



Proud to Care

LGBT Dementia Project (June 2018 – July 2020)



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Introduction

There are over 850,000 people in the UK living with dementia. Dementia does not discriminate and although every person's experience of dementia is unique there can be additional challenges that are specific to people's sexual orientation or gender identity. People from the LGBT community often face barriers to accessing good health and social care support, and even when they are able to access care, it sometimes fails to meet their specific needs.

Funded by the **Life Changes Trust**, our LGBT Dementia Project was a 2-year capacity building initiative that delivered a number of interlinked activity strands aimed at increasing understanding of the issues faced by LGBT people affected by dementia, and helping to equip service providers to deliver inclusive services that better meet their needs.

LGBT Health works with a wide range of professionals to provide a strong, informed and credible voice for the interests of LGBT people. Since the delivery of our LGBT Age Capacity Building Project (2012-15), our capacity building work has continued to have a strong focus on older LGBT people.

Publications by the Alzheimer's Society, Age UK, National Dementia Action Alliance, as well as work undertaken by Alzheimer Scotland have also highlighted a growing interest in the experience of LGBT people affected by dementia and how we ensure services are well placed to respond in an informed, affirmative and culturally sensitive manner.

We thank them for their work to date which helped shape our initial learning.

The delivery of the Dementia Project was led by a full time Development Worker, with a second (part time) Development Worker, on secondment from Alzheimer Scotland, joining the project in year 2.

Aims of the project

The LGBT Dementia Project's key aims were to:

- Increase understanding of LGBT issues in relation to dementia, both in relation to LGBT people with dementia and LGBT carers
- Build the capacity of the dementia sector to respond to these issues
- Develop an LGBT and dementia toolkit.

A central aim of the project was to gain an understanding, in a Scottish context, of people's current experience, to enable us to support services to become more welcoming and inclusive to LGBT people with or affected by dementia.

LGBT people affected by dementia, are often not 'out' within dementia support services, and therefore often constitute a very invisible and overlooked group.

The project was guided by lived experience of those affected by dementia as well as by people working in the dementia sector. Both those perspectives were key to informing the development of the training, the toolkit and recommendations (call for action)

We wish to thank everyone who participated in this project for their useful insights and support.

Why is this project needed?

The needs of lesbian, gay, bisexual and transgender (LGBT) people living with dementia are often poorly recognised and researched due, in part, to assumptions that all older people are heterosexual, further compounded by the persistent ageist stereotypes that older people are asexual.

Older LGBT adults are however in fact significantly more likely to require support and reside in care homes as they are more likely to be single, live alone and not have children (for example, only a quarter of gay and bisexual men and half of lesbian and bisexual women have children, compared to 90% of heterosexual women and men).

Service providers do not always appreciate that LGBT people may rely more on their family of choice, or their wider social network, than their family of origin (their 'logical' rather than 'biological' family), yet recognition of this informal care network is likely to be crucial to providing holistic and person-centred care.

In relation to dementia, there is limited knowledge and understanding of how LGBT people are affected, due to the 'invisibility' of older LGBT people in dementia and carers services. LGBT people may find the culture of some services as not openly welcoming of their identity.

Mary's story

Mary lives alone in a small village and has had contact with a worker in dementia support services. She felt people in the village were quite judgemental and not very accepting of her sexuality. She felt embarrassed because she was older and worried about how her sexuality would be viewed.

Generally, her life experience had always been quite negative in relation to her sexuality. She stated that she didn't feel comfortable telling people she was gay for fear of being judged.

She was eventually referred to support services by someone she knew. She was happy to receive the help, but was very apprehensive, especially at first and commented to the worker she wouldn't have sought out support independently. She said that she feared she might encounter the same negative attitudes she had experienced before when asking for help.

Christine's story

Christine contacted a Dementia Services Worker in order to discuss her partner June who has dementia and is in a care home. Christine was 15 years younger than June, who was in her late 70's. They had known each other as close friends for many decades. June had been in what was described as a 'very unhappy marriage', until her husband died a few years ago.

Christine and June then started a relationship, but had kept this secret as they feared the reactions of their peers, family and in particular, June's adult children. Christine also feared being 'out' in her work where she held a high-profile position in social care. June's children lived a long distance from their mother, but held Power of Attorney for her. As June's dementia developed, Christine was her sole carer.

