suspected of dementia and by the end 33 people were. This isn't a significant change in the overall percentage of adult MacIntyre supports, but it is a very positive direction of travel.

This may indicate that the reported increases in staff knowledge and confidence helped them identify signs and symptoms of dementia which led to a recorded suspicion of dementia. The Project team were clear that diagnosis itself was out of the hands of MacIntyre staff, but that a move towards increased suspicion of dementia was a good step on this journey.

"Improving the timeliness of diagnosis is not something one organisation can solve. It is reliant on lots of people working together. Our organisation has created resources but we cannot diagnose ourselves so it is difficult to measure change. We have raised awareness amongst other professionals and we have helped our staff understand that dementia is a possibility to be considered. We are working on giving our staff more confidence to speak with clinicians." (Project team member)

Table 2: Proportion of people diagnosed and suspected of dementia at Project start and end

	Project start 2016	Project end 2018
Proportion of adults supported who are diagnosed with dementia	2% (25 people)	2% (25 people)
Proportion of adults supported suspected of dementia	2% (24 people)	3% (33 people)

The number of adults diagnosed and suspected of dementia at MacIntyre is small and people come and go from the services over time. Therefore merely comparing the overall proportion of people diagnosed or suspected may miss important changes in the diagnoses of individuals. Table 3 shows how the diagnostic status of individuals supported by MacIntyre changed over the course of the Project.

Twenty-five people supported by MacIntyre who had no signs of dementia recorded in 2016 were suspected (19) or diagnosed (6) with dementia by 2018. This is a significant rise and suggests that there may have been a real change in noticing the signs and symptoms of dementia.

38% of people who were suspected of dementia in 2016 were no longer suspected in 2018. This may also be a positive trend, as staff become more confident about knowing what is a sign of dementia and what is not.

Table 3: Tracking diagnostic changes over time for people supported by MacIntyre

2016 numbers	2018 numbers			
	Not supported (9)	Not suspected (10)	Dementia suspected (36)	Dementia diagnosed (27)
Not supported by MacIntyre (8)			3	5
Not suspected of dementia (25)			**19**	**6**
Dementia suspected (24)	3	9	12	
Dementia diagnosed (25)	6	1	2	16

Managers and frontline staff gave examples of how the new processes for recording information about people's health and behaviour were helping towards suspicion and timely diagnosis of dementia.

"After completing the Wellbeing for Life training, services are now more aware of the signs and symptoms of dementia for people with a learning disability and know that if they are noticing a change within the person they have all sorts of resources that they can refer back to and who to contact if they need more support. They also now have the confidence and are beginning to question health professionals locally as many doctors (not all) will say that the changes in the person are due to their learning disability and not a different underlying health condition. The Health Calendar has had a huge impact - being able to record the person's changes in health and having a 'health history' when supporting the people we support to the doctors is brilliant evidence, and has helped get people a timely diagnosis, and this is not just exclusive to dementia but other health conditions as well. Staff overall are now more proactive, more confident and are active upskilling themselves by attending the Dementia Special Interest group, accessible dementia friends sessions and using the e-learning Wellbeing for Life Toolkit." (Area manager)

"Sometimes the really early signs of dementia are difficult to see as the behaviours of people we support can sometimes mask the signs and symptoms of dementia. Staff initially would question 'is it something different or is it part of their learning disability?' However staff now know and feel confident that they can ask questions if they don't think something is quite right and to keep being persistent. An example is a person we support had numerous tests. Staff were relentless in the sense that they knew something wasn't right and kept being persistent which resulted in a diagnosis of Parkinson's disease." (Area manager)

It was also noted that the health recording documents provide a legacy for improved care for all people supported by MacIntyre, not solely those developing or diagnosed with dementia.

"Managers feel the documentation is easy to use and very relevant, for everyone we support. There are still massive health inequalities and while people with learning disabilities are living longer they are still dying earlier than the general population and sadly at times the cause of death should have been preventable. For example, outside MacIntyre people with learning disabilities have died due to constipation: something which is definitely totally avoidable. If used consistently, the Health Calendar is one tool that can help monitor people's health and wellbeing in a dignified and respectful way." (Area manager)

Quality of care

Activities to improve the quality of care

The third key objective for the Dementia Project was providing training to improve the quality of care that MacIntyre provided for people diagnosed, suspected or at risk of dementia. The Project undertook the following activities to improve the quality of care:

- developed an online toolkit of eLearning modules and booklets known as 'Wellbeing for Life' and made these resources available to MacIntyre staff in three areas (as well as 35 health professionals known to MacIntyre for testing, 7 of whom used them).

- ran 183 training events for staff, including events spanning two hours, half-days and full-day events. This included training about topics covered by the eLearning modules, health recording documents and other training about dementia. It does not include general awareness raising sessions or visits to services or staff meetings as those are described in an earlier section

Methods used to explore impact on the quality of care

The Project **achieved its objective of providing a significant amount of training and resources**, but MacIntyre wanted to go further and explore whether the Project began to impact on the quality of care for people at risk, suspected or diagnosed with dementia. The following methods were used to assess impact on quality of care:

- Audits of a sample of person-centred plans were undertaken at the start, part way through and at the end of the Project. At the start and middle of the Project the records of 47 people diagnosed, suspected or at risk of dementia were reviewed, comparing areas with early access to Project resources (22 people) and other areas (25 people). At the end of the Project the records of 56 people diagnosed, suspected or at risk of dementia supported by MacIntyre were audited. The audits looked at the extent to which pre-defined standards of good practice were documented in MacIntyre's care records. The audits looked at the records of as many of the same people as possible over time, with substitutes for people who were no longer with MacIntyre. The audits reviewed the previous 12 months of care.

