Oor Mad History
Ten Years On

Human Rights Mad activist
Lived experience Validation
Improving lives *Changing policy*
Collective Advocacy
Community *Recognition*
Redressing power imbalances
Diversity **Stronger together**
Empowered ***Peer work***
Breaking down stigma
Grassroots Passion *Justice*
Shared understanding
Service redesign Speaking out
Real changes *Raising awareness*
Challenging preconceptions
Truth to power *Connectedness*
Safe space **Determination**
Seat at the table Experience led
Volunteering **Trauma Informed**
Breaking down stigma
Sense of purpose

Oor Mad History: Ten Years On

Oor Mad History Ten Years On

A celebration of collective advocacy and mad activism in Lothian 2010-2020

VIKING

Dedication

In memory of Jim McGill
A wonderful friend and fellow traveller.

With respect and thanks to Louise,
Donald, Kevin and all of Jim's family.
Jim would be immensely proud.

Contents

Foreword

Ten years, wow! What an absolute honour to be invited to write the foreword to this very special collage of social history, of activism, imagination and human spirit. I started to read this on a Sunday morning, and I just couldn't stop until I'd finished. It was truly fascinating, like flicking through a wonderful scrapbook with mementos and memories of so many special people, events and happenings spilling from every page.

It has been some ten years! So many achievements, so many people inspired to reclaim and retell their stories, to positively influence change which benefits so many others. Oor Mad History is such a great example of people power through a myriad of forms of expression and creativity. For me, and to paraphrase Michel Foucault, (whom I'm sure would have loved the challenges to power!), Oor Mad History has made windows where once there were walls. So much has been opened up by the work that has been done and continues to be done; glimpses and immersion in other people's stories, other experiences and other truths.

I'm so pleased that I've been able to be part of Oor Mad History over the last ten years, for me it's a complete manifestation of the power of the collective. I recall at times being at difficult meetings, feeling uncomfortable hearing other people's truths of the impact of policy or law; feeling challenged, inspired and provoked attending the Out of Sight Out of Mind exhibition; feeling tearful and upset hearing of the impact of decisions made and unintended consequences – "For it is our scars that make us know that our past was for real" (Jane Austen).

And I remember feelings of joy and pride at listening to people talk about their studies and their experiences of learning and teaching health and social care professionals; of feeling awed and inspired at hearing people's stories; of having fun and laughing until your heard hurts with the colleagues and friends I've made in the last ten years.

I'd just like to sign off with a massive thank you to everyone who has been part of this incredible movement, to Jim and Diana who would have been so delighted to see this book in print and for everyone who is yet to be part of this movement which will continue to grow. Here's to the next ten years – to more challenges and provocations; radical change, to more global collaboration and local activism, to more education, art and all that inspires us!

Dr Linda Irvine Fitzpatrick
Strategic Programme Manager, Thrive Edinburgh, NHS Lothian

Acknowledgements

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Everyone involved with the Lothian mental health collective advocacy and activism movement, past and present, for having the enthusiasm, persistence, and strength to speak up for what you believe in. We acknowledge the various mental health collective advocacy organisations and groups in Lothian, who have supported Oor Mad History, including AdvoCard, the Royal Edinburgh Hospital Patients' Council, West Lothian Mental Health Advocacy Project, and CAPS Independent Advocacy.

Oor Mad History volunteers, past and present, for their role in creating this book. We appreciate each person's contribution to the project, no matter how big or small.

We owe a special thanks to everyone who has shared their experiences, thoughts, and memories with us while creating this book. We are grateful to everyone who took part in an interview, submitted a written piece, and shared their artwork or pictures. Your contributions have made this book what it is, and we value your openness, energy, and passion. We recognise that there will be gaps in this book, and also wish to acknowledge absent friends whose voices have not been captured.

We are grateful to everyone who has been involved in creating this book in such a short timescale and during a global pandemic. We couldn’t have done it without you!

With thanks,
Oor Mad History collective advocacy group

CHAPTER 1

Oor Mad History: An introduction

Oor Mad History is a community history project which aims to celebrate, promote, and reclaim the local history of collective advocacy and activism by people with lived experience of mental health issues in Lothian. We are based at CAPS Independent Advocacy and funded by NHS Lothian.

The story so far

Oor Mad History started in 2008. Since its inception, it has been driven by people with lived experience of mental health issues and supported by people from the mad studies and community history fields. The project has a longstanding relationship with Canadian 'Mad Activist' and educator, David Reville, and his Ryerson University colleagues, who developed a course called Mad People's History. Since the early days of Oor Mad History, CAPS has also maintained a relationship with the Scottish Oral History Centre (SOHC) at the University of Strathclyde and with Lothian Health Services Archive (LHSA).

CAPS first appointed a community history worker in 2008 to co-ordinate the Oor Mad History project. At this time, a steering group was also formed to take forward three key tasks:

1. To interview people involved in the Lothian mental health services user movement, using an oral history approach

2. To gather and organise material stored by the various 'user-led' groups in Lothian into a community archive

3. To create a book to celebrate and promote the history of collective advocacy and activism in Lothian, and to increase the accessibility of archived materials.

In 2010, the Oor Mad History archive contained various collections of memorabilia from the Lothian mental health services user movement and over 70 oral history interview audio files and accompanying transcripts. The main archive is kept at the LHSA in George Square, Edinburgh, and a smaller 'capsule' version is kept at CAPS office in Musselburgh. The Oor Mad History archive is the first of its kind in Scotland and is a unique and valuable living resource, which continues to grow as new material is gathered and new donations are made.

The first Oor Mad History book and accompanying CD was launched in 2010. The book is entitled Oor Mad History: A Community History of the Lothian Mental Health Service User Movement[1], and captures people's memories and stories from the 1980s, 1990s, and 2000s. CAPS is very proud of this work, as it is a testament to the power of oral history as a way of creating a space for the voices of people involved in collective advocacy and 'mad' activism in Lothian[2].

Since the launch of the first book, the Oor Mad History project has continued to thrive and has inspired developments in two key areas: Mad Studies and Arts As Advocacy. This story will be picked up in Chapter 2.

New book project

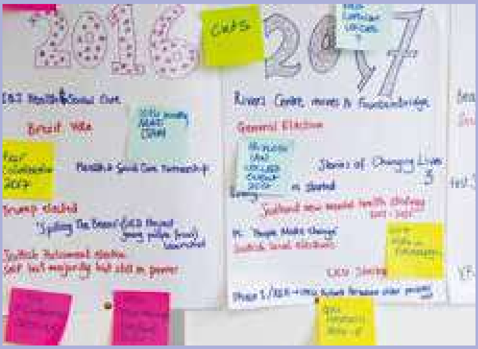
Work on the new Oor Mad History book started in 2019. At this time, the Oor Mad History collective advocacy group visited LHSA and started to make plans for updating the community archive and creating the new book. The group also held a workshop in 2019 to put together a timeline of the key developments in society, mental health services, and collective advocacy and activism, in the last 10 years. The focus of the new book is on what has happened in local collective advocacy and activism since 2010.

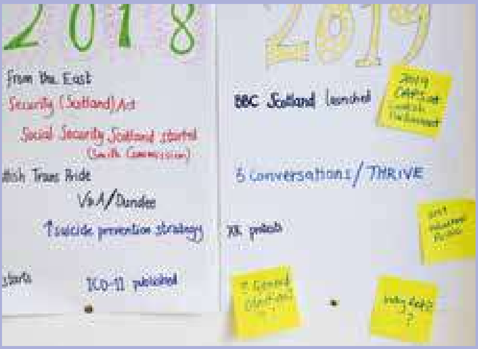
During 2019, the community history worker attended oral history training at the University of Strathclyde and received advice and support from the Scottish Oral History Centre (SOHC) to create the Oor Mad History participation paperwork. This paperwork contains an information sheet about the project, as well as consent forms for taking part in the interviews and making donations to the archive. The community history worker delivered training sessions for members of the collective advocacy group on oral history interviewing techniques and archiving skills, with advice and support from the SOHC and from LHSA. The collective advocacy group created and piloted a set of interview questions and drew up a list of people to approach, from the Lothian collective advocacy movement. The first set of Oor Mad History interviews were conducted in late 2019/early 2020. However, progress was interrupted in March 2020 due to the Covid-19 pandemic.

When the UK went into lockdown in 2020, CAPS moved to remote working and an online Oor Mad History collective advocacy group was formed to drive the project forward. During this time, the group met regularly on Zoom to discuss and plan the new book. They discussed ideas for book content and structure and began selecting materials for inclusion in the book, including quotes from the first set of interviews and pictures from the Oor Mad History archive. Sadly, the community history worker left CAPS at the end of 2020, and the project was on hold until a new worker was recruited to co-ordinate the project.

The second set of oral history interviews were conducted during the summer of 2021. Due to ongoing Covid-19 restrictions, most of the

Clockwise from top left: Oor Mad History ideas and opportunities workshop; Oor Mad History timeline workshop 2019; Oor Mad History archive folders





interviews were done remotely via Zoom. Some people submitted written contributions as an alternative to being interviewed. We also invited written contributions from key allies of the movement. The interviews were led by Oor Mad History volunteers and supported by the community history worker. They were audio recorded by the community history worker and transcribed by self-employed staff. Members of the collective advocacy group were involved in screening the interview transcripts and written contributions for key quotes for possible inclusion in the book.

We have had regular Zoom meetings since March 2021 to work on developing and compiling the contents for the book. This way of working has been challenging at times, as everything had to be done remotely. However, we had an in-person workshop once Covid-19 restrictions were eased, to select the final contents for the book. We worked with a book designer, who consulted with us about how we wanted the book to look and feel. We took inspiration from book covers we liked and decided which colours we wanted to use in the design. We chose to put key words and phrases associated with the collective advocacy movement on the cover. We also wanted the book to have a 'celebratory' feel as we planned to launch it as part of CAPS 30th Birthday celebrations in late 2021.

The primary focus of the Oor Mad History project is on oral history as a means of recording and preserving the history of collective advocacy and 'mad activism' across Lothian. Quotes from the oral history interviews make up most of the content in this book. However, we also accepted written contributions as an alternative to oral interviews if people preferred to express themselves in writing. We conducted 24 interviews and gathered 10 written contributions for this book. The oral history interviews and written contributions included in this book will be stored in the Oor Mad History archive, along with any donations people have contributed as part of the book project. This book will also be deposited into the archive.

We are excited about sharing and promoting this book as it demonstrates the strength of collective advocacy in bringing people together to amplify the voice of lived experience. Oor Mad History is an ongoing project, and it is important for us to acknowledge that this book is only one part of it. We now plan to continue developing the Oor Mad History archive and wish to create a digital version of it to improve the accessibility of the material. We also hope to continue celebrating and promoting the history of collective advocacy, through seeking opportunities to disseminate our work.

We have tried to be as representative of the movement as possible but recognise that there may be gaps in this book, which we are unaware of, or people who may not have been included for a variety of reasons. Some important people are sadly no longer with us, while others were not contactable or were unavailable while we were creating this book. We wish to acknowledge the valuable contribution absent friends have made to the collective advocacy movement and have great appreciation for everyone who has shared their stories within these pages. Due to space constraints, we have selected a limited number of quotes from each person. We have been in contact with the people who contributed to this book during the editing process to make sure we have represented their voices authentically.

Lindsay Horton,
Community History Collective Advocacy Worker

Oor Mad History group comments

"The oral history training was marvelous and of a very high standard. We discussed examples of good and bad interviewing techniques and had the opportunity to practice with each other. Doing the interviews was a wonderful experience. I learned so much and really enjoyed it. I learned a lot of technical terms from the people we interviewed and some of the ideas people shared were new to me. There was a lot of humour too – a lot of laughs! It was great to hear about other people's experiences. I'd say the Oor Mad History group was a good collaboration. The Zoom meetings were great for me as I can hang about in my pyjamas and still go to meetings! The great thing for me about Zoom is that I don't hear voices. It's good for my concentration and focus and feels like a safe space. I feel I can speak my mind. The group has kept me going and Lindsay (community history worker) has made things easy for us." **James**

“I first joined the Oor Mad History steering group in 2018 after doing the 6-week Mad People’s History and Identity module at Queen Margaret University. When the first lockdown started, and we were having to do all our groups on Zoom I didn’t think we would manage to pull off the new book. But we have done it! When Lindsay joined CAPS at the beginning of this year things started to move at bit faster and everything came together. The core group was quite small. It was good to work in such a small group, as we became tight and got things done. I really enjoyed the whole process, and it was fun.” **Samantha**

“When I was involved originally, the time of the meetings suited me, and I felt part of the group. I have since met other members and that was great. But over the last few weeks, I have, it seems, been having a Fibro/ME episode. My sleep is all over the place and I am exhausted most of the time. So, it was just me managing and unfortunately not getting a lot done. I did enjoy doing a couple of interviews and I would have loved to have done more of them. I always enjoy doing interviews. It was part of my job in finance and in benefits years ago. I actually felt useful. I have missed seeing people, but it was good to meet up recently with one or two I hadn’t met before. So that was very enjoyable. Overall, I enjoyed being part of the Oor Mad History group over the year. I enjoyed meeting the group and I do hope to see them all again when my disabilities allow me to go out again.” **Cait ni Cadlaig**

“I found working on this book an engaging and enjoyable experience. I loved meeting all the other group members and talking to them about everything from the weather to the state of mental health services. We also did some work on this book. At least I think we did. If the rest of the pages are blank, you’ll know we spent too much time blethering away.” **Lauren Stonebanks**

Overview of book contents

The focus of this book is on the voices of people who have been involved in collective advocacy and ‘mad activism’ in Lothian in the last decade (2010-2020). Quotes from the oral history interviews conducted in 2020 and 2021 are accompanied by images from the Oor Mad History archive as well as images shared with us by the people we interviewed. In the spirit of advocacy, we wish to let the quotes speak for themselves. However, we have added some linking passages for context.

NOTES TO CHAPTER 1

[1] Oor Mad History: A Community History of the Lothian Mental Health Service User Movement is available as a PDF and can be downloaded from the CAPS website.

[2] We use the words 'mad activism' in this book as an umbrella term to describe a collective identity. The use of the term 'mad' in this way is a political reclaiming of the word, and we use it in this book to describe activism by people with lived experience of mental health issues. We acknowledge that 'mad' is not used by everyone involved in collective advocacy and activism.

CHAPTER 2

Oor Mad History, Mad Studies, and the birth of Arts As Advocacy

The Oor Mad History project led to the first Mad Studies course in Europe in 2014 and also laid the foundations for the Arts As Advocacy project at CAPS. In this chapter, we present quotes from key people involved in setting up these projects.

Oor Mad History

Oor Mad History was inspired by the work of Canadian 'Mad Activist' and educator, David Reville, and his Ryerson University colleagues, Kathryn Church and Geoffrey Reaume. David Reville visited CAPS in 2007 to speak to the various collective advocacy groups across Lothian about the Canadian psychiatric survivor movement and Mad People's History course at Ryerson University in Toronto. This visit sparked the desire to record the history of the Lothian mental health services user movement, and CAPS first received funding from NHS Lothian in 2008 to take this work forward.

Keith Maloney was the Co-ordinator at CAPS during the early days of Oor Mad History. In the quote below, he reflects on the relationship between CAPS and the Canadian 'mad activism' movement, which dates back to the early 2000's.

"In 2001, the subject of service user run services had led to a visit by folk from Canada, in the UK with their film 'Working Like Crazy'. This international connection with Canada would be given a further boost with a visit a few years later, in 2007, by David Reville with news of the 'Mad People's History' project at Ryerson University, Toronto. The visit provided inspiration and a focus to local efforts, resulting in Lothian service users own Oor Mad History archive and publication, an expression of the service user movement's ability to construct its own history, written in its own words." **Keith Maloney**

In 2009, the Oor Mad History group had the opportunity to visit Canada to learn about the Psychiatric Survivor Archives in Toronto and Mad People's History course at Ryerson University. This visit provided the group with inspiration for the Oor Mad History community archive, book, and exhibition, and was a catalyst for what was to become Scotland's first Mad Studies course. Kirsten Maclean, the Oor Mad History community history worker at the time, reflects on the visit to Canada below.

"I think we had at least one visit in that initial three-year period to Canada and Jim McGill came along as well, and Steve Tilley. We got to go over to Toronto and meet with David Reville and Kathryn Church at Ryerson University. We sat in on one of David's classes and then we met with Geoffrey Reaume and people at the Toronto Psychiatric Survivor Archives. [It] was quite an amazing experience to get over there and meet some of the activists and see the links between the movement in the community and the university and how the two kind of bump up against each other." **Kirsten Maclean**

Following their visit to Canada, the Oor Mad History group had the task of gathering and sorting materials for the archive.

"It was a real process of rooting through boxes and sorting them into piles and taking out the staples. I had to have a tetanus jag thinking it was rusty staples everywhere. It was quite a lot of time spent down in that basement room with the Gaelic radio on whilst doing a lot of the sorting through of it. It did help to have people like Jim that would've been involved and would recognise some of the material." **Kirsten Maclean**

The Oor Mad History group also conducted over 70 oral history interviews with people involved in the Lothian mental health services user movement. Once the interviews were done and the archive was created, the group had the idea to create a book.

"I think we did know that we needed to have something else, not just the archive and the oral history interviews on disk. We needed something more accessible for people or more engaging, because not everybody's gonna want to look through an archive or listen to hours and hours of recordings… [We came up with] the idea of a book that would be a bit more condensed but would have some images and have little excerpts from interviews and be a bit more accessible. Because it was about getting this word out about this history and making sure that it tried to influence the way and show the agency and activism of people to a wider audience." **Kirsten Maclean**

The Oor Mad History book was launched in 2010 along with an art exhibition. The quotes below from Kirsten Maclean and Anne O'Donnell, LEARN Co-ordinator at CAPS, show how the seeds were sown for the subsequent developments in Mad Studies and Arts As Advocacy.

"It was originally just a three-year project and that ended with the book being published and launched at the Drill Hall. We had an art exhibition as well because people wanted to express themselves through art as well. The exhibition was supposed to be just a small bit of it, but then the more people heard about that and wanted to put artwork in, the more it kind of grew." **Kirsten Maclean**

Oor Mad History Book Launch 2010

“When the book came out it was really exciting. We had this real strong sense of ‘we’ve done something really good, and we want it to carry forward’, so we had an exhibition out in West Lothian, and then we had a small exhibition at Queen Margaret. Out of that, Elaine Ballantyne, who was an occupational therapy lecturer there, spoke to Kirsten, and there was some talk about a course, because we were inspired very much by what was happening at Ryerson, and in Toronto. There was an historical archive there, and that’s what got us thinking about Oor Mad History. They also had courses at Ryerson called ‘A History of Madness’ and ‘Mad People’s History’, and that really inspired us.” **Anne O’Donnell**

Mad Studies

Since the launch of the first Oor Mad History book, CAPS has worked in collaboration with Queen Margaret University and NHS Lothian to develop and embed learning opportunities in Mad Studies, both in the university and in the community. Dr. Elaine Ballantyne, senior lecturer in Occupational Therapy and Mad Studies at Queen Margaret University, has been instrumental in establishing the Mad Studies courses in collaboration with CAPS. In the quotes below, Kirsten Maclean and Elaine Ballantyne reflect on the introduction of Mad Studies at Queen Margaret University and the importance of maintaining links with the community.