When June's condition worsened, Christine informed June's children about their relationship. June eventually had to move into care to have her needs met. Christine reported June's family were beginning to discourage her from visiting June in the home, they claimed her visits were 'upsetting' and 'tiring' for June, and were informing staff of this. Because June's children were biological family and held power of attorney, Christine's protestations were ignored. June's communication was poor and her decision-making capacity was being questioned as her cognition had deteriorated significantly. The children had put up pictures of June's husband around her room, which had been against June's previous (but unrecorded) wishes. They were also considering moving June to a care home nearer to them, which would effectively prevent Christine from visiting at all.

Christine felt she couldn't ask for help from local services as she feared doing so would 'out' her publicly. She also worried if she pushed too strongly back at the children, they would prevent her from seeing June indefinitely.

A number of individuals who engaged with the project relayed instances relevant to their close family or friends which were strikingly similar. They involved a person who in the past had been estranged from or shunned by biological family members - some for decades - because of their identities. The person was excluded from family life, told not to attend occasions or gatherings or not to bring their partner.

Many individuals engaging with the project reflected on this with some empathy for the person affected. Some of the situations improved in time with new generations coming through and gradual shifts in attitude, but not all. Many expressed a sense of sadness and loss for the time 'wasted' apart between family members. They reflected this was unnecessary and hurtful, but demonstrated the prevailing prejudice and discriminatory societal norms of the time.

We know that in Scotland today many LGBT people continue to face prejudice and discrimination and have poor experiences of healthcare. This inevitably means that for this group, the attitudes found in society, and within the healthcare provision, are a very significant barrier to help-seeking. In relation to dementia this can mean delays in getting a timely diagnosis and appropriate support, leading to more acute situations and poorer outcomes.

Practitioners working with, and supporting, the LGBT community also highlight specific health concerns within the community that must be taken into account, both in relation to carers and the cared for individual. The prejudice faced by LGBT individuals is likely to have a serious and ongoing detrimental impact on both their physical and mental health.

LGBT people are more likely to smoke, drink or to take drugs. Poorer mental health is widespread with higher levels of depression, anxiety, eating disorders, self-harm and suicide. Certain forms of cancer are more prevalent. A large proportion of those living with HIV are gay and bisexual men who are ageing and are now having to manage not only their existing medication but new medication as they get older and experience age related illness/conditions.

Transgender people who are taking hormones and have conditions that impact on their memory may forget to take their hormones, or may suddenly stop altogether, putting them at risk of serious health problems such as osteoporosis.

Therefore, with this background context we can see why greater cultural awareness is required to improve the understanding of the lived experience and needs of LGBT people. Without this understanding we cannot optimise culturally appropriate care for LGBT people, and ensure individuals are protected against disadvantage, discrimination, harassment and victimisation on the grounds of their sexual orientation and/or gender identity.

Jean's story

Jean is 78 and is a lesbian. She lives alone and has no children or a partner. She is reasonably isolated geographically but goes along to an LGBT meet up when she can. She is sure she has dementia but is struggling to get support or a diagnosis. She has been struggling for a few months now trying to get the help she wants. She says she doesn't always understand or remember what is happening at the doctor – what they have said and what tests they have done. Jean was asked to bring someone with her to her next doctor's appointment who she sees every day and who would be able to speak to changes in her behaviour. Jean doesn't feel she has anyone like this.

Jean hasn't told many people within LGBTQIA services about her memory worries because it is upsetting to think about and doesn't want people to think of her differently.

The work of the project



People involved in the project

6 people with dementia

6 carers



Open call training

3 sessions in Edinburgh, Dingwall and Dundee

39 workers attending

23 organisations



Bespoke training

9 organisations trained

151 people attending

The project initially sought to connect with people who had or were affected by dementia. Whilst we did connect with people this was a challenge in itself as many of these people are not 'out' in services so our reach to them was limited. However, the project managed to engage with 6 LGBT people with dementia, as well as with 6 LGBT carers. Their involvement proved crucial in informing the project's focus and development.