- The Project looked at records of safety incidents such as choking and falls for the past 12 months to compare any changes in participating and non-participating areas.

- A sample of staff who took part in training sessions were followed up by telephone to see whether they had done anything differently as a result of training.

- The Project looked at the results of MacIntyre's customer satisfaction survey to see whether there were changes over time. The people MacIntyre supports are asked to provide feedback every year.

- All staff who completed eLearning modules provided feedback about their usefulness afterwards using an online survey. There were 6,377 responses over the course of the Project.

Impact on the quality of care

Staff-reported changes to practice

All MacIntyre staff who completed an ebook or module in the Wellbeing for Life toolkit were asked to report the extent to which the content was useful. Across all of the resources, 95% of staff said that they knew more about dementia as a result of using the resource. 92% thought they could better identify people with dementia as a result of completing the resource and **95% reported that they felt more confident supporting someone with dementia** as a result of the resource.

Feedback from surveys and interviews with people who had used eLearning or Wellbeing for Life training sessions suggested that they were making changes to their practice.

"I am now more aware about dementia and the effects of dementia. Before the training I just thought that dementia affected your memory. I had no idea how it affected vision, movement, eating habits etc. I am now more aware and when I go into my service I look to see if the environment is friendly - does this drawer need a label on it with a picture to make it easier for the people we support? Does that rug really need to be there on the floor as it may confuse and put off someone with dementia from coming into the room?" (Support worker)

"I've learnt about the signs and symptoms of dementia and that it also effects the visual side of things for the person we support such as they may need their environment changing to help them live well and independent with dementia i.e. have a red toilet seat so that they can see that it's a toilet and can go independently. Also that they may look in a mirror and not recognise themselves so they may get upset and to be aware that this may be scary for the person we support. I also learnt that dementia can affect your swallowing and taste and that things someone may have liked before they may dislike now due to their taste changing. I am actively more aware of this and look for special recipes." (Support worker)

"We now have the awareness of what aids are available to support a person living with dementia and awareness in making adaptions in the house to enable a person to live well in their home. We found the Dementia Friendly Environment eLearning really upskilled us all in this .Learning new skills can really have a huge impact on the person." (Support worker)

The most commonly mentioned changes to practice were:

- keeping better records using health calendars and a traffic light system
- using a primary colour (red, blue or yellow) for bedding, plates or cups
- putting pictures on the wall or in books or memory boxes to help people remember
- feeling more confident during safeguarding conversations
- using tools to help people eat well or manage their weight (Box 4 provides an example)

Family members also provided feedback about how staff at MacIntyre were making a positive difference.

"My brother lives at MacIntyre … and has early dementia. MacIntyre have supported the family all the way and explained so many of the issues that he is facing and the family are facing. They seem to really understand the problems and to be thinking one step ahead." (Family member of person supported by MacIntyre)

Box 4: Case study of using Wellbeing for Life modules to improve care

People with a learning disability are more likely to be severely overweight than people in the general population. Women with a learning disability are even more likely to be obese. People who are obese are at much greater risk of health problems such as heart disease, high blood pressure, stroke, diabetes and mobility difficulties. For most people, bringing their weight down to healthy levels involves exercising more, eating healthier foods and avoiding less healthy foods and sugary drinks. In MacIntyre's experience people with a learning disability are less likely than others to do regular exercise and eat a balanced diet with enough fruit and vegetables.

The Wellbeing for Life toolkit contains tips to support someone with a learning disability to have a healthy diet and be active. One MacIntyre team used the tools and advice included in the toolkit to help someone they support. A team member said:

"Faye, a person we support, has lost quite a bit of weight... From her heaviest weight of 9 stone, 11 pounds, to currently being 8 stone, 1 pound, she has lost an incredible 24 pounds, which is such an achievement considering she is not even 5 foot in height.

With Faye's eating, it has really been about the small changes that have made a big impact. When we first started working with Faye, she would have three meals a day, but then also a sandwich and crisps at around 8pm in the evening. We had to slowly reduce this. We found that Faye loved bananas so these were a really good alternative to crisps. We then discussed with her about only making half a sandwich, then over time changing half a sandwich to a piece of fruit. It really is about finding what they enjoy and offering those as alternatives.

One of the other things that we changed was Faye's milk, from a green top semi-skimmed to a red top skimmed milk. Faye has always drunk a lot of milk – she has around six cups of milky tea a day and will drink warm milk at night as well as having it in her porridge. Some days Faye easily got through three pints of milk. In terms of the levels of fat Faye was consuming, this small change made a really big difference. We spoke with Faye about the benefits of skimmed milk and trialled it, and it worked!

We also kept a food diary of what Faye had eaten each day to enable staff to ensure that she wasn't getting too much of something or lacking in something else. One thing that this helped us to identify was that Faye was often given food when she appeared upset or anxious, even if she wasn't asking for food. However, now Faye only has snacks when she wants them, which she rarely does.

We have made an effort to make sure that even though we are conscious of Faye's weight and diet, she still has the foods that are important to her. She has a hot breakfast every morning (even in the summer), whether it's eggs, beans or porridge. We also visit her dad's chip shop twice a week for dinner.

We are all so proud of the progress that Faye has made with her weight, even with other factors out of her control affecting it."

Impact on quality of care

Despite staff reporting that they were changing their day to day practice, there were few statistically significant differences in numerical indicators of the quality of care in areas that did and did not have immediate access to Project resources and at MacIntyre overall during the Project timeline (see Table 4). This may mean that whilst staff had increasing knowledge and confidence, this was not always reflected in how care was undertaken or recorded in practice or that the statistics were not sensitive enough to capture the impacts of small changes in the support provided.

