DEEP Scotland Meeting Tuesday 25th January 2022

Eric Liddle Centre, Edinburgh

Notes by Graham Galloway

11.00 – Introductions

Rachel went over some housekeeping and ground rules for the day, then the group introduced one another to themselves, including revealing their favourite way to eat a cream egg (sooking definitely won). Gerry then started the session proper with the aims of the day to share, learn and support one another.

11.25 – Martin Robertson notes on Meetings with Scottish Government

Martin Robertson, member of both the Alumni and Ecredibles, spoke about a couple of Scottish Government meetings he had recently attended. The first was a key stakeholder meeting for the development of the National Care Service. While there were people with lived experience of other conditions there, Martin was the only person living with dementia in attendance. Martin raised the important point about access to SDS not even being standardised across a local authority, never mind nationally.

The second meeting was of the Dementia Policy Unit's Covid Recovery Sub-group. This was the first meeting people living with dementia had been invited to attend, and on the agenda, it was also billed as the last meeting of this short life group. Martin was understandably angry about this apparently tokenistic involvement of people with lived experience. He also expressed his frustration about being refused an invite to a meeting on the 19th January with Kevin Stewart, the Minister for Social Care. Please see these notes for Martin's account of these two meetings.

MEETINGS WITH SCOTTISH GOVT.

10/01/22

This was regarding the design of the National Care Service. I wormed my way in, but now represent the Alumni. Age Scotland sent an executive member. There were plenty of disabled and carers there, not just me, however I was the only one with dementia. There was a briefing about Co design and then Q's and A's.

Most of these were how could this Care Service work when there are so many cash issues in the here and now.

I raised the point that if, even within the same Local Authority; 5 miles apart, SDS had different rules due to different Care Managers how could it be standardised nationally. The answer was a culture change would be needed.

17/01/22

This was the last meeting of the Post COVID Recovery Group, but the first that independent individuals had been invited to. The SDWG have been there since it's inception. I am afraid that I got quite angry at this, not helped by the fact that there was a meeting arranged with the Minister on the 19th, I asked if I could attend. The initial answer was "no" as I was not representative of people with dementia. The Civil Servant was suitably embarrassed when I pointed out nor were the SDWG. She then said it was too late.

There was much talk of including independent voices in the future. We are awaiting Minutes of the meeting with the Minister and figures showing numbers with dementia in each Partnership. I pointed out that it took me about half an hour to collate this on my own.

Both Willy and Adam were there so they might have different views.

11.35 – Share, Learn and Support

Everyone attending was invited to describe the project they were involved in, the work they carry out, where they are funded from, and their hopes and aspirations for the future.

About Dementia – Maxine

About Dementia is Scotland's dementia policy & practice forum. They have 5 years funding from the Life Changes Trust as one of the trust's national legacy partners. Hosted under Age Scotland, About Dementia has initially focused on 15 different subgroups, including housing, transport and human rights. They have also identified several broad themes that sit across these groups. About Dementia work with people living with dementia on consultations and policy drop-ins. Looking into the future Maxine spoke about some of the exciting plans they have on the horizon, including new funding for Dementia Friendly Communities and Meeting Centres; human rights groups; a film addressing the

stigma that still surrounds dementia; and storytelling resources to ensure people with later stage dementia can have their voices heard too.

Martin questioned the involvement of people living with dementia in government meetings, saying “Why can’t we be at every meeting?”. Maxine agreed to take this point back to Dr Kainde Manji, the manager of About Dementia. Mike then stood up for the level of engagement he had experienced with About Dementia, saying “They are very positive in many ways”.

STAND – Irene & Willy

STAND is a peer support group based across Fife. They formed 3 years ago with support from Dementia Friendly Fife manager, Ruth McCabe and Gerry. They are involved in a wide variety of projects across fife, working with the community and schools, and are very much driving the local dementia policy within Fife. They have worked with the Life Changes Trust supporting the learning network of the trust’s small grant programme.

In September 2021 STAND were involved in running the 100-6000 conference, the first ever conference that was run by and for people living with dementia. They are also currently involved in the development of Meeting Centres across Fife. They have now run two in person sessions of their “Good Life with Dementia” course, a programme developed by STAND members with Innovations in Dementia, aimed at people who are newly diagnosed and/or have had no or little support since diagnosis.

Irene spoke about the strength of the group coming from the peer support, and that even though it has originally been set up as a group for people with early onset dementia, there were now satellite groups for “all ages and stages of dementia”. The group is involved in policy development at both a local authority and national level, and they try to represent everybody.