When discussing LGBT issues with organisations we often heard the "we don't have any LGBT people using our services". With 5-7% of the population identifying as LGBT this is unlikely however it perhaps goes some way to highlight the considerable challenges around barriers to accessing services and the invisibility of this minority within services.

However, encouragingly, we found that there was a great deal of willingness from many working in the care sector to discuss the issues. The project was able to engage with a wide range of services that were enthusiastic to champion LGBT inclusion and rights.

It was also important that we engaged in a debate that "treating everyone the same" was not a way to tackle inclusion and this may continue to maintain invisibility. We emphasised the need to make positive change by celebrating diversity and embracing difference. By taking this approach we were also able to link this work to how services uphold and demonstrate their commitment to implementing the values contained with the health and social care standards.

Given the difficulties we encountered engaging with LGBT people affected by dementia through other care providers, we also focussed some of our attention on the work of our own LGBT Age project (working with people 50+), as a route to engage LGBT community members in discussions around dementia and caring. There was considerable interest in this and people spoke of their fears for the future, even if this was not a live issue for them at present.

Community discussions

The project hosted 2 community discussions. The purpose of these were to bring people from the LGBT community together to share their experiences. These discussions were crucial in enabling us to understand the current experiences of community members, and some of their fears, hopes and aspirations in terms of what good and inclusive practice from service providers would look like.

The community discussions (held in Glasgow and Edinburgh) also benefitted from the contributions from a range of organisations:



Key discussion points from the community discussions included:



- The invisibility of LGBT people affected by dementia. Services are often not asking people with dementia the “right” questions to uncover this. Need for active discussions to take place when people start receiving support. We can’t expect LGBT people to be 100% open straight away. We need to give space for people to decide for themselves what they want to tell service providers, but crucial for services to create an open and accepting atmosphere.
- It’s good to let people decide for themselves what language they want to use - ensure people are not under pressure to provide a label that suits other people.
- People spoke about their anxiety and distress about coming out to services. One of the ways that we can demonstrate that our services are inclusive environments is to start having a more active voice on LGBT issues. For example, Alzheimer’s Scotland participated in the first Highlands and Islands Pride event and have a LGBT Champions Network.

- The presumption of the nuclear family unity, where people with dementia are presumed to have children or partners to provide care, which acts to invalidate and make invisible the lives and experiences of LGBT people.
- People facing multiple stigma – sexuality / gender identity, diagnosis of dementia and age.
- LGBT people feeling excluded from dementia groups.
- The importance of using inclusive language – this can be the difference between someone being out or not being out.
- People not knowing how to, or wanting to, make official complaints – how do we know if people are not getting a good service.
- That it isn't enough to put signalling measures in place (such as rainbow lanyards or rainbow flags) without ensuring you have policies and procedures to back this up. Staff need to know how to respond to any incidents of prejudice and discrimination that may arise between people you are supporting if you are making diversity a talking point.
- Common narratives around dementia might not fit the lives of many LGBT people. For example, an LGBT person may be caring for someone with dementia who is not supportive of their LGBT identity. LGBT people may have caring responsibilities in their family of choice as well as their family of origin, creating greater strains on their time, resources and wellbeing.



“Most complaints are only recorded if people use the official complaints process. Lots of people might not feel confident enough to use these processes. Complaints should be considered anytime someone says **‘I am not happy about this’ or ‘this doesn’t work for me.’**”

“I got a lot of info that will be helpful to me... tonight was so well organised and very positive... moving forward there will be changes that will improve the lives of LGBT people with dementia that was clear after listening to the folk who represented the organisations there.”



Community discussions reports

- **Forget Us Not:** <https://www.lgbthealth.org.uk/resource/forget-us-not-community-discussion>
- **Over the Rainbow:** <https://www.lgbthealth.org.uk/resource/over-the-rainbow-community-discussion>

Awareness training

The delivery of awareness raising training was a key element of the project. The training developed and evolved over the lifespan of the project, informed by the personal stories of the LGBT people affected by dementia that we engaged with, as well as by our work with service providers. Importantly, the delivery of the training enabled us to engage with a range of staff working directly with people with dementia and/or carers.

Very frequently, staff expressed some initial confusion or scepticism about the subject matter – why was this relevant for their service? Common barriers articulated by professionals and managers included time pressures, lack of training opportunities and funding more generally.