There were some positive trends, particularly in the proportion of people's care plans that included a good level of detail about life story work. This proportion increased from less than about 5% across MacIntyre overall in 2016 to about 20% in 2018. However this still means that only one in five relevant care plans contained an appropriate level of detail about life story work.

There were trends towards slightly more care plans documenting in good detail the type of dementia support people needed and indicators of pain and distress, but less than one in five relevant care plans contained adequate information about this.

These are disappointing results. They suggest that four out of five people supported by MacIntyre who are suspected or diagnosed with dementia could be benefitting from better written records in care plans. This does not necessarily mean that the care provided is substandard, just that **indicators of best practice are not being routinely recorded** and the reported improvements in staff knowledge and confidence may not always be embedding in practice, at least in written records.

The person-centred care plan audits were undertaken by MacIntyre staff independent of the Project team and provide a good indication of whether best practice in dementia care is being recorded in people's plans. In early 2018 the audit found that there was much scope to improve the quality of care recorded and the Project team decided to target services for follow-up based on their audit results. The aim was to use the monitoring information to support real changes in practice, providing additional support and training to these teams and following up with area managers to highlight areas for development. Although this was set as a priority, the Project team ultimately decided to focus most on other things in the final six months of the Project and the follow-up audits showed no improvement in practice. The team did email every team supporting someone with dementia with specific advice, but learning suggests that this alone may not have been sufficient to encourage change.

There appeared to be a reduction in GP visits and outpatient visits over time but a slight increase in hospital visits and stays. Trends about service use could not be attributed to the Dementia Project.

MacIntyre provided good quality care prior to the Dementia Project so the rates of choking incidents and safeguarding incidents was low. This means that it was unlikely that the Dementia Project would be able to demonstrate any improvement in these indicators and this was reinforced by the data available.

Table 4: Indicators of quality of care before and after the Dementia Project

	Areas with early access to resources		Other areas		MacIntyre-wide at Project end
	Mid 2016	Early 2018	Mid 2016	Early 2018	Late 2018
Person-centred care plans fully described type of dementia, if relevant	17%	14%	0%	15%	**9%**
Person-centred care plans fully described dementia supported needed, if relevant	8%	10%	0%	15%	**14%**
Person-centred care plans included good detail of life story work	9%	5%	0%	13%	**20%**
Person-centred care plans included detailed end of life care plan if relevant	9%	14%	0%	14%	**9%**
Person-centred care plans described pain and distress indicators in detail	0%	9%	0%	16%	**14%**
Average A&E visits per person per year	0.1	0.2	0.1	0.4	**0.8**
Average admissions per person per year	0.1	0.1	0.1	0.1	**0.3**
Average outpatient visits per person per year	4.6	2.7	3.7	2.5	**0.8**
Average GP visits per person per year	8.6	6.5	10.4	9.1	**7.2**
Proportion on non-drug therapies	14%	45%	36%	56%	**34%**
Proportion with dementia on dementia medication	25%	33%	42%	78%	**38%**
Proportion with dementia prescribed antipsychotic medication	8%	33%	33%	65%	**19%**
Proportion of all supported by MacIntyre who fell	28%	17%	26%	29%	26%
Proportion of all supported by MacIntyre who choked	2%	0%	5%	1%	3%

Note: The records of 47 people diagnosed, suspected or at risk of dementia were audited in mid 2016 and again in early 2018. The records of 56 people were audited in mid/late 2018 near the Project end. Records of the same people were reviewed where possible, but substitutions were made when someone was no longer with MacIntyre. The proportions who fell or choked are out of all people supported by MacIntyre, covering records for the past year. These give rough approximations as people may have fallen more than once but the proportions were calculated by dividing the total number of incidents by the total number of people supported.

2018 proportions in green show trends towards improvement since the start of the Project. Proportions labelled red show trends towards no improvement since the start of the Project.

Impact on perceptions of care

Every year MacIntyre invites the people it supports to complete a customer satisfaction survey. There were no differences in the satisfaction of people MacIntyre supported in areas that received the Dementia Project resources and training before others (see Table 5).

People who shared their stories in case studies described the benefits of good care (see https://www.macintyrecharity.org/our-work/supporting-people-with-dementia/macintyre-dementia-Project/). This suggests that the Project did have impacts for individuals but that overall improvements in the quality of care may not have been embedded throughout MacIntyre within the Project timeline.

Table 5: Feedback from MacIntyre's annual customer satisfaction survey

	Areas with access to resources		Other areas	
	2015	2017	2015	2017
MacIntyre staff get it right when they provide support	83%	88%	81%	79%
Said staff support them to keep themselves safe	96%	94%	95%	100%
Said staff support them to feel good	98%	100%	95%	100%
Said staff support them to feel healthy	91%	94%	89%	100%
Said they get the support they need with their health	99%	100%	96%	100%

Note: In October 2015, before the Project began, 616 people that MacIntyre supported filled in an annual customer satisfaction survey. In October 2017, 42 people took part. There were no statistically significant differences between groups. Information from the 2018 customer satisfaction survey was not available at the time of writing this report.