“It was wonderful to see the course get off the ground, and then of course there were people that have always been really committed making sure that it doesn’t just disappear into the university. It’s important to keep the knowledge rooted within the community itself.” **Kirsten Maclean**

“One of the core philosophies of the new Master’s is about generating Mad knowledge, and privileging the knowledge that the learners come with, but also making that widely available. We hope to create a body of knowledge that challenges dominant ways of thinking about madness, and wider socio-political influences… Our plan is that we will not become an abstracted academic space that then becomes a wee bit of an ivory tower that is self-fulfilling but doesn’t actually reach back into the community or to the movement.” **Elaine Ballantyne**

"The partnership with CAPS and other activists is hugely important in that feeding back of what's generated here. We will have a steering group of students and activists, people using services, to help with what the curriculum is, and to partner in these research projects. It's about knowledge, connection, and challenging the dominant ways, of thinking, through scholarship." **Elaine Ballantyne**

"I think that what we've achieved is a sense of connectedness."
Elaine Ballantyne

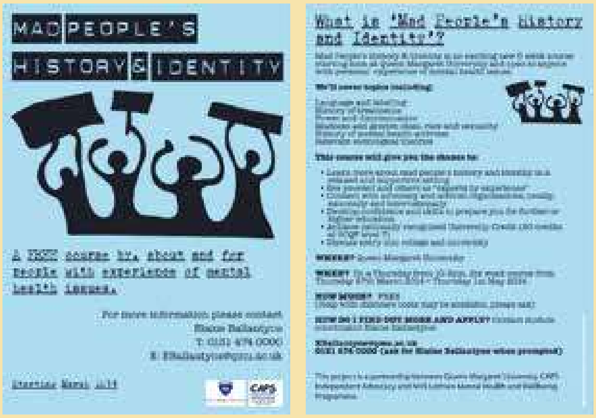
Mad People's History & Identity (MPHI)

The 'Mad People's History and Identity' (MPHI) module began at Queen Margaret University in 2014 and was the first Mad Studies course available in Europe. Elaine Ballantyne tells us about her role in the development of the module in the quotes below.

"I've always worked in mental health or social work, so I've been interested in people's experiences, and I guess working with people who are experiencing oppression has been a political part of my upbringing, and my world view. I've always been interested in critical ideas and critiques of psychiatry and therapies."

"I was approached by our vice principal, Professor Alan Gilloran, who's a Sociologist by background, and he said that he'd received an email from CAPS Independent Advocacy. They were looking for somebody within the university that they could pair up with to launch the first Oor Mad History research, and I had come to mind. So, he asked if I would meet up with Kirsten Maclean and see if it would be possible to do something here."

"We wanted to promote the work of CAPS and of other people that were involved in advocacy and activism. Kirsten then started a conversation with me about her and Anne having been over at Mad in The Academy, over in Ryerson University, and about them having a Mad People's History module. Kirsten asked if she thought there was any chance of doing a similar course here at Queen Margaret. I think they had tried for a number of years to get



MAD PEOPLE'S HISTORY & IDENTITY

A FREE course by, about and for people with experience of mental health issues.

Starting March 2014

What is 'Mad People's History and Identity'?

Mad People's History and Identity 2014 flyer

a course started at Edinburgh University and had been unsuccessful. So, from that, we started having the conversation and we pulled in partners from Public Sociology and NHS Lothian's Mental Health and Wellbeing programme. Linda Irvine Fitzpatrick agreed to fund the 'Mad People's History and Identity' course for 5 years. Most of that funding was to make sure that we had lecturers on the course that had their own lived experience, because that was a core philosophy of Mad People's History."

"Doing the research with the students is probably my happiest memory. Them being co-researchers and socialising and learning together, because I wasn't an expert on participatory action research, and none of us were, so there was a lot of learning while we were doing... We wrote a book chapter together about the course, and that's a nice memory. That was four of the students and myself, and Kirsten [Maclean]. A few of the researchers have said that it was good to be an author. It's another positive label that they're now authors of a book chapter." **Elaine Ballantyne**

Two of the students from the first MPHI module in 2014 reflect on their involvement in the quotes below.

"I was part of the first year of Mad People's History and Identity back in 2014. At the time I was kind of lost because my mental health was really bad, and I thought I needed to do something. I'd seen the advert in AdvoCard, because I lived in Edinburgh at the time, and I thought 'that sounds interesting'... The 'expert by experience' thing just hit something with me, and I really enjoyed it, but I see it from a sociological point of view. At the time I thought that mental health and mental wellbeing were more of a sociological issue; it was more of issue to do with society than it was to do with medical issues, and I still believe that." **Liz D**

"I never thought that I would be able to study at uni. I never thought that I was the right sort of person. I still don't feel an academic. I very much have imposter syndrome." **Liz D**

"I got into Elaine's research because she was asking for co-researchers for her participatory action research project for her PhD, and I thought it was a perfect opportunity, quite selfishly, for myself to learn how this sort of research project runs... It was amazing because there was three or four of us that were co-researchers. It was great to do work on analysing and getting those themes to the research and taking part in the exhibition of the artworks." **Liz D**

"I've really enjoyed getting up in front of people and grabbing their attention. Not for myself, but to push this thing of Mad Studies... Kirsten [Maclean] asked me to come over to Glasgow when she was doing her PhD and talk about the course to a group of students. I've done an awful lot of talking... I am always pushing the 'experts by experience' thing and trying to get people to listen and maybe become allies... I think part of the reason why I do what I do is, not 'advocacy-wise' but activism, is to make people aware of [collective advocacy] groups and get that little activist going." **Liz D**

"It was amazing just watching people getting involved and talking about this stuff; usually it's all talk around you rather than people talking to you about this stuff... People were saying that nobody's ever talked like this to us, and you think 'yeah, it's true'. When you're in hospital you feel you're being talked around. Nobody actually talks to you about the actual issues and stuff you're going through... Everybody knew we were in a safe place; everybody had your back and people were coming out with stuff. It was just so heart-warming. I don't know if they were talking about experiences for the first time, but I used to say if we could link the energy in that room to the national grids, we'd be laughing." **Alison Robertson**

"Just so many people in the one room bubbling with energy." **Alison Robertson**

"The idea of adding that kind of academia and validation to experiences I just felt was fantastic, because, it's getting better, but there's still a 'them' and 'us'... It gave you a bit more strength and control or power over stuff, you know? And seeing how other people had survived and how they were coming across, you just think anything you say is maybe not taken seriously, you're frightened to be controversial in any way. And then you see other people coming out and staying stuff, and you're going 'damn right'... It wasn't just you fighting your illness, it was about analysing it, and taking it apart... it just gave you a bit of power over it." **Alison Robertson**

"I think it's a fantastic idea to put the theory and context behind it, how helpful that is when you're dealing with your own mental health to give it context. I think it's very powerful, and also it gives people a way to feel less isolated and know that they have power and they can join groups, and with that power they can help change things so that other people don't go through the same stuff. It won't happen overnight. Nothing ever does, but it's good to be part of that movement." **Alison Robertson**

Community-based workshops

CAPS has also developed and delivered a series of community workshops called 'Changing Times, Changing Minds' as part of the LEARN project at CAPS. Anne O'Donnell and Tom Frank from the LEARN project reflect on this workshop below.

"I was keen on doing something around Oor Mad History... We came up with 'Changing Minds, Changing Times' and I think we delivered it four or five times. The first part was about the past and we looked at the history of collective advocacy, where it came from. I could talk for hours about that.

And we had a timeline on the wall. It started in 1948, which is the start of the NHS, and it's also Tom's date of birth. We were able to ask people to think about when they were born, when had they first started using services, or when did they first start working in services, and when were they aware of mental health and stigma." **Anne O'Donnell**

"We tried to get people to think that you're all contributors to Mad History. We started in 1948 with the start of the NHS, and we got people to say when they were born. So, part of our flipchart was all the events since 1948 and then little references to when people were born, and we compared their perception of mental health with other people's perception in terms of their age, in terms of their own experiences." **Tom Frank**

Changing Minds, Changing Times workshop pictures

Master's in Mad Studies

Building on the success of the MHPI module, CAPS was also involved in developing and delivering the first international Master's degree in Mad Studies, which was launched at Queen Margaret University in 2021. CAPS appointed a Mad Studies Collective Advocacy Worker, Sarah Golightley, to help facilitate teaching on the new Master's course. We are excited to see how this course develops and see it as a major achievement. Some comments about the new Master's course are presented in the quotes below.

“I think one of the big achievements which is down to everybody who came before Queen Margaret, CAPS and all their connections, is to launch the first Master’s in Mad Studies in the world. This has been quite an unexpected and very welcomed achievement... I think you need a lot of support to get these projects in universities. But the challenge is also to make sure that they’re embedded and sustainable, because we work in a business that can axe things that are non-profitable. I think it’s really important that they get embedded and promoted and that there’s a real sustainability vision when you start them up.” **Elaine Ballantyne**

“One of the things that we hope to achieve is to have scholars who are activists with lived experience as permanent members of the Mad Studies team here. As lecturers on the same scale with the same respect and terms and conditions. For me, personally, if you’re talking about valuing knowledge, then you have to value that knowledge as part of the system.” **Elaine Ballantyne**

“I think we’re in a perfect situation at QMU since the start of the Mad Studies Master’s, which is the first in the world as far as I know. I do think having the money to have people do the Master’s and some of those scholarships is fantastic. I look back and I think ‘when we first started this, it wasn’t even on the table’, we didn’t even think it would go that far.” **Liz D**

“The Mad Studies MSc is the first of its kind in the world. The course is led by, and designed for, people with lived experience of mental distress. Everyone involved is passionate about Mad Studies and creating classrooms with innovative, challenging, and exciting conversations about mental health in society. The enthusiasm of the first group of students has been very encouraging. We are hopeful that the course will continue to grow and develop while retaining its connection between activism and academia.” **Sarah Golightley**

What’s in a name: ‘Mad’ Studies

“Embedding [Mad Studies] within a university, and people understanding what it is, has been a challenge. But it also opens up conversations because it has ‘mad’ in the title. I have had many an email from irate people, both in academia and in practice, and also people within the movement saying that they are appalled to see a course with ‘mad’, and that it’s a deeply offensive term, as part of their history. So, while I would respond to that and acknowledge that it’s not an individual identity, really, it’s more a political and collective term, I can understand why people would find it absolutely an unacceptable term.” **Elaine Ballantyne**

“It’s a political reclaiming of a term of abuse. So, it’s a re-appropriation of something that was used to oppress and abuse you. It’s about taking ownership of that word back, but I think there’s a bit of a misconception because it’s new, is that we’re promoting that you should identify yourself as ‘mad’. What we’re promoting is that this is a mad identity; a collective political identity, but it’s not something that you necessarily would use to identify yourself.” **Elaine Ballantyne**

“When the word ‘mad’ started getting used in Oor Mad History, I had this really positive association with the word ‘mad’. It was a word of energy, of action, and it wasn’t a medical word. ‘Service user’ was about your use of services; not everybody wants to be reminded of that. But other people really struggled with it. We only had a couple of negative responses when we started Oor Mad History. Every time we went to talk about it, I was steeling myself for having to explain the word ‘mad’, but people were totally fine with it.” **Anne O’Donnell**

Arts As Advocacy

In the quotes below, Kirsten Maclean talks about how CAPS Arts As Advocacy project developed out of the Oor Mad History exhibition and book launch in 2010.

“For the exhibition we made big blow-up images of key quotes [and images] from the archive, so in a way we had a visual summary of the book… Just quotes about what motivated people to get involved and what they got out of it or key achievements of the movement, so that kind of thing… I suppose then that’s where the Arts As Advocacy stuff would have grown from. Because that exhibition and book launch, we did it as part of The Scottish Mental Health Arts and Film Festival.” **Kirsten Maclean**

Out of Sight, Out of Mind

Elspeth Morrison was involved in organising the first ‘Out of Sight, Out of Mind’ (OOSOOM) Exhibition in 2013 and talks about her involvement below.

“Kirsten [Maclean] invited us to go and look at the Lothian Health Service Archives with her. Amongst the items that the archivist brought out, were these series of letters written by a psychiatric patient in the Royal Edinburgh in the 19th Century, and it turned out that he’d written, over several months, over a hundred letters, basically saying, ‘Let me out. Let me out. Please help me. Please help me.’ ”

“The law at the time was if letters from a psychiatric patient in the Royal Edinburgh Asylum showed signs of psychiatric ill health, or were critical of the asylum, or were written to famous people, they weren’t sent. So, it’s the ultimate form of censorship. So, these letters survived because none of them were sent… I just felt such an emotional response to those letters not sent, those letters of distress. And having spent time in psychiatric hospital myself, what this guy was writing, one hundred and fifty years ago, was very close to my own experience of being in hospital.”

“A lot of it wasn’t psychosis, it was reaction to confinement, and I still see people behaving that way, because it’s a perfectly normal human reaction to the loss of liberty. And then the double whammy of being judged for your mental health, on top of that.”

“That first meeting with Kirsten and other people… then led to another meeting where we checked out the old Animal Hospital at Summerhall, as a potential venue. And because it was an institution, and because it had cages it’s so relevant to what I’d been reading, and what I wanted to do. I just somehow ended up on the committee for organising that exhibition at the animal hospital. So that’s, I guess, how it formally started.”

OOSOOM 2013, The Old Animal Hospital, Summerhall, Edinburgh. Artwork by Elspeth Morrison, title 'Patient Letters'. Photo Credit: Elspeth Morrison

"And then we had to find a name for the exhibition... [Out of Sight, Out of Mind] particularly suited what I wanted to do, and what I was thinking about, because the whole idea of locking mad people away, is out of sight and out of mind. And people would prefer not to think about it or see it. So, to play on that by having it in an old institution with cages, and people's association with being locked away, but to make that a public, free event. There was a nice contradiction between those two things for me." **Elspeth Morrison**

Arts As Advocacy collective advocacy group

Pam van de Brug has been involved with CAPS since attending the Out of Sight, Out of Mind exhibition in 2013. In 2017, she was appointed by CAPS to co-ordinate the Arts As Advocacy collective advocacy project. She speaks about OOSOOM and the Arts As Advocacy project in the quotes below.

"My creative and personal life has been hugely influenced by coming across Out of Sight, Out of Mind and CAPS in 2013. The old Animal Hospital at Summerhall was filled with artworks, objects, words, paintings, and images. It was clear that these were the real, and sometimes raw, voices of people who had important things to say about their own experiences and about the experiences of others... Shortly after that I met Kirsten Maclean at CAPS who was supporting the Exhibition's Planning Group. It seemed that I too was welcome to be involved and I have been, in various ways, each year since.”

“Arts As Advocacy has been a collective advocacy project since 2017 and it really makes sense to me that it is recognised and supported as an effective method for advocacy. People have long used the arts as a way to express themselves. As I understand it, Out of Sight, Out of Mind happened when various individuals and organisations heard about the Scottish Mental Health Arts Festival and said together – let’s have an exhibition. It wasn’t the other way round, it wasn’t an organisation saying it would be a good thing for people to do, and those people went ahead and did it and CAPS have supported it ever since.”

“The exhibition is still organised by a planning group of individuals with experience of mental health issues which ensures that the exhibition is doing what it should for the people who want to show their artworks. The Planning Group are almost all volunteers now and they each put a lot of work in each year – whether that’s writing the press release, curating or painting plinths at Summerhall! They work to make the exhibition as professional and also as accessible as they can. I have seen them take care with every single person’s artwork and show it to the best that they can. A small pencil drawing is given as much care and value by the Planning Group as a large installation.” **Pam van de Brug**

OOSOOM Exhibition Launch 2018, Library Café Galleries, Summerhall, Edinburgh, Photo Credit: Chris Scott

OOSOOM 2020 Poster,
Summerhall, Edinburgh

Pam talks about how the OOSOOM Exhibition has developed in the quotes below.

"The exhibition has grown and developed quite a bit. It almost became too big at one point. In 2019 we had nearly 180 exhibitors and 540 artworks submitted. There's just no way we could possibly show it all so people had to put in less artworks."

"We now have an Out of Sight, Out of Mind afternoon tea in May so that people can meet others who take part in the exhibition and organise it. It's good that people know that it's about people's voices, and it's for people, and it's not about the quality of artwork."

"In December 2020 the exhibition was awarded funding from Thrive Edinburgh. It's really good to think that it's going to be there for people for five more years at least, possibly even eight years! I also think it's testament to the people who were instrumental in organising the first few. Although the exhibition has grown in size and the processes, and the space is a bit more formal now, the ethos and principles haven't changed and that's what makes it what it is. I still think it's unique and real, and often raw." **Pam van de Brug**

CHAPTER 3

A changing landscape: 2010-2020

In this chapter, we hear about some of the important contextual changes that have affected collective advocacy in Lothian since 2010.