Within the training we highlighted some basic facts about LGBT history, to place learning in a wider social and historical context. This is particularly relevant given the likely age of the majority of the LGBT people affected by dementia, and the significant social and legal changes they will have experienced over the course of their lives. This contextualising of the LGBT experience proved crucial in promoting greater understanding, and was well received by attendees.

Our positive and enabling approach to the training, rather than a pointing out where practice is wrong, was well received and was repeatedly commented on as being particularly helpful in the feedback we received. Creating a 'safe' learning environment was vital as it allowed people to ask questions they may have been worried to ask in other environments; this helped challenge taboos and encouraged open discussion and debate. However, we were also clear about the requirement for respect for others, which at times did require careful facilitations by our trainers.

Lots of training attendees were generous in sharing their own family and work 'stories' relating to the training content, which has been invaluable for others in terms of peer learning. It has been very encouraging that attendees have felt able to do so, so frequently. This noticeably occurred in every training session we delivered.

As mentioned, in our experience, before the training the vast majority of attendees wondered if the training was relevant for them, their service and their practice.



“I think the session really clearly and compellingly summed the whole issue up for me. It put across the problems, the fears there are for LGBT people, and the fact that I don't think most service providers have even thought about this before.”

“Today has really made me think differently about the LGBT issues. I'm going to make contact with my local LGBT group, let them know about my service and vice versa.”

“I hadn't appreciated some of the fears people had about using services and how they felt they would be treated. This was highlighted even more with some of the personal discussions during the session.”

“Chance to talk about complicated, emotional subject matter in safe controlled environment.”



However, after the training we were struck by how many participants not only seem to ‘get’ the relevance for their service, but were also considerably more confident, enthused and motivated to consider the need to make changes, and understood why these might be important and necessary. In fact, during the training sessions, many attendees quickly begun to suggest possible practical ways their organisation could improve their inclusivity.

There was a lot of interest in clarification of terminology. Trepidation prior to training about ‘saying or doing the wrong thing’ and offending people unintentionally or ‘getting into trouble’ in this way in the work place. Most people who admitted to this initial trepidation, remarked that the training had helped them overcome these fears. In essence, the training content and discussions seemed to open the way for conversation and helped break down barriers to asking questions. This seemed often to lead attendees to begin discussing ways they could turn their learning into practical improvements in their workplace.

Training also allowed for discussion and sharing of positive examples of good practice. Attendees focussed on what they felt they could work on and change. We acknowledged the importance of making it seem possible and achievable to translate new learning into practice. Particularly given the considerable pressure the dementia and care sectors are already under. We therefore wanted to stress this was not so much an additional ‘ask’, as something that could easily be connected to existing work that providers do to demonstrate their practice and person-centred approach, such as by linking inclusion work to the Health and Social Care Standards.

It was a particular achievement to deliver one of the ‘open call’ training events in Dingwall. The Scottish Highlands are an often-underserved community in terms of learning and development opportunities, and running a training event here gave us the opportunity to hear from practitioners operating in a rural context, and to explore what LGBT needs might look like in this context. Participants came from organisations including The Red Cross, Alzheimer Scotland, local care homes, dementia groups and Eden Court Theatre Company. Some participants highlighted that they felt attitudes towards LGBT people were still particularly negative, and for that reason many people might move away or remain closeted. This would also create isolation for the LGBT people who were out/living in the area.

Alongside ‘open call’ training sessions, we also delivered bespoke training to staff at Hillcrest Futures. Those present were responsible for front line care and support of people with high level complex needs including dementia.

“It’s a really important topic to all of us as everyone will be touched by dementia at some point in our lives, even if indirectly by knowing someone who has it. So I think it’s such a relevant training topic that will only increase in relevance. In particular, I felt that this training was really great at highlighting the stigma and particular challenges associated with living with dementia and being LGBT. I have known straight people with dementia and they were all cared for by family members. I know this wouldn’t be possible for many LGBT people.”

“Really interesting topic -was quite new to consider for me and it was presented really clearly and compellingly.”

“I’ve been on different training before, but I kind of didn’t feel like I could ask questions...and get it wrong (laughs) like I could today... it was really interesting.”