Although there were no statistical changes in perceptions of the quality of care available for people supported by MacIntyre, the Dementia Project collected many anecdotal pieces of feedback from service users and staff about how Project activities may have directly impacted on people. Examples include:

"L came to the Memory Cafe off her own back and said I have dementia and this will help me. Well this was back in 2017 and L never misses a cafe if she is able to come. She really gets involved and I watch from the sidelines and she is so confident in interacting with the local community and I feel that she feels empowered when she is at the Memory Cafe, feeling safe and a place that she can be herself. Having this service championed by the Dementia Project is an extra source of support for L and she is flourishing." (Project team member)

"We have seen both [Dementia Project Assistants] grow in confidence by presenting at conferences, working in small groups facilitating discussions , helping to prepare and run training workshops and work in the office building skills in admin too. The impact this has had has been amazing for their wellbeing and has given them a feeling of real teamwork." (Project team member)

Winning an award at Dementia Congress

Lessons

Key points

This section summarises some of the things MacIntyre learnt when implementing the Dementia Project. The main points are:

- The Project helped MacIntyre showcase the importance of considering dementia in people with a learning disability. It has shown other health, care and voluntary organisations that change is possible and that there are simple things that organisations can do to help staff understand more about dementia.

- The Project shows that **people with a learning disability can be centrally involved** in planning and implementing improvement programmes. It is important to build in funding and time to support this involvement.

- The team learnt that it **took more time than expected** to develop and check the eLearning resources, develop easy read resources and deliver training. Having a clear programme timeline and aligning every activity with the Project objectives was important to guard against spending a lot of time on activities that may not help to achieve the objectives.

- It was useful to have a **broad range of people in the Project team**. The Project had a small core team working on the Project day-to-day, but drew in help from many others, including web designers, MacIntyre's communications team and external experts specialising in dementia and evaluation. A director of MacIntyre had overall responsibility for the Project which helped to maintain support at senior level.

- The Project provided a total of 591 outputs at a direct delivery cost of £381,344, or £645 per output. This does not include evaluation.

Photo: Memories and Miles event at Milton Keynes

Success factors

This section describes things that helped towards the success of the Project. Information for this section was drawn from interviews with the core Project team, interviews and an online survey with the Project steering group and other stakeholders at MacIntyre, feedback from health professionals who have begun testing the eLearning resources and a log of successes and lessons based on feedback received from meetings, events, social media posts, telephone calls and emails.

Drawing together a broad team

Reflecting on what worked well in the Project, members of the Project team and steering group said that having a broad range of people working on the Project was useful. The Project had a small core team working on the Project day-to-day, with a range of skills and experience. As outlined in the Activities section, working alongside the people supported by MacIntyre and seeing these people as key members of the Project team was integral to the way MacIntyre does things.

Photo: 'Keep Going' advisory group

A director of MacIntyre had overall responsibility for the Project which helped to maintain support at senior level and address any potential blockages promptly.

"There were good relationships within the core team. It was a strong tight knit team – not just one Project manager juggling everything. There was someone with a strategic role, someone practical with experience with the people we support, someone with a coordinating role and an administrator. All have different roles, and it all works. Having a member of the director team in the Project team means there is leadership buy-in and if there are barriers or areas of confusion those can be ironed out quickly." (Project team member)

In addition, the Project drew in help from many others. MacIntyre's web design and education team were central to designing the eLearning, the communications team developed and implemented a communication plan to promote the Project and external experts assisted with specific knowledge about dementia and evaluation. Project members said that it had been particularly helpful to involve members of the communications team from the outset so they could promote the Project widely and present it appropriately.

As well as those implementing the Project, a Project steering group included MacIntyre regional managers, trainers, external helpers and representatives from other organisations. People supported by MacIntyre were regular attendees.

Photo: Dementia Project steering group

A Dementia Special Interest Group made up of people throughout the organisation interested in dementia were kept up to date and gave advice where needed. This approach meant that the programme was embedded within the organisation as a whole rather than being seen as a small standalone Project.

Photo: MacIntyre Dementia Special Interest Group

The Project also encouraged frontline team members to become 'Dementia Champions' and run Dementia Friends sessions in their areas. This helps to build sustainability, because regions are not reliant on a small core team for training and support. Box 5 provides the story of one support worker who trained as a Dementia Champion.

Box 5: Story of a support worker who now runs Dementia Friends sessions

"I never properly understood what dementia meant as I was growing up although I knew people who had it. If you don't know about an illness it can be quite scary. I wanted to learn more about it… I decided to attend an information session run by the Dementia Project which I found incredibly useful. It was there where I learnt a lot more about dementia and how I could help in the community. I was told about the dementia champion role, which I thought was a great idea.

I attended a dementia champion session where I met lots of other people that wanted to help raise awareness of dementia and to understand where they could help. Some people that I know or have known have had dementia (or similar) and I was excited to know more. At the start of the session we all answered questions on what dementia meant to us and how we think the world sees it. Unfortunately, many people still don't understand what dementia really is as I have come to find out through running sessions and talking about it. It became clear that people often had a negative view on dementia and how it affects people. A word commonly used was that people 'suffer' with dementia implying that perhaps people can't live well with dementia which we all know is not true. The session was really great and I found out lots of new information that I could use to help people in the community. I learnt that everyone who is living with dementia experiences it differently, for example the progression rate of the disease in a person and the impact on the family.

Now I run my own training sessions to raise awareness about dementia. My favourite part of running the Dementia Friend sessions is to help raise awareness and help point people in the right direction of the support they can access.

I am definitely not a big fan of presenting myself so this was the biggest challenge for me but once you get into the session it's not as bad as you may think. When attending the dementia champion session, my Dementia Friends officer was really supportive and helped me with this issue. The group was very encouraging as they were all there for the same reason and knew what it was like to stand and present in front of everyone. We practised many times before leaving and this really helped me. So far I have delivered two sessions and I hope to deliver more.