Re-tendering of advocacy services

"I was on the [CAPS] management committee from 2003 to 2013. One of the big things we did was around the re-tendering of advocacy services.... before then we worked with a group called 'Edinburgh Users Forum', and that's how I got on the management committee. I was first a representative of the group on the management committee. And I became chair, or convener as we called it. We were based at Cadzow Place. Keith Maloney was the manager... We had to stop working with Edinburgh Users Forum because of the review of advocacy and then the decisions to put advocacy out to tender... I remember going to a lot of meetings at the City Chambers. I remember speaking in the chamber with Monica Hunter from People's First about the importance of having small, local, grassroots advocacy organisations, because [the council] were very much in favour of having one big provider, because it's easier for them." **Anne O'Donnell**

"Neo-liberal economic pressures, target driven efficiency savings and outcomes measured in numbers have narrowed the conversation about advocacy, sometimes resulting in a lack of understanding of what is being commissioned on the part of those responsible for procurement. Outcomes for individual advocacy services are easier to express in numbers, which, in turn, are easier to measure when expressed in terms of number of hours, number of people, number of issues, than in terms of system change. Competition between groups has been encouraged through competitive tendering, favouring larger organisations more able to dedicate time

and resources to management, tendering paperwork and the collection of data with the result that smaller, local groups have often been unable to compete and have disappeared. The competitive tendering process is driven by the needs of commissioning bodies whereas a community development approach leads to outcomes driven by the needs and aspirations of the community. Outcomes for advocacy should, but seldom do, include the extent to which imbalances in power have been addressed."
Keith Maloney

"When we create a voice together and share our thoughts and experiences and dreams, we also create a community of belonging and support. Something very vibrant and very special. It is strange that with the success of some of the key advocacy projects across the country that those very communities can depend for their continuing existence on competitive tendering and business plans. There is a certain tension there. Groups of enthusiastic people, trying to make a better world have had to organise and become business like in order to create change. Setting budgets, evaluating and monitoring, all the technical work that needs done to make sure that a community's voice can flourish. We need this if our yearned for change might happen and yet we still need to retain the comradeship and sense of a shared journey that draws us together."
Graham Morgan

Royal Edinburgh Hospital reprovisioning

"I was involved with quite a lot of the reprovisioning. We split it up, so that people took sections that they were familiar with. So, I was involved with the acute adult care, the rehabilitation service, and ECT [Electroconvulsive Therapy], but we always went to these meetings with a collective view... It was involvement, because we were involved with reprovisioning, but we also put forward our own views, but also those of our patients, which we were collecting at the time. So it wasn't, as we practice now, true collective advocacy..." **Patricia**

I remember quite clearly, patients saying they wanted an outdoor space." **Patricia**

“I was having ECT at the time. Just finished a treatment, went to the meeting and described what it felt like to have ECT in that room down there… It was a dark waiting room with other people, and it was very very unpleasant. I could hear the trollies clicking as they were moved into the other area, once people had had their treatment, and I’m still traumatised by that room down there. When I described it at the meeting… the architect phoned the project manager for the new build, to say, ‘Look, we’ve got to change all the plans for the new ECT suite, after hearing Patricia’s story’. And it was completely redesigned. And it’s a far more user-friendly space now.” **Patricia**

“We didn’t want it to be such a clinical place. I think with the artwork around, it’s perhaps made it more comfortable, it’s quite difficult to not have a clinical air…” **Patricia**

“When they eventually decided to recommission the new hospital at first they wanted to move it to the Little France site. So, the whole Royal Edinburgh, 200 years of history, and a community on the doorstep they then wanted to move it to Little France. I don’t know if the land’s cheaper, and of course they would get a lot of money for the Royal Ed in Morningside, so basically there was an absolute outcry from lots of people involved, so they had to do a consultation. So, we’re all invited to the Hibs ground, with the big chandeliers and all that… You had all these questions, you needed to weight them in order of importance and then rank them in order of importance… What kept happening was they kept putting ‘clinical excellence’ and they were basing that on the proximity to the new Royal Infirmary. So obviously in people’s heads clinical excellence was very important, but that was going to make the Little France site come out on top. And we all thought ‘this is a fix.’ But there was a lot of activist groups there: CAPS and the Patients’ Council and different wee groups, and we all called it out as a fix. The new building’s so far away from Morningside. If you’ve got a five-minute pass, you’re gubbed.” **Alison Robertson**

Recovery

“[Recovery] was never applied in the spirit that it should have been applied; it was seen as just yet another bureaucratic way of repackaging what people had done for years... And it was based on this misused notion of person-centred; everything became person-centred, but it forgets that our individual needs are unique, yet there’s a lot of commonality, so there’s a simplification. Anyway, under-resourced services might talk about being person-centred, but the system doesn’t allow them to be so.” **Tom Frank**

“I got involved because I wanted to change the system, but the way the system has changed was not how I envisaged it. It wasn’t something I was really happy with. I think partly it was the push to get people out of services quicker in the name of recovery, but really it was about money... When you do research with people with lived experience, you say ‘what do you value? What makes a good mental health service?’, and they talk about continuity, about relationships, about opportunities. When you think of how many people have developed mental health problems and been invalidated throughout their lives and have been traumatised, whether they were traumatised before, during, and after their contact with services, especially if you’ve been an inpatient.” **Anne O’Donnell**

Updating of CAPS constitution

“It was a huge piece of work, which got rid of a lot of bits in the constitution that weren’t relevant today... I know there’s quite a bit of controversy about it, by widening things out a little bit... but it means [we] were in a much better position to work with other organisations and to apply for funding and to ensure that CAPS keeps going... I think [CAPS] did need to update it, but it was also very hard, particularly for established staff to see how upset some of the people were about the changes. To try and balance that and have something that puts CAPS in a position where it can feel like it’s got a good chance at keeping going, and keeping making sure people’s voices are heard, but at the same time the potential loss of people who’ve been really integral to CAPS, and really important to it.” **Kirstin**

Human Rights

“One of the things that I think has been a really positive development in the last 10 years is the Human Rights agenda seems to have really moved into the spotlight. This is something I am passionate about and feel really hopeful and optimistic that this is now a lens that we are beginning to focus through.” **James**

“One of the interesting things I think LEARN did was getting involved with the Patients’ Council and Community Voices and AdvoCard. We had a one-day conference called ‘Mind Our Rights’ up at the Royal Edinburgh Hospital because we wanted to have it in a space where people who were in the hospital could attend... I think human rights is a growing driver in Scottish policy generally, not just health or mental health. So, I think it’s a good time to be doing it.” **Anne O’Donnell**

“I’m doing a piece of work as part of the Mental Health Law Review; I’m on one of the sub-groups on economic, social and cultural rights. One of the key things that comes through is the importance of independent advocacy, especially collective advocacy. I think collective advocacy’s going to be stronger in the new act.” **Anne O’Donnell**

“When I discovered the UN Convention on the Rights of Persons with Disabilities [CRPD] and the penny dropped of how radical it was... So, when we go to the wards and people complain about restrictions and passes and tribunals, before that you were saying, ‘Well that’s the law, that’s the system we’ve got. There’s nothing we can do about it’. I guess CRPD gave something that we could advocate around and campaign around, so that’s why I latched on to it like a barnacle and I haven’t been knocked off yet.” **Simon Porter**

“We’re still at the beginning, we’re still at the foothills of this. We’ve got a long, long way to go, but at least we’re at the bottom of the mountain...” **Simon Porter**

I've always taken like a human rights approach to my individual advocacy, but I guess when I heard about the CRPD I thought, 'Well, we could really use this.' You could connect so much that patients are saying, and it gives you just more clout, more leverage, new arguments to make. Gets debates and discussions going." **Simon Porter**

"Some of the professionals need to change their mindsets, they need a lot of re-education about human rights... The education gap is in them, and there's something sort of empowering in that. We can at least say, 'Maybe there's something wrong with you, you know, maybe you're lacking, maybe you need rectified.' " **Simon Porter**

"I feel like we're getting somewhere with it now. In Scotland we have much more of a human rights focus than we do in other parts of the UK. It's so important to know your rights. It takes somebody actually telling you them, which really shouldn't be the way. You should be informed from the moment you're there, if not before. It's part of the Mental Health Act. And it's deeply saddening that that still happens to this day, people do not know their rights." **Safina Bibi**

"I think we're making a lot of progress with the human rights focus. The work AdvoCard and Edinburgh Community Voices are doing with the Scottish Mental Health Law Review is very important for people who are staying in mental hospitals. It makes a big difference if they have that approach – trying to encourage the patients to make those decisions. It's a more patient-centered approach. That's real progress." **Anonymous**

"The SIAA (Scottish Independent Advocacy Alliance) success in lobbying and promoting the role advocacy can play in supporting human rights has led to increased resources being made available through the Scottish Government's Social Security legislation but, as with other Scottish Government legislation that has included references to advocacy support, its focus is on individual advocacy provision and as funding has grown so has interest from non-independent service providers who do not necessarily share the values of the independent advocacy movement." **Keith Maloney**

Welfare Reform

“We’ve done quite a lot of work to do with the benefits changes over the years, meeting with Angela Constance, the local MSP, to highlight real life experience and difficulties accessing welfare benefits, we fed into Westminster about welfare reform, which went to committee, and we now support a volunteer to participate in the Scottish Government Experience Panels. When self-directed support first came in, people could access a budget to go and buy their own support, supported breaks etc. Further changes to the local policy mean many people are being assessed as being able to afford to contribute to the cost of support and that has changed quite a lot for people. Due to the volume of people raising issues with this we hosted a collective meeting with the financial assessment team to share issues being experienced. Collectively we challenged the policy and the implementation of it and the outcome was that a further review process was put in place meaning advocacy can support people to have their financial situation reviewed after the appeal process.” **Kathy Hamilton**

“Finance and income are really important for people, and it’s one thing people with any disability need to feel secure especially if they are relying on welfare or in low income jobs. If somebody came and said, ‘By the way, you’re going to have to have an interview/assessment every year, and you might get your salary cut’, you’d be stressed. It’s not a good thing to put on people with disabilities.” **Kathy Hamilton**

Inclusivity

“I think with the two new projects [for people who identify as LGBTQI+ and for people from minority ethnic backgrounds] we’ve certainly made a start, but I think we could do more to include trans people and people of colour who have darker skin, because colourism is a big thing. In the [ethnic minority] group, we’re all very pale. I mean we’re not white, but we’re very very light skinned. And so, I’m hoping we can get some more Black people, or any Black people involved, really, because it’s not good that the only people influencing this are the lighter skinned ones who have light-skin privilege.” **Lauren Stonebanks**

“I suppose in the past few years, we’ve had a lot of younger people involved, whereas the original [Seen But Not Heard] group were older actually... Most people are between, I would say eighteen and twenty-six, so that’s been a huge shift in terms of what the priorities for the group are. I think that’s why the shift has become on transitions between services and also the awareness raising in high schools and universities... There’s two guys involved now which is different. We’d never had guys involved before. So that’s brought a different dynamic to the group as well.” **Anonymous**

“[Men Matter] is open to any man and the Women Matter group is open to any woman, and we are absolutely inclusive of everybody. We believe in inclusiveness and the Andy’s Man Club is the same. If you’re a man struggling, you’re more than welcome to walk through the door.” **Jay Haston**

“I believe that humans are humans and should be treated so.”
Jay Haston

“The Much More Than a Label group did have LGBTQ+ members and people with disabilities, and I was a person of colour in the group... It would be nice to see a deliberate focus on expanding an intersectional analysis of what personality disorders mean and the specific kinds of traumas that people from these different communities face.” **Vivek Santayana**

“I think [Mad Studies] has made a space that is very diverse. A change that has actually happened is our students and our lecturers, that would identify as non-binary or transgender... and that has been the last, maybe, two to three years. We have applicants, and we have lecturers, and we have learners who self-identify as non-binary, or transgender. We’ve certainly had a high proportion of learners that have a range of multiple labels in relation to their mental health... I think we’ve had every diagnosis possible, and people with up to eight or nine varying ones depending how long they’ve been within the system. A large amount of people that would identify as LGBT, quite a lot of learners that would say that they have lived experience of mental health but are also disabled.

We've only had three learners that would identify themselves as people of colour. So that is an underrepresented [group]. We've seen an increase in young people. The last course there was more young people coming on the course." **Elaine Ballantyne**

"We took part in a lot of West Lothian Let's Talk Equality events. So, we were feeding into the council at that point about equality issues. And if my memory serves me right that involved a broad spectrum of people with different disabilities. The reps provided focus group meetings to do with access and mental health services, and that was then sent back to the consultant psychiatrist to be incorporated in the work of the quality improvement team." **Kathy Hamilton**

"I think we're very inclusive [at Mad Jam], everyone's welcome, we're breaking down stigma, and breaking down barriers, and educating, as well." **Martin**

"We'd try to be as inclusive as we could to anyone who walked through our doors. It was very much an open-door policy... I would have liked, and it was my own personal bias, to have a lot more people of colour to be with me on the Patients' Council and I definitely held that personal bias in terms of trying to recruit new patients. While I was advocating on the wards, I was like 'please come on, I'll be your buddy!' "
Safina Bibi

"Valuing diversity seems to be slowly improving, though there is still a long way to go." **Fiona Macdonald**

The value of lived experience

"What I'm finding is with advocacy as well is government are more willing to get involved with advocacy and volunteers and groups as well, which is pleasing. And the new buzzwords are 'lived experience.' Angela Constance mentioned it I think, every MP now and MSP and councillor is talking about lived experience, it seems to be the new buzzword. As an activist, it's time to hold them to account on that and make sure they use their voice of lived experience.” **Jay Haston**

“I kind of jokingly, tongue in cheek, tell people ‘I’m a walking case of trauma so study me’, and I’ve always said, even in therapy I’ve said, you know, ‘I’m a lesson to be learned from, so use that’. And I use that when I speak, because I believe the voice of lived experience is really powerful and important… We’re the generation that are going to start the eradication of child abuse and neglect. We might not be the ones that do it, it might happen in a hundred years, two hundred years, but we will be the generation that made that change, and it’ll be through the voice of lived experience.” **Jay Haston**

“I do think the positives of this group outweigh the negatives, because people do get a real sense of being able to use their experience in a really productive and purposeful way… People do get on really well in the group, and they do develop good friendships and connections, and I think that’s been a real positive part of it. People from completely different experiences, backgrounds, and because they have the common thing of they all experienced an eating disorder, no matter what eating disorder it was, there’s that shared understanding that, I think, really helps… I think that’s been a huge motivation as well, is that there are universities now that are getting lived [experience] input, there’s schools that are getting people with lived experiences, mental health being spoken about. The huge positive is that there are changes being made as a result of people having a voice.” **Anonymous**

“People with lived experience having expertise, we need to be front and foremost in what happens around mental health policy services, responses, and just understanding what the different experiences are when you have a breakdown, or psychosis, or low mood, or whatever it is. The sense you make of that is really important, much more than what you’re told about it.” **Anne O’Donnell**

“I think it is taking the role of people with lived experience seriously and listening to that. That doesn’t seem to me to have been the case ten years ago, in the same way. Whereas I think now, it is.” **Lewis Reay**

“The value of lived experience has been recognised by allies in the third sector and public bodies, supporting the active involvement of service users in the professional development of their staff through user led training programmes. There continues to be support and growth in service user research and experience led projects.” **Keith Maloney**

“There’s been a lot of the learners doing teaching... We’ve stayed true to the core of this being a partnership. Most people who teach on [the Mad Studies courses] have their own lived experience. More and more we’re getting a group of scholar activists who actually are involved in the Mad People’s History course and the MSc in Mad Studies.” **Elaine Ballantyne**

“There’s a lot of rich wisdom that comes in trauma from not necessarily experiences that you’ve been through, but the other side of that, and keeping going on... I think that by having courses and information put together from authentic voices, then it’s come directly from the horse’s mouth... And until we can shift that balance back to more equality, then there’s a whole load of stuff that people will miss out.” **Andrew**

“I think the last 10 years have seen more of a shift towards understanding the causes and impact of trauma, beyond simply management of mental health symptoms. Alongside practitioners learning from practice and developing new approaches, I believe that people with lived experience speaking up and being involved has been key to these changes. Though at times we are still faced with ‘non-sense’, we are careful to express our responses and appreciation from a place we can all build.” **Fiona Macdonald**

“I think having people with lived experience [in the partnership group] has made the Crisis Centre run better. I was on crutches for ages and I stayed at the Crisis Centre, and they have an accessible bathroom downstairs, but they have nowhere to sit in it, and they had no railings... So, I raised that, and they then got a shower seat and railings put in, and a toilet seat and stuff put in.” **Sarah**

“The great thing about Out of Sight, Out of Mind is that it is created by people with lived experience and it does demonstrate that everybody’s experience is different, is unique, and the art that they create is different and unique.” **Margaret Drysdale**

Covid-19 and the move to online groups

“I find [Zoom meetings] really worthwhile. It’s given me something to do, and something I can do even when I’m not feeling particularly well, especially with the online stuff at the moment, because that’s just brilliant. I don’t have the stress of having to get dressed and to actually get into town and get to places and deal with public transport… It’s made it so much easier to be involved. I get that for some people that’s a barrier, the online stuff, maybe their internet connection’s not good, or they don’t have a device that’s capable of doing this, but I hope we get to keep some of this.” **Lauren Stonebanks**

“I suffer a bit from isolation, and having regular contact with all the guys, it’s been quite helpful. Keeping me in touch with the planet.” **Tommy**

“I think CAPS have done a really good job of keeping in touch with people… That’s more important than ever in something like the pandemic because things move so fast, and services change so fast, and it’s easier than ever in circumstances like that for people’s voices not to be heard.” **Kirstin**

“Each year of the [Out of Sight, Out of Mind] exhibition is unique and each has had its challenges, but hopefully 2020 was a one off! Despite the challenges of the COVID pandemic it did actually happen. The Planning Group continued to meet online even though no one knew if an exhibition would be possible. We worked with a web designer to create an online exhibition so that even if a physical exhibition couldn’t take place then something would be possible. However, in the autumn, a break in restrictions meant that it was. So, we had both! The physical exhibition went ahead at Summerhall with COVID measures in place. The online exhibition meant that people who could not attend could also see the work. For the first time OOSOOM exhibition at Summerhall had a booking system which meant that a reduced number of visitors could enjoy the work in person and the online exhibition had thousands of visitors, many from around the UK and beyond! The online launch gave many of us a chance to celebrate the exhibition 'together.' " **Pam van de Brug**

Zoom OOSOOM Afternoon Tea 2020

"Zoom meetings have been a revelation to me and have made my engagement so much easier. It has helped me as I hear voices but during Zoom meetings I have not heard this, focusing on the screen has drowned them out. I think services need to recognise the advantages discovered with the online environment that has been established during Covid; Choice!" **James**

"I would say we have managed to really adapt to being able to have meetings online to push what we know to be true in spite of a whole load of other things being against us, so whether that being a pandemic, or whether that just being to try and get your voice heard as we get further up... People are committed, and we're still turning up and we're still doing things. And that support is still there from CAPS as well." **Andrew**

"Before the first lockdown in March 2020 I was on a manic high. It was ten weeks of hell. I should have been in hospital, but because of Covid-19 they didn't want people in hospital. Over the years I have been told I have insight, so I have to manage my illness myself. Extra medication obviously. When I go on a manic high, I go on the drink. So, I started on the red wine and takeaways and started smoking. I kept getting stains on my top and I couldn't get the stains out, so I named it my Lockdown Top. This was the start of me developing my top. After applying many food products, I then used oil paints. I thought to myself if Tracey Emin can exhibit her dirty garments, why can't I. Some of the objects represent the things we all missed during lockdown. Hope I don't need to make another one..."

Samantha

Artwork title: 'Lockdown top.' Photo credit: Samantha

"When Zoom came along it was perfect for us in a way. It gave us a chance to do what we wanted to do next and that was reach out nationally and get guys in nationally to speak over Zoom for folk who couldn't make local clubs if there's no local clubs in the area. Because obviously 'Men Matter' we called it; we wanted every man to matter and every woman to matter. So, we wanted to provide a service like this, where people could come online and talk if they couldn't reach their local clubs. So, it affected us as in we had to close the group down, because of the [Covid-19] restrictions, and take it online. But it benefitted us as well because we managed to outreach, and we've got members all over the country now." **Jay Haston**

"The online meetings have been a lifeline for me."
Anonymous

"The shift to online communications has felt both enabling and disabling. I always feel conscious of 'absent friends' alongside appreciating new possibilities in connecting. There seems to be a proliferation of trauma resources and remedies available online. It would be good if there was more advice on how to navigate choices safely as a number of opportunities, including training, seem to be increasingly monetized. It can be hard to tell which sources are safe, regulated or approved. Structural inequalities have also meant people, knowledge and ideas with much to offer were and are still 'excluded.' " **Fiona Macdonald**

CHAPTER 4

Key developments and achievements in collective advocacy since 2010

In this chapter we outline the key developments and achievements in collective advocacy in Lothian during the last 10 years using quotes from the interviews. The timeline on page 72-75 shows the key developments in collective advocacy in the last decade.

Peer work and volunteering

"I wanted to do some volunteer work, and I'd went to the volunteer centre in Musselburgh and spoke to the girl there, and she had suggested CAPS. So, I went up to CAPS, and I quite liked it... CAPS had never had any volunteers before. So, I was their first volunteer, and I just made myself at home in the office, really, and made cups of tea and faffed about and helped whoever needed help at the time... We went and had a stall for CAPS at volunteer things, and people would come and ask us questions and try and enlist more volunteers. And we did end up with quite a few volunteers, eventually... It wasn't just me anymore, there was other people. And then, there was somebody whom the volunteers could actually approach. Because when I first was at CAPS, they were all really nice to me, all the staff, but sometimes I felt like I was being a bit of a nuisance because they weren't quite sure what to do with me. But they got better at it and I just fitted myself in really. But with Victoria [Volunteer Co-ordinator] there, there was a more set place for volunteers to be." **Theresa Trotter**

"Most of my work in the [Health in Mind Anxiety and Depression Support] group has been peer support facilitator. The group has been about giving people a space to share their experiences, and other people to share what has helped them, rather than, necessarily, provide advice or intervention.