The experiences of carers

Within the LGBT community, men and non-binary people are as likely as women to provide informal care. Many of the issues experienced by carers within the non-LGBT community will be shared by LGBT carers such as the need for information, recognition and support. However, LGBT carers often also experience a number of additional concerns that are specific to them.

Drawing on personal experience and testimony provided by LGBT carers, these can include:



- LGBT carers might worry they will not be recognised and supported as a carer by practitioners or family members of the person that they care for
- LGBT people are often more likely to be estranged from their family of origin and therefore have less family support when they take on caring roles
- LGBT people may not be 'out' to the people they are caring for, which can cause considerable stress and mean they cannot necessarily rely on their chosen family or partner for support with their caring role
- LGBT people may also be caring for people who are unsupportive of their LGBT identity and as a result regularly experience discrimination at very close quarters. For example, this might include misgendering someone, or not acknowledging their partner
- LGBT carers are more likely to experience poorer mental health due to a range of factors and when combined with a caring role, this can mean they are disproportionately in need of support to ensure their mental wellbeing
- Older LGBT people also highlight that as they are more likely to be single and childless, assumptions are made they therefore have more time and capacity to take on a caring role.

During the training, many of these common narratives around caring for LGBT people were also discussed.

Ben's story

Ben is caring for his dad who has dementia. He is not out to his family – and says he never will be. His mum also cares for his father but he is becoming more aggressive and he worries about leaving his mum alone. He says it is assumed he has lots of time to care for his father because he doesn't have children or a partner.

Engaging with the community at Pride

Throughout the life of the project we sought to engage with community members who were already in contact with our LGBT Age Project. A number of joint events were delivered by way of introducing the project to people that might be directly involved or who knew people that were affected.

In addition, we saw the annual Pride events as a way of making contact with community members that we were not already connected with. At both Edinburgh and Glasgow Pride events we started a dialogue with people around dementia and caring. At our Edinburgh Pride stall we asked people to participate in an exercise that looked at what might worry them about dementia, if they had experiences of using services what were they like, and what they thought LGBT carers needed.

From the many comments we received on the day we created a zine of quotes to highlight the topic of dementia in the LGBT community. In partnership with Alzheimer Scotland and the National Dementia Working Group (Alzheimer Scotland's involvement group for people with dementia) we disseminated these along with information about dementia and the Dementia Working Group. As a result, a gay man who is caring for his partner with dementia contacted the Working Group directly and they are looking to join the group.



We also produced a '[Guide to Pride](#)' for people working in the sector who want to engage with Pride events across Scotland in 2019.

Work with organisations



Playlist for Life is a Scottish charity, founded in 2013, working towards everyone with dementia having a unique, personal playlist and everyone who loves or cares for them to know how to use it. Building a personal playlist means exploring someone's life story to gather the tunes that are most deeply attached to memories and emotions.

After working in partnership with us to deliver a 'Music and Memories' event held as part of LGBT History Month, staff at Playlist for Life fed back that they had noticed some areas for development in their work. Often the questions used to reflect on past experiences in training are very heteronormative and include things such as - have you ever been married? Do you have children?

As a result, they thought it was important to open up how they talk about identity in their training sessions, and how to facilitate this in a more inclusive way. For example, this includes changing their guidance to be more general about exploring people's pasts and identities to ensure that trainers do not fall into heteronormative assumptions.

We worked with Playlists to develop a LGBT Playlist of the music from the event which will be available on their website (as per of their identity series on Spotify). The Playlist includes songs that were shared by people attending the event and it was promoted by both organisations.



MECOPP is an organisation that support black and minority ethnic carers to access supports and services appropriate to their caring situation. They support service providers, both statutory and voluntary, in the development of culturally competent services.

We worked with MECOPP to produce a briefing paper to explore the needs and experiences of LGBT people with caring responsibilities. The briefing is aimed at anyone who is part of a community of carers, or who works with people who are caring for others.

The '[Informal caring within the LGBT community](#)' briefing is available online.



During the life of the project we have met with representatives from the Care Inspectorate to hear about their work on LGBT inclusion, and to explore how we can work together now and in the future. Representatives also joined the project steering group, participated in a community discussion and attended awareness raising training.