Throughout my sessions I think I got people really engaged as they asked lots of interesting questions and at the end they all wanted to become a Dementia Friend and help in the community which was great news! The thing I would do next time would be to practise a lot more so that I didn't look too nervous. I have been researching some questions that I was unsure of too because they were really interesting.

I hope to carry on running these sessions for MacIntyre and the public and to help raise awareness as much as I can because there are still lots of people who do not have an understanding of what this means. I would like to help work towards a dementia friendly community and spread the word to help others around them.

At the end of each session you are asked to write a dementia friendly action that you will commit to and it doesn't have to be too big! Even wearing your badge will help to get people talking and raise awareness of dementia. You can live well with dementia and I am proud of what I am doing and the people that are motivated to help and learn as a result." (Support worker)

Using a wide range of methods

Another factor thought to be important to the Project's success was using a variety of methods to increase knowledge and confidence. In addition to involving people supported by MacIntyre, the tone of all resources and training was seen to be important, focusing on personal stories and the human impact.

"We are having big impact externally, people are coming to us – that is due to the way we're doing it, not just providing info, we are bringing it to life, making it practical for staff – we have an emotional impact on people." (Senior manager)

The Project recognised that people have varying learning styles so a variety of training options were available including eLearning, booklets, short films, roundtable events, one-to-one sessions with the Project team, visits to services by the Project team and workshops with staff and people supported by MacIntyre learning side-by-side. The Project team highlighted this as a learning point for others: that it is important to take different learning styles into consideration and be flexible rather than doing things 'the same old way'.

"I learned how important a positive approach is when introducing new systems and learning, how the Wellbeing for Life resources enabled and empowered staff to take control of their own learning and the way they could pick and choose modules made the eLearning less daunting… I am really proud of how my teams engaged and have taken on board the importance of how they can learn, support people better and prevent unnecessary illness or behaviours from the way we use and record data. They are more confident and empowered to act on finding as there are clear actions that they need to take. This is driving staff to be more aware of outcomes and work harder for them to be achieved. Most of all I am so pleased that the staff are involving the people they support in recording information about themselves, health and wellbeing and this means we are doing what we should be." (Frontline manager)

Frontline staff were particularly positive about workshops and valued speaking with an expert in dementia. They felt that this reinforced the things they were doing well and provided new insights about other things to try.

The eLearning modules focused on topics that had wide applicability for care within MacIntyre, not solely dementia. For instance modules about eating and drinking and end of life care might be applicable to many people. In this way the Project aimed to make the modules attractive to the widest range of staff and deliver best value for money by ensuring high uptake. The toolkit's title 'Wellbeing for Life' also emphasised this broad applicability rather than being tied to dementia.

The Project team felt that constantly reminding staff about the resources was important as was having resources that people could return to again and again rather than delivering one-off training.

Reflecting on learning

Another thing that MacIntyre did well during the Project was to use information to guide improvement. The eLearning modules and training were revised following testing and feedback from staff and experts. The Project team kept a log of successes and lessons, based on all feedback received via email, social media, at training sessions and at meetings. The team reflected on the logs at monthly team meetings, using them to identify gaps and areas for development. Thus the team was not only regularly collecting feedback, but using it to guide next steps. The team noted that they plan to use such logs from the outset of future Projects as this was a useful method for monitoring progress and identifying areas for further work. Some of the main learning points that the team drew out of reflections included:

- Different areas and teams require different approaches. It is important to have a **flexible approach**, be able to think outside the box and adapt plans for training or advice to be more appropriate for local teams. Resources should be developed to target various learning styles.
- **People supported by MacIntyre** can and should be involved in Project activities. This not only strengthens the Project, but can make a significant difference to the knowledge and confidence of the people supported.
- **It takes time** to embed new tools and processes into a service, and continual follow up and consistent approaches from core teams are needed to provide support while new approaches are tested.
- Having a **core team** available to answer questions and provide reassurance is important as frontline teams like speaking with people rather than solely reading resources.
- Training sessions and site visits take time to plan and organise. Telephone calls work better than emails when arranging visits. Working closely with administrative teams in services and regions to promote training increases the number of people who attend workshops.
- It can be challenging to **engage health professionals** in learning and testing resources as they have many other priorities. When working with health professionals on Projects it is important to allocate extra time to build and maintain relationships as losing contact can mean that these professionals do not benefit from resources or do not take part in partnership working.
- It is important to ask people to take action, perhaps using **action plans** or providing examples to encourage people to do something differently after training.

Managers and teams who worked with the Dementia Project team said the team acted on feedback and that they felt like the Project was developed as a partnership between the people MacIntyre supports, frontline teams and managers and the Project team.

"The whole experience and development of the Dementia Project has been a really steep learning curve for everyone involved and we have gone along on the journey - there have been challenges at times but we have tweaked and changed things along the way. We have grown as we have progressed through the Project and I feel that things have always been open to change. Everyone has had an opportunity to input and this has made it feel more free-flowing and that staff have been listened to. Feedback from staff teams and families is that it has been really helpful and beneficial for them." (Area manager)

The Project team noted that it was helpful to have external supporters experienced in evaluation as part of the programme to provide a critical eye and fresh perspectives.

Learning for development

The Project was implemented well, but there are always areas for development in any Project. Members of the steering group, core Project team and other stakeholders provided suggestions for development in the final six months and for other Projects to consider in future. Comments were made in the spirit of ongoing improvement, not critique. Not all stakeholders will agree with all of the comments in this section.