CAPS Volunteer pictures

We made very clear to the group that none of us are in a position to authoritatively help others or advise other, but what we can do in this group is share our own experiences, and create a space where people feel validated and understood.” **Vivek Santayana**

“Some of the people who have been coming to the [Health in Mind Anxiety and Depression support] group as participants have now trained and become facilitators for the group. And they see it as giving back to the group what the group has given them… Seeing people take ownership of their own recovery and their own process of coping, and actively creating that community and supporting each other has been a huge achievement.” **Vivek Santayana**

“I was part of the first NHS male group therapy session called ‘Beyond Trauma’. And it was for people who had difficult childhoods and problems with childhood… When that finished, I went out into the community to see if there were any similar groups, and there was none. So, I started my own, Men Matter… That was 2018. At the beginning of the group, it was myself and a fellow person that was in the group with me at the hospital… It was me and him that started up the Men Matter project that eventually got backed by the community and by another charity, and they’ve eventually made their own group out of that as well. So, it’s benefitted the community and it’s benefitted charities.” **Jay Haston**

“The main achievements of [Men Matter] is that it connected charities to other charities, it connected the charities to the community, it created a counselling service in the community, it created a workshop in the community.” **Jay Haston**

“What peer work itself reflects, is changing the power dynamics within mental health services and the wider culture around mental health. This reflects people with lived experience coming together and taking autonomy and control over their own experience, and shaping the narrative with which mental health is talked about within the communities that they create… Now, this is certainly very sophisticated but also a very slow process of people coming together from the grassroots of lived experience effectively, of creating these communities through mutual collaboration.” **Vivek Santayana**

“The side effects peer research; that means a lot to me. The Emergency Card; that’s a major achievement. Patricia [Rodger, AdvoCard Community Collective Advocacy Development Worker] worked very hard to keep the Outlook Project going. We’ve met some really interesting people through the group.” **Anonymous**

“We realised from people with lived experience that people’s experiences of A&E weren’t very positive. When they attended A&E, either for mental health grounds, or for physical health when they also had mental health conditions. So, we came up with a plan, and interviewed lots of people, and wrote a report, and went to A&E and talked to Sara Robertson about it... And she was on board, and we ran a couple of information sessions for nurses. They took it really well. They were really interested. And we came up with a safe card. A sort of information card that you can fill in and take with you to A&E. They’re available in A&E, but they’re also available from AdvoCard and various mental health resources places, to help people’s transition through A&E be a better experience for them.” **Sarah**

Emergency Card

Please read the information on this card. It will help you give me the care I need.

My name:

Emergency Contact

Name:

Number:

PLEASE TURN OVER

I want you to know that:

•

•

•

It matters to me that:

•

•

AdvoCard A&E | All & Equal Emergency Card

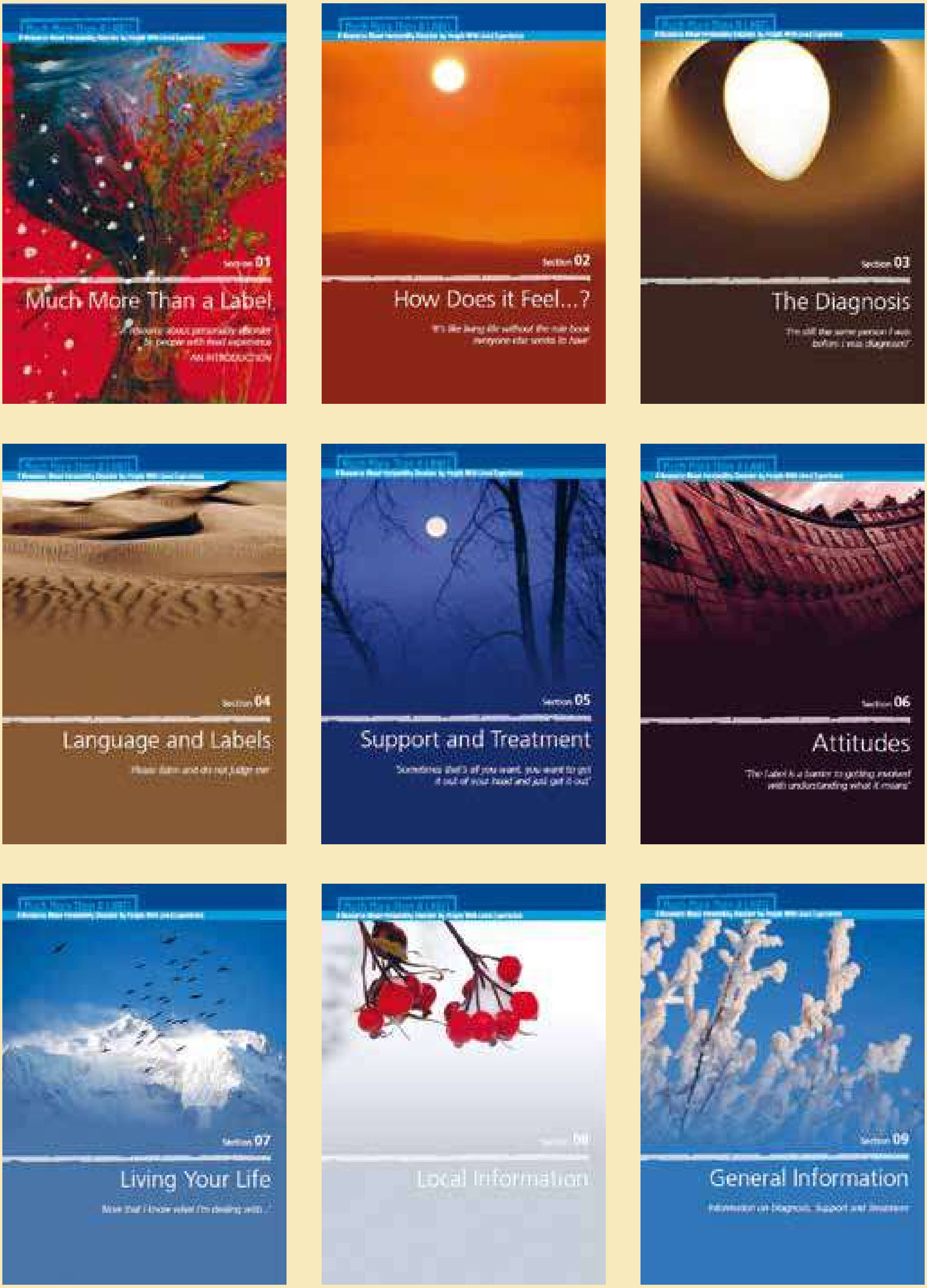
"I remember at AdvoCard particularly when people coming to the ordinary community meetings were being denied travel. And I said, 'But you can't do that! This person won't be able to get across unless you give them a taxi. I'll share mine with them.' So that's how we started it, and then they got their own taxis, and they were able to come, and be seen. And it gave them a life. But then when we started the Open Mic and that was another liberation for people, because people were coming out of their homes on a Saturday night, into the city to a place they felt safe, and where they enjoyed being, and it was wonderful." **Dianna Manson**

"I suppose that shift towards valuing lived experience, we've been part of that. We were doing that before it was a thing, but how it's been taken up is a bit difficult. Peer support's a similar thing, because we've been doing peer work since we started. I remember I was telling somebody about peer support, and she goes 'oh we used to do that for nothing.' " **Anne O'Donnell**

Much More Than a Label group

"[Much More Than a Label] had a lot of different kinds of activities happening simultaneously. There was the policy work that happened through delegations to various conferences and policy development groups, and there was also the training programme of providing training to clinicians or trainee psychologists, or any other interested party, on what personality disorders were. Finally, there was the much broader project of compiling literature for the benefit of people who are given a diagnosis of personality disorders. At the time I got the sense that the multifaceted nature of this group was the result of how advocacy work itself straddles so many different domains." **Vivek Santayana**

"I know for a long time it was just me and Sue holding Much More Than a Label together. We were doing all of the training for the best part of two years. And that's a lot for just two people. And then we got an influx of new people so then we were like, 'there's too many people that we don't know, don't like this either'... Also workers constantly changing. [We] seem to get worker after worker after worker and it's like 'We



Much More Than a Label toolkit

thrive on more consistency'. But I mean it's not CAPS's fault, it's just life." **Lauren Stonebanks**

"I think the Much More Than a Label group has done great work in creating a fairly robust training module that is emphasising lived experience, rather than clinical definitions, which is laying the foundation for information for trainee psychologists and mental health professionals to change their understandings of personality disorders… The project has asked the right questions and moved the conversations about personality disorders forward in a way that has been immensely beneficial, and the project of compiling the booklet is something that is quite substantial." **Vivek Santayana**

LEARN, 'Education as Advocacy'

"I started calling it 'Education as Advocacy', because I think LEARN workshops are about people's voices, and what people think is important to be put across. And that's particularly true in 'Experience of Psychosis' and 'A Human Experience.' " **Anne O'Donnell**

"[A Human Experience] was able to develop a sense of a group online, when none of us were used to doing that kind of thing online. We run workshops called 'A Human Experience: Living with Mental Health Issues'. What we actually talk about in that can change quite a lot, depending what we're interested in at the time. It kind of goes back to my strong sense that the best learning we do is collectively, and that conversation is a great way of breaking down barriers and preconceptions." **Anne O'Donnell**

"When I started [with LEARN] there were many more people involved with a professional background. Now, I seem to be one of the few people tarred with that brush. The people involved have all come from our advocacy movement, even the people who were hired by CAPS to coordinate." **Tom Frank**

"I've always had a snobbish view that training is very functional, whereas education is very much broader, where you don't have any clear outcomes, you just want to develop people's inquisitiveness and curiosity. And there's never an end to education... In fact, it's quite interesting when I think of my role in Collaborate to Educate, it was very much a brainwashing exercise in recovery. And we were the recovery bus." **Tom Frank**

"We're less involved in particular issues and more involved in just providing experiences for people so they really understand from a point of view of lived experience. Maybe it's a sign that the earlier work of CAPS and AdvoCard putting lived experience on the agenda. Pushing people about the way services work is no longer as simple as it used to be. It used to be very simple because the services were so out of touch with everything. Now the services are still pretty meagre, but they speak the language. The issues are kind of harder to deal with on a political level because all [services] have to say is 'we know, but we don't have the resources', whereas before they didn't even know." **Tom Frank**

LEARN office

“The offices [at Argyle House] were really gloomy and dowdy, so I moved a bit of furniture around, and I brought throws in from home. I put them on the sofas and made them look really cosy. It just made the place feel a bit more welcoming, and the sofas are very popular, when we have workshops or meetings. Because it’s just nice sitting down with a cuppa and chatting to people.” **Anne O’Donnell**

“I first attended a LEARN training where I saw, first-hand, how the sessions were carried out. It felt comforting to see eating disorders being spoke about in a way that seemed real and authentic to my experience, rather than what I was taught in school or misconceptions in the media. I felt seen and validated for the first time in my experience, which was amazing. The first time I read out ‘my story’ at the LEARN training was very significant for me because I had never sat down and took the time to think about my eating disorder in the timeline of my life. It helped me to make connections and look at my health from a distance, seeing the progress I’ve made and recognising important moments during those times. The feedback from everyone at the training was extremely positive- which really boosted my confidence and made me feel less ashamed about my past. I always felt completely alone in my experience and because I never had a proper diagnosis for an eating disorder, I felt like my experience was not valid. So, when I learnt that this had been the case for others, I felt like I could finally be taken seriously and accept my mental health issues.” **Mohasin**

Seen But Not Heard group

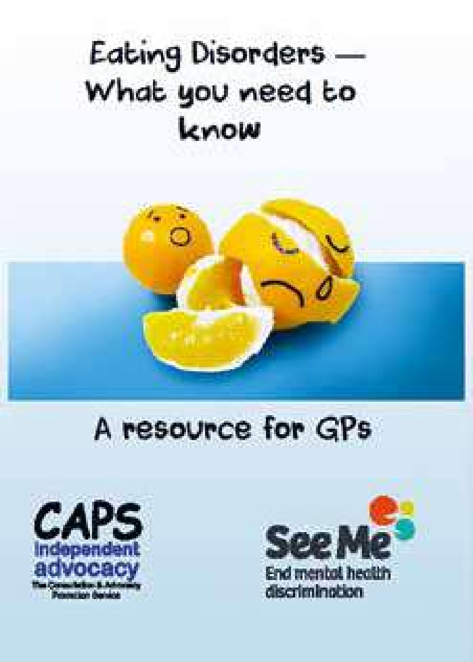
“People wanted a film to be made to create awareness and to help people understand a little bit more about eating disorders, but from a lived perspective, rather than being told the medical facts about it. So, I became part of a steering group. There was quite a few of us in the steering group, and we met regularly... We all went to the Scottish Parliament during Eating Disorder Awareness Week. There were other things going on as well, but we had an opportunity to speak about the process of working with CAPS to produce the film. All three of us spoke, and then we showed the film. And it just got a huge response.” **Anonymous**

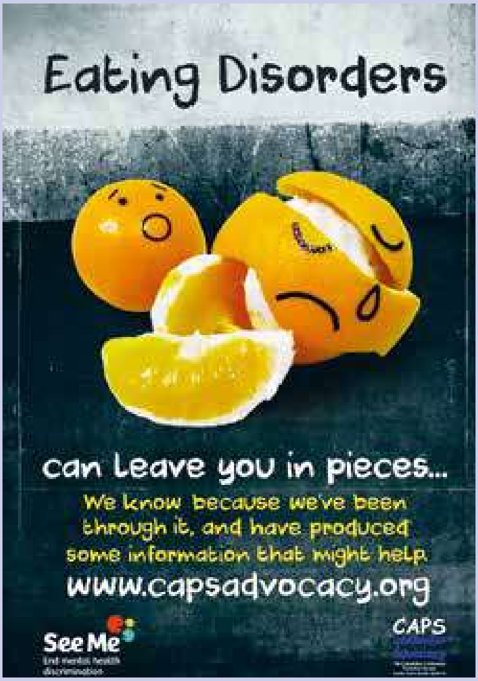
“[In 2014] we first went into QMU just using the film and then our own experiences to create awareness... The group, at that point, decided that one of the key areas that they wanted to look at was GP’s knowledge of eating disorders. Some people had had some really good experiences that we really wanted to draw on, but then other people had had some negative experiences that we also wanted to highlight. So as a result, we decided to make a GP resource pack... The group all worked together to do the resource pack. We all decided on the images, we did the images ourselves and put the whole thing together. Luckily one of the people had an art degree, so she knew all about formatting, it totally saved my life. We got a grant from See Me to print it.” **Anonymous**

SBNH group with
GP resource pack

“The Eating Disorder Service [had] always been a member of the Strategic Planning Group for Eating Disorders in the Lothians, which is an over all general group that met regularly to talk about how the services were. And then in 2017/ 2018, they started to do a redesign of the service, and we gave them our lived experience input, and we got a seat at that table. I started to go regularly to those meetings and give people’s input...That’s still an ongoing thing. So, although it started in 2018, the group is still meeting and there’s still plans that are being talked about, and things that came up from the survey that we initially took, that [we] are still fighting to try and get them to listen to.” **Anonymous**

“I think the GP resource pack is probably my number one [achievement]. It just felt like a really meaningful project, and to give people a voice in both a positive and a negative way. So, it didn’t feel like, ‘This is what’s really wrong with the system’, it was more so, ‘There’s been great people, who’ve really helped, and why can’t we draw on more of that, rather than criticising?’... Those booklets are still really highly received by everyone. We use them in trainings and everything, people just seem to get a lot out of them.” **Anonymous**





Eating Disorders
GP resource pack
and booklet

Eating Disorders conference, 2019

"[The eating disorder conference] was really relevant to what the group has been doing, because it gave the people who have been involved a chance to talk about their own experiences, but also a chance for the services themselves to stop and think and listen. It really felt like people were actually listening on that day." **Anonymous**

Mad Jam Open Mic

"Edinburgh Mad Jam open mic was started possibly about seven or so years ago as part of the Scottish Mental Health Arts and Film Festival. We got premises at Southside Community Centre, and we put on our first show in April 2016... It's equally a place for people with mental health issues or not with mental health issues, but mainly with mental health issues to come along and be in a safe space where they can go up on stage, perform, whatever their ability is, and knowing that they're in a place where they're going to be respected and not be heckled. Everyone's going to appreciate and encourage what they do. So that, I would say is our raison d'etre. And while we do that it's a jolly good place for people who find it difficult to get out on their own or to go to somewhere more mainstream, or maybe can't afford to go anywhere where it's more expensive." **Julie Ross**

"We do what we always did but we're better known and it's on a bit of a larger scale." **Julie Ross**

“We have to thank the initial people who set up the Mad Jam, there was a group of five, six, seven people, initially. Some have moved on, and left Edinburgh, and are no longer involved, but it was a good thing to do, and it’s been a definite success... The proof of the pudding is we’ve kept it going for four years now, and we still get an attendance. On a good night, say we’ll get 35, 40 people, including the volunteers and the performers... It’s a peer led group. Those of us with lived experience of mental health issues, putting together something that other people can come to, all inclusive, you know?” **Martin**

“We want to give a good night’s entertainment, and a supportive, encouraging space for performers and everyone. It’s a good thing to be involved with. I have got involved with that because I wanted to, very selfishly. I enjoy it, and it is a night out for me.” **Martin**

“In terms of the Mad Jam, and the Music Sanctuary, it’s a recognition that it’s not technically mental health advocacy, but it’s amplifying the voice. It provides a focus round which people can see the strengths of a peer led group coming together and organising this and keeping it going in a successful way. Recognition of that is a recognition of the voice of the mental health community, and the abilities within that.” **Martin**

MAD JAM
OPEN MIC

Experiences of Trauma group

"As survivors, it can seem like we are bearers of inconvenient truths... It seems really positive there is now an Experiences of Trauma group and we are being invited to give our views. Though at times, it still seems like the early days of 'user involvement' in mental health, before there was a real understanding of peer values like mutuality, equality and reciprocity. Hopefully involvement will continue to grow and we can take part at all stages where relevant, knowing that trauma can touch many of our lives, whatever our role... I still struggle with the words 'trauma-informed', though in some ways they are easy to understand. I hope we can avoid some of the past mental health focus on illness and deficits and in some ways be more survivor informed. This might bring fuller recognition and invite more of our creativity and potential." **Fiona Macdonald**

"I feel a lot of progress has been made in formally recognizing the impact of trauma, including diagnoses. Yet in other ways it seems there are societal disconnects. I guess there may be a reluctance at times to name traumatic events because of social stigma, taboos and concerns words may be triggering. Not long ago, naming seemed more powerful. If it is OK to do, it is OK to tell. I don't want to collude with denial and avoidance, even though these may be part of our survival strategies too. In the first decade of OMH, people were talking about 'Beyond Trauma'. I feel like I hear this less now." **Fiona Macdonald**

"We stand on the shoulders of giants. I like discovering when people now draw inspiration from trauma survivors speaking up, just as we did when activists and supporters were paving the way in mental health." **Fiona Macdonald**

"I think it is good there is more recognition 'out there' about developmental trauma, ACEs (Adverse Childhood Experiences) and intergenerational trauma. People are also talking more about inequalities and the impact of poverty. Yet since the first OMH book, as just one example, the structural need for food banks has increased in the wake of new policies and political decisions. I wish things could be more joined up around prevention and equality, with fairer access to health and wellbeing.” **Fiona Macdonald**