“We believe that everyone has the right to feel included and have a sense of belonging. We recognise there is definitely a willingness within services to promote people’s rights, and we see the very positive progress made by staff working all across social care to make sure that being part of the LGBT community is not a barrier to experiencing the best possible care and support. We also recognise that there is often still limited understanding of the lived experience and needs of LGBT people, which can make it difficult for services to always provide culturally appropriate and inclusive care. This is especially true in relation to LGBT people affected by dementia. We have therefore welcomed the focus the LGBT Dementia Project has brought on these issues, and the way it has stimulated conversations about Equality, Diversity and Inclusion with a view to increasing understanding and, ultimately, ensuring services can more often provide a more positive experience in care for LGBT people with dementia. There is still more to be done, and the Care Inspectorate will continue to promote the rights of all people, everyone matters, everyone counts.”

Peter Macleod, Chief Executive



The service supports people with dementia in the Stirling area to stay connected to their communities by offering a range of support services.

Two of their Dementia Development Workers attended our community discussion. Following this they reviewed some of their practice, with a view to ensuring that it was inclusive. This included reviewing their equality monitoring forms to ensure that these included open questions about gender identity and sexual orientation.

In addition, the staff and volunteer team also participated in awareness raising training. The training helped people feel more confident in having conversations around gender identity and sexual orientation. The “fear of offending” often results in a lack of open dialogue, which in turns compounds the invisibility of LGBT people. Feeling equipped to discuss identity and record this can help promote overall inclusion and person-centred practice.



On Bi Visibility day, we delivered a joint campaign with TIDE exploring the specific needs and experiences of bisexual people caring for someone with dementia. Bisexual carers highlight the prevalence and impact of assumptions made about their identity in the context of care and often report feeling invisible.

For example, if they are caring for a partner of a different gender they are assumed to be straight and similarly, if they are caring for a partner of the same gender, it is assumed that they are gay.

[Blog written by David Ward for LGBT History Month 2018](#)

The campaign with TIDE focused on challenging assumptions which are generally made and identifying easy steps that people can take to be more inclusive of the needs of bisexual carers. As a result of the campaign one openly bisexual carer has joined the TIDE network.

Participation in one of our training sessions, led to the TIDE 'Pride and Shame' blog to coincide with Pride 2019, looking at issues of intersectionality and inclusivity.



Alzheimer Scotland's 24-hour Dementia Helpline supports thousands of people with dementia and carers. The helpline is often the first-place people turn to for information and support. It is staffed by trained volunteers, many with personal or professional experience of caring for people with dementia.

We delivered an LGBT awareness session to the Dementia Helpline staff and volunteers. We also hosted a stall at Alzheimer Scotland's Staff and Volunteer Conference, which provided a good opportunity to engage directly with people delivering front line services. We were able to share and hear more anecdotal evidence of the need for the LGBT Dementia Project and the impact of our work.

Development of the toolkit

To ensure the resources developed as part of the project were as relevant, useful and practical as possible, it was crucial for the project team to gather intelligence from a number of sources to help inform their development. Input from members of the LGBT community was vital, as was information and feedback from dementia service professionals, front line service delivery staff and volunteers, as well as learning from carers and people with dementia.

Information was gathered in a number of different ways. Existing research and literature were examined in the early stages of the project. The community discussions helped feed into our overall project knowledge base. In particular, this helped build a picture of lived experience in the current Scottish context, what 'best practice' in dementia support services might look like for community members and why.

In November 2019 a steering group was set up to support the development of the toolkit. Involvement in this group included representatives from:



Drafts of the toolkit were disseminated to key professionals for feedback. Meetings with key professionals from the private, public and charitable sectors also took place to discuss the project, to learn more about the context of their work, the challenges they face and to help identify the opportunities for enhancing LGBT inclusion in their work. Feedback was also sought on core documents, for example through Scotland wide contacts held by bodies such as Scottish Care.

Training attendees were asked for anonymised feedback via survey monkey, which asked participants to evaluate the training, but also how they might implement the learning. This feedback, alongside our many discussions with both front-line staff and volunteers, as well as managers, provided concrete pointers, in a range of different contexts and services, to changes that would feel achievable.