Martin questioned about whether the group was able to criticise the local authority, as Ruth was a council employee. Ruth replied that she had worked with people living with dementia for years and had never had an issue with criticising the local authority. “Being a council employee doesn’t stop me saying what need to be said”.

Willy spoke about the impact STAND had had on him. After being diagnosed during lockdown he found that there was little support for people at his stage

of dementia in Edinburgh. The support he then received from STAND and Capital Theatres was liberating. “Here are people who just understood”. Highlighting again the importance of peer support he said “STAND has changed my life”.

ECRED – Rose, Agnes & Yixuan

Rose introduced ECRED, which stands for Edinburgh Centre for Research on the Experience of Dementia. ECRED is Edinburgh University’s dementia research group that includes people living with dementia, researchers, charities and wide variety of other stakeholders.

Agnes spoke about being involved with the group since it’s inception, and explained how it had come about as a new idea for people living with dementia to work alongside Edinburgh University. Agnes spoke about how the physical environment of the university was not very dementia friendly. She spoke about perceiving with the group over 7 years, and that progress was being made “from little acorns” she said she was excited about the future of the group.

Yixuan introduced herself as a new member of the group. A PhD student at Edinburgh she has been part of ECRED for 3 months. She spoke about ECRED being a centre for research where the main strategy is coproduction with people with lived experience of dementia. She also mentioned the importance of the monthly informal meetings the group hold.

Ecredibles – Martin, Agnes & Paula

The Ecridibles are a sister group od ECRED which as formed as peer support for researchers living with dementia. Martin spoke about how the group was easily accessible and how it was made possible to engage at a level that you are comfortable with. Rosie Ashworth’s support for the group was mentioned by several people “she keeps us going”.

Agnes made the important point that people with dementia don’t lose their skills at diagnosis. They can still use their skills when they are properly supported. Paula’s support for the group was also mentioned “the woman who makes it happen!”. Paula herself stated that the Ecredibles belong to everyone, and they are about upskilling everyone involved. They were “putting people with dementia in the driving seat”.

The Alumni – Agnes & Martin

Agnes spoke about how the Alumni formed after a period of trauma, where some of the longest serving dementia activists felt they were being side-lined by the newly diagnosed. The group spent 18 months discussing how they wanted to move forward, and they have gone on to produce several booklets. These have included “How to Access your GP” and “Planning for the unexpected” Martin spoke about how he had joined as he had a desire and a drive to get involved in research.

Agnes mentioned the importance of the support she had had over the years from her mentor, James McKillop. She also mentioned a new game for children the Alumni were developing which would be fun, informative and educational. Agnes also mentioned that after years leading the way Scotland was sliding backwards in dementia support. “We need to pull our socks up! Nothing about us, without us!”

Kirrie Connections – Graham & Bob

Graham explained how Kirrie Connections had originally been funded as part of the first cohort of dementia friendly communities funded by the Life Changes Trust in 2015. He spoke about how important the culture of sharing and collaboration that had been nurtured by the Life Changes Trust had been both for Kirrie Connections and many of the other groups in the room.

Since 2018 the primary focus of Kirrie Connections has been the Meeting Centre model of social community support for people with dementia. This evidence-based model had originally started in the Netherlands, and Kirrie Connections have been working with Worcester University’s Association of Dementia Studies to develop the model in Scotland. Meeting Centre’s are effectively social clubs, where people living with dementia and their family carers can be helped to adjust to the changes that come with a diagnosis of dementia. Kirrie Connections operate from a community hub building in Kirriemuir where they offer support 5 days a week, with a range of activities including music, art, sports, games as well as Cognitive Stimulation Therapy.

Robert spoke about his involvement with Kirrie Connections. He was originally refereed to them by his post diagnostic nurse. After an initial meeting with Graham, Robert decided that he would like to volunteer at the hub. This eventually led to Robert being offered a seat on the Kirrie Connections board of trustees. “I’ve found it to be invigorating. It means a lot to me”.

Graham then went on to speak about the strategic development of Meeting Centres in Scotland. The Life Changes Trust final Legacy Fund for Post Diagnostic Support featured three pillars, Dementia Friendly Communities, Peer Support and Meeting Centres. The trust had also funded Graham to carry out some strategic work to develop Meeting Centres across Scotland. Because of this we are hopefully looking at 14 fully funded Meeting Centres across Scotland by the middle of 2022.

Finally, Graham spoke about the lived experience event Kirrie Connections had hosted in person in December 2021. This event had been inspired by discussion with Martin during sessions of the Scottish Meeting Centre Working Group, and also by the energy created by the 100-6000 conference in September 2021. Representatives from Worcester University, About Dementia, the Life Changes Trust and 10 people living with dementia (including many who are in the room here today) came together to discuss how we meaningfully embed people with lived experience in the development of Meeting Centres on both a national, regional and local level.