“One of the things that I’ve realised is that as I heal and get better, I want to let people back into my life, because I do like being around people, I was just around people that didn’t really appreciate me before, or maybe saw my self-worth and I didn’t see that at all. And that’s kind of changing now. It’s important to be amongst voices where you can just be yourself and be acknowledged and be accepted for that. There’s something really powerful in that… To have that opportunity of being around people that have been through traumatic experiences and are still here and still moving forward and helping others is transformative. Because it shows you that there’s another world and there’s another life out there, and that you can be moving forward. That’s a really important, powerful message when people are not understanding what’s going on inside of them and killing themselves. We’ve got something else to say about that and there’s a better world out there, you just need to tune in.” **Andrew**

“It’s one of the most important things that I’ve been involved with ever… I spent 20 years with therapists and doctors and all the rest of it, getting it wrong about me, telling me I had anxiety… I once said [to a therapist] ‘I think I’ve got post-traumatic stress disorder’, and he was just like ‘well I think we all get a bit of that, Andrew’, and that was a conversation, closed and shut… I was up against that sort of stuff, and being ignored, to ‘Andrew, we’d be interested in what you have to say on this’, it’s very surreal, and I’m still trying to let this land and hit with me… So, it’s like ‘ah, I’m being involved in my own life, I’m being involved in things that I’m knowledgeable about, because I’ve got direct experience. I’m not reading a book here; I’m going into flow with myself and just talking. I’m not thinking about what I have to say’. And all these things have helped [me] to learn to re-trust myself and my own words.” **Andrew**

“There is a respect there for each other, and I’ve never felt like I couldn’t get a point across, or somebody was taking over. It’s not like that, there’s a respect there.” **Tommy**

"I'm so pleased [the Experiences of Trauma group] did that piece of work, because I've used the Rivers Centre while they've been at Fountain Bridge library. At the time they were doing the whole self-referral thing, and I just referred myself, went along with my support worker, and got into the service and then have received various things since then. It's really changed my life, you know, the therapy that I had there… Nothing I'd had before really lasted, you know? So, I'm very grateful for that." **Lewis Reay**

Wave Trust 70/30 campaign ACEs in Action event

"We put on an event called 'ACEs in Action' and that helped fund the counselling project and put a psychologist in the local GP's for one day a week… The ACEs in Action event that we held, it was a charity fundraiser. I felt that after I found out about the science of ACEs, and I found out about my own complex trauma it was a penny-drop moment for me and when we opened the clubs we thought, you know, there was an awful lot of talk about resilience and about adverse childhood experience, but nobody seemed to be doing anything. So, we dared to throw an event called 'ACEs in Action', knowing fine and full well that there was West Lothian ACEs hubs and established groups, but again we thought they were doing too much talking and not enough acting, so we did an event called 'ACEs in Action', for that purpose… That was collective advocacy; that was just pure a group of individuals coming together, throwing the event on. It was in a pub. We were told it wouldn't work, because of the charity. Not only did

Jay Haston, lead ambassador for Scotland for the WAVE Trust 70/30 campaign it work, we put it on for 12 hours, we had it on during the day, kids came, parents came, Macmillan Cancer came along, Wellbeing Scotland came along. From that event that's actually where the partnership came from the charity and the trust to create the counselling projects. So that one of our big proud moments." **Jay Haston**

Mental Health Advocacy Project (MHAP)

"A lot of our collective work has been about auditing services and we did quite a big one for Barony in West Lothian. So, we met with people in Templar Rise, Buttries View, and Mill Court and the feedback we gathered was sent back to Barony to inform their working practices. Service user volunteers carried out an environmental audit of day services in West Lothian and fed back to service managers improvements they would like to see in relation to the environment. As is our practice, service users themselves identified what questions they wanted to ask people, what was important to them about the environment, and they then surveyed the sites, assessed the welcome, asked questions, recorded their findings and sent the outcome of that to the day services manager. Following on we developed an audit tool, so we could assess how the services improved the environment, according to the outcome of the survey. Much was identified and improved consequently." **Kathy Hamilton**

"We were awarded funding from Edinburgh University Innovative Funding Programme to train a volunteer to work with service users to set up a training programme for medical students, and that's still running today. So, when medical students are at St John's Hospital, it's timetabled in that they spend an afternoon at MHAP. We have a group of service users who have spent quite a lot of time putting their own stories together, their experiences etc, and they share this with the medical students. Over the years, we've had really good evaluation feedback from the medical students." **Kathy Hamilton**

"MHAP supported service users to design and produce a questionnaire to survey service users' views of services in West Lothian. The service users identified services that were helpful to them and why, and what they thought of existing services. The report and survey findings were then submitted to the health and social care partnership, to help inform, the service redesign process.” **Kathy Hamilton**

“We participated in a project into the emotional impact of psychosis. This informed the work of a PhD student’s research. The student couldn’t find volunteers anywhere else in the Lothian area however through MHAP nearly forty people volunteered to participate in West Lothian.” **Kathy Hamilton**

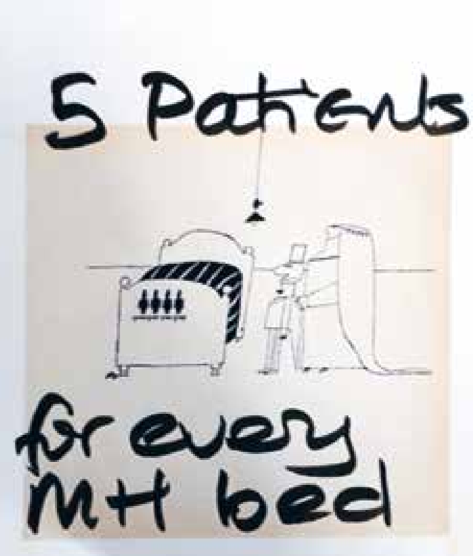
Voices of eXperience (VOX)

“Voices of experience (VOX) traces its origins back to a conference in Dundee, in 2004, when 102 service users came together from across Scotland. At the conference, there was a strong sense that, whilst there were opportunities to influence local decision-making, this was not happening at a national level in the same way, and often relied on one or two local groups trying to influence national policy development. A lot of hard work took place between 2004 and 2006 to set up an organisation to represent those with lived experience of mental health issues at a national level, funding was secured from the Scottish Government, and VOX was born in December 2006. The model developed being a membership organisation governed by a board of directors, the majority of whom have lived experience of mental health issues.”

“Over the last few years VOX has ensured that our members’ voices are heard and make positive change at a national level on a range of areas. To ensure we have captured key issues we have used a ‘snapshot approach’ where we have engaged with our individual members on particular topics via discussion sessions, surveys or interviews, in addition to utilising support from our more active group members to help us to create a national picture of what is happening and what needs to change.” **Wendy McAuslan, VOX Manager**

Peoples Conference: *top two rows* – 2015; middle row – 2016; *bottom row* –2017

Peoples Conference: *top two rows* – 2018; *bottom two rows* – 2019



Lothian Voices

Lothian Voices started in 2013 as a response to the 2011 Lothian Mental Health Strategy ‘A sense of belonging.’ The People’s Conference came about because people with lived experience of mental health issues were looking for a place to come together in a protected space. The first conference was held in QMU in 2014 looking at people’s responses to the strategy and the findings were presented at the 2014 NHS Lothian Taking Stock event – an annual review of the work being done in mental health in Lothian. Lothian Voices went on to design and facilitate a People’s Conference every year on topical issues that were important to people. Each year, Lothian Voices presented their findings at the Taking Stock event, while it continued.

When the Health and Social Care Integration agenda came into being in 2018 the Lothian Strategy ended. The Lothian Voices group adapted to continue with an annual People’s Conference and to find other ways to have their voices heard. They now attend the Cross Party Parliamentary Group on Mental Health, responding to national issues like the update of the Mental Health Act. The group also formulated their ideas for a new LEARN course that looked at people’s experience of living with mental health issues – now known as ‘A Human Experience’.

People’s conference reports 2014-2021

Timeline: Key developments in collective advocacy 2010-2020

2010

Detention report with Edinburgh Users Forum

East Lothian collective advocacy transferred to CAPS from East Lothian Involvement Group (ELIG)

'Much More Than a Label' Personality Disorder toolkit was produced

Launch of Oor Mad History book and CD

2011

Collective Advocacy in Edinburgh transferred to AdvoCard

Experiences of Psychosis started

NHS Lothian Mental Health and Wellbeing Strategy 'A Sense of Belonging' 2011-2016

2012

Lothian Voices started

CAPS 'Living with Labels' film funded by See Me

'Fluctuating Outcomes' report on experiences of the Work Capability Assessments

2013

First 'Out Of Sight, Out Of Mind' exhibition at Summerhall

CAPS moved into Old Stables

OMH archive transferred to Lothian Health Services Archive in George Square

2014

First Mad People's History & Identity course at QMU

'LEARN' set up in Argyle House

First People's Conference

Butterfly Bursary led to eating disorder project and 'Seen But Not Heard' film

Welfare Reform Individual Advocacy

2015

'Conversations for Change' funded by See Me

Eating Disorders GP resource Pack and booklet funded by See Me

2016

SCIO status for CAPS

Health and Social Care Integration legislation passed

Experiences of trauma group formed to input into redesign of Rivers Centre

Arts as Advocacy project started

‘Spilling the Beans’ eating disorder film

2017

Stories of Changing Lives 3

Young People’s Mental Health Advocacy report

Eating Disorders awareness raising event with BEAT

2018

Peer Collaborative

‘Changing Minds, Changing Times’ new LEARN course

Experiences of trauma group involved in developing work on Adverse Childhood Experiences (ACEs)

Universal Credit resulted in huge demand for Individual Advocacy in East Lothian

2019

Change to CAPS constitution

CAPS Eating Disorders conference

‘Understanding Psychosis’ experience led course

CAPS Collective Advocacy event in the Scottish Parliament

2020

Advocacy moves online due to Covid-19 pandemic

CAPS secures funding from Thrive Edinburgh for projects for people from ethnic minority backgrounds and people who identify as LGBTQI+

Mind Our Rights! Report launched at Human Rights-Based Care Partnership Symposium (joint work by AdvoCard, Patients’ Council, CAPS)

CHAPTER 5

Involvement in the Lothian collective advocacy & mad activism movement

We spoke to people from various collective advocacy groups in Lothian and asked them about their involvement. People told us about how they have been involved in the movement, spoke about what collective advocacy means to them, and shared their memories.

How have you been involved?

"I got involved in the [Much More Than a Label] project [first]. I started doing training with Napier University and then actually delivering the two-day training course... and then gradually got involved with other things. Kirsten [Maclean] was doing the exhibition, before it was Out of Sight, Out of Mind. My boyfriend was putting artwork in, so I put some artwork in because I was feeling left out, and that was the only reason I made anything. And then Kirsten asked us to be involved in organising it and that's when Out of Sight, Out of Mind was born in 2013... I was involved with Lothian Voices for a while, because I was doing the People's Conference for a bit, and then the ethnic minority one and the LGBT+ one, as well. And I'm also on the management committee now, which I swore I would never do." **Lauren Stonebanks**

"I was immensely fortunate in that the [Much More Than a Label] group was flexible enough that people could take up whatever they felt they had the capacity and the right skill set for. And in terms of the way the group ran, it was incredibly supportive as well, because whilst it wasn't a support group, all of us worked together with a sense of sensitivity and mutual care that meant that we all felt supported... And that I think was the most powerful and empowering thing about this group, that it created an environment that enabled each of us, who had faced specific barriers to participation because of the nature of our conditions, to then overcome those barriers and participate in the various, somewhat higher levels of engagement, including things like providing training, or policy consultation or whatever else.” **Vivek Santayana**

“I’m a really big fan of peer support. At the moment, I facilitate for Andy’s Man Club. They asked me to help them set up in West Lothian, so I’m actually facilitating Andy’s Man Club the now as well as having the Men Matter... [Andy’s Man Club] is a nationwide one, and in West Lothian I’m the facilitator for the group with another guy. So, we facilitate the groups and make sure the guys get on well, and that they’re heard, and that they’re understood, and there’s no judgement, and they all leave on a happy note, and if there’s any concerns then [connect] them with the relevant authorities.” **Jay Haston**

Peer work is...

“I’ve been going to [the MHAP group] since it started, and I’ve found that really good. There’s an awful lot of websites out there that service users can go to, to find out information about service providers, but the MHAP group actually provides a space where service users can go, like myself, whose got groups and advertise Men Matter or Andy's Man Club or the WAVE Trust, but also users can turn up and see what's on offer in their community, so they can actually engage and talk and see what one's better for them. Because there could be a men's group that specialises in one thing or in one area, and there could be one in another area that's better suited, so for a user's point of view the MHAP group's been amazing, because it gives service users, people who are looking for something a place to go and actually speak to the people who are running these organisations." **Jay Haston**

"I went to AdvoCard for advice, and they told me about the Crisis Centre advocacy group... I sat on the partnership group until it disbanded last year." **Sarah**

"Since joining CAPS I have taken part in delivering LEARN training and also presentations at QMU. I have also been involved in writing my story for the Humans of Scotland book, which was a great opportunity! The [Seen But Not Heard] group has been involved in many exciting events since I've joined but I missed out on a few due to other commitments. Although I wish I could have taken part I am grateful for the flexibility and no-pressure of the group. It fits around my needs, and everything is optional." **Mohasin**

"I didn't go out deliberately to be involved in advocacy. But when I did get there, it was the right thing for me I'm quite a strange person really – Even if I could work in employment for money, I wouldn't... Maybe on a bit of a selfish note, doing all this good stuff was good for me because it helped me, and gave me something. I was getting back as much as I was giving, really. Even though I wasn't getting paid with money... I think it was good for me because I'm a bit of a loner. So, without the Open Mic night, CAPS, and all the things that were involved with it, then I would've just been on my own all the time, I wouldn't be with other people. I like to be with other people when I'm doing something good, I don't like to be wasting my time." **Theresa Trotter**

"I felt like I was doing something helpful for people." Theresa Trotter

Poetry books by Jo McFarlane

"In the 1990's I was active in collective advocacy with CAPS; then progressed to influencing reform of mental health and social care through poetry recitals and publications. Over the past ten years I've presented at over 300 events across the UK and written several books, so I was offered by CAPS the opportunity to share some of this work at SMHAFF through bespoke events, some of which I co-collaborated on with others, including, most notably, my partner, Sally Fox... It has always been a nurturing and supportive collective, and very well organised. One of the things I've appreciated most is that I've been given opportunities and a platform to present whatever I wanted, rather than having to follow 'party line', so to speak. This artistic freedom has enabled me to take risks and explore challenging themes in my work, which seem to have been appreciated by audiences even though it has sometimes challenged them. And most importantly, I feel that CAPS has always had my back. Whether they agreed with my views or not, they defended and supported my right to express them." **Jo McFarlane**

“I think everybody that probably has got involved with this has been through so many challenges in their life. They’ve got this inner resilience that’s inside them that they can just [snaps fingers]. You know that pilot light isn’t going to go out, so there’s a strength in that. There’s a strength in numbers. So, whatever comes along, we’ll move through it... It’s nice to be in company and it’s a privilege to be amongst people that have managed to get through some really difficult things, and still want to keep going and doing something about it.” **Andrew**

“I sat on the board on the panel for Midlothian for their new services for lived experience and I sat for hours going through all the tenders and applications, just to see that there was basically a person-centred roadmap out for people. So, people weren’t getting me with this old school nonsense of what therapy is. ‘Do as I say and not as I do’, nah, nah. Your days are done.” **Andrew**

“I think there’s something to be said for being able to do it from your own personal lived experience, something that’s close to you. But there’s also a place in volunteering for working with completely different groups. People that you just want to help. For instance, myself, I work with ELCAP, so I don’t have anyone with Down Syndrome, or learning disabilities, or on the autistic spectrum, but I go and try and help them anyway. So, it’s different from just me being concerned about me. You can be concerned about other people as well.” **Tommy**

“I asked Jane if I could go along to one of the meetings, and I went along with her. And since then, the head of the Integrated Joint Board asked me to come and speak to her, so I did, and now I get invited along to Adults with Complex Needs, which is fine. Feels much more like you’re actually doing something, even if you don’t say a word, and you just sit in the meeting... Since they got involved with the integrated joint board, health and social care partnership teams, it’s felt more included in what’s going on around East Lothian. I found that quite useful in my other voluntary work with ELCAP. So, until then it didn’t feel as if there was so much going on, but now it feels a lot better.” **Tommy**

Dianna Manson had a long involvement with collective advocacy in Lothian and was a strong advocate for the value of lived experience in developing mental health strategy. Sadly, she passed away in 2021. She was well respected by her peers and will be greatly missed.

"[Dianna Manson] was wonderful – she had natural leadership ability, which did well for AdvoCard and Edinburgh Community Voices. She was involved in advance statements and got me involved too. She put me in touch with poetry writers because she knew I write poems. One of the nice things about Dianna – she did speak a lot, but she was considerate. She listened and she gave you a chance to say something. What she had to say was always interesting and very considered, and she was in the genius category. She had brilliant ideas about mental health." **Anonymous**

Dianna Manson

Miguel the Cat

We interviewed Dianna in 2020 with Miguel the cat. She speaks about her involvement below.

"I think it's absolutely essential that people with the experience, the lived experience, are represented in all aspects of things." **Dianna Manson**

"I've taken a great interest. I was trained as a doctor, so that initiated me into interest in all aspects of what I was involved with, within my experience, within the service. And it allowed me a great love of interacting with people and my fellow peers, and an understanding of where they might be at times, because I had been in the position myself...

I just think we've come so far, thanks to the activists of the past. I really don't consider myself to have been an activist, I just think I was around. I was just seen, just had a loud mouth. Just had an opportunity, as well. I don't know, I suddenly found that I was on all sorts of things."
Dianna Manson

"At one point, the cat was blackballed from here. And we had a charge nurse who would not tolerate having a cat on board, only therapets were allowed in hospital. And he kept making an appearance, and he was so persistent that he's won over. And that's what is a great example of persistence and diligence." **Dianna Manson**

We think Miguel the cat would make a great activist too!