“Thank you so much for such an interesting and engaging talk last week. It was one of the most thought provoking things I have attended. The verbal feedback has been really positive and several people have asked if this is something you would do again **here.”**

Real life anonymised 'case studies' were gathered throughout and these were an essential component in understanding some of the scenarios which staff regularly encountered and sought advice on dealing with. The project team also attended conferences and gave talks to enhance dementia care and support organisations engagement with the project, and to encourage inclusive practice.

The fears, hopes, preconceptions, knowledge and training needs of staff were noted throughout the training process, from the development of the programme to evaluation and future planning.

A similar approach was used in the development of the toolkit, which evolved as we learnt from our conversations with people, and reflected on the issues that were raised as part of the training.

To ensure the content of the toolkit was easily understood, user friendly, fit for purpose and would stimulate work towards project aims, we sought to ask relevant organisations involved in dementia support to try out the toolkit and provide feedback to the project team. The intelligence gathered through the piloting of the toolkit was fed into the planning, fine tuning and designing of the materials produced as part of the project. It was hoped this would allow deep, meaningful user insights to help shape the toolkit.

Senior staff from **Hillcrest Futures** of Dundee and Angus, (formerly Gowrie Care), had shown interest in the project at a very early stage. Hence, they were the first organisation to become formally involved in working closely with our project team to start piloting the toolkit.

“We have really enjoyed working on the project with you.... and we have learnt so much too and have identified changes we can make to become more inclusive, I was really pleased when I called HR and they were already looking into this from their angle, so I will hopefully be working with them on this ...”

It is important to consider that dementia services cover a really broad spectrum, from diagnosis and early stage support, right through to the later stages of more advanced dementia. Services focus on providing information, one to one support, peer support, day services, supported housing and care homes. There are also a wide range of care providers, from health care and social care, to private and charitable organisations.

We therefore felt it would be advantageous to try to share the draft toolkit with a range of organisations, and approached a number of organisations that had undertaken awareness raising training and had expressed a keenness to eventually use the toolkit.

**Cluny Lodge
Care Home**



**Alzheimer
Scotland
Helpline**



**Queens Manor
Care Home**



The toolkit is aimed at helping providers take stock of their current practice and explore ways that this can be enhanced. It does not set out to provide a definitive checklist of everything that needs to be in place to ensure inclusive practice, but provides a starting point to engage, inspire and support. It includes a self-audit element that is directly linked to the health and social care standards in Scotland. It guides practitioners through 15 points of good practice and 16 points of best practice for including LGBT people in services. It offers space to reflect on what providers are doing well, and to identify achievable changes and steps for improving services.

The toolkit can be found at <https://www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit>

Recommendations: a call to action

The recommendations outlined here are based on all the capacity building work carried out over the lifespan of the project. These recommendations have been shaped by community members, training participants and a wide range of organisations and stakeholders.

The project has undoubtedly made really positive strides in putting a spotlight on the need for more inclusive practice. But much work remains to be done.

Our work with community members and those working in the care sector has continued to build momentum over the life of the project and has started to generate a rich dialogue around how services can better meet the needs of the LGBT community.

'Proud to Care', the title of this report, reflects the positive engagements we have had with service providers. It is clear many people care about the issues raised by the project, and care providers can be proud of caring about these issues and of working towards LGBT inclusion.

The toolkit, and these key recommendations, offer a concrete roadmap for care providers to continue to implement positive changes.

Our work on this project has told us that in order for services to be LGBT inclusive, providers should:

- Ensure that staff are informed about LGBT issues, feel able to discuss these openly and are equipped to provide culturally appropriate care and support
- Make sure LGBT people are visibly and pro-actively welcomed into services
- Ensure that LGBT people know their confidentiality will be respected
- Have in place workforce development training, which challenges assumptions and increases awareness
- Create a safe space and address issues of prejudice and discrimination, including from others using their services
- Have policies and practices in place that support LGBT inclusive practice
- Support the development of an LGBT 'champions' scheme to support visibility and buy in for inclusive practice across the board
- Share and celebrate models of good practice!

LGBT Dementia Toolkit: <https://www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit>



This project was delivered by Megan Johnston and Faye Smart

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