Several outcomes were committed to at the event, principal of which was to adopt the strategy of "a third, a third, a third" i.e., a 3 way split between those living with dementia, those representing care partner perspectives and those representing dementia care professionals. The plan is to establish this aspiration within the National Meeting Centre Consortium, with a clear message that this is what we would expect on regional groups and advisory groups to Meeting Centres.

The Beacon Club – Nancy

Nancy told us about The Beacon Club day care service, which has been running in Edinburgh for over 30 years. The club is opened 4 days a week and supports 40 people living with dementia. They also offer befriending services and carers support. "We just aim to give people a great day out and for carers to have a day off".

Nancy highlighted how difficult lockdown had been for people living with dementia, and the very high levels of stress they have seen amongst cares. "Carers are on their knees". She was also concerned about the lack of support there often was for people at the later stage of their dementias, and how it was very important that their voices were heard too.

Regarding funding Nancy highlighted the precarious situation many third sector organisations often find themselves in. She felt that youth services often found it much easier to access funding, with older people's services having a much harder time.

Looking into the future, Nancy hoped that The Beacon Club could offer more choice to their members. There must be a range of choices available, with a strong focus on fun and relaxation.

Ceartas- Michelle

Ceartas is an independent advocacy service based in East Dunbartonshire. They run the Dementia Voices group, an advocacy group for people living with dementia. Their model is to support people with dementia to live well, ensure they can access the services they are entitled too and have their voices heard. The project was set up with funding from the Life Changes Trust.

Michelle spoke about how the group didn't meet during lockdown as video calling simply didn't work for many of their members. Instead, she developed a regular newsletter which became hugely popular. "It went from 2 pages to 40!".

Her hopes for the future were to make more connections, with both organisations and individuals. "It's easier when you have a relationship and know people's strengths". Michelle spoke about the difficulties of lone working, and that it could get lonely at times, so it was great to be at an event with such support. She also mentioned how much support she had got from the people living with dementia that she worked with.

BOLD – Magdalena

BOLD stands for "Bringing out leaders in dementia". BOLD is a social leadership programme for people living with dementia, carers of people with dementia, artists and professionals. The programme is a collaborative project between Edinburgh and Queen Margaret Universities and is one of the Life Changes Trust's national legacy partners, along with About Dementia. Although currently a project, BOLD is considering setting up as an independent organisation.

BOLD is based on the theories of Julian Stodd, whose work envisages a society where everyone can flourish. BOLD is firmly based on using creativity as a

method to amplify the changes people are creating. Connecting people through stories, art and creation and nurturing a sharing culture of support.

As well as the training programme, BOLD is also developing several other initiatives. These include the BOLD mini-commissions small grant scheme, which is open to anyone who has completed the training and has a creative idea they would like to develop, and the BOLD Sparks residential programme to help develop new BOLD facilitators. They also have a website, which has both public facing pages and a community website for people who have completed the course. The community page is both a source of varied and interesting resources, and a portal where BOLD members can collaborate and share their work.

Capital Theatres – Alex

The Capital Theatres dementia project was also initially funded by the Life Changes Trust. Starting with a relaxed performances the theatre then looked at making the building itself dementia friendly, by looking at signage and training front of house staff. Alex commended the work done by Karen Richardson and Paul Hudson in the theatre but said that when current manager Dawn Irvine came on the scheme she was “unstoppable!”.

The work Dawn had carried out during lockdown was particularly singled out, with highlights being their livestreamed “tea parties” with the forget-me-not choir, and the “Where the sun meets the sky” production with Traverse Theatre which had its plot shaped by people with dementia.

Alex mentioned that the Life Change Trust funding was coming to an end, but that fortunately they had a new CEO who was completely behind the dementia arts programme. There are plans to not just continue the existing work, but to grow it, with the development of the King’s Theatre into a dementia friendly community hub being particularly exciting.

There were several supporting comments about the amazing work Dawn and her team have been carrying out. Maxine said “fabulous work from the festival theatre!” and she spoke about greet experiences with them in a previous position. Willy highlighted that there is a Radio Scotland program on the iPlayer about his involvement with the theatre. And Nancy spoke about taking groups to the relaxed performances and said they are “doing an amazing job!”. Finally Agnes spoke about the work Edward McLaughlin was very important in

the field of art and dementia, and reminded us not to forget those who had put a lot of important work in the past.

Afternoon session:

Cross-pollination – discussions. (notes by Michael Cheung)

1: How Scotland groups and initiatives can stay connected (cross-organisations) for sharing, learning and support on an ongoing basis.