Prioritising activities

The Project delivered more resources and training than initially planned. The extent of training, service visits and external promotion meant that the small core team were sometimes spread thin. Team members managed their time well, but there were pressures from delivering a vast Project with limited time and capacity.

Steering group members did not always agree with the way that activities had been prioritised. There was consensus that all aspects of the Project were important, but some felt that the Project could have focused on its funded deliverables before widespread external promotion, for example. On the other hand, from a strategic perspective, promotion may strengthen the sustainability of Project outcomes and help better implement the deliverables. An important learning point was that stakeholders may not have been clear why attending external events was important, with whom the team connected, what was learnt and how this was used to strengthen the Project. Communicating the reasons and impacts of these things to stakeholders may be important in future Projects.

Recommendations made by the Project team, steering group and other MacIntyre stakeholders for planning and prioritising in future Projects were:

- It is important to have a clear vision of what the Project wants to achieve but be prepared for the unexpected and have some flexibility to explore this.
- Ensure senior organisational leaders are part of the Project so they can support a whole systems approach and culture change.
- Involve the people supported as much as possible, but recognise that this requires time, energy and funding.
- Bring together stakeholders at the start of the Project to share learning from other initiatives and jointly plan to ensure links with existing related work.
- Have a clear Project plan from the outset that links every activity to the objectives to be achieved. This avoids focusing on activities that may not help to achieve the priorities. Check back regularly to ensure that the objectives are being achieved.
- Plan clearly before acting to ensure that resource is allocated effectively. In this instance there was a perception amongst some steering group members that the Project may have initially rushed to do things without fully planning the process.
- Get a wide range of people involved and use their skills to create an open and honest culture from the beginning.
- Build in enough time to develop, test and refine resources rather than rolling things out before they are ready.
- Consider peer review of resources by those with expertise in the topic area to ensure materials are up to date and follow best practice. Time for this should be built in.
- Link with other training initiatives across MacIntyre to avoid duplication and make the most of limited resources and time.

Because a large focus of the Project was on offering training and resources, there may have been less time available to directly follow up with services and teams to see if they were putting their learning into practice. For instance, the audit of person-centred care plans identified where a number of services could improve. Detailed direct follow up work with these services may have helped them understand how and why they could change. The Project team did email each service supporting someone with dementia or suspected of dementia to let them know about available resources, but did not specifically point out the results of their care plan audit or the fact they would be reaudited. This was potentially a lost opportunity. The learning point is that in a Project with such a large scope, planning needs to strategically consider how the Project could gain best outcomes from the time invested. The Project team have learnt from this and taken steps to provide more targeted support in future. For instance, a baseline health assessment example has been produced for services supporting someone diagnosed with dementia. This helps teams see what is expected from them regarding health recording, so they can adapt and implement in their own services.

Regardless of the decisions made about prioritisation, the Project team used a rigorous approach to plan their work and this acted a role model to other teams and departments.

"People internally have seen the discipline our team used to set goals and work towards a workplan, always testing, reflecting and evaluating what we did. This is different and something that people have drawn inspiration from." (Project team member)

Photo: Project team responding to enquiries and learning new skills

Allocating enough time for development

The Project initially planned to make resources available to some areas in 2016, test these for a year and then rollout resources to all MacIntyre services in 2017, allowing a further year of embedding and sharing externally before the Project ended. The creation of the final Wellbeing for Life toolkit to a standard that MacIntyre was happy to share internally and externally took longer than anticipated. Although resources were largely created in 2016 and early 2017, a planned review by internal and external experts found that numerous modifications were needed. This ultimately delayed releasing finalised materials until 2018.

It was appropriate to spend time on revisions given that the Project aimed to test and refine materials, but it may have been frustrating for services that did not have access during an extended pilot period. In hindsight, team members said they would rather have tested resources with one or two services rather than all services in three regions. This may have allowed for a more rapid cycle of testing and incorporation of learning than moving straight into widespread release of partial materials.

The piecemeal approach taken to developing and reviewing materials was also potentially time consuming and frustrating for those preparing resources and staff trying to access them.

"This has been a learning journey in terms of this sort of Project. It has proved that we are capable of doing this, however the scope in terms of production of the online modules increased massively from initial scope. Final agreed content delays and then a major review of the content provided quite a challenge to production and delivery. If we were to do this again, then sign off and agreement from all, before sending content on for production would have a huge impact and reduce pressure." (Steering group member)

Given that the team spent significant time in 2016 raising awareness of the Project, there was a significant gap between the promotion and awareness raising and what the Project was tangibly delivering in terms of high quality resources available for release and tangible support to change practice.

Increasing uptake

Whilst an extensive suite of eLearning modules has been developed, not all staff are aware of them or have used them. It is positive that half of staff in participating areas have completed one or more modules, but some staff said it was difficult to have ringfenced time to do the modules. Some stakeholders thought that it would be important to continue promoting the resources, recognising that staff have many competing priorities.

"Always stop and think about what will work for the people you are trying to help / work with / engage. Just because something is your priority doesn't mean it is going to be top of the list of someone else's priorities." (Steering group member)

Staff often requested further face-to-face training rather than eLearning and the Project team acknowledged the value of this.

"I would reflect that eLearning (even eLearning as good as ours) doesn't engage staff in the same way as face-to-face, and that is an issue across the social care sector. You cannot talk to a computer and get the same level of feedback as you can from human interaction. I do think the toolkit does serve its purpose as a standalone, we cannot pack more in content wise, the only 'improvement' now would be to have all modules interactive, but the re-enforcement provided by extra face-to-face support takes the learning to a whole new level, and I think we all know that and acknowledge that. Undoubtedly, any other provider picking up this training package would see an improvement in staff knowledge from completing the toolkit only, but the translation into staff practice would be much more widespread with face-to-face backup." (Steering group member)

It would not be feasible and cost-effective to deliver such training to every service team. The Project could look at ways to further promote the benefits of eLearning and to support interactions. For instance, one team completed eLearning modules together so they could discuss the issues raised. It may be useful to work with regional managers and frontline managers to showcase this way of accessing the modules.