"Carry on regardless, you will then be seen and heard. That's a good thing to live by; persistence, and you will then be seen and heard." **Dianna Manson**

"I suppose my motivation to get involved is I've got to a point where I'm not in the middle of a crisis all the time, and so I've got the energy and the time to get involved with something that I hope will make a difference for me, and also has the sort of outcome that's making a difference to other people." **Lewis Reay**

"Being on the CAPS committee was a really good opportunity to meet lots of people from different backgrounds. It was a good opportunity to get into the guts of understanding the work CAPS is doing and what it needs to keep doing it... [CAPS] was just full of people who were just so passionate about what they were doing, and they were taking their own experiences, and they were really proud and open about their own experiences of using services. And they were using those to make things better for other people... It was constantly inspiring to see the work that volunteers were doing, and that staff members were doing, and how hard the staff members worked, you know? How passionate they were about their jobs, and how dedicated to the principles of independent advocacy, and making sure there aren't conflicts of interest, and how essential it is that it really is independent." **Kirstin**

"I never for a moment considered myself an activist or even at times an advocate as part of the collective advocacy movement, because I just very much thought I'm just being myself." **Safina Bibi**

"I am so proud to say I was once, or am still, associated with [the Patients' Council]. I really love that side of things, and hearing people such as myself being so vocal and advocating their experiences and how things should be a certain way, should not have been the way they were, and continue to be in some instances... That very much resonates with me a lot... There was something about it that seemed very authentic and very in keeping with my own values, particularly a lot on the human rights side of the things and patients' rights side of things and I just knew I wanted to be part of it." **Safina Bibi**

"My most recent involvement with collective advocacy was when I was in hospital in 2010. After having accessed Mental Health services in the past I thought it was a good opportunity for me to give back, to contribute, pay it forward so to speak. I felt that I owed a debt of gratitude, although not getting the treatment I wanted to make it better, I wanted to make things better for those coming after me. My very first experience of advocacy was when I was in 1993 in hospital in England. I had an advocate who worked with myself and my wife, it was wonderful, someone to represent my voice!" **James**

"We thought we'd do some things in the Scottish Mental Health Arts Festival, and we did a collaborative piece called 'Art Builds Bridges.'... We decided to make a big piece and it was about three panels big, and we thought about art building bridges, and then we thought about the road bridge. So we'd all sorts of things on the bridge and underneath the bridge." **Marianne MacKintosh**

"I have been involved with CAPS / Out Of Sight Out Of Mind for 9 rewarding years as an artist, designer and volunteer. The most important achievement for me has been the continued presence of the exhibition in Summerhall. It has thrived and grown and reached out to many people. It has been talked about and now has a high profile that reflects the quality and diversity of work within it and those that have worked and continue to strive towards its success. The main challenge has always been perception and attitude of some elements in society. However, these have and can be transformed and shaped by the ongoing positivity of all involved. Thinking about the future prompts me to say, 'Keep going; dazzle, inspire, blossom, and be…' " **Michael Dawson**

OOSOOM 2020, Artwork by Michael Dawson, titled 'Craving in Cointown'. Photo Credit: Michael Dawson

OOSOOM posters 2013-2021,
Artwork by Michael Dawson

“I was running an adult education project called ‘Outlook’, and with a background in the arts was always keen for people to participate in the arts. I believe that arts is a great medium for everyone to have a voice… I think the building bridges is a good example of people coming together and talking about what they want as part of an art piece… I think the collective voices in doing a collaborative piece like The Bridges, does mean that it opens up to discussion and it’s sometimes quite nice to have that space where you can listen to the voice of another person.” **Margaret Drysdale**

“You felt you kind of belonged to something, it was just a fabulous group of people in various stages of recovery… Every month, we’d go into a ward, there’d be no staff if the room, and patients could just be asked ‘What’s going well? What’s not going well?’ [People raised issues about] toilets, washing machines, lockers, somewhere to keep your stuff, and staff saying, ‘well there’s no room here, you know, it’s not a hotel.’ Or just, attitudes and things you felt could be looked at. There was just a kind of malaise, a kind of, ‘No. Don’t ask us for anything, you’re lucky enough to be here’… There was a time where staff were so demoralised. I think they felt they were getting it from management and patients, and nobody was really going ‘but actually, you know, you do get it right.’ I think the Patients’ Council [are] quite good at celebrating the good, but also pointing out [what] has to change.” **Alison Robertson**

“I had been involved using arts as a form of self-expression for my mental health always, either formally, with CAPS, as part of the Arts as Advocacy and SMHAF, and Out of Sight, Out of Mind. Before that, as part of a writing group, and before that with LGBT Health and Wellbeing in their art therapy groups, and women’s groups, and various other things… Despite the fact that I’m an author, writer, and various things, and have studied English literature, I have always found that I suffer from a paucity of language when it comes to describing my emotional turmoil and mental health. I guess I didn’t learn an emotional vocabulary when [I was] younger. So, I’ve always found that sculpting my emotions in a figurative sculpture way, has been my way of externalising, expressing, and sharing what’s actually going on with me.” **Elspeth Morrison**

So, am I an Activist?

I first became involved with Out of Sight Out of Mind in 2015, initially exhibiting two pieces of work – Dreamscapes of Light & Sorrow and Spiritual Strength, Impermanence & Fragility. Latterly, joining the Oor Mad History collective advocacy group in 2018/19.

At this point in time (2015) I had been a Make-up Artist for over 20 years and had only recently started incorporating body art and photography into my work. Each allowed a space to work from that enabled me to manage severe episodes of depression, which I have experienced since childhood. Dreamscapes of Light & Sorrow explores the fluctuating emotions and thoughts experienced during depressive episodes, whilst drawing influence from Japanese art as well as the spiritual practice of Buddhism. Spiritual Strength, Impermanence & Fragility, aims to understand that everything in life is impermanent, highlighting that depressive episode do not last forever; that beauty is always with us, despite our fragility and vulnerabilities. Both investigate the subtleties and fluidity of thoughts, which can dwell in the shadows of deep sorrow, yet move into moments of fleeting clarity, before retreating once more.

From taking part in the 2015 exhibition at Summerhall, I was invited to join the OOSOOM planning group, which I accepted. This led to other opportunities, such as having a solo exhibition, Strokes of Light, included in the programme of the Audacious Women Festival, 2016. Strokes of Light was a visual timeline spanning three years of a distressing life event that documented my relationship with chronic depression and a deeper reliance on my creative practice, which has become integral to my wellbeing.

I did not have any experience of collective advocacy work before becoming involved with OOSOOM, and I was unaware of how collective advocacy supported individuals or a community. I didn't even know the meaning of the word advocacy. So, when I joined the planning group, I was tentative in my approach. I doubted my presence and contributions to the weekly meetings as having any purpose whatsoever. The planning of the exhibition had existed previously to my attendance and could continue without me. What could I be contributing to the wider outcome?

However, it seemed I had missed the point entirely; as little by little, over the weeks, months and years, I began to grasp the power behind collective advocacy and its impact, not only on an individual, but as part of a community of people with lived experiences of mental health issues. My artwork gave a voice to my inner most emotions. Emotions I was not ready to articulate in the form of words, as they were too raw, too personal. Collective advocacy, whether through OOSOOM or Oor Mad History, gathers the stories and lived experiences of others in one space, galvanising many voices into one, heard in unison. A powerful platform indeed for those that are marginalised and often go unheard by an able-minded and able-bodied society.

I use my creative practice as a way to express myself. To capture ephemerally my inner and outworld through body art and photography, and in more recent years, botanical art and illustration. I had never considered myself an activist, or someone who had the courage to be an activist. Collective advocacy has allowed me to see that when I create, it is with the intonation of a mental health activist first and foremost. I share my lived experience with the hope that it has the potential to resonate with others and effect change, using collective advocacy as a means to do so.
Nisi Conyngham

Left: Dreamscapes of Light & Sorrow, Nisi Conyngham
Right: Spiritual Strength Nisi Conyngham

What does collective advocacy mean to you?

"For me, it means representing the view of everybody. It's about abandoning your own views a little bit, and again coming back to those vulnerabilities of exposing yourself to an opposing view, even though you might have a certain view yourself." **Safina Bibi**

"Collective advocacy is a group of people having more power together than they have apart, and making their collective voices heard." **Kirstin**

"A bunch of people coming together, making a lot of noise together in a room and finding bits that they agree on, and thinking 'yes, yes, we need to do something about this', and then amplifying each other's voices. Saying the same thing and trying to make those in power listen." **Lauren Stonebanks**

"It's very open-ended. You get a group of people with similar vested interests and from a conversation within that group they identify issues that they want to pursue. It might be to ask questions of services; it might be as we're doing [in LEARN] to provide structured conversations. There's something very organic about collective advocacy." **Tom Frank**

"I think it means absorbing groups of people and allowing them to contribute in their own way to making a difference to their life in the services provided, and their life in general in society, the way they're recognised in society." **Dianna Manson**

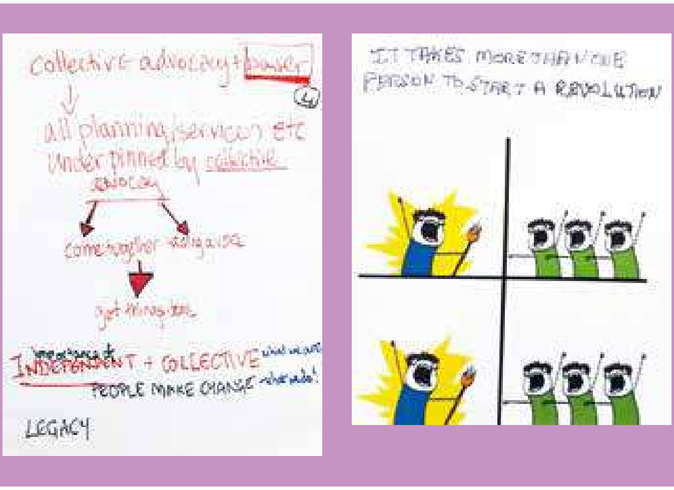
“I think what’s really significant is that so many people want to be honest about their experience, and want to connect about their experience… It’s the fact that these are the unheard voices, and this is a scream to be listened to.” **Elspeth Morrison**

“I think in modern mental health advocacy it’s about amplifying that voice.” Martin

“There’s someone that can speak on somebody’s behalf, and say what they want to say, and I think that is just a good, honest thing.” **Theresa Trotter**

“For me it means people who have some form of shared experience, and that can be all sorts of things, but getting together and saying ‘Well, what do we want changed? What do we want said and heard? And, and how can we do that?’ It’s this big, massive, broad umbrella, because for me collective advocacy is getting together to put a submission to government in response to some sort of call, but it’s also a giant piece of art that talks about what it means to have a particular label, or what it means to experience discrimination.” **Kirstin**

“It’s not just about us standing up and telling people how awful trauma is, and what all our traumas were. It’s about saying ‘this is what has happened to me’ in a really safe way, ‘and this is what living with it felt like when I tried to be around other people, services… And that might have been a library,



Left: Collective Advocacy and Power
Right: It takes more than one person to start a revolution

that might have been a professional, that might have been the lollipop lady. It might have been anybody, but this is what it felt like when I tried to interact with them, and this is how they can do that better in future.' " **Andrew**

"Collective advocacy for me means a group of people with similar experiences coming together to support and empower each other to create change and educate others." **Mohasin**

"It's about people's voice being heard, but actually having spaces that are about a much more collaborative conversation. For me that feels like it's a helpful way of people's voice being heard because there's lots more listening and people trying to reduce the us and them dynamic." **Fingal**

"When I think about what collective advocacy means to me I could use all the buzz words... 'Validation, meaning and purpose' they would all be true!" James

"For me it means everybody coming together for a common cause. For me, I've addressed three of them over the last three year and that's male mental health, suicide, mental health as a whole, drug abuse, and I've managed to tie the correlation into trauma. As three of Scotland's biggest problems, and three of West Lothian's biggest problems, and it all goes back to childhood trauma. And that's why I campaign for the WAVE 70/30." **Jay Haston**

"Listening to the here and now, what people have to say about what's going on. Hearing people's experiences and then taking that to whoever can maybe do something about it, and just giving a voice to people who are telling us what's happening... Feed that information to the right people where hopefully change can take place." **Alison Robertson**

Memories

"The last [Out of Sight Out of Mind exhibition] that was on in the autumn there, I took my friend along to see it, and also somebody who's non-verbal autistic, and he was fascinated by the interactive things, you know, there were things with sounds and there were the ones you could draw on and touch and all that.” **Marianne McIntosh**

OOSOOM Exhibition launch 2019. Artwork by Mia McGregor titled ‘the cube.’ Basement Galleries, Summerhall, Edinburgh, Photo Credit: Chris Scott

“Somebody from CAPS turned up and just said, ‘D’you wanna do something for the SMHAF exhibition at The Chaplaincy Centre?’ And I did a piece. I think it was a Snakes and Ladders about how there were far more snakes than ladders, no matter what you try to do, the path was always inexorably downwards… I remember going to The Chaplaincy Centre just to see it on the wall, and I stood behind this woman, and she just said, ‘I totally get that, totally get it.’ And I thought, ‘That’s why I do what I do’… I did a piece many years later. A sculpture called ‘Unfinished Grief’ because the sculpture itself was made out of stone, and it was unfinished, but it was deliberately unfinished, and it was so raw, and when you looked at the face of the sculpture it was just, you know, all the emotions. And there was this one guy at the exhibition, and he just said, ‘I totally get it, totally get it.’ That’s what we all do with art, in a way, it’s an emotional response. And it bypasses words, and I think bypassing words can sometimes be stronger. Like we bypass labels that are given to us, because often our emotional responses are entirely valid to what’s happened to us, and yet they’re labelled, and othered.” **Elspeth Morrison**

“I particularly enjoy the exhibitions every year. They are very diverse, well curated, and broadly representative. I think the work is of a consistently high standard. In terms of events I’ve taken part in, my favourite was

‘Is This Love: a celebration of the therapeutic relationship’ which Sally and I co-collaborated on with our friend Elspeth Morrison. It seemed to really touch the audience because we were not afraid to show our vulnerability. I think people connect with that because, being human, we all are vulnerable, yet we live in a world that suppresses and despises us for showing it. And, of course, my all-time favourite memory from SMHAFF was meeting Sally at the film awards ceremony in 2013 and falling in love with her at first sight!” **Jo McFarlane**

> ***“We all are vulnerable, yet we live in a world that suppresses and despises us for showing it.”*** Jo McFarlane

OOSOOM Exhibition Launch, 2017. Artwork by Penumbra Group. Basement Galleries, Summerhall, Edinburgh. Photo Credit: Chris Scott

“Living in Summerhall. Taking bags of stuff and just having whatever anyone needs, like hammers and spirit levels, and all sorts of things. It’s like a big happy occasionally dysfunctional family. It’s art and artists and mental health and people with very artistic outlooks, so yeah, there’s always going to be some dysfunction, but you know, it makes it interesting… We get a lot of really positive comments, like people saying ‘I never thought of it this way’. One of my artworks included a bit on side effects, so I had the little book of drugs, and the giant book of side effects. This GP wrote and said they never really thought about it, because I covered that book in cut-outs from the BNF listing all the side effects of all the drugs I’d ever been on. And so [the GP] was going to think more about that when prescribing things in the future. I'm like, 'Yes!' It's one person, but you know, it's something.' " **Lauren Stonebanks**

OOSOOM 2018. Artwork by Lauren Stonebanks, titled 'Brexit Bunker.' Basement Galleries, Summerhall, Edinburgh. Photo Credit: Ian Dodds

"The ridiculousness of what we were dealing with. Laughter can bring a group of people together. Tom Carey, at meetings about the crisis service, he'd go 'oh we've been campaigning five years' then the next meeting 'ten years', and then it would be like 'since the start of time', and his arms would get bigger and bigger. I used to get annoyed cause I'd go 'Tom that's not right, it was actually this many years', and then I realised that actually, it's about his passion." **Anne O'Donnell**

"I presented for See Me in the Royal College... There I was on a plinth, speaking to all these people who, in days gone by, I would have bowed to at the end of my bed... But there I was in front of them, telling them what it was like to be one of their patients, and that was marvellous... There was a very very nice roadie, and he came up to do my butterfly mic, and then he came to help me come down off the stage, and I said to him, 'You know, Oliver, we all need a roadie like you, instead of all that lot out there in the audience', and I was still mic'd. And they absolutely fell apart, so, anyway, it broke the ice." **Dianna Manson**

"There I was... speaking to all these people who, in days gone by, I would have bowed to at the end of my bed." **Dianna Manson**

"I remember doing a talk once with the OT students. I was brave enough to say 'This is who I am. This is the way I am, and I have this label, but it doesn't control me.' The label doesn't control me, my mental wellbeing sometimes controls me. I think that's opened up conversations in certain situations that I've been in with people that you assume don't have lived experience. And people have come up to me and gone 'Well, thanks, actually, because I don't like to admit it, but I do have lived experience, and to see people like you talk about it, it breaks the barrier of talking about it.' " **Liz D**

"I go and talk to baby psychiatrists at the Royal Edinburgh hospital. And they're fourth year medical students, and it's their first rotation in Psychiatry... I'm the first potentially ravingly insane patient that they see. And they come through that door, and 90% of them are terrified. They are terrified. And you think, 'That level of othering has already happened', and I have to fight over the next hour, hour and a half, to connect with them, and get them to connect with me, and see me as a real person... I had a lovely last session, where the female psychiatrist said: 'Have you got any words of wisdom for the students?', and I just said, 'Please treat people as people, please treat humans as humans, and you're human, and your patient is human, and what they're struggling with could happen to you in the blink of an eye, so don't other them' at which some of them looked more scared than when they walked in. She just said, 'Yeah, very good advice, thank you for leaving us with that thought'. So, it's messing with people's heads... in a good, compassionate, thoughtful way." **Elspeth Morrison**

"We came runners up in the Glasgow Herald Awards for widening participation...The awards ceremony was a moment that I'll remember because everybody was there, and it didn't really matter we didn't win. It was just nice to be at the table." **Elaine Ballantyne**

"Going to the students union after the course is where I think my best memories of actually just chatting is. Human beings relating to each other. I have good memories of these informal chats..." **Elaine Ballantyne**

"They were trying to set up 'The Safety, Privacy and Dignity Meetings', where the Patients' Council would bring comments and things from collective advocacy on the wards, and then meet up with staff and say 'these things are happening...' But you kind of felt it was preaching to the converted. The nurses that would come to the meetings were already of that mind, but I think [they] found it hard to fight against the old-school culture... It was quite strange at the beginning, going into meetings with management and head nurses and things, especially when I was still on a ward... And the acronyms, oh my goodness. When you first start, you're like, 'What's the SPD group?' And that's 'Safety, Privacy, Dignity'... It was quite intimidating at the beginning trying to get a head for it all." **Alison Robertson**

"There's been lots of good performers who've come, lots of good performers. And sometimes I think, for some of the performers we've had, the Mad Jam venue could be a stepping stone in their careers, because we're such a safe, encouraging, supportive environment for a musician just testing out their material. And that is how we promote ourselves, we give performers an opportunity to perform to an audience that are very welcoming." **Martin**

"I would sometimes take Ciara [the dog] out if Kirsten was busy, I'd say 'I'll take her out for a wee and take her for a wander round'. Having a dog there was wonderful for me. I'm pretty good with animals, so that was a helpful thing for me." **Theresa Trotter**

"I was in the Mad Studies group. And that was quite good. I liked the bits where you took photographs and things because that involved getting a skill." **Theresa Trotter**

"My strongest memories of CAPS aren't about the committee meetings, delightful as they were, and always including biscuits. But they were about the collective experience of these events where loads of people were getting together and being creative and being peers as well. Because I'd been working in the NHS, I was very used to these events where you have professionals, and you would have people with lived experience and that would very much be the divide, as if that is a natural divide, which it's not. Just to be at an event where everybody was there, and everybody was equal, and everybody was having their say in really creative ways, I think that was the strongest thing for me. Just the power of it, you know?" **Kirstin**

"At the beginning there were some more edgy situations where, where people had very much their own fixed ideas, and that was wee bit uncomfortable, but what was wonderful is that eventually we understood each other, and the fixed ideas just melted away…The other memorable bit, and it's a sad bit, is that when people decided not to come back to the group, especially people who had contributed well in them…They were very much part of the group…and they were missed." **Tom Frank**

CHAPTER 6

Challenges and the impact of collective advocacy

In this chapter, we hear from people we interviewed about the challenges they have encountered and about the impact of collective advocacy.