(Consider the rural challenge and large geographical spread)

- Willy remarked that there are too many Zoom calls discussing the SAME things and MANY people are not being reached.
- Martin said there should be a central person with dementia employed 3/5 hours a week to pull things together.
- Graham said About Dementia has all the initiatives. A working group, doing what Martin is saying, has evolved from the 100/6000 Conference to Meeting Centres idea. Had first meeting with SDWG. Kirrie Connections are forging links with STAND. Graham surprised that LCT were not at this meeting
- Nancy said she felt it was important that smaller organisations were there and involved.
- Agnes says that government need to listen and that when lived experience is involved in these meetings there is a bigger impact.
- Mike said it is too much for one person to coordinate from one organisation to another organisation.
- Maxine says that About Dementia DO listen and want to find a way forward in ensuring the voices of people living with dementia are present and heard.
- Martin says he wants lived experience people to be <u>more</u> involved

2: How can we ensure voices of people living with dementia are united and amplified in Scotland? And how can we ensure we are united in our conversations with Scottish Government? (notes by Irene)

- Maxine – helping to amplify the smaller/fewer known voices.
- We aren't entirely united in our needs. We have a multiple voices. We should be united in one fact – it's **Our** voices to be heard.
- Issues around trying to access 'ordinary' services for issues like travel insurance.

- Actually listen to our carers (young and old). There are still examples of undemocratic practice.
- Agnes says: There are strong voices in leaders – all different – and conflict is inevitable. People are strong/passionate. We need to create safe spaces where ALL voices and aspects are heard and respected.
- Gerry says: Living with dementia we do need the support of folk to help get the best of us. We wouldn't be anything without the support from you. From a national umbrella group smaller organisations and groups can contribute and be a part of this
- Martin says that organisations need to have a majority of people with dementia as the majority of the group.
- Michael says we need to encourage people with dementia that their voices can still be heard – its all about empowering. The key aspect is meeting other groups/ cross-pollination.
- Many facilitators are experts in getting the information from people with dementia and sharing more widely. Rachel reminded people about the power of capturing voices on film and audio when they are not able to be in the room e.g. Dementia Diaries.
- Mag – Trust needs to be given and gained. Voices need to be held strongly.
- Maxine says People find that trust is difficult if it's been broken.
- **Trust and partnership working is key**
- Rachel mentioned the Dementia Action Alliance that had been created in England. Government funded to bring organisation together to share. However, host funding was given to a big organisation/charity who didn't necessarily have the best links/relationship with smaller organisations, so Trust and partnership were compromised and always in question. Can his be done differently with a smaller impartial organisation leading?

Summary Top 5 points

- We may not be united in our needs, but we need to be united in our voices.
- People living with dementia's voices can often be heard loud and clear, but we can also benefit greatly from those facilitating to ensure quieter voices are amplified and heard.

- Ratio of groups/organisations needs to be more equitable e.g., ½ and ½ 0r 1/3, 1/3, 1/3.
- Historically giving high levels of funding to major organisations has been less impactive and lead to discouragement. So, encouragement could/should be given to smaller organisations taking the lead.

3: Is there a need for Scotland DEEP network, or should we form something completely new. (notes by Paula)

- DEEP was funded by LCT for 4 years. Rachel is the UK wide coordinator since funding from the National Lottery started in 2020. How can we maximise the opportunity across Scotland to share, learn and support each other. LCT was the common denominator for all of us. What happens next? Is it time for a re-birth?
- Ruth said – I don't think STAND would be anywhere without DEEP. When lockdown started DEEP gave us a Zoom link and we connected with other facilitators too. It gave us a real feel for what ZOOM can do. DEEP has fantastic resources and connections and I think it would be crazy to re-invent the wheel.
- Michelle says – Being part of something through the newsletters, facilitator support and Dementia Diaries. Encourage others that they can do this. As a sole worker in dementia, it is so encouraging to make connections. We are a part of DEEP and we have our own page, we produce a newsletter – I am not sure how much more I can do with my limited hours.
- Agnes says We don't want to reinvent the wheel. My personal opinion is that we have to build trust in Scotland, Damage was done (not by DEEP) – the trauma of the post diagnosis, with trauma you need to re-build trust. Not about personality. We need a Scottish flavoured DEEP network, based on localness and Scottishness. We are smaller we need in-roads in to government But we need to build trust first.
- DEEP is not an organisation – it is a network. YOU are DEEP/
- Martin suggested renaming DEEP in Scotland as Domhainn which is Scots Gaelic for DEEP.