Another approach may be to hold larger training sessions, spanning several areas, with representatives from many teams tasked to take the learning back to their own services. Using a 'train the trainer' model, whereby the Project trains champions in local areas to roll out the resources and modules, may also be a fruitful approach.

Filming training sessions and making these available online might be another option to explore.

Some of the training events were not well attended. The Project team learnt the importance of promotion via senior staff and administrative staff. Local services needed to be engaged to promote the training themselves. The team found that building relationships with local administration teams was important as they were key influencers. Having posters and making reminder telephone calls before events also boosted uptake.

Engaging with health professionals

The resources created during the Dementia Project may be useful for others working with people with a learning disability and MacIntyre is actively promoting wider rollout, with the Wellbeing for Life Toolkit freely available on MacIntyre's website. MacIntyre wanted to test whether the eLearning and other resources were useful for health and care professionals outside MacIntyre, particularly as these could help fulfil the NICE guidance about supporting healthy ageing in people with a learning disability. MacIntyre invited 35 external health and care professionals to test the eLearning modules. The external people invited to test resources comprised hospice staff (9), NHS learning disability nurses and other team members (9), NHS speech and language therapists (4), Alzheimer's Society staff (3), local authority housing officers (2), NHS occupational therapists (2), Royal College of Psychologists members (2), a mental health nurse (1), a clinical commissioning group manager (1), a physiotherapist (1), and a social care worker (1). These people were chosen based on existing contacts from the three MacIntyre regions that the Project team initially worked with to test the resources plus others that the Project team contacted to get a wide range of perspectives. Two family members also tested the resources.

When they completed a survey before accessing the Toolkit, 30% of these external testers said they were not aware of the signs and symptoms of dementia to look out for in someone with a learning disability. **40% said they were not confident identifying dementia in someone with a learning disability and 50% said they did not have access to enough resources** about helping people with a learning disability who may have or be at risk of dementia. This suggests that there is a gap in the knowledge and resources readily available to health professionals that the Wellbeing for Life Toolkit could help to fill.

However there was low use of the Toolkit, with only 7 professionals looking at one or more modules (19%). Those who used the modules were positive about the scope and accessibility of the materials. In follow up interviews, these people said that the resources were easy to use and would be particularly helpful for those providing frontline care.

The limited uptake was cause for concern. Even when health and care professionals were provided with free resources that they said they wanted to test, they did not use them. Some did not like having to log in to a system to use them (when the resources were not publicly available). Others said they had too many priorities and others said they did not see the relevance of the resources to themselves or their teams based on the promotional material or introductory email circulated. The learning here is to make resources very easy to access, via for instance social media links, videos and freely available a website. In addition all emails or promotional text letting people know about resources should showcase how materials may help people in their day to day roles.

One of the Dementia Project's objectives was to promote timely diagnosis of dementia, which will largely happen as a result of the input of health professionals. Thus the inability to engage fully with health professionals to test and refine the resources was a shortcoming. Potentially identifying and working with health professional groups from a much earlier stage, before we were ready for those professionals to test resources, may have helped to build up relationships more comprehensively. The team could also have approached one or two NHS departments and asked to share the resources with the entire team, rather than taking a more 'scattergun' approach to recruiting testers. Whilst some time was put into engaging with health professionals, this was allocated a lot less time than training internal staff about health recording documents for instance (where more than 100 training sessions were run), going to external conferences and other 'promotional' activities. This leaves the team with a set of resources that are valued internally and have been highly promoted, but which have not be tested for feasibility and applicability for health professionals.

However there is anecdotal evidence that the resources are useful and well received by professionals. Public Health England invited MacIntyre to attend two large health inequalities events and share all resources with participants, where they were well received. Admiral Nurses made a link with MacIntyre after attending Memory Cafes supported by the Project. They have since invited MacIntyre to many events where Wellbeing for Life Toolkit resources have been provided and Admiral Nurses are now using these resources in their day to day practice. MacIntyre also took part in a webinar for Dementia Action Alliance attended by 52 health and care professionals. Many emails were received afterwards from health professionals requesting support and resources. Professionals have also emailed positive comments or tweeted after downloading resources made available on MacIntyre's website. These examples show that the Project did share resources with health and social care professionals, it just did not formally test their usefulness for these audiences as initially planned.

Budgeting for wide involvement

Over a 2.5 year period, MacIntyre spent £381,344 directly delivering the Dementia Project, with additional costs for engagement and evaluation. For this budget, the Project delivered a total of 591 'outputs', including training sessions, eLearning modules, booklets, conference presentations, awareness raising sessions, easy read documents, health recording documents, blogs and newsletters. This equates to £645 per output provided or **£46 per eLearning module and training place completed by staff** (a total of 8,207 places and modules were completed). The Project team believed this was good value for money.

> *"The health and care system is struggling, we need maximum impact for minimum input – this Project was cost-effective. We all need to share and work together – we have shown how this can be done. We made it real, people engaged with it and remembered it."* (Project team member)

It could be argued that this was a significant amount to spend with only a total of 39-60 people supported by MacIntyre who are diagnosed or suspected of dementia. However the Project developed a legacy of 32 eLearning modules (interactive sessions and eBooks) that can be used to train staff for years to come. All of the eBooks and films will also be made freely available to other organisations online.