Challenges

“I suppose whenever you’re going to bring a group of people together who have had their own personal experiences of the mental health system, that is going to be challenging in itself. Everybody wants to have their experience heard, their view heard… We all come with those personal biases, so sometimes the sort of working relationships could be challenging in themselves. I think that’s just advocacy for you. People are very passionate… When they come together like that, it can be explosive at times… and that can be very difficult to manage when you yourself and those around you are themselves experiencing mental health difficulties.”
Safina Bibi

"People that have been through the system do come with views of what needs to change, and trying to put those groups of people together, it can be explosive, and I think that needs to be embraced, and supported." **Safina Bibi**

"Oh, there's lots of challenges. One is a lot of people don't understand advocacy, or why it needs to be independent. Originally CAPS had been called a 'Consultation and Advocacy Promotion Service' because we were there to promote consultation, advocacy, people being involved. Advocacy seemed a really radical idea when I first heard about it, and I really didn't know if it would work." **Anne O'Donnell**

"[Collective advocacy] gets confused with user involvement which is basically when you're responding to someone else's agenda. People don't understand it, including some advocacy providers... But I think there's going to be a bit of a resurgence in interest with the rise of the human rights agenda, and one of the things under the UN Convention on the rights of People with Disabilities is that governments and others need to consult with disabled people's organisations, which is really important." **Anne O'Donnell**

"I think there's a growing recognition of the need for collective advocacy. One major challenge is that very few places in Scotland have it. Like, real collective advocacy; Lothian: very strong, Highland: strong, and that's about it." **Anne O'Donnell**

"Sometimes funding has seemed rather precarious. Things seem to be going okay, I mean the [Out of Sight, Out of Mind] exhibition has got at least five years funding with the possibility of it being extended to another three." **Lauren Stonebanks**

"There's the ongoing challenge for any third sector organisation of sustainable funding and knowing what you're going to do for a couple of years. And I know CAPS have also had difficulty where they think they've got funding the next year, but perhaps a larger organization, say, the local authority or the NHS, aren't able to confirm it until the last minute... And if you can't confirm it 'til the last minute, well CAPS still has staff to pay, and an office to rent." **Kirstin**

"Sometimes flinging one spear at a monster ain't gonna kill it, but it's whether you end up feeding that monster by them turning it into a publicity opportunity, saying, 'Look! We're doing this'. No, you're not. You're not doing the real thing that you should be doing. So that's a fine balance to play, and I'm not sure how you play that, politically. But the essence of mental health advocacy is to provide a voice for the people who need it, and who need help saying what they want to say. And it's not just saying what they want to say, it's making the changes that need to be made, and one shouldn't take the place of the other. And I guess that's as political as I get." **Elspeth Morrison**

"People just worry about speaking to power and authority. Whereas it's actually fine." Tommy

"Certainly, for me as an advocacy worker there was a big thing about how much of myself do I bring to this and how much do I not. I think I bring a lot more of myself now." **Fingal**

"It was the first time I was allowed to speak about my own personal experiences. I think at first, I didn't edit it enough. I just splurged it out, and when I look back on it, I'm a bit ashamed it was incredibly clumsy. Through the years we've become... [better at tailoring] what [we] say about [ourselves] to the circumstances of the conversation, so it never comes out just as a monologue, but it's part of a conversation. And I think that's a huge change." **Tom Frank**

"The other challenges that we had very often is when we were running conversations, getting quite worried about individuals and trying to work out whether it is our responsibility to try to work out whether what we were doing might have affected them negatively. I think it was a challenge, but I think it was a very healthy challenge, because it meant that we always followed up with people. And Anne took a major responsibility in that." **Tom Frank**

“It can be a challenge for communities to have their work displayed because the established art world often excludes people that will exhibit at Out of Sight, Out of Mind, which I disagree with. It’s brilliant that Summerhall has opened it’s doors up to an event like Out of Sight, Out of Mind because Summerhall itself is part of the established art scene and so many of them exclude and don’t welcome others.” **Margaret Drysdale**

“When I started, CAPS were desperate for anybody who met the values and principles of CAPS, because there were three people when I joined [the management committee], and three was the bare minimum… So, I think early on when I started it was just about getting folk on the committee, so they were safe, but then they did a really good lot of advertising, and they started to get more people applying.” **Kirstin**

“I think Patients Council’s had to be brave, and Simon’s the captain of the ship as it were, and he’s had to be brave and sometimes say things that are needing to be said, speaking up for the patients, but that the management find it difficult to listen to. The subtle approach is a good approach, but sometimes things need to be courageously and bravely brought up for discussion.” **Martin**

“So, we were talking a lot about education, wider awareness, rather than just talking to mental health trainees but actually how can I change the discourse in wider society? Something like psychosis still quite taboo and how can we impact that?” **Fingal**

“A lack of people willing to be involved. Either because they don’t really like doing things in groups, or they just don’t have the time or the energy, or they’re not well enough to contribute as much as they’d like.” **Lauren Stonebanks**

“The biggest killer of men in Scotland between 21 and 55 is suicide. Men just don’t talk. There is so much stigma attached to it, and I started doing videos on Facebook and putting them out there after I’d got help, saying that there was nothing to be ashamed of and I truly believe that it’s a masculinity problem. Men can feel emasculated talking about their feelings and that's still a big challenge, even today." **Jay Haston**

"I really enjoyed the peer work that I did in the [Health in Mind Anxiety and Depression support] group of supporting people at the grassroots level. But then I felt I was hitting a wall when it came to trying to work towards structural change, to mitigate these problems in the first place, and that's what then got me motivated to get involved with collective advocacy." **Vivek Santayana**

"The Crisis Centre partnership fell to pieces when the localities came into place, and the Crisis Network took over. And the Crisis Centre partnership felt that there were too many meetings that were very similar, so they were going to disband the partnership. But that means no-one with lived experience has been on the committee helping run the Crisis Centre for the last year...They had an engagement event, but very few people with lived experience were there. It was mostly professionals because it was a big daunting event. And a few people with lived experience that came, left early because they were overwhelmed... So, we're pushing for a new partnership group to open, or something similar... What came out of the Crisis Centre meeting was that they feel they need a second Crisis Centre, because the Crisis Centre can't cope with the capacity issues, and can sometimes take four hours to return a phone call... Which is too long if you're in crisis. They direct you to MHAS, and MHAS direct you back to the Crisis Centre." **Sarah**

"I have had experience in the past of running my own peer group. Whilst I am glad that I did this I do have regrets about this now. It led to a real split in the user movement and I felt managing this tested my loyalty and when it collapsed I felt some responsibility for this and that was very hard for me. It was difficult when providers changed and people had to make choices. We had good intentions and we were well organised it was a great start, but it was so hard to maintain on our own." **James**

"That's what keeps me going, keeps me driving, that we're going to overpass all this stuff. They're going to have to hold themselves accountable. Why weren't they paying attention and listening to people that were speaking articulately, eloquently, etcetera, about really important subjects? And everybody that's involved with CAPS has a very important insight and viewpoint as to what's went on before, and where the solutions may lie for some of the issues that have come along, because you've survived it, and you've had to get through it. It's vital information. You can't bang on about mental health and not listen to us and take on board what we want to say." **Andrew**

"The tension that emerged in the advocacy movement at the beginning of the decade between activism, as a critical and campaigning tool and advocacy, as a service provided to individuals to help mitigate personal problems, remains." **Keith Maloney**

"I have seen few new collective advocacy projects. The main ones have carried on but sometimes their future has felt uncertain, and money has felt tight. This is not surprising. I am used to the frustration of people who have been speaking out, saying what needed to change thirty years ago still needs to change thirty years later. It can get disheartening." **Graham Morgan**

"Our commissioners; do they really understand? Do they recognise that our collective voice is about anything that is important to our members and that that is how our communities gain presence, sustainability and credibility? I worry when I see large organisations able to attract funds standing in for our own community's voice. Now it is routinely necessary to involve and consult us, it becomes a bit distasteful to see our voice just there to fill the latest box on an involvement exercise." **Graham Morgan**

"I am both thrilled and alarmed by what I see on social media. I worry that collective advocacy groups rarely have a very visible presence here and that our collective voice has been subsumed by the very visible and sometimes very confrontational voice of multitudes of individuals. Mental health/illness has taken off in the last decade with many people speaking about it; especially young people. We need to make sure that we remain or become relevant to this population." **Graham Morgan**

"[At VOX] we have always tried to ensure that priorities are determined by our members, and that the people who we work with are those most likely to be impacted by the subject we are discussing. Reflecting over the last few years, I would say, given our small staff team (three part time staff), we have not always been able to have the depth of involvement we would like to and have had to be pragmatic in terms of influencing change... In addition to capacity issues, challenges have occurred over the years, especially in relation to representing a broad range of viewpoints. Points of view have ranged from those who feel the whole system needs a complete overhaul, to those who want to see positive changes take place within the current structures and services, and of course everything in between! We have tried to stay true to a membership approach where an array of viewpoints are captured, although this has sometimes caused frustration and anger from those who feel there needs to be a specific direction of travel. No more has a light been shone on this than in relation to views about compulsory treatment, and particularly what that means in terms of a human rights framework." **Wendy McAuslan**

Impact

"I think for volunteers themselves, if they have mental illness issues themselves, or someone in their family does, I think it can be helpful in dealing with their personal life as well. I think it can be rewarding in the way it was for me, I mean, I don't have a great self-esteem, but I feel like I was doing the best I can... Personally, I think that volunteering is a wonderful thing. And if I ruled the world nobody would work for money. Everybody would volunteer to do something and do the best that they could in what they volunteered to do." **Theresa Trotter**

"I've made so many lasting friendships that have also really really helped and been supportive and just been amazing really. And that's aside from all the things that we were actually setting out to do like delivering training and making booklets, and actually trying to improve conditions and get better health care, raising awareness and all the other things that we're doing... I mean with the Much More Than a Label project feeding into clinical psychologist training and art therapist training, music therapist training, mental health nursing training, that is really really important. It's like, you know, 'get them while they're young.' " **Lauren Stonebanks**

"Compared to lots of other things, the way [collective advocacy] works is brilliant, because everyone gets to have a voice, and then together you amplify each other's voices... I notice a difference when I go to other events and I'm suddenly invisible again, like, 'Ha! Stealth mode activated'. Actually, no I don't want to be in stealth mode, I've got stuff to say." **Lauren Stonebanks**

"It gives us a sense of actually achieving something. It gives us community and helps with feelings of isolation. There were so many friendships that come out of it as well." Lauren Stonebanks

"I have gone from sitting round a table with a group of guys, shooting the breeze about everyday stuff to sitting in high-profile conversations with the Drugs Minister and all sorts of other MSPs and councillors, to try and influence policy change for adverse childhood experiences and reduce them. So obviously terminology at the type of meetings that I've been attending's been from casual to formal, even on Zoom it's shirt and tie to talk to some MSPs and MPs and get their support and backing... I'm passionate about making a change to society. I'm passionate about people coming together and creating a voice of change. When you see some of the stats that we've got the highest murder rate capitals in some places, the highest suicide capital, the highest drug deaths capital, there's two million kids in the UK who are suffering from abuse or neglect. You've got to do something. This gives me something to do. I probably am running away from all my own problems by helping everybody else, but it helps me by helping everybody else." **Jay Haston**

"Personally, it's given me more control of my life, and I'm much less likely to end up in A&E now. Just being involved in advocacy has given me more courage, and more self-worth that I don't need to self-harm so much." **Sarah**

"The Mental Health Act, that was a major impact, and the Crisis Service. It's really easy to point to those big ones, a lot of them, it's just subtle stuff, and you can't attribute it to us, but we certainly have contributed to changing things. Some for the better, some that seem to be for the better, but turn out to be a bit worse. I think the fact that we're still here and we're still speaking, still doing stuff. A lot of it's kind of hearts and minds stuff, I think the impact on the people who get involved can be quite profound." **Anne O'Donnell**

"I like that disruptive element that art can play. It's not just a nice discreet exhibition in a basement, you know, it erupts into people's consciousness." **Elspeth Morrison**

"I think the main benefit of [Arts As Advocacy] being enabled, facilitated and funded through collective advocacy is the direct challenge/invitation to change the world through what we are expressing in our art. Most of the time, mad art is represented as purely a cathartic endeavour for the person making it, which reinforces our marginalisation as people who are seen not to contribute anything to society. But the fact that here we are activists gives our art an urgency and agency to transform the world." **Jo McFarlane**

"[I like the] social aspect. You meet new people. I haven't been working full time for a few years... it was giving me things to do, during the day time. Otherwise I'd be in the house." **Marianne MacKintosh**

"A lot of things were happening to me, and nothing was being done about it, but the support I got from CAPS, from AdvoCard, from VOX, from See Me, I was supported by the very organisations who got the least finance and the least recognition, and that was who supported me through those dreadful years. Mental Welfare Commission, they came and went, but it was the advocacy organisations that really supported me." **Dianna Manson**

"I think groups like CAPS are fantastic and I think the history of advocacy groups and patient groups, survivor groups, whatever you want to call them, have been really important. They do have a big influence." **Liz D**

Toolkit for Demonstrating the Impact of Independent Advocacy

"Not everything that can be counted counts and not everything that counts can be counted"

Scottish Independent Advocacy Alliance

Scottish Independent Advocacy Alliance (SIAA) Toolkit for Demonstrating the Impact of Independent Advocacy. Photo Credit: SIAA

“What is good about Collective advocacy and the way it is organised is that is a common purpose for the common good! It’s not often you get that – if only democracy worked the same way! It is so lovely to have a common voice and some groups have really helped with that, like the Hearing Voices group in the hospital.” **James**

“I don’t see [Mad Jam] as first and foremost educating the outside world. I see us as getting together in our place and being ourselves, and that the education is something that flows from that in the main... We’re not a resource centre but we are in a way, and the people themselves are sources of information. Some people do tend to say ‘Hi, you know, I’ve been feeling this, I’ve been doing that, I’ve got this problem, I don’t know how to find this’, and if they’re at a table of eight people, chances are somebody will be able to point them to a place where they can find the answer.” **Julie Ross**

“We did a research project about the impacts of being on the [Mad People’s History and Identity] course, and within that I think there was an increased confidence in lots of areas, one about themselves and their identity, and whilst many of them weren't comfortable with the idea of being labeled as 'mad', because of the abusive connotations, there was a feeling of confidence in being part of a Mad movement, and Mad Studies. Some of the learners said that they felt more confident in discussing themselves, their diagnosis, their treatment options with therapists, nurses, and with psychiatrists. So, it gave them a language, and I think also a confidence in their own experiential knowledge." **Elaine Ballantyne**

"I think I would be a bit grandiose if I said, 'I think that it's changed the world, what we've done here', I think it has had an impact on people individually and collectively who are on an ongoing struggle for emancipation and change… Maybe what [Mad People's History and Identity] has done is politicised learners more, in relation to their rights. I think there's actually more a kind of assertiveness, and maybe this raising of consciousness which makes people angry, rather than passive, is a good thing." **Elaine Ballantyne**

"I think [the Patients' Council] gives people a sense of belonging. That you are involved in something to try and improve services, so that one day people [won't] go through what you went through and people you love went through." **Alison Robertson**

"They're not support groups, but they are supportive, and they've given me so much support. To be honest, I'm not sure I would be here, or be as well as I am, if it hadn't been for the Much More Than a Label group. When I was diagnosed, things were really, really, bad, and I think I might have done something rather drastic if I hadn't found that." **Lauren Stonebanks**

"I think there's that thing of chipping away, isn't there? You know, and it's having to say things over and over again. Real change can be quite slow, but it's that continual focus, I think, and eventually that does bring about change." **Lewis Reay**

"I think the very fact that there's advocacy there, is holding people accountable." **Tommy**

“When I sit in a meeting it’s not necessarily anything that I’ve got to say, it’s the very fact that I’m there at all. They know that they’re being held accountable... I feel like that we’re actually speaking to people that are nearer the coal face, that can actually change things. And that they’re listening, so that’s better.” **Tommy**

“I need to write all this stuff down because I forget and I have to be reminded of stuff. It’s very strange, it doesn’t seem to land with me, this stuff. I know I have been involved with so much important stuff, but it just doesn’t really land with me, so I don’t remember... But it will land with me one day, and I will believe this, but it still feels like I didn’t do any of that stuff... it was somebody else’s life and I was just there.” **Andrew**

“I might not say anything on a call, but the fact that I’m just sitting here, it feels like it gives me purpose, and it feels like I have agency inside myself as well, because I’m communicating. Even though I’m not saying anything, I’m still here, and that’s very important.” **Andrew**

“Things won’t happen overnight... It’s taught us a wee bit about patience and seeing that, if you give it a bit of time, you do start to see the sprinkle of changes. And I think we will see that more so. To me that’s like an impression of where I came at the beginning of just being really lost and not knowing what I was doing, to being in a position where I’m sitting amongst company and feel privileged to do so on a journey to leave our mark.” **Andrew**

“I think for a lot of people it’s finding peers, finding commonalities... There’s something very freeing about seeing people who have historically been silenced and oppressed getting together and saying ‘This is what we want. This is what we have to say’, and making it be heard. It also makes you braver in your own life as well, because you realise, as part of this group my voice should be heard, but also, in general my voice should be heard as a human and a citizen.” **Kirstin**

"I think from my experience working with a range of different organisations, for people to believe so strongly in an organisation they work for is not that common. I think it's a real tribute to all of the staff and volunteers, because if you didn't have all of the tonnes of volunteers, who give so much time and effort and passion and energy, it would be a very different organisation. And I'm sure that those volunteers feed the passion of the staff as well, so it's all a snake eating its tail." **Kirstin**

"The impact [of Men Matter] has been huge... It's improved people's lives, it's improved men's lives. Going into the campaign, it's improved families' lives, children's lives, and as I say, it's already helped change policy and is changing policy as we speak." **Jay Haston**

"I have gone from one man creating a page to raise awareness on adverse childhood experiences to sitting on a cross Parliamentary group for the prevention and healing of Adverse Childhood Experiences (ACEs) representing Hearts of ACE, the National Council Of Lived Experience. This shows the power of speaking out and that anyone with enough determination and passion can help make changes at grassroots level all the way to Holyrood." **Jay Haston**

"Sometimes people understand their friends or family members better, through seeing their artworks. I've spoken to people who have said they know someone who's going through something similar, but through coming to see the exhibition they've understood that particular issue more, or in a different way. We've had people from the medical community come along and understand an issue in a different way. Often there's current issues that are touched on. The exhibition can be a space for a lot of thought and also for actual conversations." **Pam van de Brug**

"There are always ways which Patient Council or other places can improve but it definitely was a lifeline for me and I'll never forget that. I'd say it did help me... find my voice again, and I'd lost that."
Safina Bibi

"I think [Out of Sight, Out of Mind] has profoundly moved audiences, and at times, transformed opinion. It has challenged preconceptions and encouraged empathy and understanding among us all. And it has fostered a sense of community and fellowship amongst the collective of artists and our network of supporters. It has given us a focal point each year to come together and celebrate our work." **Jo McFarlane**

"My life would be very different without collective advocacy. I feel I would be very lost without it, I have come to depend on it, it gives me meaning and purpose – seeing some things changing! The more you see others getting on and improving the more you get on and improve yourself!" **James**

"I think being involved in CAPS has made me become more at peace with the fact I struggle with mental health. It has taught me that there are others who have gone through the same thing, which shows me it is somewhat 'normal'. It has allowed me to reflect on my past experiences and realise that many times I was not taken seriously and was treated unfairly. With CAPS I feel empowered to share my experience and speak for what I believe in." **Mohasin**

"I ended up on the front page of The Evening News's Scotsman, attacking the government, and I didn't intend it, but the front page was 'We are in the dark ages' in big, black capital letters, with my face next to it in the interview, and Nicola Sturgeon actually responded to it." **Jay Haston**

"I actually think that, working in a creative way... is the vehicle that brings in the conversations and the dialogue and the interactions, and both are really important. You could be working in a creative way to produce something and not produce it in the end for whatever reason. So, you could have the conversation, the dialogue, the interaction sharing without the art. But I think the conversations stem from that kind of creative space." **Margaret Drysdale**

CHAPTER 7

What lies ahead?