4: Funding issues – where is our future money going to come from? (notes from Paula)

- Nancy introduced this issue. She said that during COVID funding was out there. Now funding is harder to get. There is a real worry that dementia ais not 'Sexy' enough for funders. Smaller organisations competing with smaller organisations for a smaller pot of money.
- Martin says we need to make it sexy – we need to billboard it in printed media and tell personal stories.
- Willy says print media is dead. Electronic media is the way forward. There's no concerted campaign except dementia is dreadful and carers are broken give us money. There's nobody to send press releases on behalf of to. We need an organisation best representing the people with dementia are the people with dementia along with the people whose voices don't get heard. We can find ways to represent the voices not heard.
- Nobody offers me counselling – if I had cancer I'd be offered it- where is the Maggie's Centre for dementia?
- Agnes says I feel a campaign coming on. We need a powerful statement in Scotland. Let's make a battle plan. Decide on a call to action. Tweet about it (let's have a take-over) Lets make 'sexy' comments. Get our voices out . Make a press release.
- Maxine suggests getting in touch with Martha Pollard an Heather Wilkinson re counselling. Funding for smaller organisation soften in the shape of friendship support. 3rd sector organisations are often the first person people see.
- Graham suggests targeting the minister for social care Kevin Stewart. He has spoken a lot about the importance of coproduction. Let's ask him for funding for the DEEP network in Scotland. We need a STAND in every town.
- Nancy says the future in collaboration.
- Some groups find being involved in some pieces of work involves getting funding but these are often short term projects.
- Gerry says some groups are great fundraisers and the network can share tips.

5 The future of the Knowledge is Power booklet. (notes by Paula)

- Agnes said the funding for this is important. It was a collaboration between 4 groups based on an idea from Wales. It was funded for an

initial print run of 5,000 in Scotland. A bi-lingual English/Scots Gaelic resource.

- Ruth said the information embraced so much more as it comes from people with dementia.
- Some suggestions of Age Scotland, Alz Scot but it was felt that branding remained impartial

Post it notes content (includes comments from morning session).

- Domhain Scotland – (Gaelic for DEEP)
- Question related to ECRED/SMARTIES - As About Dementia we get a lot of requests to pass on details for people living with dementia to be involved in research. How do people with dementia feel about these requests?
  Answer – Please see the Taking Part section
  https://www.dementiavoices.org.uk/deep-groups/taking-part/
  And also take a look at Dementia Enquirers
  https://dementiaenquirers.org.uk/
- I am not sure if 'another' board is needed. I have eard the same discussions that we are talking about today that Agnes and James talked about 20 years ago. We should all speak with one voice when policy is being decided but share knowledge when help required.
- Question for Martin. I know you have your own blog. Would you consider posting meeting summaries there? Answer from Martin: Yes
- About Dementia have asked people to be involved with interview panels etc. Baby steps to having our voices heard.
- The issue of people with lived experience attending the government meeting was raised again at the meeting on the 19th. Progress is slow, but there is an acknowledgement that it needs to happen.
- Willy says I am getting confused between different groups discussing the same things.
- What does representative of people with dementia mean? !?
- National Board - half and half people with dementia and professionals.
- Martin – How can we ensure that people living with dementia are in the room/at the table with all conversations/meetings?
- Lovely sense of community in the Ecredibles group.
- Will asked if professionals who support a group but funded by an organisation as a paid worker – is there a conflict of interest.

- Brilliant attitude Nancy. It is all about the dong – making a difference and not just talking and hoping to make a difference.
- About Dementia . Sub-groups. The lists/topics they can look at is endless. More important is that it is not controlled by Local Authorities or Scottish Gov.
- Catnip to the brain. Ecredibles.
- How do we reach the people who are not being reached?
- Martin - A central person? With dementia? Who keeps a list of who is doing what. Paid 3/4/5 hours a week. Works with all organisations to bring it together and do a newsletter
- Question for STAND How do consultation processes at a local authority compare to consultation at a national level?
- Question to Michelle from About Dementia. Are you Kirkintilloch based? Is there scope to visit you or are guests restricted by COVID . Answer We understand a date is on the cards.
- Provision of transport to meetings/activities?
- If equal partners need a rotating chair.
- Wrong priorities and pet projects. Rural! Too central belt. In the Grampians and Highlands NOWT!

Next Steps

- Summary of main points in film/photo/bullet point montage.
- Did DEEPly into our address books and consider who needs to be part of this bigger conversation and action!
- Collate an action list – RN to collate and share for comments.
- Setting a next date and who can host/fund?

All notes and the film are available on this page
https://www.dementiavoices.org.uk/group/the-network-of-scotland-deep-domhain/