MacIntyre did not budget for the costs of involving people supported by MacIntyre in the Project, yet this was key to its success. MacIntyre contributed additional funds to support an advisory group made up of people supported by MacIntyre and to hire two part-time Project assistants with a learning disability. Future programmes might benefit from budgeting for this type of involvement as it has added significant value.

The Project benefited from external help, such as from an expert in dementia who led some training sessions, wrote and reviewed some eLearning materials and attended meetings to provide advice. This support was important for quality assurance and ensuring the resources were up to date with good practice. Staff highly valued having access to such expertise at workshops. The Project did not initially budget to cover the level of involvement required of such experts and this is another learning point for other programmes.

Planned next steps

Funding from the Department of Health and Care ended in October 2018, but MacIntyre has embedded ongoing work so the legacy of the Project is sustained.

"The funding for the Dementia Project is finishing but I know our work in dementia and supporting those growing older definitely will not end. We are committed to continuing to build on very solid foundations developed." (Project team member)

MacIntyre Trustees have made a commitment to underwrite salaries for the Dementia Project team from charitable funds so the team will continue to provide training and support focused on health, wellbeing and dementia. MacIntyre is actively seeking grant funding for health and wellbeing related projects to support sustainability. Marketing via social media will continue and all ebooklets are being made freely available on the MacIntyre website. MacIntyre is in discussion with various organisations about hosting the e-modules so anyone can access them. The 'Keep Going' group will continue, though with less staff support.

MacIntyre is clear that there remains more work to be done.

"We have done a lot in this Project to raise awareness and provide training, but the skills are not a skill that once you have learnt, you know it all. To continue getting it right for the person supported, it takes constant reflection and each interaction needs careful consideration and a thoughtful approach to work for that person. Just like with the Dementia Project as a whole, an approach to supporting someone or championing a diagnosis might not work, but it is okay to change, to try new things, to take risks. All to benefit communication, interaction and supporting people to live a life that makes sense to them. There is more work to do and we are determined to build on that legacy." (Project team member)

MacIntyre is planning to work with Admiral Nurses to make a joint film or other resource. MacIntyre also plans to work with the Alzheimer's Society to consider how the people MacIntyre supports can be trained to be Dementia Champions and run Dementia Friends sessions. Many organisations have invited MacIntyre to run workshops, including a Dementia Friends session and dementia awareness raising training for Thames Valley Police.

The Project team are presenting at the Dementia Action Alliance conference in 2019. Dementia Action Alliance has changed its 'I' dementia statements to 'we' statements in response to working with MacIntyre and hearing that this was more aligned to the values of people with a learning disability. Easy read versions are being developed for release in 2019.

An important component of the Wellbeing for Life Toolkit is the seven-module end of life care theme. Awareness and support for end of life care was identified as a learning need for MacIntyre staff so being able to create these resources and run a roundtable training session about end of life care has helped to begin end of life care conversations within MacIntyre. MacIntyre wants to continue this work beyond the Dementia Project, to make the topic of death and dying accessible to people with learning disabilities, alongside providing staff with the information and support that they need.

Summary

MacIntyre's Dementia Project made good progress towards achieving the objectives of raising awareness of dementia, supporting processes for timely diagnosis and training staff to improve the quality of care. The Project had ambitious objectives and has delivered many more outputs than originally funded.

Some of the objectives have been more fully achieved than others, particularly around tangible changes to the quality of care. Considerable successes have amassed, including increasing the confidence of some people supported by MacIntyre, helping some staff feel less isolated when caring for someone with dementia and enhancing the reputation of the organisation amongst external partners. The Project has implemented new approaches to record keeping and advance care planning that have far wider implications than the Dementia Project, and will leave a legacy to support people with dementia and other conditions.

Whilst the knowledge and confidence of staff improved and there were reported changes to practice, this did not lead to improvements in the quality of care reported in people's care plans. However, improvement in practice takes time and may be unlikely to be evidenced within a short period. It requires changes in staff habits and behaviours. The Dementia Project appropriately focused on increasing staff knowledge and confidence, with the hope that there will be longer term impacts on practice and quality indicators, though more targeted work could have been done to address simple quality indicators such as recording life story work in care plans. A learning point was the value of setting people explicit actions and checking the extent to which they followed though.

Key to the success of the Project has been the involvement of people supported by MacIntyre, a strong core team with Director-level oversight, a focus on promoting the successes and learning from the Project widely, good use of external expertise, using a range of implementation approaches and good links with other organisations. The team learnt valuable lessons about project management and prioritisation, costing for the involvement of people supported by MacIntyre and keeping good records of successes and lessons throughout.

The Dementia Project has not only made a difference to the lives of the people MacIntyre supports and the staff supporting them, it has left a legacy so that other health and care organisations and families can continue to benefit. It has helped to show other organisations and policymakers that it is possible and desirable to involve people with a learning disability every step of the way and it has showcased the good practice espoused in the NICE 2018 guideline about care and support for people growing older with a learning disability. For a relatively modest investment, this Project has shown that culture change is possible and that learning disability and dementia should be considered in tandem.

"We are sowing the seeds for long-term change. We have raised awareness, we're supporting more timely diagnosis and we've run so much training. We might not see all the rewards immediately, but we have definitely made a difference to people's lives. We've proved that resources are feasible and useful, we've shown the wider sector the value of working side by side with people we support and we have put thinking about dementia in people with a learning disability on the map. Not a bad achievement in two years." (Senior stakeholder)

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