We asked people what more could be done in collective advocacy and what needs to change in mental health services and in society. We also asked them what they would say to people wanting to get involved.

What still needs to be done?

“What do we need for the future? Hmm, I think more of the same. Continuing to increase numbers, diversity, more seats at the table. I worry that there are still so many people who haven’t and aren’t able to access services and advocacy. Not everyone finds it easy to speak up, join in, and I like to think that in some way I am speaking for them through my own experience.” **James**

“I’m a huge advocate for universal income. I think that would solve so many problems, but sodding Westminster... Because then we could just take on whatever jobs we wanted to when we could do them, and it wouldn’t impact our benefits. We wouldn't be terrified if we couldn't manage the job at a particular point, it would be fine. The system just keeps people ill." **Lauren Stonebanks**

"Voluntary work is so important; it does frustrate me that I don't think it's recognised as much as it should be by government. Because it's not bringing any taxes, people are not being paid a wage, so they're not paying taxes. But voluntary work, for many of us, is what we do, it's what we can do. We can't work for a wage, but we can do this, and we can contribute, and we can help." **Martin**

"I believe that the government should be funding peer support because it's that crucial. If you look at the numbers at Andy's Man Club just the last week there was 865 men crossed the door across the nation. So, the government should be backing peer support, funding it, or even taking the numbers, and including it in their research for when they're divvying out funds for mental health. For example, when the government calculate their funds, they only take the official records of people who's gone to doctors and hospitals. If they were including the 800 men that went to Andy's Man Clubs, the 40 odd guys that come to Men Matter in West Lothian, the thousand members that are in my online peer support group. If they were to take all these numbers, that would make a dramatic impact on their statistics and how much money they would allocate mental health. As much as that's a tricky one, it's a hard one, I will bat it straight back at the government and say that they should be involved and backing it." **Jay Haston**

"Certainly we have come forward, don't get me wrong, I just can't pinpoint all the things we have come forward with. I think recognition on government level, recognition on boards, each board has a representative person with lived experience, people are given an opportunity to contribute to the teaching of nurses, doctors. We're on more of an equal level, there's more equality for nurses, doctors and patients alike, and that's what I like to see, as well. Because after all, who's different from anyone else, except for the provision of what they give? You know, and we all have something different to give. So, parity of esteem is pretty important." **Dianna Manson**

“We need to have structures where we can be noticed for the need to have greater finance than we’re given, greater recognition for the work we do in advocacy... And the infrastructure needs to be built up and I don’t know where we can help there, apart from sitting on these government committees and cross-party committees, to act as people on the shop front, who are there straight from experience, who can identify immediately, without it coming through a second person, or a third person.” **Dianna Manson**

“The human rights aspect needs to be recognised, as well, but I think we have to highlight to the authorities, that is the council, the NHS, and anybody who provides monies, lottery, whatever it is. I think the universities need to recognise that if they’re using us for lecturing, that needs to be funded for, because funding is imperative for organisations such as CAPS and AdvoCard. We all need to be funded, and funding is a horrendous thing to deal with. The worry that that entails, and having to actually get up and fight for your actual existence is a desperate thing... We shouldn’t have to fight for our existence, these are necessary provisions.” **Dianna Manson**

“There’s a lot to change. Progress is a rounded thing, sometimes it turns around completely, and goes back to the beginning, but there’s a lot of work to be done in that rotation of the wheel.” Dianna Manson

“VOX has recently been successful in receiving additional funding, and for the first time since VOX’s inauguration we will have five staff members who will be able to work more effectively and methodically to utilise our members’ expertise, and through this, create positive change. Unfortunately, there is still widespread systemic discrimination and insufficient access to much needed mental health support and services. However, we now have a more solid national voice which will enable us to further develop our ability to provide a reality check between national policy and people’s experiences.” **Wendy McAuslan**

"In the future, especially with the Mad People's History and the Patients' Council, or any other group, I think it'd be great to see people actually get properly paid employment for their experience. I remember at a meeting saying, 'we should be paid consultants wages.' " **Alison Robertson**

"The establishment of Mad Studies at QMU has opened up new critical pathways for mad agenda. The challenge will be to keep the academy and the community connected and created a platform for the mad community to remain politicised and active." **Keith Maloney**

"What more can be done? How can I say this? I think we need to be more vulnerable to uncomfortable conversations... If we're going to progress as a society, and in my view, attain the human rights that everybody deserves, irrespective of their sex, the colour of their skin, who they want to share a bed with, or who they don't want to share a bed, whatever... let's hear about it, let's talk about it, let's have those uncomfortable conversations, but let's not shy away from them. They are uncomfortable. We can't deny that, and let's give each other some space and some time to process that. Because there's such a massive history involved in trying to include people from different groups and it's challenging... We need to recognise the sort of experiences and discrimination that people have had, including myself, it comes with long lasting trauma itself." **Safina Bibi**

"I like the idea of where things are going with enhancing peoples choice of involvement in decisions about their own treatment – a moral choice." **James**

"I don't like their arbitrary age bands in mental health. Nothing is necessarily going to change just because you're 18 turned 19, you know? There's nothing necessarily going to change when you're 65 turned 66, and yet you get changed from one group to another, and continuity's one of the things that seems to be helpful... Personally I feel that they're still working on a plan that they decided on last century, and they need to reorganise things to be fit for the 21st century, in both health and social care. I think they've got a review coming up, so let's see what they decide." **Tommy**

"I think it's absolutely essential that this break off point of 65 is totally disregarded, I mean it's an absolute obscenity. People are living longer lives, and although we have this desperate stricture on us of having a lesser life expectancy than others, we still, with good care, can go on, and our peers following after us will go on, and hopefully have an extended life like everyone else." **Dianna Manson**

"I don't want Arts as Advocacy to be written off as a soft option, as a safe footfall exhibition for a venue, a money spinner, whatever it is, raising awareness." **Elspeth Morrison**

"Don't just raise awareness, do something about it, do something about it." Elspeth Morrison

"When it comes to LGBTQI people, and when it comes to people from minority ethnic backgrounds, mental health issues are a big problem. The more marginalised you are generally in society, the more likely you are to have a mental health issue, and the more difficult your experience of services can be… I think there's a lot more we can do as a whole, but then we are products of quite a white society, that only until recently has had to realise that we are more diverse, and that that's a good thing." **Anne O'Donnell**

"A few new people got involved [in the Experiences of Psychosis group] over the time, but slowly. We still don't represent the wide range of people that we need to and should do, in particular like lots of minority groups. One thing that's hugely important in terms of psychosis is that we don't have young people in the project." **Fingal**

"I think the [eating disorder] conference also showed that there are huge barriers to men and eating disorders, and how to access services, but also to the LGBT community as well, and how they access services, and how often they can get missed. So, there is a plan to meet with the LGBT centre at some point soon." **Anonymous**

“One of the things we’ve discovered is peer support has never been available in Eating Disorder Services, because of the risk. It’s something that the group are hoping to change as a result of the service redesign, but it’s something that’s not been offered because of people being triggered or developing unhealthy relationships.” **Anonymous**

“More and more governments and services include service users’ experiences as part of policy and service development which is good. However, this is not always achieved in a collective way, a way that really captures experiences, views, and opinions of people who struggle to participate or hold services to account. Collective advocacy services are in a very good position to inform policy and developments, challenge and raise issues but this needs to be better coordinated, recognised, and funded.” **Kathy Hamilton**

“And, you know, like, putting your hands up, because I’ve had to do that with my life, and be like ‘I got that wrong about that person. I got this wrong about this person. I got lied to. I got messed about in so many different ways, I didn’t understand what was going on’, and I couldn’t put my hands up and be like ‘right there was something that wasn’t working inside of me, and that was related to trauma’. That kind of understanding of stuff instead of just slapping labels on people, chucking pills at people and saying ‘right, just get back on with it’. It’s not how you help people. So, we’d need to see that change. And there are seeds of that happening, but we do have a fight on our hands.” **Andrew**

“I do think that there’s still quite a lot of work to be done in what it actually means to have everybody who needs to be there, there, with the right invitations.” Anonymous

“From a trauma perspective, I would like to see more parity of esteem in understanding the long-term physical impacts of trauma together with mental health. If things were more holistic, perhaps we could resolve things and re-calibrate or re-set our bodies at an earlier stage and avoid some of the potentially chronic, long-term effects that we sometimes experience across a lifespan… I liked when ‘recovery’ developments shone a light on more holistic approaches in Scotland around 2005. It seems like there's now more of a conversation about somatic responses and solutions. As there are so many of us who experience the effects of trauma in our bodies, I hope we can have a key role in unravelling the 'embodied' impacts on our lives and shift things more for ourselves and future generations... I think some headway is already being made through mindbody approaches like somatic experiencing. Perhaps closer links within health and social care contexts can support more collaborative working with and among peers, practitioners and researchers." **Fiona Macdonald**

"Perhaps moving forward more attention could be given to acknowledging and understanding attachment. Some approaches focus on both trauma and attachment. Life changing decisions to do with attachment are already made in health and social care contexts, disruptions to attachment may be seen among Adverse Childhood Experiences and we sometimes need to learn more about healthy and unhealthy attachments. Perhaps if there were more understanding of the significance of attachment in Covid planning, this would make a difference moving forward too." **Fiona Macdonald**

"I increasingly find that professional bodies are discovering that they have similar concerns to our own communities and that, perhaps, between us, we could ensure major change can occur. We now have people who have been involved in collective advocacy for over three decades; it is worth treasuring this expertise." **Graham Morgan**

"I volunteer with HUG [Highland User group] and am struck that we have a couple of decades worth of reports, films, artwork. Almost none of it is visible publicly at the moment- let us treasure what we have said and done in the past and build on it with the new stories and experiences we will be sharing in what will probably be an everlasting attempt to speak truth to the world around us. What that truth might be is of course another subject!" **Graham Morgan**

What would you say to people getting involved?

"I would say, 'try it out. If you don't like it, you don't like it. If you do, you might make some great lifelong friends.' " **Lauren Stonebanks**

"I think, just to believe in yourself and what you are doing and to go for it. Too often, we succumb to negative messages coming from ourselves and others that we are useless, worthless... and that's just not true. It's an insidious lie that eats away at us and destroys our creativity and connectedness to others. All of us have massive potential to transform our lives and to touch the lives of others through everything we say and do. Making art and sharing it, whether through a visual medium, spoken word or whatever, is a calling to take up our rightful place as active citizens; and it is essential to our being human. Our gifts and experiences are far too sacred and important to hide so this is our chance to shine and influence the world around us. And yes, of course it makes us feel better too." **Jo McFarlane**

"I guess that the most important thing to me is, be authentic... Be open to what it will do to you, and the journey it can take you on, and the change it will not just bring forward in society, hopefully, and in law, but to you as an individual as well." **Safina Bibi**

"Don't be scared. Don't be overwhelmed by the professionals, you probably know more than they do." Sarah

"I think, for me, if I was a person coming into collective advocacy, I would feel more comfortable with having a worker who had lived experience, maybe not necessarily an eating disorder. I just think you feel more appreciated, you feel like your experience is being listened to... In a lot of cases it's professionals telling you what you should be doing or what it should look like. [Collective advocacy] is a different dynamic, rather than it's them and us." **Anonymous**

"It takes a lot out of you. Especially when you yourself have been through some of the many things that we listen to and advocate for within the mental healthcare system. It is so important to look after yourself, because the problems are so big you can't just carry the burden yourself. It will take you under so always prioritise yourself. It's so easy not to." **Safina Bibi**

“I would recommend mental health advocacy and activism to everyone who has struggled with a mental health issue. You don’t have to be particularly knowledgeable or have any specific skills to join, but I would recommend researching about relevant organisations and events that you can work with to build more connections. The activism is all in your hands so it’s good to know how you can share your voice.” **Mohasin**

“I’d say, ‘With your passion for things, do try to get your passion recognised, but if it goes to the extent that it affects your mental health, back off, because your passion will have been hurt. Back off and allow yourself space for the next time round’. Sometimes people are so involved that it affects their own mental health, and that shouldn’t happen.” **Dianna Manson**

“CAPS is a safe place for people with issues with mental health to go and get involved and see that they don’t have to feel like a train wreck all the time. They could feel like a spaceship, or something, you know?” **Theresa Trotter**

“I would say go for it. It’s great to be part of a movement that’s doing something about what we’ve all been through, you know? It’s trying to push it forward and change it for the better. Keeping what’s good and absolutely dumping what’s crap.” **Alison Robertson**

“One of the brilliant things about collective advocacy is you meet a range of very interesting people. I would encourage people to be open to meeting new people and that you don’t have to agree. Cause often I think people get very upset when there’s disagreement. If there are grievances or problems happening, speak up sooner rather than later. Take care of yourself. Prioritise the group and the process over the outcomes and the action, because if your group is solid, and you’ve got good relationships you’ll achieve more in the long run.” **Anne O’Donnell**

“Don’t just focus on the mental health stuff, on the services, look wider in society, look at what other types of activism do, try and make connections, even if it’s just in your own mind. I think having been involved in different

TOP 10 REASONS TO GET INVOLVED

(ACCORDING TO CAPS VOLUNTEERS)

'Nothing has felt as rewarding as the work I've done through CAPS, and how supported I've felt to contribute to the groups I do.'

'Feeling accomplishment through helping others to understand mental health disorders'

'It's an opportunity to talk about mental health which isn't something I do anywhere else.'

'Getting to be around other people who are non judgemental and empathetic'

'The inclusiveness of a CAPS collective advocacy group not only proved supportive from the peer aspect but gave my voice a magnified power that not even I believed could be heard with such force.'

'In previous times, never having had the experience of being listened to non-judgementally I started working with CAPS. This proved so beneficial to the perception I had of where I was within my mental health journey that I started moving forward and have never looked back'

'Affecting real change'

'I've always found CAPS meetings to be "safe spaces" and I've benefited enormously on the mental health front at them'

'To gain confidence working with others and presenting to groups of people'

'Getting involved with CAPS is an opportunity to be yourself in an accepting environment.'

CAPS independent advocacy

kinds of activism besides the mental health stuff has helped me take a broader picture." **Anne O'Donnell**

"The most important piece of advice that I would give is to trust your authority on your own experience. Because fundamentally the work that we do through mental health collective advocacy, is addressing structural inequalities that, by their nature, alienate you from your own voice and undermine your sense of understanding or insight into your own experiences." **Vivek Santayana**

"Get out there, feet to the ground. Get people talking, get people round a table, create steering groups, create groups, you know? Create partnerships. You'll only create advocacy by reaching out and talking to people and bringing them round the table and seeing what can come of it. A lot of the big problems now is funding, and a lot of people don't want to work with other people because of funding. Stop fighting over the funds and start maybe collaborating and jointly applying for funds, and doing projects together, you know? But most of all use your voice. Use your voice and make it count." **Jay Haston**

"Just get involved. There's a strapline for you: 'Just get involved.' " Andrew

Afterword

So, we reach the end of another ten years! The memories, stories, and experiences shared in these pages reflect the vibrancy of the Lothian collective advocacy and ‘mad activism’ movement, and we are inspired by the passion of the people who have contributed to this book – their enthusiasm and determination underpin the accomplishments of collective advocacy in Lothian in the last decade.

We have seen so many important developments in the last decade, with greater inclusivity in collective advocacy, increased awareness of mental health in society, increased understanding of the impact of trauma, and more recognition of the value of lived experience being some of the most exciting changes. We can see in people’s stories that collective advocacy has a positive impact on the people involved, and it is clear from the achievements we have seen that it has the power to challenge stigma and raise people’s awareness and understanding of mental health issues. The reach of collective advocacy now means that people with their own experience of mental health can influence how services are delivered and result in real changes in policy.

The growing number of collective advocacy groups across Lothian reflects the increasing diversity within the movement, but we know there is more work to be done. In the future, we would like to see more people from under-represented groups, such as people from ethnic minority backgrounds and people who identify as LGBTQI+, getting involved.

The move to online services during the Covid-19 pandemic has made involvement in collective advocacy more accessible for some people. However, it also must be recognised that the lockdown has made it difficult for others to stay involved. The changes we have seen during the pandemic have shown us what is possible. We hope, moving forward, there will be a mixture of in-person and online contact, so that people can contribute in a way that suits them.

How encouraging it is to hear people talking about the increasing value placed upon lived experience! Mental health services and decision-makers are becoming more receptive to the views of ‘experts by experience’, and people with mental health issues increasingly have a ‘seat at the table’ when decisions are made about mental health policy, legislation, care, and treatment. Nevertheless, some key challenges remain. We know from the first Oor Mad History book that the shift from ‘closed’ spaces to ‘invited’ spaces took a long time, and there is still more to be done to create opportunities for genuine ‘shared’ spaces. Power imbalances still exist between people with lived experience and people in positions of ‘authority’.

In the last decade, collective advocacy groups have created new spaces for involvement through projects such as Arts As Advocacy and the People’s Conference. These ‘created spaces’ provide a platform for people with lived experience of mental health issues to set their own agenda and enable them to invite service providers and decision-makers into their space. We hope to see more spaces like this being created in the future and see them as a way of reducing the ‘us and them’ dynamic between people with mental health issues and service providers and decision makers.

This book is a celebration of the power of collective advocacy as a means of galvanizing the voice of lived experience. The developments we have seen over the last decade have been shaped and driven, with tenacity and purpose, by the people involved! The fledgling Human Rights based approach that we see developing gives us hope that collective advocacy as an agent for change has new prospects for the future. We hope this book will inspire people to continue being involved and help us move towards a future where people are empowered to have greater influence over the issues affecting them and the people in their lives.

Oor Mad History collective advocacy group

CAPS

CAPS is an Independent Advocacy Organisation which provides Collective Advocacy to different groups of people across Lothian with mental health issues. These projects provide opportunities for people to get together and support each other to explore shared issues, speak up about their experiences, set their own agenda, and find a stronger voice to influence the things that affect their lives.

CAPS also provides Individual Advocacy to people from East Lothian and Midlothian who have mental health issues or are using drugs and alcohol. We also provide advocacy for children and young people going through the Children’s Hearings process, in these areas.

If you wish to find out more about the work of CAPS or about the Oor Mad History collective advocacy project at CAPS, get in touch at:

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Oor Mad History: Ten Years On

This book was first published in December 2021

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Oor Mad History is an innovative collective advocacy project which reclaims and celebrates the community history of collective advocacy and activism by people with lived experience of mental health issues in Lothian. Our first book was launched in 2010 and captured people's memories and stories from the 1980s, 1990s, and 2000s. In this new book, we share the memories and experiences of people who have been involved in recent years and look at what has happened in local collective advocacy and activism from 2010 to 2020. This is Oor Mad History – Ten Years On!

"There's nothing like the power of people with lived experience telling their stories." Lewis Reay

"There's something very freeing about seeing people who have historically been silenced and oppressed getting together and saying 'This is what we want. This is what we have to say', and making it be heard." Kirstin

"Lothian seems to be a place where collective advocacy is acknowledged and valued and has flourished. Hopefully every region of Scotland can follow that example; maybe future legislation will help in this." Graham Morgan